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Dr. Mary Schroth, Chair of the FSMA Medical Advisory Council, and Charlie Sykora, SMA Type I
As a Board we have had a busy six months. We have added five new Directors to the national board. Our new members are Douglas Erwin, Robert Lockwood, Steven Ragland, Richard Rubenstein, and Melissa Milinovich. These new Directors bring a variety of experiences and expertise to our organization that will help us continue to thrive in our mission. If you would like to find out more about the new Directors, or any other board member, please go to our website at www.fisma.org/AboutFSMA/Board/.

The Board has also been working on a number of new initiatives that include; increasing the support the national office provides to our local Chapters, developing new ways to increase our revenue to help support our research efforts and strengthening our Advisory Boards by making sure we have the best clinicians and researchers advising us on where best to invest our dollars.

The annual conference is right around the corner and this year we will be on the west coast. Every year our conference continues to increase in attendees. Last year we had over 900 families and researchers attend. This year we are anticipating that number to also increase. The conference promises to be another great event providing families the opportunity to gain knowledge about SMA, receive updates on the status of research and have the opportunity to meet other families with SMA.

Thank you for your hard work and support that you give FSMA! We are able to accomplish all that we do because of each and everyone involved in the organization.

Best Regards,

Paula Barrett
Chair, Board of Directors

Mission Statement
Families of Spinal Muscular Atrophy is dedicated to creating a treatment and cure by:

- Funding and advancing a comprehensive research program;
- Supporting SMA families through networking, information and services;
- Improving care for all SMA patients;
- Educating health professionals and the public about SMA;
- Enlisting government support for SMA;
- Embracing all touched by SMA in a caring community.

Our vision is a world where Spinal Muscular Atrophy is treatable and curable.

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We are excited to have reports from the first formal meeting of the new FSMA Medical Advisory Council in this issue of Directions. Dr. Mary Schroth, the chair of the Council, is on our cover and provides details of the initial goals and projects the group is working towards. The MAC is helping us map out our longer term plans for improving SMA patient care.

A first task for the MAC was assisting with the patient care and family support workshops at the upcoming 2010 conference in California. We are expecting a record of over 1,000 attendees and our agenda includes over 40 specific workshops and demonstrations. See page 4 for details. The members of the MAC, who you can see listed on the following page, will be leading the workshops and also launching a special newly diagnosed program this year.

Our core strength at Families of SMA has always been in our community and the amazingly strong connections and bonds we have between families and also with our researchers.

The annual conference is always a highlight for us as we get a chance to make connections in person. This newsletter Directions is another way we try and build our community and bring us all closer together by sharing stories and experiences. Our online presence helps us all connect on a virtual level now while we are spread out all over the world. The curesma.org website receives over 250,000 unique visitors each year.

Families from all over the world connect with each other through Families of SMA to chat, organize, and share stories, photos, news, and information – and most importantly hope. Knowing there are others out there fighting alongside you is incredibly empowering, and the advice and personal anecdotes can make a real difference in the lives of our families. And working together we have the strength to get us to a treatment and cure.

Thank you for all your support and dedication to Families of SMA and the goals we are trying to accomplish to develop a treatment and a cure and improve care for all patients today.

Sincerely,

Kenneth Hobby
President, Families of SMA

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As a Board we have had a busy six months. We have added five new Directors to the national board. Our new members are Douglas Erwin, Robert Lockwood, Steven Ragland, Richard Rubenstein, and Melissa Milinovich. These new Directors bring a variety of experiences and expertise to our organization that will help us continue to thrive in our mission. If you would like to find out more about the new Directors, or any other board member, please go to our website at www.fisma.org/AboutFSMA/Board/.

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Best Regards,

Paula Barrett
Chair, Board of Directors
Dear Members of the SMA Community,

I look forward to seeing you soon in Santa Clara, California. The Families of SMA Medical Advisory Council (MAC) met in January 2010. We are a diverse group of clinical experts with a common vision. Our vision is to provide proactive, creative, and collaborative leadership on issues that improve the quality of medical care for those affected by SMA. Our mission is to continue to advance the standard of care for SMA; increase knowledge of SMA diagnosis, intervention, and care management among health care providers, affected families, and the general public; and to facilitate translating the results of new research for use in clinical practice.

Of the many projects underway, a project that the MAC is proud to present is an afternoon session for newly diagnosed families at the annual conference. The Newly Diagnosed Program will provide an opportunity to welcome new families to the SMA community and Families of SMA. In addition, the program will provide orientation to the conference and the care issues surrounding SMA.

A key component to improving care of individuals with SMA is to reach out to health care professionals with educational and training opportunities. The MAC is exploring methods to optimally reach health care providers including a website based resource center, local presentations, medical professional training programs and care center development. Additional Care Series booklets are in development including nutrition and musculoskeletal information for families.

On behalf of the FSMA MAC, we thank you for the privilege of serving the SMA community.

Sincerely,

Mary K. Schroth, M.D.
Chair, FSMA Medical Advisory Council

MAC MEMBERS

Mary K. Schroth, MD, Chair
American Family Children’s Hospital Madison

Susan Apkon, MD
Seattle Children’s Hospital

Vanessa Battista, RN, MA, CPNP, CCRC
Boston College School of Nursing

Thomas Crawford, MD
Johns Hopkins Hospital

Richard S. Finkel, MD
The Children’s Hospital of Philadelphia

Albert Freedman, Ph.D.
Child Family Psychologist- Goshen Executive Center- West Chester, PA

Robert Graham, MD
Children’s Hospital Boston

John Grayhack, MD
Children’s Memorial Hospital Chicago

John T. Kissel, MD
The Ohio State University

Richard M. Kravitz, MD
Duke University Medical Center

Kristin J. Krosschell, PT, MA, PCS
Feinberg School of Medicine-Northwestern University

Garey Noritz, MD
MetroHealth Medical Center/Case Western Reserve University

Karen Patterson, MS, PT, PCS
University of Wisconsin Physical Therapy Program

Richard Shell, MD
Nationwide Children’s Hospital and The Ohio State University

Kenneth Silver, MD
University of Chicago Comer Children’s Hospital

Brian Snyder, MD, Ph.D.
Children’s Hospital of Boston

Barbara J. Godshall, MMSc, RD, CSP, LD, CNSD
Cincinnati Children’s Hospital Medical Center
# 2010 SMA Conference Schedule at a Glance

**Thursday, June 24, 2010**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1:00pm</td>
<td>Registration Open for Newly Diagnosed Families</td>
</tr>
<tr>
<td>2:00pm</td>
<td>Pre-Conference Program for Newly Diagnosed Families Dinner Provided</td>
</tr>
<tr>
<td>5:00pm</td>
<td>Registration Open for all Conference Attendees</td>
</tr>
<tr>
<td>7:00pm</td>
<td>Welcome and Introductions Kids PJ Party and Movie Ice Cream Social and Relay Race with Researchers</td>
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**Friday, June 25, 2010**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>8:00am</td>
<td>Registration Open - Continental Breakfast</td>
</tr>
<tr>
<td>9:00am</td>
<td>Opening General Session Workshop Session #1</td>
</tr>
<tr>
<td>12:00pm</td>
<td>Lunch on your Own</td>
</tr>
<tr>
<td>1:30pm</td>
<td>Workshop Session #2</td>
</tr>
<tr>
<td>3:15pm</td>
<td>Workshop Session #3</td>
</tr>
<tr>
<td>5:30pm</td>
<td>Family and Researcher Banquet</td>
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**Saturday, June 26, 2010**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>8:00am</td>
<td>Registration Open - Continental Breakfast</td>
</tr>
<tr>
<td>9:00am</td>
<td>General Session Workshop Session #4</td>
</tr>
<tr>
<td>12:00pm</td>
<td>Lunch on your Own</td>
</tr>
<tr>
<td>1:30pm</td>
<td>Workshop Session #5</td>
</tr>
<tr>
<td>3:15pm</td>
<td>General Session</td>
</tr>
<tr>
<td>5:00pm</td>
<td>Demonstrations Dinner on your Own</td>
</tr>
<tr>
<td>6:30pm</td>
<td>Family Carnival</td>
</tr>
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**Sunday, June 27, 2010**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00am</td>
<td>Full Breakfast Buffet Concluding General Session Q&amp;A Session: Research, Clinical and Medical Panel</td>
</tr>
<tr>
<td>12:00pm</td>
<td>Conclusion of Conference</td>
</tr>
</tbody>
</table>

**Children’s rooms open during meeting times only.**

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For more information and to register for the conference, see the FSMA website: [www.fsma.org/FSMACommunity/Conference/]
Patient Care and Family Support Workshops Announced

Families of Spinal Muscular Atrophy is excited to announce the patient care and family support workshops being offered at the Annual SMA Conference, held this June in Santa Clara, CA.

This year’s conference will be especially exciting as we are rolling out new focused workshop tracks for newly diagnosed families, adults with SMA, and specifically for each type of SMA. We are expecting a record attendance of over 1,000 attendees.

Our initial agenda includes over 40 specific workshops and sessions!

The Workshop, Activity, and General Session Topics for 2010 Include:

**GENERAL SCIENCE & RESEARCH WORKSHOPS:**
- Therapeutic Strategies for SMA
- Q&A Panels with SMA Researchers and Medical Professionals

**RESPIRATORY & NUTRITION WORKSHOPS:**
- Respiratory Care Choices for All
- Nutrition for All

**PHYSICAL & MEDICAL MANAGEMENT WORKSHOPS:**
- Physical Therapy, Occupational Therapy and Bracing
- Orthopedic Management Issues
- Exercise for SMA
- Pre-Hospital and Emergency Room Care
- Primary Care Topics

**RECREATION & THERAPY WORKSHOPS:**
- Benefits of Yoga for Kids
- Playtime for All – Adapting Toys for a SMA Child
- Aquatic Therapy
- Music Therapy
- Power Soccer Demo

**EDUCATION & INDEPENDENCE WORKSHOPS:**
- College Bound
- Accessible Housing
- Assistive Technology to Communicate Independently
- Opening the Doors to Adulthood
- Estate Planning
- Insurance Working for You

**SELF HELP & WELLNESS WORKSHOPS:**
- Healthy Living for the Caregiver
- Healing Process Part I
- Healing Process Part II
- Travel for SMA Families and Patients
- Adolescent Issues

**OPEN DISCUSSION & SHARING WORKSHOPS:**
- It’s a Wonderful Life!
- Knowledge is Power - Sharing Your Experience – Type I
- Knowledge is Power - Sharing Your Experience – Type II
- Knowledge is Power - Sharing Your Experience – Type III
- Knowledge is Power - Sharing Your Experience – Grandparents
- Knowledge is Power - Sharing Your Experience – Grieving

- Adults With SMA Roundtable
- Getting Involved - Legislative Initiatives

**JUST FOR KIDS WORKSHOPS:**
- Siblings Talk it Out
- SMA Kids Talk it Out
- SMA Kids Scene

This year we are also launching a special newly diagnosed program. This will include the following:

- Understanding Genetics
- Coming to Terms with a Diagnosis/Choices
- Respiratory and Nutrition Care
- Muscle/Orthopedics/Function
- Welcome Dinner for Newly Diagnosed Families

Our 2010 family and researcher fun activities will include:

- Family Fun Carnival
- Family and Researchers Banquet
- Relay Race with Kids and Researchers
- Fun Filled Children’s Program with Activities, Games, Toys and Movies
- Ice Cream Social
- PJ Party and Movie for Kids
- ‘Create a Bear’ for Children
- Professional Portraits of SMA Children
In 1947, doctors told Ralph Braun’s parents their six-year-old son had Spinal Muscular Atrophy and would probably live to be an early teenager. The doctors encouraged his parents to keep Ralph at a large children’s hospital where he could be studied and made comfortable. They declined.

The doctors who handed Ralph his dire sentence were wrong. Not only has he lived far past his teen years, he went on to found BraunAbility, the world’s leading manufacturer of mobility vehicles.

It wasn’t an easy road. When Ralph couldn’t rely on his own two legs to walk and he’d outgrown piggyback rides on his father’s back, he began using a wheelchair. Life went on, and Ralph was determined to find a way to keep up with it. He wanted an education, a career and a family, just like anyone else; he just had to work a little harder at it.

First he invented a motorized scooter, the Tri-Wheeler, so he could conserve energy and keep his job as a quality control inspector at a nearby factory. When the factory moved a few miles from his home, he outfitted an old postal Jeep with hand controls and a hydraulic lift so he could have reliable transportation to and from work, no matter the weather. As his mobility increased, so did attention from the disabled community.

When full-size vans were introduced to the consumer market in the early 70s, Ralph quickly engineered a way to install a lift in the side door of the vehicle. This invention revolutionized the mobility industry, and with the passage of the Americans With Disabilities Act of 1990, the disabled community was awarded unprecedented access to public places. Demand for mobility products skyrocketed, and BraunAbility scrambled to keep up. The company quickly outgrew its manufacturing buildings and expanded its facilities and product lines to accommodate the growing market.

Today BraunAbility has over 700 employees and is the largest manufacturer of wheelchair-accessible vehicles in the industry. BraunAbility vehicles, lifts and other mobility products are available worldwide as personal vehicles and public transit vans and lifts. Capitalizing on the age-old saying, “Necessity is the mother of invention,” Braun found opportunity in his disability and, in the process, has brought independence and mobility to thousands.

Ralph is now 69 years old and recently published his autobiography, *Rise Above*. Proceeds from the book will benefit The Ralph Braun Foundation, which will help bring mobility to individuals who cannot afford it. The book is available through the company’s website at www.braunability.com or at www.amazon.com.
Hugs from Montana

Everyone at Families of SMA would like to send a very heartfelt thank you to Nora Gooden’s grandmother, Cindy Bobolz of Townsend, MT. Cindy has been so incredible by providing us with her beautifully hand crafted quilts, which are sent in the Type I and Type II Care Packages. When Nora was diagnosed in July of 2009 at the age of 6 months, Cindy used her 37 years of quilting experience to help relieve stress and as a way to help other new families. Newly diagnosed families who receive these amazing hand crafted quilts love the fun pattern and uniqueness that each individual quilt provides. Countless families have commented on how thankful they were to receive one of these quilts, knowing how much time, love and tears were put into each and every one. We cannot thank Cindy enough for her creative approach to “sending a hug” to every newly diagnosed family. It is families like Cindy’s that show us why this organization is called Families of SMA!

Documentary on Spinal Muscular Atrophy
Features Six SMA Individuals

PBS series “Florida Crossroads” aired a moving documentary titled “Andy’s Army” inspired by the story of Andy Butler, who lost his battle with SMA last summer.

In an effort to raise more awareness for Spinal Muscular Atrophy in the state of Florida, several families in our Greater Florida FSMA Chapter were asked in December 2009 to talk about their personal SMA experiences on camera by “Florida Crossroads” producers. “Florida Crossroads” is an award-winning documentary series that airs statewide on all PBS stations, reaching 99% of Florida’s population. The interviews were developed into a moving half-hour episode of the series, titled “Andy’s Army”, after 5-month old Andy Butler passed away.

The documentary includes the stories of many SMA individuals including Andy Butler, Abigail Judge, Joie Smith, Allison Kerns, Elio Navarro and Tyler Hernandez.

You can view the documentary on the web at http://www.wfsu.org/tfc/fx-22_season.php. Scroll down to the bottom of the page and click on “View Now”, which is next to the entry for “Andy’s Army.” You will need Real Player to view the documentary.

Families of SMA would like to thank all of the families who shared their inspiring stories to help raise awareness for SMA.
The doctor cleared his throat. “I’m sorry, but I have bad news.”

He paused, looking down at the floor. He looked back up at her. He started to say something and then stopped, looking back down at the floor.

That’s when Pat began to cry.

She’d argued with herself about even coming to the doctor’s office. Her baby was a year old, and he hadn’t started crawling yet. He tried, yes, dragging his legs behind him as he struggled to make it just a few feet on the floor, but it didn’t look right. Everyone told her she was worrying over nothing, and maybe she was, but she told herself that she would take him to the doctor, just to be safe…

“Your son has a neuromuscular disorder called Spinal Muscular Atrophy,” the doctor said. “It’s a form of muscular dystrophy that primarily affects children.”

Pat was speechless. Everyone had told her she was silly. She had hoped she was wrong, prayed she was wrong, but still…she knew.

“What’s going to happen to him?” she managed to say.

“Where most children grow stronger as they get older, your son is going to get weaker. He’ll lose the ability to move. He’ll lose the ability to breathe on his own. And one day, he’ll catch an infection that will spread into his respiratory system, giving him severe pneumonia…”

She held up her hand to stop him. “You’re saying he is going to die?”

He nodded. “There are three types of SMA. Caught this early, your son almost certainly has Type I. Most children with Type I die of pneumonia before the age of two.” He paused. “I’m sorry.”

Pat looked up into his face and saw that he really was sorry. It made her angry. Not because of his pity, but because in this man’s eyes, her baby was already dead.

“Don’t be sorry,” Pat said, wiping tears away from her face. Her voice was suddenly very calm. “He isn’t going to die.”

“It’s important you understand the situation, Mrs. Morrow. The pneumonia… he won’t be able to fight it.”

“He won’t have to,” she said. “I’ll fight it for him.”

The miracle of mothers

Over the next 16 years, I had pneumonia 16 times. But I never died. It sounds strange to say it, but my mother wouldn’t let it happen.

She orchestrated a team of more than a dozen doctors. She slept in a chair beside me in the hospital, sometimes for as many as 30 days in a row. She pounded my chest and back every two hours to loosen the mucus, covering my chest and back with bruises.

Today, at 27 years old, I’m one of the oldest people in the world with my type of SMA, and people tell me it’s a miracle. And I agree, it is. But the miracle isn’t just me. It’s a mother who fought like only a mother can to keep me alive.

By “alive,” I don’t mean just “not dead,” either. You’d think my mother would have been satisfied for me to live at home, tucked away from the world where she could protect me, but for her, that wasn’t living. She insisted that I be great.

When my elementary school principal decided that disabled children didn’t have a place in her school, my mom appealed to the school board and turned every board member’s life into a living hell for two years.

She won.

When I wanted to play basketball, she forced an astounded coach to reinvent the rules of the game so that I could be the “ball carrier” for the team, and no one could take the ball away. Not surprisingly, everyone wanted me on their team.

When I could no longer pick up a pencil, she arranged for honors students at local colleges to help me with my
I’ve always had to fight to get people to listen to me.

The worst part about being disabled isn’t the pain or the struggle, but how the world tries to shove you into a corner and pretend that you don’t exist. After all, what could you possibly have to contribute? You’re going to die soon, poor thing. Here’s a nice, quiet room and some morphine to ease the pain.

They don’t proactively hold you back, no, but they don’t expect you to succeed either. I’ve spent my entire life fighting against the weight of those expectations.

Like when university professors were flabbergasted when, on the first day, I asked my attendant to raise his hand, so I could answer the question that no one else could.

Or the vaguely constipated look on the face of a venture capitalist when I asked for $500,000 of startup capital for my first software company.

Or the disbelieving stares of people at a real estate conference when I gave a talk about buying million-dollar homes without even being able to get up the stairs to see the inside of them.

Their disbelief has never stopped me, of course. It’s not a matter of persistence or strength or attitude, as some people think. It’s a matter of shame.

How could I possibly look my mother and father and all of the others who have sacrificed so much for me in the eye and tell them, “I can’t”? I couldn’t bear it. The shame of dishonoring their sacrifice by giving up would poison my soul.

And so I fight

If my mother could ignore a doctor who would condemn me to death, then I can ignore my inner demons who tell me I’ll never make it as a writer.

If my mother could demand that I achieve straight A’s in school, then I can demand greatness from every blog post I publish.

If my mother could lobby school administrators and government agencies to get me the help I needed, then I can lobby bloggers and social media power users to get my idea the attention it deserves.

Not to imply that I’m unique, because I’m not. Yes, I’ve had to overcome a lot of adversity, but so does every creative person who wants their ideas to see the light of day.

If you want to succeed, you can’t wait for the world to give you attention the way a cripple waits for food stamps to arrive in the mail. You have to be a warrior. You have to attack with the madness of a mother whose child is surrounded by an army of predators.

Because, let’s face it, your ideas are your children. Their future is as tender and delicate as that of any newborn.

That means spending ten hours on a post, instead of 30 minutes.

That means writing a guest post every week, instead of one every few months.

That means asking for links without any shame or reservation, not because you lack humility, but because you know down to the depths of your soul that what you’ve done is good.

You have to realize that your blog is more than just a collection of ones and zeros floating through cyberspace. It’s more than the words on the page. Your blog is a launch pad for your ideas, and you are the rocket fuel that lifts them off the ground.

So burn it up, baby.

Your ideas are counting on you.
I t has been several years since the birth, diagnosis, and loss of our first son to Type I SMA. In the seven years since I have learned what SMA is, so much has changed with regard to the availability and options of care that are now much more widely known about SMA. I frequently feel out of touch when it comes to the newer pieces of equipment, the dietary changes, therapies, surgeries, and treatments because so many things have changed since I have had to deal with it first hand; however, one of the things I am sure to stay current with is child passenger safety, or the way we transport kids in vehicles.

I became interested in car seat safety after my son Marshall was diagnosed with Type I when he was eight weeks old. I remember working feverishly with the physical therapist trying to find a comfortable and safe way for Marshall to ride in our vehicle before we had a car bed. I knew that due to his age and size he must ride rear facing, but I didn’t know that our current arrangement was suffocating him. It seemed that more and more often he was experiencing choking episodes in the car seat. I did not know that something like a car bed even existed.

I dreaded having to take him anywhere. I knew he was going to choke and turn blue when he was in his car seat, but I also knew it was not safe to hold him unrestrained while we drove. Once we learned about the car bed and started using it, things got a bit easier when we had to go anywhere. With the limits of the older style car bed though, I feared what would happen when he grew out of it. I knew some of the kids rode in modified vests while lying across the back seat. But I also knew many of them were much smaller than the minimum requirements for using such a restraint. But there were no other options. I promised myself that I would do what I could to learn more about special situations and safely restraining our SMA kids in vehicles with the hope of helping to improve the current options.

In 2007 I took a child passenger safety technician course, which gave me the certification to inspect and install car seats and to teach parents and caregivers how to do it correctly. Two months later, I took the special needs portion of the certification. While I learned a lot from the courses with regard to typical children and even our Type II and III kids, there was still a gap that needed to be filled for the little ones who have outgrown the car bed but do not yet meet the requirements for a modified vest. In December of this past year, I learned of something that is being developed currently that should fill that gap. Soon there will be a larger car bed on the market that is designed to handle children up to 35 pounds and 30 inches. This is a great development since the older version of the car bed (Snug Seat) was discontinued several years ago and those seats are now all expired. The increased weight and height limit are a huge benefit. I am really looking forward to acquiring some of these seats, which are expected out in April, for the kids who need them.

For those with stronger Type I children and Type II children who can tolerate a more upright position in the car, I strongly suggest a rear facing convertible seat. Remember the old standard? When the baby turned a year old and if he weighed 20 pounds most people turn their seats forward facing, because it’s what we’ve learned to do all along. The new minimum recommendation is now 2 years old and 30 pounds. There have been many studies and crash tests that support rear facing to the limits of the car seat for typical children with normal muscle tone. I can’t emphasize how much more important it is for children with lower muscle tone. Not only does a rear facing car seat provide much more support than a forward facing one, it has been shown to be 500% safer than a forward facing car seat in a crash. Why is this? Because although the spinal column will stretch up to 2 inches, the spinal cord itself will only stretch 1/4” before breaking. This is referred to as internal decapitation and causes paralysis and death.

In a frontal or side impact crash, the rear facing car seat cocoons the child and supports the head and neck. In a forward facing car seat, the child’s shoulders are held back by the harness straps but the head continues to move forward, increasing the risk of spinal injury, paralysis, or death. 96% of all crashes are either frontal or side impact. Most car seat manufacturers have answered the call by increasing the weight and height limits for rear facing seats. There are several new seats on the market that will now hold a rear facing child to 40 or even 45 pounds and there are many new options for forward facing children who ride in harnesses.
that will hold them to 65 or even 80 pounds before needing to switch to a booster seat. Since 2002, The American Academy of Pediatrics has recommended that ALL children ride rear facing in their seats until they meet the limits of the seat (a minimum of 2 years old and 30 pounds). For those of you wondering where your child’s legs will go, please see the pictures below of my son Anders. He is 2 years and 5 months old. He weighs 31 pounds and is still currently rear facing (quite comfortably!) in his car seat. His sister rode rear facing for almost 3 and a half years, when she outgrew her rear facing seat by weight. At 5 years old, she continues to ride forward facing in a seat with a 5 point harness. I feel good knowing that both of my children are as safe as they can possibly be.

Some points you may wish to remember when installing and using your safety restraints:

• Always read the seat’s manual and adhere to the limits and recommendations.

• When installing your car seat, there should be no more than 1” of movement at the belt path.

• Retainer clips, also called Chest clips, (for rear and forward facing seats) belong at the armpit level.

• The harness straps should be snug enough that you cannot pinch the harness together at the shoulder.

• If the child is riding rear facing, the straps need to be at or below the shoulder level.

• If the child is riding forward facing, the straps need to be at or above the shoulder level.

• Heavy coats and car seats don’t mix. The excess bulk prevents the straps from being as tight as they need to be. In the event of a collision, the bulk can compress, leaving straps loose enough to allow for ejection. If it is cold out, blankets or coats can be placed over the child after s/he has been securely restrained.

I continue to volunteer in safety seat check points and conduct private seat installs when time allows. I recognize the special circumstances of transporting kids who have special needs and continually take these into consideration. If I can answer any questions with regard to the safe transport of your SMA child or your typical child, please contact the FSMIA national office for my information. Wishing you all safe travels!

An Ongoing Sports Rivalry Between two Researchers and a Family who has two Kids with SMA!

By Natalie & Tim Gibbs of Roeland Park, KS

Over the nearly 11 years that our family has been a part of this SMA journey, we have met many wonderful, caring, intelligent and passionate people along the way. One couple truly stands out for our family. We are so fortunate to have Drs. Chris and Monique Lorson of the University of Missouri in Columbia, MO as part of our team! Nearly every year that we have had the Cure SMA Race-n-Roll in Roeland Park, Kansas, he would highly encourage his lab to attend the event and run the 5k along with him. A couple of times, he would be pushing a double stroller with his boys, Zach and Oakley in it, across the 5k finish line! He really wanted his lab to understand just who the lab is really working for. Because of this relationship with him, we have gotten to be great friends and enjoy the company of his wife, Dr. Monique Lorson, who is also working on grants for SMA, and his two great boys. Since Tim went to Baylor University and the Lorson’s are at the University of Missouri, we all try to get together any time the two teams meet up against each other in either football or basketball. This fall, we had the pleasure of making a trip to Columbia, MO to watch an exciting MU/Baylor football game with the Lorson family and our family. We all had a great time, but now Baylor is up on Missouri! It was a sad day for the Lorson’s, but a joyous day for the Gibbs Family! Our girls, Lauren and Claire, said that this was a good day to be in a wheelchair since Baylor beat up on MU and the girls had on their Baylor Gold and Green and no one would mess with two girls in chairs!
“I Love You Mom”

By Debbie St. Ongé

“I love you, Mom” is one of the many things that people who don’t live in our SMA world often times take for granted. It’s a very simple phrase, yet packs a powerful punch. It is something that I live daily to hear uttered from Veronica’s lips. Each night when I put her to bed I tell her that I love her and she says, “uh huh”. This is fine with me because that is what she is capable of saying. But my dream is that someday instead of her usual response she will say “I love you, too”.

I don’t have any doubt about how much she does love me. It is evident in her eyes through her expression, by her smile when she looks at me, through her tiny hand when she grasps my finger or through her tears when I am not here. My heart just yearns to hear her say it and it is never as imperative as it is around Mother’s Day.

Raising a child with Type I SMA is not an easy task. It is essential for parents to wear many hats, some of which are very uncomfortable. None of us enjoy having to fight doctors, insurance companies, school districts and even our own families in our pursuit to do what we feel is best for our children. We don’t like getting stared at when we go out in public and like even less how such ignorant behavior must make our child feel. We don’t appreciate doctors who feel they have input on what makes a quality of life for our child. We all want our children to have the best, most happy and fulfilling life that they so richly deserve. And God help anyone who gets in our way of doing so. You learn to be tough, thick skinned and you no longer sweat the small stuff. So why should hearing the words “I love you, Mom” matter so much to someone who is so resilient?

Every day we all run a gauntlet of emotions. We are a small community, very supportive of one another, and we keep in touch on a regular basis with each other. We love one another’s children as if they were our own, even if we have never met them in person. We worry when a child has to have surgery, we send prayers when someone is coming down with a cold or in the hospital, and we lose a piece of our heart every time we learn of yet another child who has lost the battle with SMA. Each one of us knows that it could be happening to us at any given time. Sometimes that realization makes it difficult to get through the day. But we’re hardy and we’re strong; we brush ourselves off and keep on fighting.

Fighting is easy when you know our children. When looking for a definition for inspiration you need look no further than into the eyes of a child with SMA. Veronica manages to bring out the best in everyone who knows her, just by being her. She inspires my creativity and keeps my mind young. She reminds me every day that we can overcome whatever obstacles are placed in our path. She loves life and all it has to offer, enjoying every new experience she encounters. She teaches us every day what it means to truly love another human being, all without speaking more than a few words. As a mother, that is everything one can hope for in a child, to inspire in such a way that the world is awe struck and blessed by their presence.

So I will hold onto my dream of someday hearing her say “I love you, Mom”. For now, I can take great pride in the realization that Veronica’s presence in our lives has significance beyond what we will ever understand in this world. I remain hallowed, humbled, and proud to be her mom.
The Patient Protection and Affordable Care Act: Health Care Reform

On Sunday, March 21, the House of Representatives passed a vote of 219 – 212 health care reform legislation, previously passed by the Senate on December 24, 2009 by a vote of 60 – 39. The Patient Protection and Affordable Care Act (H.R. 3590) was signed into law by President Obama on Tuesday, March 23. A “corrections” bill that is designed to alter H.R. 3590 to make it more palatable to House Democrats also passed the House on Sunday, March 21, by a vote of 220 – 211. The “corrections” legislation (H.R. 4872) presently is making its way through the Senate as a reconciliation bill, meaning that it cannot be filibustered. The bill is expected to pass and be signed into law shortly.

Collectively, H.R. 3590 and H.R. 4872 total more than 2,500 pages. The health care reform measures contain several provisions that impact the Families of SMA community.

Overview

The legislation has ten titles, which are described below:

• Title I: Quality, Affordable Health Care for All Americans – Fundamentally alters the manner in which health insurance is regulated in the United States by creating federal standards for health plans, establishing federal oversight of the issuance and purchase of health insurance, and creating new marketplaces, individual and employer responsibilities / mandates, assistance programs for qualifying individuals and small businesses, and punitive fines for individuals and employers that fail to meet certain obligations to purchase insurance. (See below for more detail on the insurance reforms).

• Title II: Role of Public Programs – Makes several changes to the Medicaid and Children’s Health Insurance Program (CHIP) to expand access and services. Requires states to provide Medicaid coverage to all individuals under the age of 65 and earning less than 133 percent of the federal poverty level.

• Title III: Improving the Quality and Efficiency of Health Care – Implements significant changes to several of the formulas through which Medicare reimburses providers in order to reduce federal expenditures and establishes new reporting requirements.

• Title IV: Prevention of Chronic Disease and Improving Public Health – Creates several new prevention and wellness programs and expands several public health and community-based health programs.

• Title V: Health Care Workforce – Significantly alters existing health workforce education and training programs and creates new health workforce programs to address the health care provider shortage.

• Title VI: Transparency and Program Integrity – Creates new reporting requirements for physicians, establishes federal oversight for nursing homes, and enhances programs aimed at combating waste, fraud, and abuse in government health care programs.

• Title VII: Improving Access to Innovative Medical Therapies – Establishes a process under which generic biological products can be licensed by the Food and Drug Administration (FDA) and expands the 340B program under which certain prescription medications are sold at a discounted rate to qualifying providers.

• Title VIII: Community Living Assistance Services and Supports – Establishes a new, voluntary, self-funded public long-term care insurance program (the CLASS program) to pay cash benefits to qualifying individuals with functional limitations for the purchase of community living assistance services and supports.

• Title IX: Revenue Provisions – Establishes several new taxes and fees to fund the availability of health care coverage to uninsured individuals and the expansion of public health, prevention and wellness, and health workforce programs.

• Title X: Strengthening Quality, Affordable Health Care for All Americans – Makes alterations to the previous nine titles and adds additional provisions, including: (1) providing coverage for individuals participating in approved clinical trials for life-threatening diseases, (2) providing incentives to states through the Medicaid program to offer home and community-based services as a long-term care alternative to nursing homes, and (3) creating of a Cures Acceleration Network (CAN) at the National Institutes of Health to support drug development collaborations between government, non-profit advocacy groups, and for-profit drug manufacturers for disorders for which incentives in the commercial market are unlikely to result in adequate or timely development.

Please see the Families of SMA web site for the full article – www.curesma.org.

Please do not hesitate to contact Families of SMA Legislative Coordinator Spencer Perlman at spencer@fsma.org if you have any questions about this important legislation or specific provisions contained therein.
**Please Contact Your Representative and Urge Them to Support the Spinal Muscular Atrophy Treatment Acceleration Act**

Now that Congress has completed its work on health care reform, it will begin to turn its attention to other health-related matters. During the next two weeks, Congress will be in recess, but staff for the health-related committees will be determining their priorities for the remainder of the year. This is a critical juncture for the Spinal Muscular Atrophy Treatment Acceleration Act.

At present, the Act has 84 cosponsors in the House of Representatives and 15 in the Senate; securing the support of 100 Representatives and 20 Senators would significantly raise the profile of the bill with committee staff. Please call your Members either in Washington, D.C. or at their district offices (or email them) to urge their support.

If you have any questions about the “SMA Treatment Acceleration Act of 2009” or for more information, please feel free to contact us at spencer@fisma.org.

See below for a current list of cosponsors, as of April 7th, 2010:

### House Cosponsors (84)

**Sponsor: Rep. Kennedy, Patrick J. [RI-1]**
*(introduced 4/28/2009)*

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<td>Rep. Murphy, Tim [PA-18]</td>
<td>2/26/2010</td>
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### Senate Cosponsors (15)

**Sponsor: Sen. Stabenow, Debbie [MI]** *(introduced 5/21/2009)*

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The Alabama Chapter has been very busy in the past year. We held several fun and exciting fundraisers and brought a lot of publicity to SMA.

**Pancake Breakfast Fundraiser**

On Saturday, June 27, 2009, the chapter held their first Pancake Breakfast at Applebees in Northport, AL. Tickets were sold to the breakfast. Tickets were also used to raffle off a three night stay at a condo in Gulf Shores, AL. Friends and families of the Alabama Chapter helped during the breakfast by cooking, serving and cleaning. A great time was had by all! The event raised $3,000 for the Alabama Chapter - not bad for a few hours of work on a Saturday morning.

**Party for a Cure**

On Thursday, October 15, 2009, the chapter held “Party for a Cure”. There were all sorts of items to be sold, such as market totes, jewelry, candles, embroidered towels, linens and burp cloths, bags, purses, etc. Terrific food was served at the event and wonderful fellowship was shared by all who attended. The best part of the entire evening was that the chapter was able to raise $700!

**Chloe’s Carnival for a Cure**

On Saturday, October 17, 2009, at the Providence School in Madison, AL, the inaugural Chloe’s Carnival for a Cure was held to raise awareness for Spinal Muscular Atrophy (SMA).

Chloe’s Carnival for a Cure was held from 10am-2pm and featured slides, moonwalks, clowns, balloon animals, face painting, pumpkin art and much more. Participation was FREE thanks to generous donations of many area sponsors. The day was very cold but the event turned out to be a huge success raising close to $4,400 for FSMA!

**Fraternity Order of Police Golf Tournament**

The Tuscaloosa Fraternal Order of Police held a golf tournament on Thursday, October 29, 2009 to benefit the Alabama Chapter of Families of SMA. Despite the rain, around 40 golfers played and raised $2,500. Everyone had a great time and a great attitude about the rain delay!

**Alabama Walk-n-Roll to Cure SMA**

On Saturday, October 31, 2009, the Alabama Chapter of Families of SMA held their annual Walk-n-Roll to Cure SMA. The walk was held in Tuscaloosa, AL. Over 220 people attended the event and the chapter was able to raise $36,000. It was a huge success!

The event included fun for the whole family. The chapter held a silent auction with items donated from several businesses across the state. The auction raised $6,200! A few of the items included photos and footballs signed by University of Alabama head coach Nick Saban, original works of art by local painters, themed baskets and vacation packages. Entertainment included a giant bounce house for the kids, clowns, face painting, pumpkin decorating and carnival games.

Members of the local Tuscaloosa Fraternal Order of Police helped cook the hot dogs and hamburgers. Local businesses donated soft drinks, chips and cookies for the lunch plates. Several local service organizations sent students out to assist with the walk as well. First Wesleyan Church allowed the chapter to use their facilities and helped to make the event a wonderful success.

Several families affected by SMA from all over the state were able to gather together to celebrate the lives of their children. It was wonderful to have so many people in attendance.

**Upcoming Events**

**Family Fun Day at Birmingham**

Baron’s Baseball Game – Sunday, May 16th, 2010

Pancake Breakfast – July 2010, date TBA, Birmingham, AL area

FOP Golf Tournament – October 2010, Tuscaloosa, AL

Walk-n-Roll to Cure SMA – Saturday, October 30, 2010, Tuscaloosa, AL

Party for a Cure – held throughout the year all over the state of Alabama. If you would like to host a party for the Alabama Chapter of FSMA, please let us know by emailing us at alabama@fsma.org.
The Arizona Chapter held their 4th Annual Walk-n-Roll on November 22, 2009 which raised an amazing $22,000 in support of Families of SMA. We had beautiful weather and a great turnout for the event!

There were several new families who attended the walk and were able to connect with other SMA families. Even the national office was in attendance to share the latest research developments.

There was a balloon release prior to the walk in honor and memory of those with SMA. Fresh N Easy, Safeway and Frito Lay donated items for lunch. There was a DJ, games and activities for the children following the walk as well as a raffle.

It was a beautiful and sunny day for our Northern California Walk-n-Roll event held on September 26, 2009. This Walk-n-Roll was our seventh annual event. We started by walking over paper “bricks” with names of family and friends affected by SMA creating a tangible reminder of the reason for our walk. We enjoyed strolling through soccer fields, near a playground, and around a pond and waterfall, talking with old friends and meeting new participants. The festive morning featured warm-up exercises, music by the Don Veca Trio, snacks galore, face painting, balloons and an exciting drawing for a Wii, an iPod Nano, a game basket and other items! Over 150 people attended and hundreds more donated. We raised over $33,000 for Families of SMA and had fun at the same time!
Rocky Mountain Chapter

On behalf of the Rocky Mountain Chapter – Families of Spinal Muscular Atrophy, I want to thank the many who donated and those who braved a cold morning on September 12, 2009, and the 300 who participated in our 10th Annual Cure SMA 5K Walk-n-Roll & Run Across America! Through your support and participation, this year’s event raised over $33,000! Thank you again for your generosity. Your support really does make a difference!

The Rocky Mountain Chapter received a check from the Mulay Family Reunion in honor of Lyza Weisman for $360. Cousin Sam Baron put together a video with old and new family photos—some dating back to the 1800’s. All nine children from the John and Catherine Mulay family were represented! The videos were sold for a donation to FSMA.

Our main event in the winter is the Gala! The 9th Annual Evening of Hope Gala was held on Saturday, March 13, 2010 and raised over $33,000. This year we welcomed back Jim Benemann, CBS4 Anchor as our Master of Ceremonies and our guest speaker was Dave Avrin, author of “The Gift in Every Day”. Kenneth Hobby, Executive Director for Families of SMA, gave an inspiring speech about the latest on SMA research. A live and silent auction, special guest musicians Arlene and Fiona Patterson, and dancing to the Bobby Marchetti Band was enjoyed by everyone! A very special thank you goes out to Joy Spellman, our Gala Chairwoman, who has done an amazing job for us over the last several years, and the hard working Gala committee for which we are grateful!

June marks the month of our Annual Golf Tournament hosted by Gillian and Martin Faith of Scottish Stained Glass. Planning for this fun day on the links is currently underway with a date and location to be scheduled soon. Our annual Walk-n-Roll is scheduled for September 11, 2010 in Denver. Julie Lino, family and crew put on an amazing event that just keeps growing.

We are interested in starting a support group for SMA Type I families. If you are interested in being a part of this group or spearheading the initiative please contact Loree Weisman. Are you interested in having more social events for friends and families of SMA to gather in the Rocky Mountain region? Any ideas, suggestions, and opportunities are welcome!

If you have friends or family in the Denver area, invite them to our next Cure SMA Walk event to be held on Saturday, September 11, 2010 at Clement Park in Littleton, Colorado.

Illinois Chapter

The Families of SMA – Illinois Chapter has been hard at work preparing for our upcoming Illinois Chapter Walk-n-Roll event. The event is to be held on Saturday, June 12, 2010 at the Independence Grove Forest Preserve in Libertyville, IL. The main walk is 2.5 miles with a shorter route option available. The trail is paved and runs through scenic areas of the preserve. There is a wheelchair accessible play area that is a sensory-rich play environment with state-of-the-art handicap-adaptable play equipment and wide paved pathways, making access comfortable and enjoyable for all visitors. Food and beverages will be offered. A DJ will help get the crowd motivated and warmed up for the walk. Lots of fun for a great cause!! Registration begins at 7:00 AM, with the walk starting at 8:30 AM. If you’re interested in participating, please register online at http://www.fisma.org/illinoiswalknroll2010.
On Saturday, May 23, 2009, Families of SMA Greater Florida Chapter held our first ever “Friends and Family Picnic” at Freedom Park, an all-accessible park in Tampa, FL. The picnic provided chapter members and their families with a wonderful chance to get to know each other better while enjoying great food and activities. The event featured a raffle and auction, with items such as diamond jewelry, spa products, theme park tickets and much more, to raise money for FSMA, as well as a balloon tribute in memory of those we have lost to the disease.

In the “Weigh to Go for SMA” campaign, which began on July 30, chapter members lost weight to raise awareness for SMA and funds for its cure. Participants asked friends and family to sponsor each pound that they lost over the course of this five-month fundraiser. On November 30, we were thrilled to announce that “Weigh to Go for SMA” participants lost in excess of 75 pounds and raised more than $3,000!

During the entire month of August, chapter members worked together on a grassroots awareness campaign in support of SMA Awareness Month. We wrote letters to our Congressmen and Senators urging their support of the SMA Treatment Acceleration Act and asked our friends and family members to do the same. We distributed press releases to the local news media to raise awareness, with articles published in the “Land O’ Lakes Laker” and “Families-On-The-Go Magazine.” We also launched a fundraising campaign with Mary Kay, raising a total of $679.80, and we attended several area bike night events, raising approximately $200.

On November 7, 2009, we held our inaugural Walk-n-Roll Across America event at Ft. Desoto Park in Tierra Verde, FL. In addition to walking, running or rolling the scenic one-mile course, participants at the event enjoyed fun activities for young and old, such as live demonstrations, music, games and prizes, while learning about the special needs that children living with SMA face each day. The event featured local celebrity host Steve Jerve, WFLA Channel 8’s Chief Meteorologist, as well as a demonstration by the Tampa Bay Crossfire Power Soccer team. A huge success, the walk drew more than 250 people and raised more than $11,000.

And finally, in an effort to raise more awareness for SMA in the state of Florida, several families in our Greater Florida FSMA Chapter were asked in December 2009 to talk about their personal SMA experiences on camera by “Florida Crossroads” producers. “Florida Crossroads” is an award-winning documentary series that airs statewide on all PBS stations, reaching 99% of Florida’s population. The interviews were developed into a moving episode of the series, titled “Andy’s Army” after 5-month old Andy Butler, who lost his battle with the disease last summer, and was broadcast during the week of February 15, 2010.

In our first year as a chapter, we appreciate all of the support that we have received from our community - by attending our events, donating to our cause, or simply cheering us on, you have helped to raise awareness for SMA and to make a difference in our fight against the disease. We can’t wait to see what happens in 2010!
During the month of February, companies and families of the Families of SMA – South Florida Chapter came together to support FSMA and it was a great night! We raised $210 on the 15% sales and $600 on raffles and donations totaling $810! Maylin and Diane worked hard to sell the raffle tickets for all the wonderful items. Maylin received donated items from various places in the community including Monkey Joes, Learning Express, Kabooms skating parties, movie baskets, Americas Backyard tree and lawn services. Thank you for all of your help and support making the night a big success! It was great seeing so many families come out to support us and connecting with one another. In addition to this success, Beef “O” Brady’s has also agreed to make every Monday night Families of SMA night and will donate 15% of their proceeds back to the South Florida Chapter of FSMA!

Then on Sunday, February 28, 2010, our chapter held our 1st Annual Families of SMA South Florida Chapter 5K Run, Walk-n-Roll, dedicated to Daniel Cevallos who passed away this past year after losing his battle with SMA. The event was a great success raising $15,117 and hosting 250 friends and family throughout our community. The Walk-n-Roll was held at View Vista Park in Davie, FL which has a Universal Access playground named Caitlyn’s Corral, in memory of Caitlyn Munson who died of SMA Type 1 and is dedicated to all children who play there.

The pathway was lined with pictures of local SMA kids and facts about the disease, so everyone was able to learn more about those affected in their local area. Families were also able to enjoy great activities such as bounce houses, face painting, nail art, free smoothies courtesy of Smoothie King, a silent auction, raffle and grilled hamburgers and hot dogs. Thanks so much to everyone that participated and donated to our event. Through your support, we are making a difference in the lives affected by SMA.
The Kansas City Chapter was once again in full swing this past October! On October 3rd, our Chapter hosted the Cure SMA Race-n-Roll in Roeland Park, Kansas (formerly known as the RoeFest Race-n-Roll). It was a chilly fall day, however that did not stop all of the runners, walkers, rollers, friends and family from coming out and supporting our event! We had about 400 participants and over 75 volunteers! This year, the Families of SMA National Office came in town to speak a few encouraging and positive words about what is going on with SMA and how all of us truly make a difference to help find a treatment and a cure! Our very own Lauren Gibbs who has Type III SMA kicked off the run by playing the National Anthem on her violin with a trio as well as two great lead singers! Our horn starter was Brett Wilson and then they were off…

After the 5k, or one mile, everyone enjoyed the kid’s dash, food, drinks, raffle and even a wheelchair accessible obstacle course! We want to thank all of our sponsors, participants, donors and volunteers for making this event such a success and so much fun! It was a great day to get together with our SMA families and truly know we are all helping to make a difference! The event raised more than $31,000!

In November, we had the pleasure of hosting a Thank You Reception for members and donors in Kansas City. Kenneth Hobby, FSMA National President expressed his gratitude to the chapter and donors for their loyalty and generosity over the years, and gave us an idea of where Families of SMA wants to go in the future. We had a nice event with many parents of children with SMA in attendance as well as some longtime supporters of FSMA.

On February 6th, some of our Chapter members were able to meet in Tulsa, Oklahoma. Two Chapter members, Lauren Gibbs and Peter Voskovitch, play on a wheelchair basketball touring team. While in Tulsa, we were able to meet up with the Nelson Family, who have two boys, Colby and Brady, both with Type III SMA. We all had a great time watching the team as well as catching up!

On February 13th, the KC Chapter hosted a Valentine’s Day Party in Overland Park, Kansas. The Cochran family, the Gibbs family, the Rice family, the Sykora family, the Voskovitch family and the Wilson/Koehler family were all in attendance! It was a really great turnout and the kids and adults had a lot of fun- we ate great food, played games, played Wii and had a Valentine’s Box contest and Valentine trade.
New England Chapter

Tupperware for a Cure!

In late August 2009, an email was sent from Owen Norton’s Mom to family, friends and neighbors regarding a fundraiser for SMA through Tupperware catalogue sales. Products in the fundraising catalogue yield 40% towards the charitable organization. The reception to the email was wonderful. Many replied that they had some Tupperware products in mind that they wanted to order, someone offered to host a party, and coworkers were eager to look at the catalogue and place an order. We put a box outside of our door for people to pick up catalogues or drop orders off. In just 3 weeks, we collected 90 orders! When the products arrived, we included a thank you with the order with a “Save the Date” for the Hingham Walk-n-Roll this spring. The end result was $1,601 for Spinal Muscular Atrophy!

In September 2009, the 3rd annual Poker Run Ride for Alex Pateakos took place with 26 bikers, raising $600 for Families of SMA.

On Friday, October 3, 2009, the Johnson family organized the 3rd Annual Families of SMA Fall Golf Tournament at the New England Country Club in Bellingham, MA. The event was a great success with generous sponsors and 178 golfers and dinner guests who helped raise just over $40,000 for FSMA. Their three year total for the fall classic is over $136,000! The 4th Annual event is scheduled for Friday, October 1, 2010.

Mike Lucci is running the Boston Marathon for Families of SMA. As part of his Marathon Journey Toward Fighting SMA, he hosted “Make it to the Point for SMA” on Saturday, February 28th. Fun was had by all with good food, a DJ and raffle items.

FSMA recently received a very generous donation from Kristine Pecora, New England chapter member.

To read Kristine’s letter, please see page 75 of our newsletter.

Iowa Chapter

On September 19, 2009, the 13th Annual Beaverdash was held on a beautiful day in Beaverdale, IA. This year we decided to change our event by making it not officially timed, but we did provide a timer for the more serious runners. With it not being timed, there were no medals, only prizes for the 1st and 2nd place men and women in the 5K and one mile. After the 5K and one mile events, we had the Beaver Trot for the little kids.

The kids love it, and each received a ribbon at the finish line to show their accomplishment. We also had a wheelchair race for the SMA kids, who love to turn up the power on their power chairs. Our mascot, Dale the Beaver, is always there to cheer everyone on. Even the Families of SMA National Office came to lend a hand by updating all of us on the progress we are making through research programs. It was nice having someone from the National Office there to see what we do. This year we made $20,000 through this event, with around 800 runners and walkers who signed up. With all the changes that we made and the economy the way it was, we felt we did pretty well. Thank you so much to everyone that donated and participated to our event, and we are looking forward to our 14th year hosting the Beaverdash in 2010!

Michigan Chapter

The Michigan Chapter of FSMA held its 6th Annual Flippin’ for a Cure Hamburger Dinner on November 6, 2009 at the VFW Hall in Portland, MI. We had a great attendance for the fundraiser. We served 450 hamburger dinners and raffled off nearly 100 prizes. Everyone enjoyed the entertainment and said that they would be back again next year. We raised approximately $4,000.

The extended Spitzley Family of Westphalia, MI held an auction at the annual family Christmas party in December. They raised $450 for Spinal Muscular Atrophy in honor of Mallory Armburstmacher, Great-Grand-Daughter of Mary Spitzley.

Mark your calendars for our upcoming 5K Run, Walk-n-Roll & Family Fun Day on Saturday, May 1, 2010 at Hawk Island Park in Lansing, MI. If you’re interested in participating, please register online at http://www.fsma.org/michigan5kwalknroll.
Greetings from our chapter and Happy 2010 to all! As we wait patiently for the snow to melt and the spring flowers to start popping, we are gearing up for a busy fundraising season. First, a shout out to Lanes Mill Elementary School for hosting a fundraiser in honor of Salvatore Morrongiello and donating $300 to Families of SMA!

Jason and Jessica Moyer, along with their good friend Phil Wandless, ran the Steamtown Marathon in Scranton, PA back in October. We all finished the 26.2 mile course in about 4 hours 20 minutes in memory of Steven Moyer and to raise awareness for Spinal Muscular Atrophy.

On April 17, 2010, our chapter is hosting Zumba Away SMA at Gold’s Gym in Dover, DE. Local Zumba instructors, including myself, will be leading several enthusiasts through a three hour Zumbathon. Hopefully this event will draw many out to exercise, while raising funds and awareness for Spinal Muscular Atrophy.

On May 15, 2010 the Potter Family will once again host Steven’s Walk to Drum Out SMA in honor of Steven Potter in Westmont, NJ. A huge thank you in advance to the Potter family and friends who always have an awesome event and turnout!

On July 23, 2010 the 4th Annual Steven’s Swing for a Cure Golf Tournament will take place at Jonathan’s Landing in Magnolia, Delaware. Please check our chapter web site at http://www.fsma.org/FSMACommunit y/Chapters/SouthJersey/ on these events as well as more information to come!

We always welcome new families in to our chapter so please contact us at southjersey@fsma.org! We look forward to seeing you at the Families of SMA Conference in June. God Bless!

On September, 20, 2010 we held our 9th Annual Walk-n-Roll event which, compared to the last year’s cold and pouring rain, was a perfectly beautiful day.

Despite these tough economic times, we were able to surpass last year’s donations, raising an outstanding grand total of $24,000, with $14,000 coming from online donations, which is fantastic! What a great job everyone and thank you so much for your generosity!!!

Check out our Top Fundraising Teams in order:

Team Sophia $4,285
Team Hennessy $4,015
Team Jack $3,755
Team Madesyn $860
Team Bradley $500
Team Bella $225
Team Lindsey $175

It was great to see each team with their brightly colored shirts walking and rolling with one another along the event path. Way to go teams and thank you for another great year!!!

So far, our Minnesota Chapter has sent in $30,000 to the National office of Families of SMA from various donations and fundraising.

SAVE THE DATE: 10th Annual Walk-n-Roll is tentatively set for Sunday, September 12, 2010 so mark your calendars and get your teams ready!
Greater New York Chapter

The Greater New York Chapter has some exciting events planned.

Our 6th Annual Walk-n-Roll to Cure SMA will be on Saturday, June 5, 2010 on the Long Beach Boardwalk at Riverside Blvd in Long Beach, NY at 11:00 AM. Registration is $25 per person. For more information please visit the walk’s web site http://fsma.org/gnywalknroll2010. The walk is dedicated to the memory of Max Rubenstein.

Our 3rd Annual SMA Awareness Day at Citi Field will be held on Sunday, August 1, 2010. Please look for details in the upcoming months on our chapter web site at http://www.fsma.org/FSMACommunity/Chapters/NYC/. This year’s event will be dedicated to the memory of Keira Sweeney.

The Greater New York Chapter was selected as the Local Charity of the 2010 Rockville Centre St. Patrick’s Day Parade. Members of our chapter marched in the parade on Saturday, March 20th. Our chapter is so honored to have been chosen and have enjoyed participating in this year’s parade events.

Many thanks to the Parade Board for selecting us.

Many thanks to Friends of Philly and the Mayer Family for donating $10,000 to the chapter from their Annual Golf Outing.

The Cure SMA New York Gala hosted by Kiley and Dylan’s Sweet Dream Foundation and Sophia’s Cure Foundation was a beautiful and inspiring evening helping raise funds and awareness in the New York Area. Congratulations to Award Recipients Dr. Darryl De Vivo, Ryan Burkett, Dennis Edison, Phillip Mayer and Dorothy Shuler. Thanks to all who attended and shared in this wonderful evening.

For more information on any of the Greater New York Chapter events or activities, please send an email to greaterny@fsma.org.

New Mexico Chapter

The New Mexico Chapter has been working hard to get their brand new chapter rolling by talking to families in the area and planning their first event. We have also had two chapter meetings which have been very productive. Our first event was a Pampered Chef Party. A group of us came together to help raise funds towards Families of SMA’s mission. The event raised $200, which is a great start. Thanks so much to everyone that attended and donated, and we look forward to planning our next event soon. If you are interested in becoming a part of the New Mexico Chapter, please contact us at (505) 353-1128 or newmexico@fsma.org.
Greetings from the Pennsylvania Chapter!

We have had a very busy year and are excited to welcome three new active families: the Schmids, the Kloibers, and the Schmidts. And huge thanks to our existing Chapter families for ALL THAT YOU DO! We also wish to welcome our two new Special Event Co-Chairs, Meghan Maggitti and Rocco Arizzi. Much gratitude to both of them for the energy, input and excitement that they are devoting to our Chapter.

Here is a little glimpse into what we are doing to FIGHT SMA!

FSMA Social at Dave & Busters - Saturday, February 27, 2010

In snowy February, our Chapter joined with the National office and the South Jersey Chapter for a Family Fun Event where over 150 family members, donors and volunteers received an informative update on our drug discovery programs and the future plans of Families of SMA. It was a fun-filled family day where good food and games were enjoyed by all. Our PA and NJ families were provided a great opportunity to network and reconnect with friends!

The Fourth Annual Emmy’s Crop for SMA – Saturday, March 13, 2010

Brandy Baugher, mom to angel Emmy Rose Baugher, kicks off her 4th All Day Scrapbooking Event to raise SMA research funds at the Old Parkville Fire Company in Hanover, PA. For 12 hours straight, scrap bookers will crop, join Zumba classes, and enjoy on-site massage therapy as they create their works of art. The day’s activities included: a silent auction, door prizes, raffles and t-shirts. Thank you Brandy for all you do!

The Jocelyn Paige Lee Foundation – April 17, 2010

Derek Schmidt, uncle to two year old Jocelyn Paige Lee, is organizing the 3rd Annual JPL Benefit Dinner/Dance. There will be a silent auction with chances to bid for trips to Myrtle Beach, Colonial Williamsburg and Atlantic City, along with a 3 day, 2 night getaway at a Wyndham Vacation Resort! Please join this Chapter family as they support Jocelyn Paige Lee and fight SMA at the Elizabeth Ann Seton Hall in Bear, DE. For more information, please visit www.jocelynpaigelee.org.

In addition, the Schmidt’s also generously donated $1,500 to FSMA in honor of their niece. Derek’s company matched that donation for a total of $3,000! Thank you so much for your generosity.

Micduff Professional Photography FSMA Photo Shoot – April 18, 2010

Professional Photographer Michael Duff has generously donated an entire day at his studio to FSMA families and friends! In half hour time slots, he will photograph your family and provide a CD with all the shots. There is no set fee, just donations to SMA! Mike is a true friend to our families, many of which know him as a beloved respiratory therapist at the Children’s Hospital of Philadelphia. If you are interested, please contact Mike at www.micduff.com.

The 5th Annual Ride to Fight SMA - Saturday, May 8, 2010

Chris Cooter, President of Calvary Riders is “calling all bikers” to the Nabrasa Brazilian Steakhouse on Rte. 611 and Jefferson Avenue in Horsham, PA. Last year, over 60 attendees enjoyed a beautiful motorcycle ride through Bucks County, PA while raising $1,688 to cure SMA! Bikers and non-bikers alike are invited to enjoy this great event. The day includes: a Ride Patch, a pin, great food, a DJ and a raffle. For more info please contact Chris at mjmcalvaryriders@verizon.net.

The 7th Annual Walk-n-Roll to Cure SMA - Sunday, May 16, 2010

Please join dozens of Pennsylvania SMA families and friends as we enjoy a leisurely stroll down the beautiful bike path along Boathouse Row in Philadelphia. The Family Fun Event takes place
at Lloyd Hall, directly behind the Philadelphia Art Museum from 9:00 am to 1:00 pm. Over 500 people participated last year in games, DJ music, and a raffle, as we raised over $70,000! Our families create TEAMS honoring the incredible strength of our beautiful children and professional photographers are there to capture the memories! Contact Pennsylvania@fsma.org for Corporate Sponsor referrals or registration info!

3rd Shoot for a Cure to Benefit SMA – Saturday, June 26, 2010
Andy Park and Erin Conner-Park are organizing their 3rd Annual 50 Target Fun Shoot in memory of their precious son, Tiernan James-Conner-Park. It will take place at FireBird Wing Shooting in Brookville, PA, from 10:00 am to 3:00 pm. New this year is a delicious Pig Roast which will be held at 12:00 Noon. Shooters eat free and only $5 for non-shooters. There will also be a Gun Raffle and a drawing is scheduled for 2:30 pm that day.

The cost is $25 per person (bring your own shells to participate in 60 shots plus side events; some 12 and 20 gauge shells will be available.) This year, the first 50 pre-registered adults will receive two Gun Raffle tickets (six guns are being raffled off) . Please contact Andy Park for more information at (814) 371-0203.

6th Annual Lukie’s Fall Festival – Saturday, October 9, 2010
In memory of her son, Luke Anthony Joseph Maida, Tara Maida is organizing another fabulous Fall Festival to help fund a cure for SMA. The all day event includes: food, raffles, face painting, pumpkins, hayrides, and tons of fun! Despite bad weather, the Maida family raised over $4,000 at last year’s event! Consider a day trip to Weona Park in Pen Argyl, PA to take part in this fun day! Please check the FSMA web site for information on this event.

Hillary Schmid fights SMA through her foundation “Sweet Baby Zane”

Philadelphia Phillies “Dollar Dog Night” to Fight SMA – Monday, September 20, 2010
On behalf of the PA Chapter for FSMA, Hillary Schmid is organizing an awesome night out at the Ballpark with the PA Chapter as the featured Charity of the night! She has reserved 600 tickets at $16 a piece, with the hope that “one and all” will come to support our cause (and watch the Phillies beat the Braves!) Please contact hillary_18@verizon.net for ticket information.

An SMA Fundraising Event at Kelly’s Bar – December 2009
A group of Hillary’s friends gathered at Kelly’s Bar last winter to raise awareness for SMA. After a fun night for all, $413 was raised and the host’s company, Bard, matched it for a total of $826 to FSMA!

Zane’s Run – September 2009
Last fall, hundreds of supporters turned out to honor the memory of five month old angel Zane Schmid, precious daughter of Hillary and Keith. It was a beautiful sunny day which began with a Fun Run and finished up with a timed 5K through scenic trails in Malvern, PA. Approximately $12,000 was raised that day and donated to FSMA research for a cure. Thanks to all who shared in this tribute to Sweet Baby Zane.

“Not a Fire Exit” Book Donations – November 2009 through Winter 2010
In the Forward of this novel, Hillary Schmid shares the emotional story of Zane’s life, as well as her family’s personal journey with SMA. In support of our mission to fight SMA, the author, Chris Finlan, donated a percentage of the sales from this novel. After his generous contribution and a matching donation from the SAP Matching Program, a total of $5,460 was donated to FSMA!

A Read-A-Thon to Cure SMA in Honor of Jake Saxton – December 2009
For the entire month of December, Sarah Deussing, a 2nd grader at New Hope-Solebury, held a Read-A-Thon to raise funds for Families of SMA in honor of her friend Jake Saxton. Sarah asked friends and family members to sponsor her. She read 760 pages and raised $400 to help find a cure for SMA! She is planning on making this an annual event and will recruit some more readers for next year’s Read-A-Thon to Cure SMA. Thank you Sarah! You are a super reader and super friend!
The Western New York Chapter of Families of SMA is off to a great start for the 7th Annual Walk for a Cure, with almost 400 corporate sponsorship letters mailed by the end of January. We will mail a follow up letter to companies who have donated to past walks in March. Even before the Corporate Sponsorship letters were in the mail we received a $9,000 donation in memory of Jake Faso. The donation came from Samuel & Son on behalf of Jake’s aunt, Paula. Jake lost his battle to SMA in 2008.

The SMART Walk will once again be held at Beaver Island State Park. We will have the same 2 shelters as last year, overlooking the Niagara River. It will be held on August 7th, with Senator George Maziarz and local KISS 98.5 DJ Nickolas Pickolas as co-chairs. A hot dog picnic will be offered at the end of the 3 mile walk. There will also be a basket raffle and 50/50 split. To participate in our upcoming event, please register online at http://www.fisma.org/wnywalknroll2010.

OKI Chapter

On behalf of the Nadeau Family and the OKI Chapter, the 8th Annual Nicole Nadeau Golf Tournament was a huge success! Jack and Kim Nadeau host this charity golf tournament in honor of their daughter, Nicole, to help raise funds for SMA awareness. The tournament raised $15,187!

The 7th Annual Walk-n-Roll will take place May 1, 2010 at the Cintas Center, Xavier University, 1624 Herald Avenue, Cincinnati, OH. To learn more about this upcoming event or to register online and begin fundraising, please check out our web site at http://www.fisma.org/okiwalknroll.

The Kentucky Walk-n-Roll will be Saturday, August 14, 2010 at Keeneland Race Course. The walk will start at 10:00AM. More information to come shortly on this fun-filled event.

Once again the OKI Chapter hosted a Halloween skating party for SMA children and their families at Skateland in West Chester, Ohio. Several children came dressed in costumes to skate to the music and lights for an hour before the rink was opened to the public. Pizza and drinks followed the skating and allowed time for families to talk and visit with each other. A good time was had by all!! Thanks to all the members that planned this event and to all the families that attended.

Camp for Courageous Kids will once again host a SMA weekend. It will be April 16th - 18th 2010. All SMA families are welcome. For more information and registration go to www.courageouskids.org.

A very special thank you to the Fraternal Order of Eagles #361 for their donation of $10,000 for SMA research.

The OKI Chapter has developed the Commitment 2010 campaign to raised funds to support Families of SMA’s mission to find a treatment and a cure for Spinal Muscular Atrophy. Consider a monthly donation of $20.10 to go towards research. To begin your monthly donations, please contact Elizabeth Lockwood at blockwood1@zoomtown.com.
**Tennessee Chapter**

The Tennessee Chapter continues to raise awareness and funds to find a cure. Upcoming events this spring include a benefit concert and a golf tournament. On March 25, country music artists came together at Cadillac Ranch in Nashville for Music For a Cure. Hosted by songwriter Warren Silvers (father of Aiden), the evening was a night to remember. In addition to performances from the country music capital, including “My Son” by Warren, there was an auction of memorabilia featuring a signed guitar.

Gettysvue Country Club in Knoxville, TN is the place to be on April 26 to Swing For a Cure. Enjoy a day out on the links with friends old and new at our sixth annual golf benefit. Radio station B97.5 will be joining us to provide a live broadcast. We are very fortunate to have this sponsor get the word out with on-air promos leading up to the event. Lunch (BBQ!) is included in the entry fee as well as beverages and snacks on the course. Test your skills in the putting green contest and go home with an item or two from the silent auction. Online registration is available at www.fsma.org/ngolfclassic2010.

These events would not be possible without the dedication of Warren Silvers and everyone in Nashville and Louise Ball (LPGA pro) and her team in Knoxville. We are truly grateful for the support of all our volunteers, after all Tennessee is the Volunteer State.

**Utah Chapter**

Shane Barber, President of the Families of SMA – Utah Chapter did an amazing job organizing their 1st Annual Utah Chapter Walk-n-Roll for Families of SMA. The event was held on Saturday, August 29, 2009 at the Willow Creek Park in the beautiful town of Park City, UT. Everyone enjoyed the festivities, especially the carnival, which included bounce houses, face painting, raffles, pony rides, games and great food. Thank you to all who participated and supported the event. Through your donations we raised over $4,500 towards research for SMA. Hope to see you all next year!

Dear FSMA,

Brynee Liston was originally diagnosed as Type I at 5 months old and a month and a half after her 2nd birthday, she sat by herself for the first time. She has since been rediagnosed as a weak Type II. For her second birthday, instead of presents we had friends and family donate to the Families of SMA - Utah Chapter. Thank you for all of the support!

*Sincerely Tara Liston*

**Wisconsin Chapter**

On August 8, 2009, the 2nd Annual Boscobel Walk-n-Roll was held in Southwest Wisconsin. This small town event raised an awesome $8,750 for Families of SMA. The day began with thunderstorms and prayers for clearing skies. At registration, the first blue skies began to peak through and by the time of the walk it was pleasant. A celebratory atmosphere included balloons, face painting and tattoos, snacks, and music provided by a local Christian rock group. The walk was followed by a $1 raffle with exciting prizes. Wisconsin kids who were there to represent FSMA at the event were: Easton (SMA Type II), Kaleb (SMA Type III), Leah (SMA Type II), and Avery (SMA Type I).

Save the Date! An Evening of Hope for Ari. Sunday, May 23, 2010, from 6:00pm-9:00pm at The Mineshaft Restaurant, Hartford, WI. Tickets are $20 each - proceeds go to support Families of Spinal Muscular Atrophy. The event includes a DJ, karaoke, raffles, appetizer buffet and knowing that you are supporting a great cause! For more information or tickets please contact wisconsin@fsma.org.

Please let us know if you have any fundraising events planned for this summer. We will be happy to help out in any way we can. You can now also join us on Facebook: Families of SMA – Wisconsin Chapter.

We know a lot of our kids have been fighting illnesses this winter. We hope that everyone is on the mend and that spring will bring health, happiness, and sunshine!

*Brynee Liston, Age 2, Type II*
<table>
<thead>
<tr>
<th>Chapter Name</th>
<th>Start Year</th>
<th>Address</th>
<th>Contact Person</th>
<th>Email Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama Chapter</td>
<td>2005</td>
<td>PO Box 71918, Tuscaloosa, AL 35407</td>
<td>Rhyan Granger, President</td>
<td><a href="mailto:alabama@fsma.org">alabama@fsma.org</a></td>
</tr>
<tr>
<td>Arizona Chapter</td>
<td>1997</td>
<td>85 W. Combs, Ste #101, PMB 410 Queen Creek, AZ 85240</td>
<td>Kaley Kaler, President</td>
<td><a href="mailto:arizona@fsma.org">arizona@fsma.org</a></td>
</tr>
<tr>
<td>Northern California Chapter</td>
<td>1998</td>
<td>PO Box 9014, Santa Rosa, CA 95405</td>
<td>David Sereni, President</td>
<td><a href="mailto:ncalif@fsma.org">ncalif@fsma.org</a></td>
</tr>
<tr>
<td>Southern California Chapter</td>
<td>1999</td>
<td>1070 E. Orange Grove, Burbank, CA 91501</td>
<td>Rosemary Roope, President</td>
<td><a href="mailto:scalif@fsma.org">scalif@fsma.org</a></td>
</tr>
<tr>
<td>Rocky Mountain Chapter</td>
<td>1998</td>
<td>PO Box 1913, Arvada, CO 80001</td>
<td>Loree Weisman, President</td>
<td><a href="mailto:rockymt@fsma.org">rockymt@fsma.org</a></td>
</tr>
<tr>
<td>Connecticut Chapter</td>
<td>2003</td>
<td>PO Box 18574, Hamden, CT 06118</td>
<td>Jonathan Goldsberry, President</td>
<td><a href="mailto:conn@fsma.org">conn@fsma.org</a></td>
</tr>
<tr>
<td>Greater Florida Chapter</td>
<td>2009</td>
<td>PO Box 13335, Tampa, FL 33681-1335</td>
<td>Katie Kerns, President</td>
<td><a href="mailto:greaterfl@fsma.org">greaterfl@fsma.org</a></td>
</tr>
<tr>
<td>South Florida Chapter</td>
<td>2009</td>
<td>PO Box 268122, Weston, FL 33326</td>
<td>Jennifer Smith, President</td>
<td><a href="mailto:southfl@fsma.org">southfl@fsma.org</a></td>
</tr>
<tr>
<td>Illinois Chapter</td>
<td>2006</td>
<td>PO Box 684, Grayslake, IL 60030</td>
<td>Janet Schoenborn, President</td>
<td><a href="mailto:illinois@fsma.org">illinois@fsma.org</a></td>
</tr>
<tr>
<td>Iowa Chapter</td>
<td>2000</td>
<td>PO Box 326, Johnston, IA 50131</td>
<td>Staci Bailey, President</td>
<td><a href="mailto:iowa@fsma.org">iowa@fsma.org</a></td>
</tr>
<tr>
<td>Kansas City Area Chapter</td>
<td>2004</td>
<td>PO Box 1189, Prairieville, LA 70769</td>
<td>Krista Scurria, President</td>
<td><a href="mailto:kansas@fsma.org">kansas@fsma.org</a></td>
</tr>
<tr>
<td>Louisiana Chapter</td>
<td>2005</td>
<td>PO Box 1189, Prairieville, LA 70769</td>
<td>Krista Scurria, President</td>
<td><a href="mailto:louisiana@fsma.org">louisiana@fsma.org</a></td>
</tr>
<tr>
<td>New England Chapter</td>
<td>1987</td>
<td>PO Box 2902, Woburn, MA 01888</td>
<td>Mike Barrett, President</td>
<td><a href="mailto:newengland@fsma.org">newengland@fsma.org</a></td>
</tr>
<tr>
<td>Chesapeake Chapter</td>
<td>1995</td>
<td>PO Box 354, Cockeysville, MD 21030</td>
<td>Barb Trainor, President</td>
<td><a href="mailto:chesapeake@fsma.org">chesapeake@fsma.org</a></td>
</tr>
<tr>
<td>Michigan Chapter</td>
<td>2004</td>
<td>PO Box 500, Ada, MI 49301</td>
<td>Ken Armbrustmacher, President</td>
<td><a href="mailto:michigan@fsma.org">michigan@fsma.org</a></td>
</tr>
<tr>
<td>Minnesota Chapter</td>
<td>1992</td>
<td>PO Box 32813, Fridley, MN 55432</td>
<td>Wanda Wosika, President</td>
<td><a href="mailto:minnesota@fsma.org">minnesota@fsma.org</a></td>
</tr>
<tr>
<td>South Jersey/Delaware Chapter</td>
<td>2002</td>
<td>PO Box 538, Medford, NJ 08055</td>
<td>Jessica Moyer, President</td>
<td><a href="mailto:southjersey@fsma.org">southjersey@fsma.org</a></td>
</tr>
<tr>
<td>New Mexico Chapter</td>
<td>2009</td>
<td>PO Box 90845, Albuquerque, NM 87199</td>
<td>Natasha Abruzzo, President</td>
<td><a href="mailto:newmexico@fsma.org">newmexico@fsma.org</a></td>
</tr>
<tr>
<td>Greater New York Chapter</td>
<td>2006</td>
<td>PO Box 322, Rockville Centre, NY 11571</td>
<td>Debbie Cuevas, President</td>
<td><a href="mailto:greaterny@fsma.org">greaterny@fsma.org</a></td>
</tr>
<tr>
<td>Western New York Chapter</td>
<td>2003</td>
<td>PO Box 444, North Tonawanda, NY 14120</td>
<td>Bonnie Shiesley, President</td>
<td><a href="mailto:wny@fsma.org">wny@fsma.org</a></td>
</tr>
<tr>
<td>Carolinas Chapter- North &amp; South Carolina</td>
<td>2009</td>
<td>PO Box 322, Rockville Centre, NY 11571</td>
<td>Rebekka Mastin, President</td>
<td><a href="mailto:greaternc@fsma.org">greaternc@fsma.org</a></td>
</tr>
<tr>
<td>OKI (Ohio, Kentucky &amp; Indiana)</td>
<td>2004</td>
<td>PO Box 54012, Cincinnati, OH 45254</td>
<td>Beth Lockwood, President</td>
<td><a href="mailto:oki@fsma.org">oki@fsma.org</a></td>
</tr>
<tr>
<td>Pennsylvania Chapter</td>
<td>2003</td>
<td>PO Box 4307, Philadelphia, PA 19118</td>
<td>Karen McRory-Negrin, President</td>
<td><a href="mailto:pennsylvania@fsma.org">pennsylvania@fsma.org</a></td>
</tr>
</tbody>
</table>

Are you interested in starting a new chapter for Families of SMA? Please contact our Chapter Coordinator, Sarah Hunsicker at chapters@fsma.org

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Tennessee Chapter (since 2001)
PO Box 7025
Knoxville, TN 37921
(865) 945-7636
Lise Murphy, President
tennessee@fsma.org

Texas Chapter (since 2005)
PO Box 1115
Hutto, TX 78634
(512) 846-2239
Eric Ostermayer, President
texas@fsma.org

Utah Chapter (since 2009)
PO Box 4137
Park City, UT 84060
(435) 901-4461
Shane Barber, President
utah@fsma.org

Pacific Northwest (since 2006)
PO Box 173
Galvin, WA 98544
(206) 284-1888
Rick Jones, President
pacwest@fsma.org

Wisconsin Chapter (since 1999)
PO Box 320516
Franklin, WI 53132
(414) 324-0499
Contact: Kate Vogedes, Laurie King, Jenny Imhoff
wiscin@fsma.org

Families of SMA Canada
Darren Bray, President
(800) 866-0016
darren@curesma.ca

New FSMA Chapters
We are extremely pleased to announce and welcome two new Chapters to the Families of SMA community.

New FSMA Chapters were recently formed in New Mexico, North Carolina and South Carolina.

Our Chapters make it their mission to support families and fundraise for SMA, giving hope to families in their community. Chapter fundraisers include Walk-n-Rolls, golf tournaments, and gala events. Chapter support includes providing resources to families affected by SMA, linking families together for mutual support, and providing public awareness in their communities for a wider awareness of SMA.

Have you ever thought about starting a chapter?

We want to hear from you.

CHAPTERS ARE REACHING OUT TO COMMUNITIES ALL ACROSS THE COUNTRY.

Families of SMA currently has over 28 chapters in the United States, but we are looking to expand!

Do you live in one of the following states?

Montana
Idaho
Nevada
Wyoming
North Dakota
South Dakota
Nebraska
Oklahoma
Arkansas
Missouri
Mississippi
Georgia
West Virginia

SUPPORT your community.
Fundraise for RESEARCH.
HOPE for families.
Begin to make a difference today.

Contact Sarah Hunsicker at chapters@fsma.org to receive more information on how to start a chapter in your state.
Dramatic Increase in Demand for Equipment in the Families of Spinal Muscular Atrophy Equipment Pool for SMA Families

Families of Spinal Muscular Atrophy currently provides services to over 70% of all SMA families. These families come to FSMA for information, support and equipment.

Just last month, we had 40 newly diagnosed families contact Families of SMA, all of which contacted FSMA within one month of diagnosis. These families are often in desperate need of necessary equipment that the FSMA Equipment Pool provides families. Some of these items include a medically necessary Car Bed for Type I infants, Bath Chairs for Type I, Type II and Type III individuals, Ez-On Modified Laying Down Vests for transport, Tumbleforms Feeder Seats, Special Tomato Feeder Seats, Strollers and Manual Wheelchairs.

The requests to FSMA for these equipment items have increased dramatically over the last year. We are now sending three times the equipment to SMA families than we did just two years ago. Families of SMA now sends over 30 pieces of equipment to SMA families each month.

If you are interested in helping us support these families with a donation to purchase new equipment items please email us at colleen@fsma.org.

Due to this increased demand we are now placing new families on waiting lists for these vital pieces of equipment. We are asking for your support.

$140 will help purchase an Ez-On Vest for a SMA toddler to travel safely.

$320 will help purchase a Tumbleforms Floor Sitter for an SMA child to sit comfortably.

$800 will help purchase a special car bed for a SMA baby.

$3,000 will help purchase a special needs stroller for a SMA child.

FSMA has Awarded Over 200 SMA Family Members Scholarships to Attend The Annual SMA Conference in 2010

These conference registration scholarships, valued at over $400 per individual, help SMA families to attend and experience the benefits of this amazing conference. Families of SMA has already given over 200 SMA family members conference scholarships to attend the Annual SMA Conference this June in Santa Clara, CA. This year, due to the positive feedback that we received from newly diagnosed families last year, Families of SMA is offering a conference scholarship to all newly diagnosed SMA families.

Families of SMA offers two types of conference scholarships. We offer scholarships to all newly diagnosed families, as well as offering a limited number of conference scholarships to existing SMA families who are interested in attending.

Through generous donations and sponsorships, FSMA will waive registration fees for any families newly diagnosed since the previous conference in 2009. This scholarship includes up to 4 immediate family members.

The meeting gives families:

- The opportunity to gather critical care and daily living information.
- To learn directly from experienced SMA physicians.
- To network with other families.
- To meet and interact with the researchers working to develop a treatment and cure.

Families of SMA has been hosting this conference for over 20 years. The weekend will be filled with workshops, a memorable kids program, a family and professional banquet, a family carnival, and opportunities to interact with other families and get first hand updates from the researchers.

To apply for a conference scholarship, please email info@fsma.org or call (800) 886-1762.

Newly Diagnosed families should plan to arrive before noon on Thursday June 24th, if possible, as we will start a special general workshop program for newly diagnosed families on Thursday afternoon.
The Rappoport Kids
Sophia Gaynor
Reagan Imhoff
Rashad Bakker
Sydney Potjer
Sara Greene
Maia Shockley
Nora Gooden
The Rush Family
Ryan Viano
Nicholas Lockwood with his Mom Beth
Michelle and Jenny Gaudreau
Rose and Dominic Lillo received a proclamation

Directions | Summer 2010
We need medicine with a heart…

The endless physical, emotional, and financial burdens that your family carries when a child is dying… make you totally incapable of dealing with incompetence and insensitivity.” - Salvador Avila, parent.

If the time comes when your child is faced with severe medical challenges you might find that you have been cast out to sea in a boat with no oars, sails, or motor. All of a sudden your life will change 180 degrees. Daily routines will have to change to support the needs of the sick member of your family and the other family members. All the small problems in daily life will now become trivial as the big question, “What is life all about?” takes precedence in your life.

You will find little help where you most expect it and some help where you least expect it. Angels in many disguises appear in your life to help you get through this transitional period.

The first thing you are going to think to yourself is, “Thank G-d I live in Canada and we have a socialized medical system; I will be taken care of.” After the devastating news of the first diagnosis you are going to find yourself bogged down in a Medical System that is under-funded, under staffed and regionally centered in large urban areas. All of a sudden you will find yourself sitting at a computer researching for the best options for your child while waiting for answers from your GP who is too busy/tired/unavailable/inexperienced in your child’s disease and whose time is spread so thin that you might feel forgotten even though the situation is life threatening.

You are now on the journey known as Advocacy. It is said that parents are the best advocates for their children’s health as they know their children the best. Shouldn’t our doctors know our children’s state of health better than us? Why are we expected to discover our children’s medical problems before being diagnosed by our doctors? Why do we have to get a referral to see a Pediatrician? - shouldn’t they be our children’s front line doctors in the first place? Why has the diagnosis taken so long using so many doctors?

We go before our doctors like Dorothy, the Scarecrow, Tin Man and Lion went before the great and all powerful Wizard of Oz. Unlike the four characters in the movie we need the help of highly trained medical professionals to deliver the best possible care to our children so that they can experience the highest and best quality of life. But in these times we look towards those we think are supposed to have more experience with our child’s condition naively forgetting that all the people in the medical profession and social work areas are only human. These professionals can suffer from the same maladies as the rest of the general population including: overwork, a stressful divorce, mental illness, addiction, abuse, depression, bankruptcy, skewed judgment, and most importantly, a belief system that is different than your own and on and on; yet we gladly hand over our children to these individuals and follow their advice without questioning their credentials, work history or getting a second and third opinion on the treatment prescribed. We give more thought to our family’s security when hiring a nanny, cleaning person or handyperson; we are talking risk management!

In Dr. Jerome Groopman, M.D.’s (Professor of Medicine at Harvard Medical School, Chief of Experimental Medicine at Beth Israel Deaconess Medical Center, and one of the world’s leading researchers in cancer and AIDS) new book “How Doctors Think” he states, “Usually doctors are right, but conservatively about 15 percent of all people are misdiagnosed. Some experts think it’s as high as 20 to 25 percent and in half of those cases, there is serious injury or even death to the patient.” According to Groopman, to be an effective consumer of medical services, patients need to realize there are two categories of physician thinking. “A physician’s emotions can color his or her thinking and actions,” he said. “Patients need to know how to pick up on negative and positive feelings.” Dr. Groopman also states, “if a patient genuinely feels the symptom is different from anything they’ve ever felt, to red flag it - ask the doctor to take it seriously, not to stereotype and make an attribution error. If you think a doctor is not listening, search out a second or third opinion.”

What is the definition of advocacy? The Oxford Dictionary describes advocacy as, “A person who pleads a case on someone else’s behalf - ORIGIN Latin: advocare (A call to one’s aid).” We are now speaking on behalf of our children. We are now researching our child’s illness to its fullest extent. We now have more scientific evidence in hand than our doctor, social worker, occupational therapist, physio therapist. We now find out that what the system wants to do for our child is obsolete, antiquated, not what we want, and that we want to pursue a different avenue of care that we believe (from our research) will have a more positive impact on our child’s quality of life. If your doctors
opinion is in contrast to your researched scientific documentation, ask your doctor for cited information or similar evidence you can read, discuss the research with them and together make logical decisions.

I have created a few simple steps that will make you an affective advocate for your child.

1) Research
Documentation and communication has never been easier and more available than with the internet. If you don’t have a computer there are many places you can use one, such as internet cafes, libraries, friends etc. It is true that there is a lot of information which is questionable on the internet, but there is also extremely timely, cutting edge and relevant medical information available to the masses. Some of this information has to be paid for, for example, medical publications of cited studies. We no longer have to use our doctors as the only source of medical information. We now have the ability to become highly knowledgeable and effective in the treatment and care of our children.

2) Doctors’ Information
Ask to see Cited Studies, Clinical Evidence, Empirical Studies, Peer Reviewed Studies and ask for their personal opinions. Take the time to ask your doctor for all documentation regarding your child’s illness. Question what you are told and ask for evidence. This is not the time to follow blindly. Speak to an expert! Caveat Emptor - Buyer beware also applies to medical services being supplied to us even though the system is socialized. You deserve the best care for your child. Ask your doctor what choices in care are available to you.

3) Support Groups
The internet is the fastest way to reach out to others that have been through what you are going through. Reach out by joining online chat groups. There is power in numbers. There are families out there that have been through what you are going through and will have great success advocating for their children. Find mentors through parents of children with your child’s illness. Often these parents will have done much of the homework before you and can cut your learning curve in half, pass along relevant cited medical information, etc. You can also reach out to doctors all over the world that are experts in the field of your child’s illness and ask them for information to give to your doctor.

4) Put it in Writing
If you have to convince someone in the medical system that your option of care is more feasible and in line with your philosophy then put it in writing along with the evidence backing up your argument. There is nothing more powerful than the written word. Before putting anything in writing, make sure you are respectful, knowledgeable, organized and formal. The whole point is to convince your doctors that there is a better way to do things and that you want to work as a team in the best interest of your child.

5) What does your medical professional believe?
You and your doctor have to be on the same page. Ask your doctor what their belief systems are in this case. Ask them what they would do for their child if they had what your child has? What would they like to see as the outcome of their medical intervention? You have to work as a team with your doctors when you have a catastrophically sick child, and if you don’t have the same vision for your child’s treatment and its outcome then you have to find someone or go somewhere where you can get the correct care delivered to your child.

6) Media and Government
Sometimes the system fails. It will seem as if you are sitting in a small room with only three people in it, screaming at the top of your lungs, yet no one hears you. When all else fails and you have used every politically correct correct diplomatic form of communication at your disposal, you might have to ramp up the pressure to get what you need. You should contact your MLA in your local government and the people you voted for. I would strongly suggest using the media. The media is a champion of human rights causes. Call your local radio and television stations.

Though our medical system often seems adversarial when you are depending on it in your greatest time of need, you must strive to find common ground and work as a team to deliver the best care possible for your child. In summary: 1) research and back up what you are asking for with qualified information 2) correspond in a respectful, logical, written format 3) if your child is not getting their needs met by your medical professional find another one that can deliver the appropriate care and 4) if all else fails go to the government and the media. I would like to end this piece with a quote I heard on the radio from one of Canada’s leading child advocates, June Callwood, “Help should be defined by those that need it, not by those who deliver it.”

Brad Fisher is the full time care giver to his 4 1/2 year old term inally ill daughter Shira, who suffers from Spinal Muscular Atrophy Type 1. Brad lives in Victoria, Canada with his wife Maxine and his 7 year old son Samuel. Brad can be reached at asonginthisworld@gmail.com.
The Importance of Independent Scientific Oversight in Prioritizing, Selecting and Managing SMA Research Projects

Who are the FSMA advisors?
FSMA has three key advisory teams, which include:

- The newly formed Translational Advisory Council (TAC), who govern drug discovery development projects
- The Scientific Advisory Board (SAB), who govern basic research
- The Medical Advisory Council (MAC), who govern patient support services

What are the main functions of our advisors in research funding?
- Advise on the best scientific strategy for our research programs
- Generate the FSMA yearly request for proposals
- Review grant applications, resulting in a rank order of all grants received
- Review requests for talks at the Annual SMA Research Group Meeting
- Develop criteria for successful benchmarks of FSMA funded projects
- Serve on management teams for funded projects, representing FSMA

What is the FSMA funding model?
The Families of SMA research-funding model is firmly based on the philosophy of expert and independent review and oversight of research projects. The FSMA strategy consists of having expert advisors review, prioritize, select, and then oversee the research projects that we fund. This system has many advantages. Primarily, it ensures that FSMA funds only the most promising research, and that the funded projects are run in a professional and efficient manner under the guidance of world-class experts. This type of system is the gold standard for effective scientific funding worldwide and is used extensively by both governments and non-profit groups. It is often referred to as “peer review”, which means scientists working in similar areas judge each other’s work.

What specific advantages does the peer review system of evaluation give?
People with similar training are in the best position to judge research.
One of the most obvious advantages is that the members of our advisory boards are leading experts in SMA, who have received many years of scientific training. Scientific feasibility of projects is often based on very detailed technical issues, which are not always obvious to the untrained. Research is highly specialized, so peers with similar expertise are in the best position to critique and understand each other’s projects. Even on our SMA-focused SAB, FSMA has carefully chosen advisors with distinct sub-specialties (mouse work, motor neuron biology, etc). Then the two advisors whose backgrounds fit best with a particular project are selected to judge that grant.

Our advisors help manage funded projects.
Our scientific advisors also oversee the progress of funded projects. This aspect is the key in the drug discovery / development area. Typically, funding in this area is provided in a series of milestone payments, meaning the project must demonstrate specific benchmarks of success in order to receive money. At FSMA our scientific advisors help determine benchmarks for projects and also decide if those benchmarks are met. This enables programs to progress more rapidly and efficiently. Second, our advisors become a key resource for project teams, by providing technical expertise, tools and reagents. These help overcome the series of technical hurdles typically encountered during projects. Finally, one of the hardest but most essential roles of our advisors is to end projects that have reached insurmountable hurdles.

How does the FSMA funding model of expert oversight impact your giving?
Importantly, our scientific funding model of project selection and oversight by independent experts does not prevent our donors from having a voice in what FSMA funds. Earmarked donations to particular projects are possible at FSMA and also still allow for project assessment by independent experts in the field. Direct donations to researchers themselves do not provide this security. Non-restricted donations to FSMA are important too and allow our advisors to prioritize research funding freely.
Families of Spinal Muscular Atrophy Research Funding Leads to the Publication of 18 Journal Articles in 2009

The ultimate goal at Families of Spinal Muscular Atrophy is to accelerate the discovery and development of a treatment and cure for SMA. To help achieve this, we fund basic research grants, along with drug discovery programs and clinical trials. FSMA research funding has contributed to the results in 18 published articles in 2009.

Funding was provided from Families of SMA to the following institutions to conduct this research:


Basic research allows us to solve critical unanswered questions in SMA biology. This then reveals new and more effective ways of making SMA drugs and helps us build a robust and diverse SMA drug pipeline. Some examples of the important results from our basic research funding over the past 25 years are:

1. Mapping and cloning of the SMA gene.
2. Identification of the SMN protein and its roles in the cell.
3. Discovery of the back-up SMA gene, called SMN2, that provides a unique and straightforward approach to develop a treatment for the disease.
4. Development of animal models for SMA to test new and existing drugs.
5. Identification of existing FDA approved drugs, such as VPA, PBA, HU and others, as potential drug candidates for SMA.

One way to assess whether our basic research funding is accomplishing what it should is the number of peer-reviewed research articles published in scientific journals. Scientific publication of the research that we fund indicates that our investments are leading to new and important discoveries about SMA.

See the Families of SMA web site, www.curesma.org for full article.

Stem Cell Based Treatment for Spinal Muscular Atrophy Receives Orphan Drug Designation

California Stem Cell, Inc and Families Of Spinal Muscular Atrophy Reach Significant Milestone in Development of Motor Neuron Treatment For SMA.

IRVINE, Calif. (December 8, 2009) – California Stem Cell, Inc. (CSC) and Families of Spinal Muscular Atrophy (FSMA) announced today that the FDA has granted orphan drug designation to MOTORGRAFTTM, a stem cell-derived motor neuron product, for the treatment of Spinal Muscular Atrophy (SMA).

Orphan drug designation, granted by the FDA Office of Orphan Products Development, provides several incentives to companies in the private sector developing novel drugs or biologics to treat diseases with relatively small market potential. These include seven years market exclusivity following FDA approval, clinical trial design assistance, reduced user fees and tax credits.

See the Families of SMA web site, www.curesma.org for full article.

Science-Business Exchange Publishes Cover Story on Families of Spinal Muscular Atrophy Funded Paratek Pharmaceuticals Drug Program for SMA

SciBX reports in their current cover story that a partnership between Paratek Pharmaceuticals and Families of Spinal Muscular Atrophy has resulted in tetracycline derivatives that can address the root cause of SMA. The biotech, together with collaborators at Cold Spring Harbor Laboratory and Rosalind Franklin University, has shown proof of concept for such a small molecule in mice.

Families of SMA has invested over $2 million in this program over the past four years with grants directly to Paratek Pharmaceuticals, Dr. Krainer at Cold Spring Harbor Laboratory, and Dr. Hastings at Rosalind Franklin University.
Natalie Quintana

Ariana Dindzans skiing at Alpine Meadows, CA

The Dougherty and Murphy Families sledding

Kale Shiesley

Anthony Cancel

Sierra Journey Factor

Owen Norton

Carolyn and Perkins Barrett

Emma and Nicholas Lockwood with their Dad Kevin

Eleanor and Jack Bolton

Griffen Kingkiner

Jenna Boguhn

Joshua Tramontano

Nora Gooden

Lizzy Hallam

Nathan Cooper

Eleanor and Jack Bolton
Reece Melber of Overland Park, KS celebrated his 9th birthday by having a martial arts party at Ko’s Black Belt Academy. Instead of presents, he told his friends that his wish was for donations to FSM A in honor of his good friend and next door neighbor Charlie Sykora (Type I). He was successful in raising $390. An interesting coincidence was that the instructor from Ko’s also has SMA. She has lived with adult onset SMA since her late teens. A successful fundraiser and a small world all in one.

Dear Families of SMA,

I am so glad to be able to help everyone in the search for the cure. My family is continuously waiting for help for Matthew. Thank you so much!

With Gratitude,

Lydia Wallis

Lydia Wallis of Longview, TX had an “Empty your Pockets for SMA” collection of change at her dad’s office. The $83.18 collected is in honor of her cousin, Matthew Wallis, who is 10 years old with Type II SMA.

Madison Verman of Villanova, PA had a lemonade stand set up to raise money for SMA in memory of her friend Zane Schmid. She was able to raise $25!

FSMA South Jersey/Delaware Chapter Students Unite to fight Spinal Muscular Atrophy

Students learn the value of hard work through lemonade stand business.

The first graders at Oldmans Township School in Pedricktown, NJ are involved in a Social Studies Unit: Work! Work! Work! The students have been learning about needs, wants, goods, and services. The six and seven-year olds have set up a class business, a lemonade stand.

The students had to vote on a name for the business. The kids liked “Lemonade Sellers!” Then, they decided on a price, 25 cents a cup. With the help of generous families, supplies were donated (lemons, sugar, cups, straws, napkins, tablecloth and spoons). The students also had to design business signs during their computer lab time. Signs were then posted around the school. Each day, the Lemonade Sellers opened for business.

Now that the class has been earning money, they have learned the difference between two words: spend and donate. The students will spend their earnings at the school’s book fair. But even better, the class has decided to donate half of their earnings to SMA! One of the students, Joelle Martins, had a sister with Spinal Muscular Atrophy. Joelle hung Baby Jaelyn’s picture at the stand. Baby Jaelyn has taught these first graders how to care and help others in need. Thank you, Baby Jaelyn and the Martins family!

Dear FSMA,

I am Zane Schmid’s cousin Cassidy Kearns. After Thanksgiving dinner my grandma helped me put on a live auction with Thanksgiving decorations my brothers, Cameron and Golden and I made to raise money for FSMA. We made over $50, we would like to donate to help kids with SMA. Thanks again.

Sincerely,

Cassidy Kearns

Nine year old Bailey Walters is a 3rd grader at Drake Elementary School in North Tonawanda, NY. She is a girl scout, loves to play outside, imagine and daydream like most girls do. She has been best friends with Kale Shiesley since Kindergarten and from this early beginning she has never seen Kale in a wheelchair living with SMA Type II. She has always been there for Kale as a helping hand and just a great companion. On her own she has been doing homework on the tremendous strides in the research, treatment and cure for SMA. So much in fact that her mother Sue would tell her to go play outside, but she demands to sit in front of the computer screen reading away, absorbing all the SMA information like a sponge. One day Bailey approached her parents with an idea. She explained the SMA research and said she wanted to help be a part of finding a cure. With her own money she would like to design a bracelet and then sell them to raise money for SMA. She told her parents that she would like to have “SMA” on one side of the bracelet and on the other “Let Them Dance”, because she believes that there will be a cure for SMA and her dream is to dance with Kale at their 6th grade dance. Bailey’s mom Sue was blown away by her request. She told Bailey that it was a wonderful thing she was trying to do for Kale, but maybe she should focus on her own disease, Juvenile Diabetes, but Bailey replied “Mom everyone knows about diabetes, but nobody knows
about SMA”. If this wasn’t enough, Bailey asked her parents if she could approach some of her family members that own businesses to help sponsor the local SMArt Walk for a Cure, and set up meetings on her own to make her presentation on Kale and SMA. Bailey is truly a remarkable girl and a true friend.

Emma Goldsberry (SMA II) is shown here with Sabrina Lee, the latest recipient of the Emma Hope Award, at the NES Elegance Pageant in Windsor Locks, Connecticut in August. Sabrina is also from Connecticut. Elegance is the latest pageant from NES director Tammy Rezendes that donates entry fees from the Emma Hope Award to FSMA. The fees from the Elegance pageants, photo contents, and other donations, have totaled over $8,000 in donations for FSMA from NES. The Emma Hope Award is given to the participant displaying the most kindness towards others.

Jonathon Goldsberry

Dear FSMA,

Enclosed please find a check for $195. This money was amassed over the past couple of months by the children (ages 2½ to 5) in our nursery school. Every Friday in honor of our Sabbath, the children bring in money (pennies, nickels, etc.) for charity. At various times of the year we choose a charity and send them money. We chose your group because a sibling of one of our students, Ethan Fantel has a one year old brother Ray with Spinal Muscular Atrophy.

I hope this helps educate people about SMA.

Sincerely,

Phyllis Deneberg, Director

JCC of North & South Brunswick,
New Jersey Nursery School

Dear FSMA,

Enclosed, you will find a cashier’s check for $158. Last fall, our student council did some brainstorming and came up with the idea of having a PJ day to raise money for a cause close to home. We have a student at our school that deals with Spinal Muscular Atrophy every day. She is an inspiration to many and the kids voted to have this year’s service project dedicated to raising money to help those with SMA.

On behalf of Ellie Stitzer of Columbia, Missouri, I would like to present you with this money to help the kids and their families.

Sincerely,

Pamela S. Brown

Hi FSMA,

These donations were collected at the combined birthday parties for Charlie and Lily Sykora. In lieu of gifts, Charlie and Lily asked for donations to be given to Families of SMA. More than 60 kids attended the party and had a great time! It was a big success and I believe that with the donations that were sent directly to FSMA, more than $1,500 was raised by them! We are very proud of Lily and Charlie. Charlie, SMA type I, turned 6 on August 22 and Lily turned 8 on August 31. Also, the Math Monkey (a math tutoring store Lily attends) and Wine Flights (an area restaurant) threw a fundraiser called PizzaPi and decided to have FSMA be the charity this year to donate their money to and raised $161!

Thanks so much!

Kim Sykora of Leawood, Kansas

Dear Families of Spinal Muscular Atrophy

At our school the first Friday of each month is dedicated to a collection for a charitable organization. The students of St. Patrick School in Washington, Illinois collected money for Spinal Muscular Atrophy this past month. The name of your organization was given to us by Mrs. Marie Taraska, a former Spanish teacher at our school.

Please accept this donation of $87 and our prayers are with the children and families.

Sincerely,

Dr. Sharon Weiss, Principal

Dear FSMA,

Please accept our donation of $1,030 for research to help find a cure for Spinal Muscular Atrophy. Our school, West Rocks Middle School of Norwalk, Connecticut worked very hard to raise money for this amazing cause and in honor of Philip “Cubby” Wax.

Thank you,

Robin Gudinger

FSMA,

Here is $615 that was raised in honor of my daughter, Veronica St. Onge’s 5th birthday party. We always ask for donations in lieu of presents and our guests came through again this year!

Thanks!

Debby St. Onge of Bigfork, Montana
Dear FSM A,

Here is a picture of a dolphin that Robyn Plaster painted in oil, and in the other one, she is swimming with the dolphins… her life dream!!!! Robyn was diagnosed when she was about a year old with SMA… She is now 16 years old and with the love, prayers and hopes of her parents and family, she has grown into a wonderful loving young lady!

Carol and Gil Albert, Robyn’s grandparents of Huntington Beach, CA

Dear FSM A,

Attached please find a photo of Ross, our 9 year old son with SMA Type III. Our family went to Catamount Mountain in Hillsdale, NY last winter. We were fortunate to work with STRIDE Adaptive Sports while we were there. They made Ross feel comfortable from the time he walked into the ski lodge. Ross had lessons with STRIDE and then skied down the mountain with their help. There were two instructors that worked with him and it was something we never imagined! We never thought that our son would ski, but the instructors at STRIDE were amazing and it happened!

Sincerely,

Alisa & Brett Rosenfeld of Roslyn Heights, NY

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Dear FSMA,

My sister, Victoria, died from SMA. Since then I have run a race and collected money so I can help find a cure for SMA, so more children won’t die from this disease. Almost every year I have run this race for my sister for a birthday present to her. This year, 2010, I have raised $800 to donate to FSMA.

Sincerely,

Philip Meneghini

---

Maija’s Valentine to sister Ariana Dindzans

Eloise Pillarellas hanging in Costa Rica

Eloise Pillarella of Staten Island, NY, SMA type III, is a freshman in high school this year who writes and draws for her school paper. Here is one of her drawings that she did for the paper, shown above.

Eloise is also involved with the Newman Club, Key Club and Environment Club. She is also in the International Baccalaureate Program and takes A.P. Art.

Dear FSMA,

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Sincerely,

Alisa & Brett Rosenfeld of Roslyn Heights, NY
uniting families with researchers to find a treatment and cure for SMA
Courtney Rosas with a butterfly

Abigail Judge

Addison Tarrence

Arianah Martin

Adora Lewis

Amelia Wong

Aiden Bundy’s 3rd Birthday

Ariana Dindzans with Dancing With the Stars Lacey Schwimmer and Gilles Marini

Brynlee Liston

Briahna Johnson as a unicorn for Halloween

Ben Nelson

Carolyn Barrett

Anthony Cancel with sister Anabella
Dear Families of SMA,

I would like to have this poem placed in the SMA newsletter in memory of my granddaughter, Dallas McKenzie Willey. She was born November 8, 1996 and died December 3, 1997. We are so proud of the progress that is being made for all the special children and adults with SMA. McKenzie’s parents are Darrell and Alice Willey from Lancaster, Ohio. McKenzie has two brothers: Shawn Willey, 18, who proudly serves in the United States Marine Corps and Nathan Willey, 8, at home with his parents in Lancaster. We all love and miss her so very much.

Thank you,
Sue Hill

“Heaven’s Very Special Child”

A meeting was held quite far from Earth. It was time again for another birth. Said the Angels to the Lord above- “This special child will need much love. Her progress may be very slow, accomplishments she may not show. And she’ll require extra care from folks she meets down there. She may not run or laugh or play, Her thoughts many seem quite far away. So many times she will be labeled ‘different’, ‘helpless’ and disabled. So, let’s be careful where she’s sent. We want her life to be content. Please, Lord, find the parents who will do a special job for you. They will not realize right away the leading role they are asked to play. But with this child sent from above comes stronger faith and richer love. And soon they’ll know the privilege given in caring for their gift from heaven. Their precious charge, so meek and mild is heaven’s very special child.”

IN MEMORIAM

Dallas McKenzie Willey
November 8, 1996 – December 3, 1997

IN MEMORIAM

Kelly Goff

IN MEMORIAM

Gabby Stack
March 3, 2009 - April 26, 2009

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IN MEMORIAM

Kelly Goff

Dear Families of SMA,

Thank you for your beautiful card and kind words, and thank you for the exquisite statue. We love all things Willow Tree and even have the Nativity set. This particular ‘Embracing Angels’ is so appropriate. We carried Kelly like that for many years! We are very touched by this gesture and will always keep FSMA in our thoughts and prayers. You have been a great comfort to us over the years!

Kelly packed a lot into her 18 years, she graduated in May with honors and was beginning as a freshman at Florida Gulf Coast University. She got to live her dream!

Thank you so much! Your words touched us deeply!

Tom, Dianne & Mason Goff
of Oakland, MI

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March 3, 2009 - April 26, 2009
IN MEMORIAM
SIDI SEYALAN
JUNE 2009 - FEBRUARY 24, 2010

IN MEMORIAM
CHRISTIAAN JANSE VAN RENSBURG
JULY 8, 2009 - JANUARY 9, 2010

IN MEMORIAM
MAGGIE LAGANA
OCTOBER 7, 2009 - FEBRUARY 3, 2010

IN MEMORIAM
PIPER WILLINGHAM
AUGUST 23, 2005 - JANUARY 26, 2006

IN MEMORIAM
CHARLIE HARRIS
NOVEMBER 26, 2009 - DECEMBER 13, 2009

IN MEMORIAM
ETHAN JAMES CARTER
MARCH 29, 2009 - OCTOBER 14, 2009
IN MEMORIAM
Nova Irene Damm
We are forwarding the enclosed donations in memory of our daughter Nova Irene Damm. Nova was diagnosed at age 6 months with SMA Type I. She unfortunately passed away due to complications of this terrible disease. She died six days before her 1st birthday. Please accept the enclosed donations in her memory and we hope that one day there will be a cure for this horrible disease.
Sincerely,
Darin & Jenny Damm of Girard, IL

IN MEMORIAM
Audrey Nicole Shutes
June 12, 2004 - April 12, 2005

IN MEMORIAM
Bella Mia Barberena
February 4, 2009 - November 15, 2009

IN MEMORIAM
Korbin Jacob Rogers
May 1, 2009 – October 1, 2009
My son was diagnosed with SMA in August. It was a roller-coaster from then on. Unfortunately, he lost his battle on October 1, 2009. We made a memorial fund for him in honor of Families of SMA. I hope this $420 can help another family dealing with this terrible disease.
Sincerely,
Isaac & Jessica Rogers of Colchester, IL

IN MEMORIAM
Layton LaFountain
June 29, 2009-December 22, 2009
Staff and Families of SMA:
We the LaFountain family can never thank you enough for your love, support and guidance. I want you to know that without your organization I would have felt so alone and lost in how to care for my son. We thank you for the gifts that made life more enjoyable for Layton.
With Much Love From,
Brad, Carrie, Colton, Hailey & Guardian Angel Layton of Cleburne, TX
It’s a BOY! I heard Jon say it first, followed quickly by the doctor and nurse. We decided not to find out the sex during my pregnancy, and when our baby boy came in to the world on March 7, 2008 at 6:02 pm, it was the most incredible moment of our lives. Owen had long fingers, that was one of the first things I noticed when they handed him to me. And CUTE, boy was he the cutest little baby we’d ever seen! He passed all of his newborn screenings with flying colors. I remember our second day home; Jon and I were lying in bed and Owen was in his bassinet next to us. I started sobbing, and when Jon asked “what’s wrong?” I said “I’m just so relieved that he is OK!” I was so worried throughout my entire pregnancy, paranoid about having a healthy baby; and here he was, absolutely perfect in every way. 7lbs, 11oz, 20.5 inches of pure blue-eyed perfection. THANK GOD.

Unfortunately, as any SMA family is all too familiar with, our story quickly changed. On May 5, 2008 Owen was diagnosed with SMA Type 1, he was just 8 weeks old. Then on July 13, 2008 he was rushed to a local hospital after a feeding incident and quickly transferred to Columbia Presbyterian Children’s Hospital. Owen would spend 35 long days in the PICU at Columbia, which would equate to 20% of his life. During his hospital stay our baby underwent a Nissen G-Tube surgery. He had a ‘terrible, horrible, no good, very bad’ time the days leading up to and following the surgery. As you can imagine he had many horrible days in the hospital, mostly due to respiratory distress. However, through all of the poking, prodding and suctioning, Owen would bounce back and give us his heart melting smile. His smile was more important than any chest X-ray to us. We would measure his good days and bad days by his smiles.

Owen was comfortable for the most part, as long as he had his favorite puppet Grover by his side. He won over every nurse, doctor, and therapist that came into his room. He became a real flirt with the nurses; he talked with his eyes and would raise an eyebrow when he was really interested. During his stay at Columbia, we had puppet shows, read books and watched movies. We gave him a bazillion kisses a day and cherished every single moment with our baby.

Things were looking up and we were preparing to take Owen home, but then on Monday, August 11, he took a turn for the worse. He fought all week long like a true warrior but the disease had progressed too quickly; it was just too much for his little body to take. On Saturday August 16, 2008 our precious baby boy drifted off to heaven while in my arms, with daddy holding on. Owen was only 5 months and 9 days old.

We are forever heartbroken, our lives forever changed, but we were truly blessed to be chosen as his parents. We will never stop fighting for our baby. We will continue to fight SMA in Owen’s name forever.

“Owen, we love you right up to the moon and back!”

Dorothy and Jon Shuler of Stony Point, NY

www.FightForOwen.com
www.teamrun4owen.com
On Tuesday, April 8, 2008, at 5:05pm, after 9 months full of expectations and a great pregnancy without any problems or concerns, came into our lives our first (and to date only) child. Any parent can understand the immense happiness that filled both my wife and me immediately after facing for the first time our little daughter, who immediately began to explore the environment, with two brilliant eyes.

Her expressions made us see how peaceful and quiet she seemed to be; almost no crying, very rarely something like light coughing substituted the crying. She began breastfeeding very well from her mother and everything seemed normal. The nurses who served her were calling her “athlete” and “the rubber girl”, because she was very pliable and cool.

After 3 days in the hospital and while all laboratory tests showed normal, we were ready to embark to our house and have our daughter enjoy her room that my wife, with care and imagination, had prepared and decorated with hand painting. To our good fortune, the neonatologist in his last minute check before departure, saw that she was a little more relaxed and subdued than normal. She didn’t have the normal reflexes and she had muscle weakness. Thus began our adventure. Our little princess was immediately transferred to the intensive care, where after a long series of tests for different diseases, she was diagnosed with Spinal Muscular Atrophy, Type I.

We were informed briefly about what it meant. The impact was great because now we knew that our princess sooner or later would return to the neighborhood of angels. The issue was when some told us she would live for 2 months and others 2 years!

However, for the first 20 days she was breathing freely on her own and drinking her mom’s precious milk. We named her Despoina, giving her one of Virgin Mary’s denominations, which in Greek also means Dame/Lady. She was moving her hands slightly, from the elbow down and feet, from the knee down, but as the time was passing by, the motion began to decrease. However, she managed to move her head far more and her eyes were fabulous; all in the I.C.U. were amazed by them and her nickname was the “little spy”. After a month, the doctors were forced to use constant ventilation and tube feeding as she was becoming heavier and heavier. She had long periods of stable condition and very few days of crisis and illness. Thanks to the nurses’ and doctors’ services and true love and dedication, she rarely had serious problems and with frequent suctions her saturation was over 90-92%, even sometimes reaching 98-99%.

However, 5-6 times she reached the thin line to pass away, but the doctors fulfilled their task and dragged her back.

With the noble concession of the I.C.U. chief, we transformed her room into a suite, with lots of toys, curtains etc. Even with the upcoming end at the back of our mind, we were very proud and happy with our generously clever daughter. And more, she was very strong, showing great patience with all medical procedures and she never gave a sign that she was afraid. She was accepting everything with great soul and she was smiling all the time.

When she was 7 months, a decision was made to make her short life easier. She had an operation for tracheotomy, in order to make her breathing lighter. Although we had our concerns if she would withstand the operation or if it would only prolong her torture, then we agreed. Everything went all right and shortly after, she began to gain weight.

Day by day, she was looking prettier, and prettier and those awesome eyes were shining gratefully to the personnel and showing love to us. We began to search for the appropriate devices that would help to supply our house in order to welcome our princess at home for the remaining time of Despoina’s life. But as we say, when people make plans, God laughs at them. So, four days before coming home, at 10 months old, her heart stopped beating and she flew away to her sky realm. It was Wednesday, February 4, 2009 at 1:45.

We would like to thank all the doctors and nurses in General – Maternity District Hospital “Elena Venizelou” in Athens for all the great services and help provided through those 10 months and we want to assure them that our “little spy” is always watching and protecting them.

P.S. Two months after Despoina’s death, we achieved in getting pregnant for a second time the normal way. We were told and believed that it’s really very rare to have a second child in a row with SMA, so we wished to bring our princess back. On the 12th week of pregnancy, the embryo was tested for SMA via CVS test; Unfortunately, it was positive. This time it was a boy. We decided to make an abort, so now we have two angels of our own playing within the clouds.

Even more, through the last six months we have had two unsuccessful tries for IVF after PGD. In both cases we found two unaffected embryos but my wife did not get pregnant. We will carry on for as long as we have the strength in order to become parents of a healthy child. We owe it to our princess.

Manos Sarafis & Elisabeth Koutidou of Athens, Greece
**IN MEMORIAM**

**Ryan Hawn**
January 27, 2009 – July 28, 2009

Dear Families of SMA,

My husband and I are sending you checks that total $2,873 in memory of our son, Ryan Hawn. Ryan was born on January 27, 2009 and was diagnosed with SMA Type I on May 27, 2009 at just 4 months of age. Unfortunately, our story isn’t different from the many other families whose children have been diagnosed with SMA Type I. He became very ill quickly. Ryan’s spirit and eyes full of wisdom touched many people’s lives in the short amount of time that we were privileged to spend with him. Our son died on July 28, 2009, just hours after he celebrated his 6 month birthday. We were holding him in our arms as he took his last breath and spread his angel wings into heaven.

To this day, we are still devastated by how quickly our lives turned upside down and how quickly this terrible disease took over our son’s life and took him from us. It seemed at the time that his suffering would last forever, and now that he is gone, it seems as if we blinked and he was born and then no longer with us. The pain is very deep.

We want the donated money to go towards SMA research. Our hope is that it will soon prevent other families from having to deal with devastating effects of SMA. The effects ripple far, to parents, siblings, grandparents, aunts, uncles, cousins, friends and friends of friends. Ryan’s light shines bright in all of us and all who knew him, however, we miss our son dearly. We hope that a cure for SMA is discovered soon.

Sincerely,
Jennifer and Christopher Hawn
of Saint Charles, Missouri

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**IN MEMORIAM**

**Christian Brian Evans**
August 23, 1995 – June 11, 2005

My Angel how I miss you so, you will hurt no more this I know, I only wish you didn’t have to leave me so soon, just when you were really starting to bloom. I know you are in heaven now, looking down at me through the clouds, how I wish I could see your beautiful face, with such a glorious smile and such grace. You can walk, run, jump, and play. I hope to see you again someday. I miss your laugh, your voice, your cry. Even those silly little questions why? Your precious little fingers are still fresh in my mind, everyone knows that they were one of a kind. You are my heart, my soul, my joy. You will always be my precious little boy.

Love Mama.

Kristi Evans of Macon, GA

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**IN MEMORIAM**

**Tony Pruitt, Jr**
IN MEMORIAM

Carter Dawson

December 14, 2007 – January 4, 2010

My grandson, Mykal Carter Edward Dawson was born on December 14, 2007. I was so happy! Carter was my first grandchild. I remember seeing him and thinking that he was the most beautiful child ever. His bright blue eyes locked with mine and we just clicked. Just moments after birth, he was so alert and attentive when I spoke to him. Just a few hours old and he smiled at me and won over my heart for life.

In January of 2008 I noticed that he was “squishy”, especially in his upper legs and when we changed his little diaper, his legs lay still and parted and didn’t kick or wiggle a lot. He was very alert most of the time and very content. He rarely cried and when he did, it was a soft cry without the lustiness that I remembered from my own children. My daughter and son in law lived with us at the time and I was so ready to “help” when we first brought him home but he was so good natured – that she didn’t need my help. I thought that my daughter had been blessed with a super good baby and I must admit that at first I was a little disappointed that she wasn’t getting the “full effect” of being a new mom (the loud crying in the middle of the night, the fussiness, the demands, etc.).

Then I noticed other things like: he didn’t “bob” his head when I burped him on my shoulder, he didn’t kick and arch his back when crying, he didn’t hold his arms/legs up when I picked them up and dropped them. I mentioned it to my husband one night and he said that he had noticed it too. I knew that my daughter had been blessed with a super good baby and I must admit that at first I was a little disappointed that she wasn’t getting the “full effect” of being a new mom (the loud crying in the middle of the night, the fussiness, the demands, etc.).

One night in particular I found myself studying him as I played with him and noticed that he really didn’t “move” a lot. I remember the panic I felt as I recalled that a few days before I had been rocking him when I noticed that he seemed to have quit breathing and didn’t respond when I tried to wake him up and when he didn’t awaken right away, I had jerked him up and ran with him to the other room but by the time we got there he was awake. I was frantic as I thought that maybe my jerking him up had “shook” him somehow. I was so afraid I had done something to hurt him but knew in my heart that I hadn’t. But what could explain the “floppiness” that he had? But he was still very alert and still very bright. Then I noticed his head wouldn’t stay up in the car seat or swing. Shay and Kenneth mentioned it to their pediatrician and she examined Carter and pronounced him “fat and lazy”. Shay and Kenneth moved out of our house and into a home of their own. They were so excited to be getting on their feet.

In early February, Shay once again took Carter to the pediatrician who upon examining him became very concerned when he couldn’t hold up his head when lifted off the table by his fingers. She set up an appointment with a neurologist at Children’s Hospital in Birmingham, AL for February 19th. On the day of the appointment, Dr. Foo examined Carter, checking his reflexes and his muscles. He said that he would need to take blood and send it off to the genetic clinic to get a diagnosis. He didn’t want to tell us what he was suspecting, but Shay insisted, so he finally told us. He explained that Carter had the “classic” symptoms of Spinal Muscular Atrophy Type I. Shay asked him if Carter would be in a wheelchair. Without answering, he stepped out of the room and returned with a chaplain in tow. He then told us what the diagnosis meant and that Carter may only live to be eight months to two years old. He explained that most children don’t reach that two year mark. We were devastated to say the least. After much crying and questions and blood work, we finally left the hospital with our hearts in pieces.

It felt like we were trapped in a nightmare. I remember feeling so devastated and mourning a child that was still very much alive, but our dreams for him had died. It was like our world had stopped and we were living a nightmare while the world around us continued to go on as normal. It was so frustrating.

We are Christians and we knew that the doctors knew what they were talking about, and being that they didn’t have a cure, we knew turning to God was the only way we would be able to survive this. After all, God is the Great Physician, The Healer. The next day we went to our friends, who are not only Shay’s godparents, but Mike is a pastor as well. Teresa and Mike prayed with us over Carter and we gave him to God. We put him in God’s hands and prayed for us to be able to keep him with us as long as God willed and give us the wisdom to be able to take care of our sweet boy and we prayed for a cure.
The next few weeks went by and we treated Carter as we always had if not just a little more watchful over him. On March 13th we (Shay, Kenneth, my husband Ron and me) returned to Dr. Foo’s office for the official diagnosis. Shay had been doing home PT with Carter trying to get more movement from him, and she had. So we were hopeful that the diagnosis would be something different, something not fatal. But it was not to be. Dr. Foo entered the room with the chaplain in tow and my heart fell. He sat down on the examining table by Carter and listened patiently as tear roll down his face as he looked at her and said “I’m so sorry but the test showed that Carter definitely has SMA Type I”. After much wailing on our part, he introduced us to Dr. Chris Makris, the pulmonologist at Children’s that dealt with the SMA babies. Dr. Makris examined Carter and checked his sucking reflexes and gave us our options. He told us that Carter would have to go through a series of tests such as sleep studies, swallowing tests, etc. He said that we could contact him in a week and set up an appointment. He answered our questions and we tried to take it all in. He told us to take our baby home, love him and treat him like any other baby.

When we returned home, we were contacted by the Alabama Chapter of FSMA via e-mail. We were told about the FSMA website and put into contact with other families in our area that were dealing with the same thing. My e-mail was flooded by mothers, fathers and grandmothers all over the United States e-mailing me about their journey with SMA and offering help, shoulders to cry on, ears to listen and answers to questions. Finally we had someone we could talk to. Unfortunately Carter had his first hospital visit on March 17th. He stayed a week and during that week my daughter was visited by two FSMA families. We were not only told but shown that SMA children DO live past age two and Can live happy fulfilled lives and we realized we had to LIVE and ENJOY every moment with Carter (the old timers would call it pulling ourselves up by our boot straps).

Throughout the end of March and all of April, Carter stayed in and out of the hospital for weeks at a time. Each stay we learned a little more and were introduced to a new machine. Carter stayed so well and we were so blessed. They moved back in with us in early June, Carter had a fundo surgery and a g-tube placement surgery. That was hard. He stayed in the hospital a little over a week. He loved to smile and he’d fight up your day with his big wide grins. Carter went to the Chattanooga Aquarium in August, we took him to the Alabama Walk-n-Roll in October and he was Elmo for Halloween. Then in early November, at ten months of age, Carter lost his swallow. He was a bright, happy, intelligent child. He could communicate without words even though he had managed to say “mama, dada, nana, bubba and hey”. He turned one year old on Dec. 14, 2008 but wasn’t feeling really well that day so his big birthday bash was cancelled and he spent the day playing with mommy, daddy, nana, grandman and uncle bubba. Then he became a big brother to Gracelyn Hope Dawson on December 22, 2008. Gracelyn is a carrier of the SMA gene but she does not have SMA. Carter loved his little sister but was a bit cautious around her. He wasn’t so sure about this little wiggly person. He loved Christmas that year and all the new toys and movies. The year of 2009 was wonderful. He was rarely sick, hardly ever fussy, always gave big smiles, made lots of friends and was basically a happy little boy. He hunted Easter eggs on Easter, swam in the pool in the summer, painted pictures, played with playdough and we learned his favorite colors, his least favorite colors, his favorite movies, and his favorite toys. He got a new puppy and loved to watch his baby sister play and try to interact with her. We missed the 2009 Walk N Roll due to inclement weather, but Carter was a Hunter for Halloween (he was hunting for a cure). In November, Carter was taken off the bipap and put on a non-invasive ventilator. He turned two on December 14, 2009 and had a big Mickey Mouse party. He really enjoyed his party with his family and friends. We rang in 2010 with great hopes and dreams of what this year would bring.

On Saturday, January 2, 2010 Shay and Kenneth had to take Carter to Children’s Hospital due to low SATs and high heart rate. Unfortunately, Carter’s lung had collapsed. Due to a curvature to his spine, his lung was not able to recover. Carter earned his angel wings on Monday, January 4, 2010 when he went to live with Jesus.

We were able to survive these past two years with the help and support of our new friends and family from the Alabama Chapter of FSMA, and all of the families that we have met along our journey from coast to coast. We are now a part of a bigger family than we could have ever imagined. Although our sweet boy’s journey here on earth with us has come to an end, our journey and work with FSMA has just begun. We’d like to take this time to thank you all and tell you that we are still here, ready and willing to fight the good fight against SMA and help find a cure for all the children out there still struggling, and those yet to be diagnosed. We love you all and thank you immensely.

Jackie (Carter’s Nana), Ron & Ronnie Allen and Shay, Kenneth & Gracelyn Dawson of Cropwell, AL
IN MEMORIAM

Daniel Alexander Cevallos
January 12, 2009 – August 28, 2009

Dear Danny:

Thank you for these wonderful 7 months and 16 days that you gave us. We can’t describe how painful it is not to have you with us. How sad it is not to see your beautiful smile, that smile had the power to light up the room and let us forget for a little while what was happening. Thank you for helping us to understand the meaning of unconditional love and what it means to love someone more than ourselves. You are our HERO. With all the LOVE that you left in us.

Your Family.
Paulina Recalde & Luis Cevallos of North Lauderdale, FL

IN MEMORIAM

Hanna Willingham
May 13, 2009 - February 12, 2010

IN MEMORIAM

June Howsden
October 5, 2009 - October 27, 2009

IN MEMORIAM

Kimberly Ann DiPietro

On January 15th my cousin Kim from Marlton, NJ passed away unexpectedly. Kim was a crucial part of starting our chapter 8 years ago and helping us with every event. Not only will I miss her because she was like a sister to me, but I will miss her being there to support all of our chapter happenings. Below are a few excerpts spoken about her:

Kim a dear friend, wonderful, beautiful, gentle soul, sweet and loving person, music lover, avid reader, loved watching movies with her family and friends, taught lessons of goodness, organ donor, Yankee fan, dear, loving cousin, the list goes on but my favorite is “Heaven is the only place big enough to hold your heart”.

Your life has made such an imprint on those of us left behind and the legacy of love for family and friends is what I will remember most. Family, like marriage, is for better or for worse, richer or poorer, sickness and in health and if there is one gift that you have left for all, it is that.

Kim wrote, “Be yourself, everyone else is taken”.

From Jessica Moyer President of the South Jersey/ Delaware Chapter
Dear FSMA,

Enclosed are donations that are given to FSMA in memory of my mother Sandra Ingram. My mom passed away the day after Christmas, after a very difficult battle with cancer. She was a strong supporter of FSMA because my daughter Ella has Type II. She loved coming to many of the summer conferences with us, and always looked for ways to help support the organization.

For her birthday party in November, she asked that people not bring gifts, but instead make a donation to SMA. She made the same request that donations to her memorial go to FSMA. The enclosed donations should total $2,800. Several others sent in checks directly to the organization, so in total it should be well over $3,000. I know how proud my mom must feel to have helped the organization and all the families like ours. I am also enclosing a picture of Ella and my mom at a family function in September.

We hope that this donation continues to move us closer to what we all hope and pray for.

Sincerely,
Clint Christopher and Family of Coal Valley, IL
**FSMA merchandise**

- **Travel Mug | $10**
- **Sport Bottle | $5**
- **Baseball Cap | $10**
- **License Plate Frame | $7**
- **FSMA Keychain | $5**
- **FSMA Car Magnet | $5**
- **Umbrella | $20**
- **Cookbook for a Cure | $14**
  - The FSMA cookbook contains almost 400 recipes from SMA families all over the world!
- **FSM A Lunch Bag | $10**
  - Insulated with bottle holder.
- **Bag | $10**
- **25 Year Grocery bag | $5**
  - Large bag with logo on either side.
- **FREE Cure SMA Bracelet with every order!**

Merchandise can be ordered online at [www.curesma.org](http://www.curesma.org) or by calling the FSMA National Office.

Check out the FSMA website for new merchandise [www.curesma.org](http://www.curesma.org).

**Families of SMA T-Shirt | $12**
- Kid sizes: 2/4 6/8 10/12 14/16
- Adult sizes: S M L XL

**FSMA “Moving Forward” T-Shirt | $12**
- Sizes: S M L XL

**Wipe Out SMA | $12**
- Kid sizes: 2/4 6/8 10/12 14/16
- Adult sizes: S M L XL

**25 Anniversary T-Shirt | $12**
- Kid sizes: 2/4 6/8 10/12 14/16
- Adult sizes: S M L XL
Caring Choices

This booklet is focused on caring choices for parents of infants newly diagnosed with Spinal Muscular Atrophy Type I.

Topics review the basics of the main care options for newly diagnosed SMA Type I:
- What is Non-Invasive Respiratory Care?
- What is Invasive Respiratory Care?
- What is Palliative Care?

And, where you can go for support and guidance.

Family Guide to Research

This guide helps to answer questions such as what the key areas of SMA research are and what the costs for conducting SMA drug development and clinical trials are. Clear definitions and graphics are included to help explain and illustrate how SMA drugs begin and the key steps involved in developing new therapies for Spinal Muscular Atrophy.

The topics in this new booklet cover the following important areas of SMA research:
- SMA Researchers.
- Drug Research.
- Gene Therapy.
- Stem Cells.
- Clinical Trials.
- Government Research and the FDA.

Breathing Basics

This new booklet is focused on the critical aspects of respiratory care for children with Spinal Muscular Atrophy. The booklet was authored by Mary Schroth, M.D., a member of the Families of SMA Medical Advisory Council, and a leading expert on respiratory care for SMA patients.

This booklet reviews the following important topics:
- Why is respiratory care so important in SMA?
- What are common respiratory problems in children with SMA?
- Elements of respiratory care management in SMA
- What are special needs of children with SMA Type I, Type II and Type III?
- What respiratory equipment will you need at home?

Two New Care Series Publications Coming Soon!

The Families of SMA Medical Advisory Council is busy working on two new publications for SMA families and professionals. The first is a booklet on Nutrition for SMA and the second is on Musculoskeletal Care for SMA. Check out the FSMA website for further updates.
Families of Spinal Muscular Atrophy is Excited to Announce Upgraded Events and Online Fundraising Capabilities

New Fundraising Materials:
- Manuals and Sample Booklet (Walk-n-Roll, Golf Tournament, Dinner/Gala & Bowl-a-Thon)
- Banners and other colorful signage
- Families of SMA “At a Glance” flyer
- Donation tags
- New plastic event bags
- And more!
Families of SMA Launches New Fundraising Stars Blog

Created to recognize the amazing fundraising efforts made by our members nationwide, which help advance research for a treatment and cure for Spinal Muscular Atrophy.

The blog is featured in a scrolling box on our Families of SMA homepage. It can also be viewed directly at http://www.spinal-muscular-atrophy.org/.

A great feature of the blog is its social networking capabilities. Each article automatically links to our Families of SMA Twitter and Facebook pages. All pictures link to our Flickr account and videos link to our FSMA YouTube page. Overall, it’s a great way to connect with the Families of SMA community, while we thank all of our amazing families and volunteers.

To learn more about our Fundraising Stars Blog, please call us at (800) 886-1762 or email fundraising@fsma.org.
Jacob’s Run, Walk & Roll to Cure SMA 2010 a Spectacular Success.
The Rappoport Family has now raised more than three quarters of a million dollars for SMA research and to support SMA families.

The 7th Annual Walk by The Jacob Isaac Rappoport Foundation was held in a beautiful setting in South Florida. Over 450 families and friends turned out to support an amazing cause, and have fun with climbing walls, bouncy castles and crocodiles! Donations are still rolling in, and the current tally for the 2010 event stands at $92,767!

The theme for the event this year was “wonder.”

An entry follows from the journal of Shaina Rappoport:

“wonder [wuh-der], -verb,
1. to think or speculate curiously
i wonder how have i lived 7 years without you here. i wonder why is this our reality. strange that no matter how many years pass, i still can’t believe it. i wonder how you’d look now. a little like max and a little like sam? each time max puts on his soccer uniform, i wonder how you might have looked in one. each time sam runs down the hallway like a lightning bolt, i wonder how it’s possible to create a person whose muscles work together so effortlessly and yet yours were so weak that you were unable to swallow. each time jordan sings a song or writes a story, i wonder what stories you may have had to tell. the more our living children do, and the more our family changes and grows, the more we are left to wonder what might have been.

wonder [wuh-der], -noun,
2. a miraculous or apparently miraculous thing or act; miracle
i know that your memory is a wonder in the miraculous sense. i guess that is what makes it so hard. i can still hear the oxygen machine, and your quiet laugh. i can remember exactly how it feels to touch your soft hair, or to hold you in my lap. i can feel the vibrations on our king-size mattress that you made with each labored breath. i can see adi making you a balloon garden, jordan reaching down to kiss you or pose for yet another picture. all as if it were yesterday. And yet, your wondrous memory is never enough. the emptiness is just too big.
as we ask you, once again, to participate in the seventh annual jacob’s run, walk & roll to cure spinal muscular atrophy, a third definition of the word wonder comes to mind

wonder [wuh-der], -verb,
3. to be filled with admiration, amazement, or awe; marvel
the contributions of our supporters fill us with amazement. the continued support of many generous people have enabled jacob’s run, walk & roll to cure sma to be an astounding success since its inaugural event in 2003. each year hundreds of people have contributed to our cause, and what we have accomplished has been nothing short of wondrous. we are so grateful for our many sponsors, fundraisers, participants, donors, committee members and volunteers who come together to make the event possible. jacob’s run, walk & roll has always been a celebration of life and love. as a direct result of our event’s success, the foundation has been an integral part of the progress toward finding a cure. and we are making a difference.”

Families of SMA is honored and privileged to have the support of the amazing Rappoport family. The Rappoports have created a memory for Jacob that has touched thousands of families in the SMA community.

Jacob is now and always will be a shining star for us all.

Meet Jacob Rappoport
Jacob was born on December 27, 2001. He was sent home from the hospital with a clean bill of health. At the age of four months, Jacob was diagnosed with SMA. He was never able to roll over, sit up or crawl. By the age of six months, he had lost the ability to swallow. On October 1, 2002, Jacob’s respiratory muscles had grown too weak to sustain him, and he died. He was nine months old. We miss him every minute of each day. Sadly, Jacob’s story is just ONE of many. We had never heard of SMA, but now we have pledged our lives to fighting this horrific disease. We have chosen to do this to honor our son’s memory.

http://www.ourshootingstar.com/
http://www.fsma.org/JacobsRunWalkRoll
Lizzy Hallam blowing bubbles
Karen, Jeff & Austin Olander
Natalie Quintana
Kale Shiesley and Bailey Walters
Maeve, Bridget, Shannon Abraldes
Andrew Murray with his mom
Leyan Hu
Larkin Bish’s 4th Birthday
Natalie Broome
Logan Patrick
The Cure SMA New York Gala was held on November 12th, 2009 and was hosted by Sophia’s Cure Foundation and Kiley and Dylans Sweet Dreams Foundation. The event was held at Bridgewaters in New York, New York. We had an amazing turnout with close to 200 attendees; there were raffles, a silent auction and a live auction. During the night, three awards were given out: The Kids Choice Award went to Philip Mayer Jr., The Wings of Hope Award went to Ryan Burkett (for his ride across country for Sophia’s Cure) and the Dora B. Martin Courage Award went to Dorothy Shuler (on the anniversary of her son Owen’s death she flew to San Diego to run a half marathon and all the money raised for the run was donated to Sophia’s Gift Registry). In Dorothy’s own words “My son can’t move his legs, but I can...”. During the event OdysseyRe also presented Sophia’s Cure with a $50,000 check which was given to FSMA. The night raised a little over $70,000 which was donated to FSMA and Columbia SMA Clinic in New York City.

From Vincent Gaynor of Wantagh, New York

Jeff & Valerie Mitchell of Elizabeth City, North Carolina held the 11th Annual Haley Mitchell Ski-a-Thon. It was in honor of their daughter Haley and was held on October 3, 2009 at the Beaver Lake Ski Club in North Carolina. Skiers competed in a slalom ski event with top notch skiers from across the country. There was a silent auction and a lot of other entertainment provided to make it a fun-filled day! The event collected an outstanding total of $35,310 to help benefit Spinal Muscular Atrophy research.

In October, Kevin and Linda Arnold of South Charleston, West Virginia held their Annual Arnold Family Golf Tournament in honor of their son Eric Robert Arnold. The event came to be in October of 1996 as a birthday wish granted for Linda who was turning 40 that year and it has been held annually ever since. This year, friends and family helped raise $17,000 in support of Families of SMA. Eric’s recent accomplishments are that he graduated Magna Cum Laude last year and is now back in school in an accelerated MBA program. He will graduate in June 2010 and has applied to Law School. We are all so proud of Eric and thank him and his family for their generosity and support!

Steve and Rozie McClay of Centralia, Washington held a Spaghetti Feed event in honor of their daughter Kiley. It included a wine tasting of their very own, Unite for the Cure Pomegranate Zinfandel featuring Kiley’s picture on the label! Overall the McClay family raised a total of $16,761 for SMA research!
The Kingkiner Family of New Jersey held their First Annual Hoop, Walk-n-Roll and it turned out to be a big success! Supporting Families of Spinal Muscular Atrophy (FSMA) has become a major focus for Beth and Frank Kingkiner since their son, 5th grader Griffen Kingkiner, was diagnosed with SMA type III almost two years ago. With the help of family and friends, the event was sponsored to raise awareness and funding for FSMAs.

The event raised over $15,000! Montgomery, New Jersey residents, friends, local businesses and surrounding communities came together to enjoy the event. Participants either walked or rolled around Van Horne Park or Hula Hooped in support of SMA. Many sponsorship donations were contributed, as well as personal and corporate donations.

The event also featured silent auction items and over 70 raffle baskets donated by friends, local sports organizations and companies. Local businesses such as Pretzel Factory, Wawa, Bagelicious and Dunkin' Donuts provided refreshments. Local Girl Scout Troop 1059, MHS Art Honor Society, MHS Cheerleaders, SBHS Cheerleaders and two live bands provided entertainment for the event. The support of family, friends and the entire Montgomery Community was amazing!

In late 2009, Families of SMA was chosen to be one of the 12 charities featured on famous NASCAR driver Jimmie Johnson's racing helmet during the Pepsi 500 Sprint Cup race at Auto Club Speedway on October 11, 2009. More than 1,400 charities were submitted to the Foundation, and FSMA was honored to be one of the 12 chosen. The program is known as the Helmet of Hope Initiative. Being part of the Helmet of Hope Initiative meant that Families of SMA became eligible to receive a grant of $1,048. Also, the Jimmie Johnson Foundation raised money by selling Helmet of Hope t-shirts – and they sold over 700! 100% of the money raised from selling the t-shirts was split evenly between the 12 charities.

After the Helmet of Hope Initiative, on behalf of Chandra and Jimmie Johnson, Chad Knaus, and the No. 48 Pit Crew, over $12,000 was contributed to FSMA in memory of former NASCAR Champion Benny Parsons. Multiple members of the Hendrick Motorsports team have been touched in some way by SMA. The group selected Families of SMA as a fitting way to honor Benny Parsons.

The Bommarito Nissan & Gateway Z Club Annual Car Show was held on August 16, 2009 in St. Louis, Missouri. This show is a People's Choice car show for all Datsun/Nissan and Infiniti vehicles hosted by the St. Louis Gateway Z Club. This annual event, which benefits Families of SMA, raised an amazing $11,770. Everyone had fun socializing and enjoying the food, vendors, demonstrations, door prizes, and the silent auction. Also, a DJ played while everyone was able to view some awesome cars! Janet Hutchinson organized the event again this year and as always Rita & Mike Schmidt, Kathy Goodyear and Janet grilled and sold food and drinks. The Carpenter Family (Brittany, Brendan, Scott & Candy) also sold raffle tickets and SMA items.

Fifth grader Kyra Scadden and her family hosted the 3rd Annual Garage Sale for a Cure to raise money to find a cure for SMA, which confines her friend Angie Lee to a wheelchair. The large group of Elementary School students worked together to raise money with tremendous support from their families and the community! This year the event had a raffle and silent auction with great prizes. The event in Naperville, Illinois was held, Illinois and raised a wonderful $11,235!

Dave and Kellie Span of Murrieta, California held a skydiving fundraiser in November 2009 for Unite For The Cure in memory of their son Zachary. This event entailed multiple fundraising efforts which included a Chinese raffle, classic raffle, silent auction, bake sale, and a poker tournament and raised a total of $10,724!

Please note: The amounts raised, are totals as of March 12, 2010, and may differ from the current totals by the time you receive this newsletter.
Dear Families of SMA,

We have always had a passion to raise funds for FSMA to help our daughter Savanna, who was diagnosed at 8 months with SMA Type I. We felt, as other families feel, completely overwhelmed. But, we also felt like we had to do something to feel like we were making a difference for Savanna and for all the other families affected by SMA. We were just a family who loved our child dearly and wanted to do something, anything, to help. I sent an email to family and friends to see if I could “drum up some support” for tackling our first fundraiser. Our first fundraiser was held the month before Savanna’s 2nd birthday. Our little group of family and friends were able to raise a little over $25,000 in our first year. Now, here we are six years later, still fighting the battle of SMA. We decided to change our format and do a 5k run with a carnival since Savanna is now in 2nd grade and we wanted it to be something she would enjoy. Although our funds were down considerably this year due to the economy, we had a great turnout of eight SMA families as well as over 100 runners for our 5k. We look forward to next year’s event and will continue to support FSMA.

Tim and Mindy Rush of Saginaw, Texas

sing for our crowd. I hope you all will help support Casey James in his quest to be the next American Idol, as he was gracious enough to come out and sing for our kiddos.

It took a lot of hard work and sweat equity, but overall the event was a success raising $10,372. We had a great turnout of eight SMA families as well as over 100 runners for our 5k. We look forward to next year’s event and will continue to support FSMA.

Casey Rush and friend

To our Friends at Families of SMA

On Friday, September 4, 2009, the 5th Annual Grant Sheppard Memorial Scramble for SMA was held at Hickory Hills Country Club in Chilton, Wisconsin. We are proud to be sending you proceeds that total $9,000 to suit the needs of FSMA.

Thank you for all that you do for the families dealing with Spinal Muscular Atrophy. Please know that the Sheppard family is available to return the help that has been graciously sent in our direction and we look forward to seeing you at the 2010 conference!

Merry Christmas,
Scott, Lisa, Peter and Lily Sheppard of Sherwood, Wisconsin

Don and Chelsea Marshall of Ojai, California held Micah’s March in honor of their son Micah and over 100 walkers were able to attend! They raised a total of $9,000 for SMA research!

Charlie and Sapna Pringle of Spring, Texas raised a total of $7,785 for Dr. Keirstead’s promising SMA stem cell program in honor of their daughter Maya!

Please note: The amounts raised, are totals as of March 12, 2010, and may differ from the current totals by the time you receive this newsletter.
Dear Families of SMA,

It is with great joy as always that we have enclosed the proceeds from our 6th Annual Lukie’s Fall Festival of $4,000. Please use this money wherever needed, either support to the Families or Research, we only request that this money not be used for embryonic stem cell research.

The work that you do is so important to us and all of the families that are affected by SMA, it gives us hope that a cure can soon be found, that we are not alone and that we can have the support of a community of people who understand and support what we have been through and are going through.

Nine years ago when we had to say good-bye to Luke, and let him go to become one of God’s Little Angels, we promised him that we would do what we can to help find a cure. This promise became Lukie’s Festival, and over the past six years of putting together his Festival it has become so much more, it has become his legacy, and ours. Luke is such an important part of our family he is always here with us with his spirit and love.

The day of Lukie’s Festival this year was not the best weather. It was cold, windy and rainy. But as the day progressed, the warmth and love of the people who came out despite the weather, seemed to change the weather with their smiles and love. We had to cancel most of our outside activities, but were able to setup as much as we could inside the community building and pavilions. We had our entertainment on the inside stage, which included performances by Alexa Dectis (SMA Type II), our local high school Select Choir, a band, and a demo by our daughter Kadyne’s cheering squad, the Rebels All Stars. We still had lots of games and fun and the carousel was still able to run since it was inside its own building. The weather could not dampen the spirits of our festival-goers, we have quite a following, and they still came out to support us and the Families of SMA.

Thank you again for all that you do, we pray for you always! “Together we will find a cure!”

With much love and prayers,

Joe, Tara, Kadyne, and Anna Maida, The Maida & De Crescenzo Families, and Planning Committee of Roseto, Pennsylvania
In the near six years that I’ve been a part of the SMA Family, I have been so lucky to meet so many amazing families. One of the most inspiring to me is the family of Owen Shuler. I went online to sign the Petition to Cure SMA and saw so many postings for a little boy named Owen. I followed his website and spoke with a family friend to obtain updates on how Owen was doing. It was heartbreaking for me to hear of Owen’s passing. I had never even met Owen or anyone in his family, but I was crushed to learn that this family had to bear this huge loss. What makes this family amazing and inspiring to me is that even though Owen was taken from them at only a little more than 5 months of age, they didn’t give up on him. They continue to fight every day to raise awareness and funds for SMA. One of the most profound things I have seen an SMA parent do was when Dorothy, Owen’s Mom, decided to run a Half Marathon on the one year anniversary of Owen’s passing on August 16, 2009 with her best friend Lauren and her sister, Maureen. Dorothy raised a total of $6,718 which was given to Sophia’s Cure (their gift registry for FSMA) and Columbia’s SMA Clinic in New York City. The funds Dorothy raised were outstanding, but I don’t think any of us can place a monetary value on the strength she exuded that day and the hope that she provided for so many of us SMA parents. Thank you Dorothy for being such an amazing woman.

Thank you,
Debbie Cuevas of the Greater New York Chapter

Chad and Cherisse Lunt of Menlo Park, California raised a total of $6,690 in honor of their daughter Lucy for the Unite for the Cure Campaign.

Mike and Kristen Lucas of Canada organized multiple events which included a garage sale, a block party, and a very successful Georgia’s Journey of Hope fundraiser in honor of their daughter Georgia. Overall they raised a total of $6,046 for the Unite for the Cure campaign.

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International Society for the Study of Neuroblastoma (SMA),
A few months back, I received an email from a stranger. A stranger that had seen Zane’s video, a stranger that was touched by her, a stranger who wanted to make a difference in the world of SMA. Although we haven’t met him yet, he is no longer a stranger, but a wonderful man who stuck to his word and IS making a difference in the world of SMA. We carry a place for him in our hearts! His name is Mike Lucci. Mike has decided to run The Boston Marathon in memory of Zane and the proceeds raised will be donated to FSMA and so far he has raised $5,288!

Thanks from Hilary, Keith and Avery Schmid of Malvern, Pennsylvania

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Michael and Melissa Howell of Canada raised a total of $5,000 in honor of their son Lexx for the Unite for the Cure campaign!

Rita Schmidt, Janet Hutchinson and Kathy Goodyear of St. Louis, Missouri raised $4,731 from donation cans placed in restaurants, and other small fundraisers.

Chris and Jennifer Calafiore of Tollhouse, California raised a total of $4,575 in honor of their daughter Hayden for the Unite for the Cure campaign.

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Since 1999, Marilyn Belcher of Lebanon, Oregon, along with her family and other dedicated volunteers, have chaired the Wannabe Charity Golf Tournament. This year’s annual golf tournament to benefit Families of SMA raised $4,148 in memory of Skylar Bahrenburg.

Team Sophie participated in the 2009 FSMA Walk-n-Roll in St. Paul, Minnesota. They raised $4,435 in memory of Sophia Denk, with support from family and friends through sponsorships and walking with Team Sophie.
Kate Sohl, mother to Macarthur Sohl, sent in donations this past winter totaling $3,475. The money was raised from two different events held at her place of employment, Cubist Pharmaceuticals.

The first event was a bake sale and silent auction, which was hosted and led by individuals working in the Information & Business Solutions department at Cubist Pharmaceuticals, with the blessing and encouragement of Cubist’s CIO. This event alone raised over $3,000.

The second event was the 2010 Cubist Pharmaceuticals of Lexington, Massachusetts Holiday Party. This event is held by Cubist’s Social Committee, and FSMA is lucky to be one of several children’s charities focused on.

Maria was just 12 years old when she passed away, and was living a very wonderful quality of life. She was in school with her friends, in multiple clubs, doing most of the things other girls her age did in her own capacity. Maria never let the fact that she had SMA and used a power wheel chair for mobility ever stop her from trying everything she wanted, as well as figuring out how to do and adapt to certain activities.

Maria’s Night 2009 was recently held in Islip, New York in honor of Maria and raised $3,304. The theme was “Peace, Love and Happiness are found in the journey”. That is truly how Maria lived her life, not only finding peace, love and joy in her goals and desires, but also and at the same time finding peace, love and happiness in her steps of living. In all she did and all she thought. She has an amazing soul and will continue to touch lives and change people from heaven as she did in her lifetime here.

The unfolding of Maria’s life, even while having SMA, was all I could dream of for her. It was awesome to feel and see that as Maria’s parent. What else can a mother ask for but to see their child’s life unfold so beautifully and magnificently as it should? We have learned over the years how to be grateful for the lives we are given and for the opportunities that come before us. Maria was living that life.

One quote has become very dear and meaningful to me. It is “all that we love deeply becomes a part of us” – Helen Keller. I know this to be true because Maria, although living in heaven, is every breath I take.

Maria’s brother Steven is 12 now and he also has SMA. It is also in seeing his strength and his love of life that continues to teach me some of the most important lessons of life… how to live from love.

Maria’s brother Steven is 12 now and he also has SMA. It is also in seeing his strength and his love of life that continues to teach me some of the most important lessons of life… how to live from love.

The Chen Family of Palatine, Illinois held a Benefit Concert on October 4, 2009 in honor of their daughter Jocelyn. There were lots of great performers, including vocal soloists Ilze Kuechler, Lindsay Metzger and many more! Following the concert everyone was able to enjoy appetizers and a raffle! This event raised over $3,100 to help benefit FSMA.

A benefit for Elijah Brock, who passed away from Spinal Muscular Atrophy Type I in 2007, was held in Betterndorf, Iowa by family and friends. They were able to generate $3,000 from their benefit and donate it to Families of SMA for research.

Dear Families of SMA,

The Foglia’s, friends of Bill and Victoria Strong, organized a bowling fundraiser at the Orleans Hotel & Casino in Las Vegas, Nevada and raised $2,325 for Unite for the Cure in honor of Gwen-dolyn Strong.

Dear Families of SMA,

The Park Family (Andrew, Erin Conner, Liadan and Keenan) from DuBois, Pennsylvania would like to send out a heartfelt thanks to all of the great people who supported us in our 2nd Shoot for the Cure we held on Saturday, June 27th, 2009 in memory of our son Tiernan James. Through the efforts of generous sponsors, shooters, friends and family we were able to raise $2,251.

A special thanks to Tom and J.R. and all of the others at Firebird Wing Shooting: once again, all of these gentlemen went over and above to make this event a success.

Thank You,
Andrew & Erin Conner-Park

Please note: The amounts raised, are totals as of March 12, 2010, and may differ from the current totals by the time you receive this newsletter.
In an unusual fundraiser on December 30, 2009, the brokerage firm of Hennion & Walsh, Inc. located in Parsippany, New Jersey, raised $1,900 for the Families of SMA. Tickets were sold and a drawing was held to determine which employee would gain the privilege of cutting off Larry Kohn’s twenty year old ponytail. Larry Kohn’s grandsons were present for the event, Chaz Weiner-13 and Max Brown-17, who both have SMA.

Hennion & Walsh, Inc. has taken an active leadership role in helping various charities over the years. They welcomed this opportunity to facilitate contributions to the Families of SMA.

Kenneth and Christy Greene of Riverside, California held a fundraiser in honor of their daughter Sara’s 7th birthday at a local Applebee’s restaurant. All together they raised a total of $1,433 for this special occasion!

Mike and Jaci Felix of El Mirage, Arizona received a donation from a local office who decided to collect money in honor of their daughter, Alexa, instead of buying Christmas gifts for one another. Overall they collected a total of $1,350!

Dear Families of SMA,
The Gamma Delta chapter of Gamma Sigma Sigma National Service Sorority at Duquesne University Pittsburgh, Pennsylvania has chosen FSMA for our Third Annual Unity in Service Banquet charity. The event was on Saturday, October 10, 2009. We had dinner, a 50/50 raffle, and a Chinese Auction. One of our sisters lost a sibling to Spinal Muscular Atrophy, and has a cousin with SMA as well. Her family acted as our guest speakers and touched us all with their stories and information about Spinal Muscular Atrophy.

We researched several different charities and we decided that Families of Spinal Muscular Atrophy was a wonderful organization that we really wanted to contribute to. We are so pleased to announce that we were able to raise over $1,314 at our Unity Service Banquet. The donation will be in memory of Allison Magoffin. The night was a great success!

We are more than honored to donate our proceeds to your organization.

Sincerely,
Jackie Dutil and Mallory McCormick

Dakin and Devon Lovelace of White Oak, Texas raised a total of $940 in honor of their son Dakin II for the Unite for the Cure campaign!

Laura Wax of Ridgeford, Connecticut held another cut-a-thon event at Shine Salon in honor of her son Cubby Wax and raised $815!

Dear FSMA,
Please accept this donation of $800 in honor of our daughter Tessa. We sold Tessa’s Angels Christmas ornaments to family and friends. Also enclosed is Tessa’s current school picture. Please use our donation in whichever way you see fit. Thank you.

Sincerely,
Lana & Marlen Weisenberger of Mosinee, Wisconsin

Dear Families of SMA,
It is with great pleasure that I send these checks to you in honor of my son Tyler Hernandez for Families of SMA Awareness month in August. We held our Annual Southern Living at Home Party with Missi McCombs, consultant and myself as hostess. This was our 7th Annual Party where we raised $750! We are committed to the cause and look forward to next August for our 8th Annual Event!

All the Best,
Megan Hernandez (Tyler’s Mom) of Lutz, Florida

Tiffany Green of Madison, Wisconsin held an euchre tournament through the Unite for the Cure campaign and raised over $700 in honor of her niece, Nora Gooden!
Dear Families of SMA,
Enclosed you will find a donation made in honor of my nephew, Jacob Cole Slaymaker. Jacob has Type I SMA and just turned six years old this past June 29th! He has been doing well, and is currently on an experimental medication that will hopefully prove to make him stronger.

My sister and brother-in-law (Laura-Lee and Justin Slaymaker) are such wonderful people. Jacob is their first and only child and they do more than I could ever imagine with Jacob, he is a very happy boy!

This past May I again took part in the Michigan SMA Chapter’s Run, Walk & Roll in Lansing (I live in Michigan, Jacob lives in Florida). I also created a website to help raise awareness and funds for SMA in honor of Jacob’s birthday, and the May event. So far over $500 has been raised (over $6,500 in the last four years), and we are thrilled with our families and friends that have been so supportive of Jacob and SMA awareness.

Sincerely,
Samantha Moucha of Chesterfield, Michigan

Amy Butler of Madison, Alabama invited Kohl’s Department Stores and their associates to volunteer their time with Families of SMA on October 17, 2009. The Kohl’s associates had a wonderful time participating. $500 was collected on behalf of Kohl’s associates who volunteered their time in support of Families of SMA. Kohl’s strongly believes in supporting communities nationwide. Thank you for your participation!

To FSMA,
Enclosed are checks in the amount of $500 from the family of Mackinley Neal Hardison.

Mackinley, born January 31, 2009, was diagnosed with Type I SMA shortly after he was two months old. His family wishes to honor him on his first birthday by donating these funds, which we wish to go towards research for a cure for SMA.

Thank you for your continued support to families who care for victims of SMA.

Catherine Brittain (Mackinley’s proud grandmother) of Dunn, North Carolina

Dear FSMA,
Enclosed you will find donations totaling $455, generously given in honor of my son Colby Russ, from Louisville, Kentucky, SMA Type I. Colby turned seven years old on July 22. His birthday party had to be postponed because he was at Cincinnati Children’s Hospital from July 15-August 15, 2009. We had his SpongeBob birthday party on September 13, with many family and friends in attendance. After his lengthy hospitalization, what a reason to celebrate! We had asked that instead of gifts, people donate to FSMA. Colby has made a full recovery from his hospital stay and we are very proud of all he has accomplished.

Sincerely,
Amy Russ

Families of Spinal Muscular Atrophy,
Enclosed are checks totaling $447 from donations raised during our annual Costume Crusade at our school, Tutor Time Learning Center of Brandon, Florida. More donations are forthcoming and will be forwarded in the future.

We support your efforts in research and wish you a productive 2010.

Sincerely,
Joseph R. Miller

FSMA,
Our 2009 holiday donation to SMA consists of four checks in the amount of $100 each. The four of us have been friends for 25 years. We decided to send donations rather than purchasing Christmas gifts for each other. Again this year, we have chosen FSMA as our charity. We know the Parrotta family. Sadly, they have lost their youngest daughter, Morgan, to SMA and their older daughter, Madison, has SMA also. Through the donations and efforts of many others, we are all hoping for a cure. In the holiday spirit, we are trying to make a difference.

Best wishes for a happy and healthy New Year.

Sincerely,
Carol A. Farber of Hamilton Square, New Jersey

Dear FSMA,
The employees of the New Jersey Higher Education Student Assistance Authority’s (HESAA) Office Relations Committee recently held a bake sale and raised funds for Families of SMA. Please accept the enclosed check in the amount of $400 from the proceeds of that bake sale.

Your group has provided support to members of our HESAA family—Mary Burzachello and Sherry & Mike Parrotta. We thank you for all you do for these families.

Sincerely,
Antoinette D’Angelo
HESAA Staff
Hello Families of SMA!

Here is a donation in honor of the wedding of Matt Hoffmann & Katie Bova. The bride and groom did an “old fashioned” bridal dance where you had to pay to dance with the bride or groom. They raised $355 in honor of the groom’s sister, Jackie Hoffmann.

Thanks for all you do!
Paula and Skip Hoffmann of Milwaukee, Wisconsin

FSMA,

Alexander Travel has partnered with the Peoria Rivermen Hockey Club to support SMA. During the first half of the team’s season, each time a specific player, Julian Talbot, scored a goal, Alexander Travel donated $25.00 to SMA. We have raised $300.00 to donate to SMA.

My 3 year old great-niece, Rebeckah Courdt, has SMA. She goes to every hockey game with her parents, Jeremy and Kim Courdt, as they are avid fans.

Thanking you in advance for your assistance.

Jody Allen of Peoria, Illinois

Shelia Murphy of Portland, Connecticut wrote the View From a Kayak in Autumn in memory of her grandchildren Cianan and Cecilia Murphy, and in honor of all families affected by SMA. Both Cianan (6/21/97-5/19/98) and Cecilia (4/26/99-7/13/00) died of SMA Type I. Shelia’s chapbook effort is intended to raise awareness of SMA, encourage contributions toward a cure, and portray the brief beautiful lives of two babies and their enduring place in her family. Poetry is Shelia’s passion and her area of expertise. From the sales of her books at poetry readings, Shelia has donated over $250!

Dear FSMA,

Please accept the enclosed check for $225 to FSMA to support research to find a cure for Spinal Muscular Atrophy. The donation is made on behalf of the Tiffin Columbian High School Class of 1994 in honor of my 19 month old son, Thomas Shepherd, who was diagnosed with SMA Type II when he was a year old. I am a 1994 graduate of Tiffin Columbian High School in Tiffin, Ohio. After learning of my son’s diagnosis, the organizers of our 15-Year Class Reunion decided to donate a portion of the proceeds from the reunion’s 50/50 raffle to FSMA in honor of my son. The reunion was held on August 1, 2009, in Tiffin, Ohio. This donation made in the midst of trying economic times in northwest Ohio was a very generous gesture by my classmates that was unexpected and extraordinarily appreciated by my wife and I.

Thank you for all of the work you and FSMA do on behalf of my son Thomas and other children and families diagnosed with SMA.

Sincerely,
Matthew Shepherd

Dear SMA Family,

I am forwarding $200 to you in honor of our son’s 1st birthday, Christopher Bruce Weber SMA I, the brother to Timothy Egan Weber SMA I (2001-2006). Thank you for all your work and devotion.

Sincerely,
Bruce & Allyson Weber of Schnecksville, Pennsylvania

A Casual Day was held at the Rogers Townsend & Thomas office in Columbia, South Carolina. They were able to raise $195 in honor of Keaja and Kalei Chisholm of Charlotte, North Carolina.

The Office of the Clerk of Superior Court of Clayton County, Jonesboro, Georgia, held a Jeans for Charity Day and made a donation of $192!

Families of SMA,

Enclosed is a donation for $175 in memory of our grandson Laikin Kale Rowland (11/18/03 – 1/25/04). Another $25 in donations was collected from donations from “Help find a cure for Spinal Muscular Atrophy” cards.

Gale Perkins of Fredonia, Kentucky

To Whom It May Concern,

Each payday, our staff has a Dress Down Day, in which the staff members make a donation in exchange for dressing comfortably for the day. During the month of February, money
was collected for “Spinal Muscular Atrophy”. On behalf of the staff at Tolland Middle School in Connecticut, we would like to donate the enclosed checks totaling $175 in memory of Alexander Toccoli of Manchester, Connecticut. We know you can always use the extra money and hope these checks will help!

Sincerely,
Roberta Gavin on behalf of the staff at TMS

Dear FSMA,
This donation of $150 is in memory of Audrey Nicole Shutes (June 12, 2004- April 12, 2005, SMA Type I). Her grandfather, Clifton Smith, raised the money through a raffle he held at a monthly grocery BINGO at his chapter of the Knights of Columbus. The winner of the raffle won a necklace and earring set that Cliff had hand-made. While some people bought a raffle ticket, others just gave a donation. Thanks to the Knights of Columbus Fourth Degree members that helped, as well as the patrons of grocery BINGO at the Knights of Columbus in Lafayette, Indiana. Thank you.

Sincerely,
Rita Shutes (on behalf of Clifton Shutes)

Dear FSMA,
On behalf of my youngest daughter Likee Ford (SMA Type II) and all the kids, we’d like to offer this donation of $115 collected from donation cans here in Ephrata, Washington. Bless the research for a cure.

Sincerely,
Annie Ford

Dear Friends,
Please accept our gift of $112 in honor of Colby Russ.

We have collected this money as a result of our 2009 Causal-for-Charity Days, wherein we drew a name from a list of employees at our Administration Building. The person whose name was drawn offered his/her “charity of choice” and the money we collected is our contribution to that organization at the end of the year.

Keep up your great work. Your services are very much appreciated.

Sincerely,
Margie A. Fetter
Greater Clark County Schools Jeffersonville, Indiana

This donation of $109 is from the penny jar that May Watts Elementary School’s Do Something Club collected. The Do Something Club participated in a garage sale fundraiser in Naperville, Illinois on September 19th in honor of Jungin Angie Lee.

This is a donation from Waukesha, Wisconsin North High School Advisory Program in honor of Reagan Imhoff, daughter of Jenny (Larsen) Imhoff, former teacher & coach at North.

Our Advisory program chooses a cause or organization to raise money for each year as a part of our community service focus. The 2008-2009 advisors decided to raise funds for SMA.

We hope this donation of $103 helps!

Sincerely,
Sarah Bristol

Dear Families of SMA,
For the past three years I have held a Pampered Chef Fundraiser in the month of December. I do this in honor of my twins Owen and Grant who were born December 28, 2004. It is hard to believe they would have been five this past year. Unfortunately, SMA Type 1 took their lives way too soon (Owen at 11 weeks; Grant at 15 weeks).

Jeanette Arnold, Pampered Chef Consultant, has once again donated her profits from the sales, plus a donation from the Pampered Chef Company totals $101.20 this year.

I know nothing will bring back my beautiful Owen and Grant, but I know the struggles and pain that SMA families face. One day, God willing, we will no longer have to lose our loved ones. Thank you for all the work that you all do for the SMA cause!

Sincerely,
Vanessa Burns Marietta, Ohio

Mary Lynne Ashley of Colorado Springs, Colorado held a little fundraiser of her own at her photography studio. Mary raised $100 and donated it to Families of SMA. We thank you so much for your generosity and for sharing your artistic passion with FSMA and others!

The Los Altos- Mountain View American Association of University Women of California raised $75 for Linda Shively’s “Be Grateful- Be Happy!” talk about ways to improve her own life and those of others. After surviving multiple life changing events she has discovered ways to be happy despite, and even because of, tragedy. Her daughter, Jessica, was diagnosed with SMA when she was three months old and lived a very full and happy life until she was nearly four years old. Ms. Shively shared her ways to be happier, less stressed and more satisfied with life, and did a very nice job!

Kay Wittman of Jerseyville, Illinois collected $75 to be used for SMA research, as she asked her class from Delhi Elementary School to donate to FSMA for her Christmas gifts. Kay raised this money in honor of her daughter Amy, who has SMA.

Please note: The amounts raised, are totals as of March 12, 2010, and may differ from the current totals by the time you receive this newsletter.
Hello!

This is a check for $30 for FSMA. We donate money to FSMA instead of Christmas presents. Here is a picture of our son, Weston. He is so happy and so healthy! Thank you for all that you do!!

Sincerely,
Jennifer Gehman of Hershey, Pennsylvania

Allyson Henkel of Rosemont, Pennsylvania raised $14 at a Giants football game (lemonade stand) in honor of her son, Peter Henkel.

Hilary Schmid and her sister Kristen have been very involved in the ongoing fight to find a cure for SMA. Kristen and her partner Lucy are real estate agents in the Devon, Pennsylvania office of Long and Foster. They have collaborated with their good friend Ron Bradly, a Sr. Loan Officer with Capital Financial Mortgage Corporation. Together, they have committed to donate a percentage of their fees to the Families of Spinal Muscular Atrophy, in memory of Zane Schmid, just for the services they already provide. Hilary and Keith Schmid continue to be blessed by everyone’s continued support.

Geocaching is a worldwide game of hiding and seeking a treasure where you can pinpoint its location using GPS technology and then share the geocache’s existence and location online. Anyone with a GPS unit can then try to locate the geocache. Justin and Shannon Kuester of Hartford, WI created a Travel Bug for Families of SMA, called “Dr. Schroth’s Mission”, in honor of their daughter Addison. Their travel bug has made it through 24 hands and traveled a distance of 304.7 miles since it was first released in 2008 in the hope that more people will learn about Spinal Muscular Atrophy. Check out their sight to follow the bug and learn more about geocaching! http://www.geocaching.com/track/details.aspx?guid=96549d9c-b898-435e-8512-2498d60c79b6

We are a non-profit, 501(c)3 tax exempt organization. Funds will be specifically directed to scientific, educational or literary purposes in keeping with a charitable organization. The organization is proud to provide funding to the FSMA newsletter and website, which provide information and networking opportunities to its members.

Submissions
To submit articles or make other contributions to our newsletter, please contact us at: newsletter@fsma.org.

Digital images are encouraged! Send your digital pictures to: newsletter@fsma.org.

Change of address
Send changes, including ZIP code to: info@fsma.org or call 1-800-886-1762 or mail to: FSMA Membership, 925 Busse Road, Elk Grove Village, IL 60007

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FSMA does not support or endorse any particular treatment or therapy. Information contained in this newsletter should not be used as a substitute for consultation with a qualified healthcare professional.
Multiple Presentations on Spinal Muscular Atrophy at The 62nd American Academy of Neurology Meeting. Including Five by the Project Cure SMA Clinical Trial Network Funded by Families of SMA.

The 62nd American Academy of Neurology (AAN) Meeting is being held the week of April 10th to 17th. Multiple presentations focusing on Spinal Muscular Atrophy will be given, including five from the clinical trials network Project Cure SMA, which is funded in its entirety by Families of SMA.

In addition, Dr. John T. Kissel of The Ohio State University is presenting a talk in a plenary session to the entire conference audience called “Spinal Muscular Atrophy: A Story of Rags to Riches”.

Dr. Kissel is a principal investigator in the Project Cure SMA clinical trials network, a member of the FSMA Medical Advisory Council, and also involved in a recent grant to Ohio State from Families of SMA to develop a Gene Therapy for SMA.

Project Cure SMA Presentations at AAN Include:


Authors: Aga J. Lewelt, Salt Lake City, UT, Kristin J. Krosschell, Chicago, IL, Charles Scott, Fort Washington, PA, John T. Kissel, Columbus, OH, Thomas O. Crawford, Baltimore, MD, Gyula Acsadi, Detroit, MI, Guy D’Anjou, Montreal, Canada, Bakri Elsheikh, Columbus, OH, Sandra P. Reyna, Bernie A. Lasalle, Salt Lake City, UT, Mary K. Schroth, Madison, WI, Louise R. Simard, Winnipeg, MB, Canada, Jo Anne Maczulski, Chicago, IL, Kathryn J. Swoboda, Salt Lake City, UT

2. Hand Held Dynamometry and Fixed Maximal Voluntary Isometric Contraction Strength Testing in Ambulatory Adults with Spinal Muscular Atrophy.

Authors: Wendy M. King, Worthington, OH, Bakri M. Elsheikh, Columbus, OH, Chuck Scott, Fort Washington, PA, Bernard A. LaSalle, Salt Lake City, UT, Kristin J. Krockell, Chicago, IL, John Kissel, Columbus, OH

3. The Role of Ulnar Compound Muscle Action Potential (U-CMAP) as a Surrogate Outcome Measure in Ambulatory Adults with Spinal Muscular Atrophy (AA-SMA).

Authors: Bakri Elsheikh, Columbus, OH, Kathryn Swoboda, Salt Lake City, UT, Charles Scott, Fort Washington, PA, Wendy King, Worthington, OH, Elizabeth Bollman, Columbus, OH, Kristin Krosschell, Chicago, IL, Bernard LaSalle, Salt Lake City, UT, Stephen Kolb, John Kissel, Columbus, OH

4. Reliability of the Six Minute Walk Test in Ambulatory Patients with Spinal Muscular Atrophy.

Authors: W. David Arnold, Bakri Elsheikh, Columbus, OH, Kathryn Swoboda, Salt Lake City, UT, Charles Scott, Fort Washington, PA, Wendy King, Worthington, OH, Elizabeth Bollman, Columbus, OH, Bernard A. LaSalle, Salt Lake City, UT, Kristin J. Krosschell, Chicago, IL, John Kissel, Columbus, OH

5. SMN Transcript Quantification as a Surrogate Outcome Measure in Spinal Muscular Atrophy (SMA) Clinical Trials: Towards a Validated International Standard Operating Procedure (SOP).

Authors: Louise R. Simard, Winnipeg, MB, Canada, F. Danilo Tiziano, Rosa Lomastro, Rome, Italy, Elzbieta Slominski, Winnipeg, MB, Canada, Giovanni Neri, Christina Brahe, Rome, Italy

About Project Cure SMA:

Project Cure SMA is a collaborative initiative between Families of SMA and clinical investigators designed to help facilitate the rapid translation of promising new therapies to individuals with SMA. A primary goal of Project Cure SMA is to develop safe and well tolerated clinical protocols to help identify truly effective therapies.

Funding for all support staff and for all clinical sites in the United States is being provided by Families of SMA. Project Cure SMA sites include Salt Lake City, Utah; Durham, North Carolina; Detroit, Michigan; Baltimore, Maryland; Columbus, Ohio, Madison, Wisconsin, Montreal, Canada, Cologne, Germany, and Argentina.

In 2001, Families of Spinal Muscular Atrophy established and single-handedly funded a clinical trials network called Project Cure SMA. This network has conducted natural history studies that increase our understanding of Spinal Muscular Atrophy disease progression, built models for designing SMA clinical trials, and now runs clinical trials with existing drugs.

Families of SMA’s investment of over $6 Million in five clinical trials is helping to test existing drugs that may lead to a treatment for Spinal Muscular Atrophy. In addition, as novel drugs currently being designed for SMA become available, having a fully operational clinical network with a sufficient number of sites to conduct pivotal SMA drug trials will help attract and encourage biotech and pharmaceutical companies to invest in SMA drug development.
FSMA Care Packages

Families of SMA is excited to announce the creation of the Newly Diagnosed Type II and Type III Care Packages Program. Beginning January 1, 2010, FSMA will now be sending care packages to all newly diagnosed families within the United States. These care packages are made up of items that have been suggested by other SMA families.

Here is some of the feedback we have received from newly diagnosed families who have received their care packages:

Dear Families of SMA,

Thank you so much for the newly diagnosed care packages for our daughters, Brielle and Brooke! It was so much fun to open the big box full of toys with the girls and see them smile and have so much fun! The Jack-in-the-box is a huge hit!

Thanks again, Sarah, Eric, Brielle & Brooke Kennedy of Mattawan, MI

Posted by Carol Schemensky:
The feelings are all over the board when you get one of these packages. The overwhelming feeling of comfort is packed in the box and is so needed when first trying to make sense of the news of an SMA diagnosis. We lost little Isaiah on December 10 (11 months old), and the comfort and blessings of FSMA helped see us through. Thank you, thank you, thank you!

Posted by Kelly Mantoan:
I just received my Type II Care Package in the mail today. All my children enjoyed opening the toys inside and sharing them with their brother Fulton. It was a nice ray of much needed sunshine. Thank you very much FSMA.

Posted by Christina Altman:
Just got Gabbie’s care package and would like to say OMG, thank you. The stuff is so awesome it was like Christmas for her all over again. I am so thankful for it. She loved everything! I can’t wait to take pictures with all the fun and cool stuff. Also, her blanket is amazing, she loves the ABC’s and it’s so wonderful, she lays on it all the time now. All of you are wonderful. Thank you again!

Posted by Nicole, Jon and Scarlette:
We received our package and no words can express how grateful we are. It brought a tear to our eyes and a smile on our faces. Our sweet angel Scarlette loves the Play-Dough. We can’t wait for the conference. See you all there! Thank you again.

Thanks to the Families of SMA for the care package and information packet that you sent. The package brightened up Jolene’s day and she is playing non-stop. You are truly a blessing to my family and we hope to be able to meet you all at the conference.

Thank you for all that you do,
Adriana Gallegos of Odessa, TX

This is a picture of the first recipient of the Newly Diagnosed Type II Care package program launched January 1st.

Thank you so much for the wonderful gift you sent my daughter, Sofia. Her face was priceless when we opened the package. I have attached a photo so you can see for yourself the smile you brought her.

Monica Santana, mother of Sofia Santana
of Hialeah, FL
All of our friends at FSMA,

Words cannot express the feeling we had when we received your “care package” last week. What a WONDERFUL unexpected surprise! Our daughter, Addison, was oh-so-excited as she pulled toy after toy out of the box! The shopping cart & barn puzzle were big hits at our house, and she keeps asking if she can get out the Play-Doh. Thank you for warming our hearts and bringing her joy!

I am attaching some photos of our family and our SMA princess.

With gratitude, Kara Tarrence, Mother of Addison Tarrence, SMA Type III

PS…On a good note: We just received word yesterday from the University of Iowa that our other daughter’s (Aspen - 8 months) test for SMA was NEGATIVE!! This was some much needed good news for our family!

The Type II Care Packages include some of the following items:

- Fisher Price Outdoor Swing
- Bumbo Seat
- Earlyears Fill ‘N Fun Water Baby Play Mat
- Fisher Price Magna Doodle
- Motorized Bubble Blower
- Sheepskin Blanket
- O-Ball
- Jack in the Box
- Silkie Security Blanket
- Large Knob Wood Puzzle
- Finger Puppets
- Lightweight balloons on a stick
- Small Pinwheel on a Stick
- Small Flag on a Stick
- Small Plastic Animal Toys
- Sesame Street Sing Along DVD
- Play-Doh

The Type III Care Packages include some of the following items:

- Fisher Price Magna Doodle
- Motorized Bubble Blower
- Fisher Price Shopping Cart
- Playskool Dog Pull Toy
- Sesame Street Sing Along DVD
- Large Knob Wood Puzzle
- Silkie Security Blanket
- Play-Doh
Dear Team at FSMA,
We just wanted to thank you for all your hard work & dedication in supporting the families & being a part of the “soon-to-be-cure.” When I call, no matter who I speak to, everyone is so nice & caring. It is so nice to have a wonderful organization associated with an awful disease. We will continue to help raise funds and be a part of the cause in memory of Zane and all the children who are affected with SMA.

Sincerely,
Keith, Hillary & Avery Schmid of Malvern, PA

We received the information packet and care package this past Friday. The information packet is very helpful as well as the care package. Morgan thoroughly enjoyed the care package. Thank you very much for being so thoughtful. It was a pleasant surprise to the end of an event filled week of snowy weather we’ve been having in the mid-Atlantic region.

There is a lot of information to absorb and will follow-up with questions.

On behalf of Morgan, thanks again, to you and your staff.

Sincerely, A newly diagnosed family from Maryland

FSMA,
Thank you so much for all of your continuing support. We appreciate all that you do for us. It means the world to all of us!

Love, Scott, Nikki & Leah Miller of Springfield, OH

The Dougherty and Murphy families enjoyed fun filled days sledding and skiing at the Beech Mountain Adaptive Learn to Ski Week in North Carolina. Gray Dougherty and Connor Murphy rode the chairlift to the top of the mountain and skied down with specially trained ski instructors. The boys had a great time flying down the mountain, leaving other family members far behind! This is just one of many fantastic adaptive sports programs available to children and adults facing physical challenges.
**Wyatt & Jack Tranby**

**FSMA,**

Thank you for the support, care and compassion. We follow the research in the fight to cure SMA and hope soon there will be a cure. Wishing you a healthy, prosperous 2010!

*Happy Holidays,*

*The Tranby Family of Apple Valley, MN*

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**The Taiwo family.**

**Families of Spinal Muscular Atrophy,**

Thank you so much for all of your support. We appreciate you so much for everything you have been able to do. In memory of Isaiah Ryan Taiwo.

*Love,*

*Boye, Erin, Isaac, and Isaiah of Burnsville, MN*

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**Dear FSMA,**

Thank you for all the support you’ve given our family and the AL Chapter. Hopefully a cure will be found soon! We hope you have a Merry Christmas & Happy New Year!

*Love,*

*Jennifer, Jason, Logan & Landry Patrick of Cottondale, AL*

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**Dear Families of SMA,**

On behalf of my parents, Butch and Sue Fransen, I am sending you this check for $23,000. This donation was part of a family trust of which my mother was the sole beneficiary. She knew of no better place for these funds than with Families of SMA. She requests that this donation be put toward your research projects in hopes that you will find a cure for her granddaughter, my daughter, Kate Pecora.

I would like to take a brief moment to tell you about my parents. They have two grandchildren, my daughters, Kate and Caroline. Kate has SMA III. I believe Butch and Sue would tell you the worst day of their lives was the day of Kate’s diagnosis in 2003. I don’t need to explain to you the kind of tailspin that news puts you in. Depression, worry, and fear hung over them for months. As with every other grandparent of a child with SMA, they were changed forever. However, for Butch and Sue they were changed in the most amazing way. They had always been kind, generous people but SMA has turned their goodwill into their lives’ project.

In 2005, Butch and Sue opened what is known as Kate’s Place. Kate’s Place is a vacation home on Long Lake in Harrison, ME. Every summer they open the home to families touched by SMA for a week at a time. They have had over 20 families enjoy the accessible home in the heart of the Lakes Region of Maine. Although they could rent the home for thousands of dollars a week, they choose to give weeks away for free each summer through a lottery held in late winter. They have welcomed families from all over New England, the East Coast and as far away as Alabama. For as much as it is a relaxing vacation for families enjoying the swimming, boating, fishing, shopping, and eating, Butch and Sue are energized by knowing that they are providing the families some priceless, treasured memories. Kate’s Place has a website where you can find more information and some pictures of the house if you’re interested: http://mysite.verizon.net/vzeyigwz/katesplace/

So, thank you for allowing me to brag a little about my parents. They’re the best parents a girl could ask for! I know you will take their donation and put it toward good use. I look forward to hearing about all the research updates.

Warmest regards,

*Kristine Pecora of Caldwell, NJ*

*Proud mom of Kate & Caroline and proud daughter of Butch and Sue Fransen*
A Childhood Worth Fighting for
The Story of Cariad Howat

Written by Her Father, Jez Howat

As a family we don’t spend lots of time on the past, or telling ‘our story’. We don’t have a website, Facebook or Myspace pages or anything like that. There are a number of reasons; we don’t fit in to a ‘support group’ mould… basically, we have never been good at ‘comparing notes’ with others, or finding solutions to other peoples’ problems. Being honest, we have enough emotional and physical baggage to carry on our own. It was hard enough coping at the time without worrying about ‘being there’ for others.

For the general public, if they have read or heard anything about SMA Type I, it’s usually in the context of people struggling to work out the rest of their lives after its impact. Or it is reflective, with parents and family remembering their angels and still trying to make sense of it. These things tend to help others empathise with the destructive nature of SMA, but for us they are hard to read – and my guess is that for many families living with SMA, this is probably the case.

Now, we have a daughter with SMA Type I, and she is six years old. We have no idea what the ratios and survival rates are but we know we are very lucky that Cariad is not only with us, but that she is living as normal a life as she can. She attends school, is reading and (with help) writing. She is also speaking… a lot! We play games on the Wii, she loves to cook and… well, she is a normal kid trapped in a disabled body! Yes, she is a little angel – but she can be a little devil at times too.

And in truth that’s one of the most important things to understand - underneath all that ‘stuff’, our little girl is a typical, stroppy, funny, loving, normal kid (depending on where you are reading this, you might like to cut this bit out for the medics).

Our journey here has been eventful with many difficult times, difficult conversations and difficult choices. However, what has occurred to me is that there is something that we could hope to offer others, and that is what we (medics, parents and carers) need to understand what we need to deal with children who live with this condition, and equally as important, what we need to forget.

We had the usual prognosis of a very short lifespan with not much air space to breath. Its no wonder that all many people see of SMA Type I is the aftermath. The worst part was that it feels so ‘medical’ and matter of fact, with little time for humanity outside of ‘medical ethics’ and palliative care.

Cariad was diagnosed at four months old. At six months she had respiratory collapse. During a 12 week drama we were asked to let her die several times. We also went through the ‘what do you want to do?’ question pretty much every day for three months - you know, the one where you get the feeling that they know the answer already, but are waiting for you to come round to it.

During that time, we knew little about the condition, and the situation seemed to move so fast. We weren’t offered any real choices of care and we didn’t know enough to make a difference anyway. This changed very quickly!

The first thing that we found essential is UNDERSTANDING. Please don’t read that as ‘knowledge’ of the condition – there is a mile of difference between knowing something and understanding it. Packaged in ‘knowledge’ is the prognosis – one of those things that parents, medics, etc need to learn to forget! Its grip on how a child will live their lives, what others expect of them and what services will be offered (or denied) is very much overstating its true place in things. Understanding the prognosis means knowing when it’s served its purpose, and disposing of it accordingly!

I remember being told, shortly after Cariads diagnosis, that “there really isn’t much point in putting a physio plan together - it’s not going to do her any good is it?” I wonder how many parents could tell similar stories. Prognosis is useful. But it is not the law. Let’s get it into perspective. Prognosis is an easy option – funding can be put into categories, care plans be made more generic, expectations put into safe boxes. It is also (to some degree) driven by a fear of being wrong (or sued) and also because it’s harder to treat each person as an individual with an ever increasing workload.

It was interesting how things changed once Cariad reached two years old, and then three. We are still asked occasionally what the prognosis is… we just retell the official prognosis and watch the reaction, before shrugging our shoulders.

OK, this is simplifying things a bit. There are hard decisions to be made
Based on what is predicted for a child’s life. Some will not make the same choices we made. Some will go further than we want to; others may think we have gone too far. That’s fine. However, it’s a parent’s responsibility to make those choices for their children with a truthful understanding provided by those who should have an understanding of the condition – grounded in the prognosis but knowing its limitations and accepting the child as an individual.

Rant about prognosis over, this brings me to the second thing we feel is needed - CHOICES.

We wanted Cariad to have the opportunity for life, and believed that she could experience this in a productive way, with the pleasure/pain/etc. that goes with that (which was the medics’ main criteria for ‘quality of life’ 5½ years ago). The treating hospital disagreed with us that Cariad could achieve this. We asked that, if Cariad had an infection, she should be intubated for 72 hours for antibiotics to have an effect (the issue is setting a timescale). However, we didn’t (don’t) want her to have a tracheotomy or permanent hospitalisation.

I am happy to say we ARE right…and based upon that simple evidence, I would expect medics to take a different attitude now. It is a good question though; what is an ‘acceptable quality of life’ in the real world? This was a lot harder than deciding whether to allow her to die. We don’t want ‘life at any cost’ but believe there must be a reasonable measurement. In some ways we are fortunate because she can now decide many things for herself.

Moving on to other choices, how about technology? We have embraced technology (Bi-pap, cough assist, suction, etc.). Technology has helped and sustained Cariad in good health, and we couldn’t be without it. You also have to choose where this stops. This brings you into funding debates; as technology is not cheap…and someone has to pay. There is a very healthy debate about technology and funding and it does help to try to see this difficult dilemma from both sides. However, better people than I are unsure about this, so it’s best left there! One thing I would like to say is that prognosis often has a major impact on the level of technology available (unless you are willing to buy it yourself). I am happy to be corrected on this, but as I have a healthy disregard for the P word, I do not think that is the most appropriate solution.

And the final tool we have discovered is TENACITY. When you have reached the right decision for you, stick to it.

I said that we chose to give Cariad a chance – even though we were being told there was none. We found that Cariad was receiving the wrong kind of care, although the hospital would not give her a Bi-PAP ventilator until she was three. We found evidence the best treatment was probably a Bi-PAP, and that children with her condition could survive longer. The hospital dismissed this evidence as it came from outside the UK. As a result of this disagreement our hospital launched us on a date for a judicial review (in the UK, if parents and medics disagree, the medics can get a court to decide…and thereby overrule).

With the help of the UK charity for SMA Type I, the Jennifer Trust, we began to stop ‘following’ and started to understand our choices, and the limits of those choices! With an offer of help from the Royal Brompton Hospital in London, we were saved from having to fight in court. They knew SMA and understood the condition. They hadn’t much experience of introducing (effectively) a baby to Bi-PAP, but gave it a go with huge success. They were then able to treat the underlying respiratory infection.

There is no point in suggesting we made all our choices without their help – we needed lots of it and were allowed to ask dumb questions, throw tantrums occasionally and also to be real people – and Cariad a real child instead of an SMA Type I sufferer. We are grateful for their ongoing support and encouragement – even though Cariad has only been back into hospital once in the last three to four years (apart from visits and check ups). It’s important to also say that we have built some significant bridges with our local Care Trust – especially post prognosis. They have implemented a comprehensive ‘emergency arrangement’ and have put a lot of effort into making sure she gets the best of care…though under the Brompton’s guidance and specialist advice.

Tenacity is extremely important in the long term survival of an SMA Type I child. Find out who needs to be involved; nutritionists, OTs, speech and language, physiotherapists, portage, educational specialists, community team. Get as high up the tree as you can and build a relationship. It is only with the support of all these people that you can be sure you are getting everything you can.

What about the future? What about the family’s life? One medic - who I would love to name but have actually forgotten his name - suggested that having a disabled child would place an unbearable strain on the family. I couldn’t possibly write my response here, but don’t all kids put unbearable strain on a family from time to time? We are actually incredibly lucky to have a family life where there is so much love, attention and effort is made to ensure that each and every day is normal and packed with family activities.

I really hope that more and more children with SMA Type I get an opportunity for longer life with non-invasive means of management. I am convinced that NIV via Bi-pap, together with a well managed package of care, is granting children with SMA Type I a better outlook, and I am very proud of the people at the Royal Brompton (Prof. Andrew Bush, Dr. Michelle Chatwin, Dr. Anita Symmonds, etc.) who are spearheading this in the UK. Most of all, I am proud of my little fighter, Cariad, who puts a great big smile on the face of every nurse, teacher and friend that she meets – I was never that sociable at her age!
The Lino Family

The Potter Family

The Saxton Family

The Liston Family

The Freedman Family

The Hernandez Family

The Moner Family

The Gaynor Family

The Tomko Family

The Burks Family

The Zurawski Family

The Rush Family

The Turnbull Family

The Fisher Family
FAMILY photos

The Eide Family

The McHale Family

The Stare Family

The Murray Family

The Vondrak Family

The Biancucci Family

The Bodzo Family

The Tate Family

The Schmid Family

The Cuevas Family

The Patrick Family

The Partridge Family
Sophia’s Cure
Families of SMA would like to thank Vincent and Catherine Gaynor of Wantagh, New York for all their hard work and dedication to raising a remarkable amount of money and awareness for SMA in the last 10 months! Shortly after they found out their daughter Sophia has Spinal Muscular Atrophy (SMA Type I) they set up a gift registry through the FSMA website and committed to raising $100,000 to “make an impact and not stand by helplessly”. In order to raise this money they immediately began spreading the word about SMA through numerous television interviews, radio talk shows, and newspaper articles all over the country! As soon as the word got out about Sophia and SMA, donations began pouring in from all over the country. Sophia’s story also inspired those without previous ties to their families such as Ryan Burkett and Dennis Edison. After reading about Sophia in a local newspaper they decided to ride their bicycles across the country from New York to California in order to help raise awareness about SMA and funding for a potential cure. Read more about Ryan and Dennis on page 81. It was not long before the Gaynor’s had met their $100,000 goal and decided to raise it to $200,000! The fundraisers that they organized were one right after another and we cannot thank them enough for their unending determination to raise this amount of money so shortly after their diagnosis. Overall, they surpassed their goal of $200,000! Way to go, Gaynor family!

When talking about Sophia, Vincent Gaynor said: “She is completely paralyzed. She may never crawl, walk, sit up, talk, swallow or breathe on her own. But that is not where her power lies, it is in her beauty and in her message. There are so many things she may never have, but one thing that I am certain of is that she will always have LOVE.”
Unite for the Cure

Unite for the Cure was a campaign started by families impacted by SMA. Their goal was to collectively raise $100,000 to help FSMA’s promising stem cell therapy program progress to human clinical trials as quickly and as safely as possible.

In only four months and with fundraisers organized by over twenty families and their friends across the globe (literally), “Unite For The Cure” (Unite) met and surpassed their goal of raising $100,000 for Dr. Keirstead’s promising SMA research. In fact, $145,000 was donated to Families of SMA (FSMA) through Unite efforts. This is an enormous accomplishment in and of itself in such a short period of time, but when you take into account that every single one of these remarkable families is either caring for their child or grieving the loss of their precious baby — it is nothing short of miraculous!

Families of SMA would like to thank the following families who took part in this campaign:

- The McClay family
- Span family
- Potter family
- Reilly family
- Schmid family
- Marshall family
- Strong family
- Gooden family
- Pringle family
- Butler family
- Trakas family
- Gustafson family
- Lunt family
- Lucas family
- Zahn family
- Ragland family
- Coleman family
- Wright-Beasley family
- Howell family
- Calafiore family
- Felix family
- Greene family
- Lovelace family
- New family
- Bolen family
- and the VanderZanden family!

Douglas & Michele Erwin

Douglas and Michele Erwin of Massapequa, New York organized the 2nd Annual NYC Half Marathon for SMA in honor of their son Greyson. Douglas and over 20 other runners ran the NYC Half Marathon on August 16th to raise money for SMA research and to raise awareness for SMA. To date, Greyson’s 2009 NYC Half Marathon Team has raised $82,924 to benefit SMA research! Congratulations, Erwin Family!

Alexandra’s 2nd Birthday

Andrea Nelson Meigs and John Meigs of Los Angeles, California set up a gift registry in place of birthday gifts that would have been given to their daughter Alexandra for her 2nd birthday (Oct. 24th) as well as in lieu of any gifts for Andrea’s own birthday (Oct. 30th). They asked friends and family to make a donation to help Families of SMA, educate others and to find a cure. The fundraiser was a way for them to honor their daughter’s memory.

Andrea said, “With your donation to FSMA, we can help spread the word and help find a cure. This truly would help give me “real” meaning of why my little angel was taken away too soon. I only pray that she has a beautiful birthday in heaven, as we raise money for a cure in her memory here on earth. Thank you for helping to celebrate Alexandra’s 2nd birthday with me in this way!”

In total they raised $14,288 in memory of Alexandra. Thank you Meigs family!

Running for Cru

Paul Kapellas of Chicago, Illinois enjoys running marathons. For the second year in a row he was “Running for Cru”, in memory of his friend and co-workers son Cruciano, who lost his battle with SMA in September of 2008. The 2009 Chicago Marathon was his eighth marathon. It was the second marathon that he has run for Cru by fundraising for Families of Spinal Muscular Atrophy. Congratulations to Paul, who has raised $9,042 in memory of Cru!
Ride for Sophia’s Cure for SMA
On September 15th, 2009, Ryan Burkett and Dennis Edison geared up to ride 3,500 miles across the country to try and raise money to help fund research for a cure in honor of Sophia Gajnori. The ride began in Wantagh, New York and concluded in San Francisco, California. The riders biked approximately 100 miles per day and arrived in San Francisco on October 29, 2009. Congratulations to Ryan and Dennis for completing this incredible journey to help spread awareness for SMA and for raising a total of $6,885!

For Ollie - Fundraising for a Cure
Neil and Rebekka Mastin of Raleigh, North Carolina began celebrating their son Ollie’s birthday every month on the 5th. Sadly, they were unable to celebrate his first birthday with him because he lost his battle with SMA on August 3rd—just two days shy of his birthday. In lieu of flowers, they asked their friends and family to make donations to help Families of SMA in memory of Ollie. Overall, the Mastin family has raised $3,805 in memory of Ollie!

2010 Boston “Jack Rabbit” Marathon
James Dietz of Canfield, Ohio has set up an online gift registry beginning February 12, 2010 in honor of Jack Kotheimer, the son of one of his best friends, who has SMA. James is running in his first Boston Marathon on April 19, 2010 – a life-long goal that he has attained after qualifying through the 2009 Cleveland Marathon. He has just started fundraising and already raised $4,990! Way to go, James! We wish you great success in training towards this goal!

Jan’s 2010 Boston Marathon
Jan Paul DeWeer of Saint Louis, Missouri has set up an online gift registry in memory of his nephew and niece, Cianan and Cecilia Murphy. Here is what he had to say…

“I’ve been given the opportunity to run in the Boston Marathon on April 19, 2010. Everyone knows that running a marathon is not an easy task, but finishing is indeed possible through consistent training, good health, support, and a little luck.

A Cure For Cooper
JC and Asia Nowotny of Winter Haven, Florida set up an online gift registry in memory of their son, Cooper Finn Nowotny to help support Families of SMA. Cooper was born on July 23, 2009. Soon after, he was diagnosed with SMA Type 1.

JC and Asia said, “Although he was only with us for a short time, he inspired us, influenced us, and most importantly showed us what life is about - always give what you can and never give up. So with your help we would like to do just that - give what you can so we don’t have to give up on our fight against SMA. In place of cards, flowers and gifts we are asking our friends and family to make a donation to Families of SMA in hopes of one day finding a cure.”

Thank you to the Nowotny family for raising $5,012 in memory of Cooper and to help Families of SMA find a cure!
My nephew and niece, Cianan and Cecilia, both succumbed to SMA after only about a year. There is progress being made towards a cure, however, and I’m asking for your support in furthering that progress and making our hopes of a cure, a reality.”

So far Jan has raised $2,010!

Jordan’s World
Todd and Rita Lott of Cibolo, Texas have set up an online gift registry in honor of their son Jordan. Here is what they have to say…

“On November 5, 2007, Jordan was diagnosed with Spinal Muscular Atrophy (SMA Type 1), at six weeks old. As a family, we directed our thoughts and prayers to God to get us through this life changing diagnosis for Jordan. September 10, 2009 Jordan will be 2 years old. What a Blessing! A few months ago we saw a marathon running event was going to be held in the San Antonio, TX area on November 15, 2009, and decided to register to run the half marathon for Jordan and all the children affected with SMA. The run will be a 13 mile run starting at the Alamo going through many scenic venues of downtown San Antonio. Dad will be running for the family this year. Hopefully next year we can get Mom out there. We are asking our family and friends to sponsor Dad as he runs for Jordan and the cure for SMA. We would like to thank all of our family and friends for all of their love, prayers, and continued support. God Bless!”

So far they have raised $1,165!

Michael’s 2010 Boston Marathon
Michael MacCormack of Braintree, Massachusetts has set up an online gift registry to raise money in honor of his neighbor Owen Norton. Michael plans to run in the 2010 Boston Marathon! Here is what he has to say…

“I have committed to running the 2010 Boston Marathon on April 19th. This year I am running to raise money for an extremely worthy and necessary cause.

Don and Kathy Norton of Braintree are close friends and neighbors. They are also proud parents of four wonderful children. Owen, the third of their four children, is 7 years old and in second grade. In June of 2004, at 23 months old, Owen was diagnosed with Spinal Muscular Atrophy (SMA), Type II. Despite his illness, which he refuses to let define him, Owen is a loving, happy and vibrant little boy. In his honor, I will be dedicating my marathon run to Owen and to raising money for Families of SMA.”

So far Michael has raised $600!

Joseph’s Hope
Joe and Natalie Szumigalski of Pittsburg, Pennsylvania set up an online gift registry in honor of their son Joseph. They asked that friends and family please make a donation of any size to help Joseph and his family along with other families of SMA. They have raised a total of $445 so far!

Jennifer Mahan
Jennifer Mahan of Princeton, New Jersey set up an online gift registry in order to raise money for FSM. In place of gifts she is asking friends and family to make a donation to help Families of SMA. So far she has raised $445!

Kerr Family 2009 Holiday
Mary Jean Dery of Rochester, Minnesota has set up an online gift registry to help support a cause near to her heart. Mary Jean’s friend Cindy Castle’s grandson, Bradley Tisher was born with SMA, a devastating genetic disorder. Mary Jean asked family and friends to donate during the holidays in lieu of gifts. Congratulations to Mary Jean who raised $330!

Tyler’s 2009 Support SMA
Tyler Reed of Laytonsville, Maryland is competing in the IronGirl Columbia Triathlon. Tyler asked family and friends to support her efforts by donating to Families of SMA. Tyler set up an online gift registry through the FSM website and raised $275!

My Kick-Butt Birthday Fundraiser for Case
Dani Doornenbal of Sioux Center, Iowa has set up an online gift registry in memory of her nephew Case, asking friends and family to make a donation in place of birthday gifts. In total Dani has raised $255!

Tiffany’s 2009 Holiday Fundraiser
Tiffany Vargas of Whitestone, New York set up an online gift registry for the holidays. In place of holiday gifts she asked friends and family to make a donation to help Families of SMA. She raised a total of $225!

Lori Dell’Oso
Lori Dell’Oso of Wilmington, Delaware set up an online gift registry in order to raise money for FSM. In place of gifts she is asking friends and family to make a donation to help Families of SMA. So far she has raised $120!
Jane Coggins

Jenna Boguhn

Jade Hobby

Katelyn Miller

Emma Mary Banach

Ian Zurawski with Grandma

Jake LaFrance

Isabella Kurek

Hunter and Thayne Devereaux

Jill & Jeremy Jarecki

Josh and Daniel Tramontano

Jane Coggins

Jason and Jacob Wright

Jadon Burks

Jackie Hoffmann

Jenna Boguhn

Jade Hobby

Emma Mary Banach

Ian Zurawski with Grandma

Katelyn Miller

Jake LaFrance

Isabella Kurek

Hunter and Thayne Devereaux

Jill & Jeremy Jarecki

Josh and Daniel Tramontano
Congratulations

- Congratulations Ken and Michele Fanaro of Glenview, IL on the birth of their daughter Gianna Marie Fanaro born on October 9, 2009.

- Congratulations to big sisters Kennedy and Jaycie and parents, Kari and Jesse, of Kingsley, IA on their new baby girl, Bentley Jo Vondrak, who was born October 9, 2009.

- The Texas Governor’s Committee On People With Disabilities offered their sincere congratulations to Sandra Spoonmore on being selected as the 2008-2009 winner of The Entrepreneurship Award as part of their Annual Employment Awards. Their judges, selected from various public and private sectors across the state, had many positive comments about Sandra’s efforts to make the State of Texas and her community a better place for people with disabilities.


- Congratulations to the Gwendolyn Strong Foundation for winning $125,000 in the Chase Community Giving Campaign on Facebook.

- Congratulations to Jordan and Sherrie Clark of Houston, TX on the birth of their son Dillon Ramsey Clark.
Who am I?
I’m a researcher and mentor who has dedicated my career to SMA. The majority of the professionals who trained in my laboratory are still active in SMA research. I hope that I have inspired their dedication to this worthy cause.

Dr. Burghes is a Professor of Molecular and Cellular Biochemistry at The Ohio State University in Columbus, Ohio. He is also on the staff of the Departments of Neurology and Molecular Genetics. He serves on the Scientific Advisory Board of FSM A and the Steering Committee of FSM A drug screening programs, along with grant review committees for the National Institutes of Health.

Why did I become active in SMA?
While working on my graduate research at the Hammersmith Hospital in London, I had contact with clinicians and attended regular conferences conducted by Professor Victor Dubowitz and his fellows in paediatrics and neonatal medicine. The focus of my research as a graduate student in London, and later as a post-doctoral fellow at the Hospital for Sick Children in Toronto, was Duchenne Muscular Dystrophy. It occurred to me that SMA could benefit from the research approaches being developed for DMD.

I have always been involved in neuromuscular and neurogenetic research, and realized while still a graduate student that these techniques could be applied to SMA. It was not until I started my own lab at O SU in 1988 that I was able to pursue my interest in SMA research. I have never looked back…

What is my contribution?
Along with the many graduate students, post-docs and research scientists who have passed through my lab, I was involved in mapping the gene for SMA as well as the characterization of SMN protein in various ways. I created the mouse model of SMA that has been distributed worldwide for use in research and helped identify chemical compounds with potential therapeutic benefit.

What do I like about FSM A?
There isn’t a lot not to like about FSM A. This is a dynamic organization founded by the fearless Audrey Lew is and funded by the most tireless families and supporters on Planet Earth! I believe the two greatest strengths of FSM A are: First, the close association with the people who matter most, the patients and their families and caregivers; Second, I am continually impressed by the relentless, optimistic pursuit of the ultimate goal – a cure for SMA. Families of SMA has what I consider outstanding personnel that run many aspects of the organization and I wish to draw attention to one of these individuals, Jill Jarecki the Research Director of FSM A, who has done a remarkable job in steering all the science that FSM A supports.
25 Voices of SMA

Arthur Burghes, Ph.D.

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25 voices of SMA

For the 25th Anniversary of Families of Spinal Muscular Atrophy we have been spotlighting “25 Voices of SMA” throughout the year. These are profiles of families, clinicians and researchers from the SMA community.

Christine DiDonato, Ph.D.

Who am I?
I like to think of myself as a gene hunter and animal modeler. My goal as a research scientist is to identify genes that are responsible for human diseases and make animals that mimic that disease. This allows us to understand how the gene works and to devise new ways to make and test therapies, so we can bring the most effective treatment back to the clinic.

I am an assistant professor at Northwestern University in the Department of Pediatrics in Chicago, IL. My laboratory is located at Children’s Memorial Research Center in the Human Molecular Genetics Program.

Why did I become active in SMA?
I started working on SMA about 19 years ago while a graduate student at Ohio State University under the mentorship of Dr. Arthur Burghes. Much of my graduate work was aimed at identifying the gene responsible for SMA.

What is my contribution?
My previous work helped identify molecular markers that were used in pre-natal diagnosis, prior to the SMN gene being cloned. Since that time, my group is interested in understanding why low levels of SMN cause disease and how we can correct this. Much of our current work uses animal models of SMA.

What do I like about FSM?
I can’t remember a time in my scientific career when FSM hasn’t been there from the very beginning about 20 years ago - either by supporting me through training fellowships, the laboratories that I’ve been a member of, with grants to conduct research.

FSM is truly a special organization that has brought the scientists and families together so that each has a better understanding of the other. I believe this helps both groups to gain support and strength to keep moving forward toward our ultimate goal of a treatment for all!!

Go to www.curesma.org for Full Profiles
Mary Schroth, M.D.

Who am I?
I am a pediatric pulmonologist who has had the privilege of working with dedicated families to help care for their children with SMA.
Dr. Mary Schroth is a pediatric pulmonologist at the University of Wisconsin American Family Children’s Hospital. She also chairs the FSMA Medical Advisory Council and is a researcher with Project Cure.

Why did I become active in SMA?
I met my first child with SMA in 1994. This family had recently attended the FSMA Conference and knew that they needed a pulmonologist. They told me about the conference and the In-exsufflator cough machine. I learned a lot from this family and the child with SMA is now 20 years old and in college. I went to my first FSMA Conference in Denver in 1998 and enjoyed every minute. I met Audrey Lewis who kept me busy with conference activities every year after that.

What is my contribution?
I have worked to expand the respiratory care options for individuals with SMA and spread the word to other physicians and caregivers. I hope that provide a balanced approach. I am a member of Project Cure and we are working to find better treatments for SMA today.

What do I like about FSMA?
Families of SMA has been fabulous in providing many resources to families for education, support and clinical care. They provide a large scale forum for SMA focused researchers to gather to share ideas and also interact with the individuals whom they work on behalf of. They have provided support to advance my career and work in SMA. I have always enjoyed calling the office and hearing a friendly voice. Thank you, Families of SMA.

The Gaudreau Family

Who are we?
We’re the Gaudreau family, Jim - Sue - Michelle & Jennifer, and we live in Dracut, Massachusetts. In June of 2002, at the age of 9 months old, our youngest daughter Jennifer was officially diagnosed with SMA. She was typed at that time as a borderline Type I/II.

Why did we become active in FSMA?
I met Jennifer’s diagnosis it became clear to us that we needed to do something more than just accept the diagnosis. We needed to fight back. And so we started searching, and found Families of SMA. After learning what Families of SMA was all about, it was clear that we needed to jump in and help out. An organization committed to supporting families and funding critical and promising research in this fight against SMA was fundamental to our newly found philosophy of not sitting back and letting this monster win.

What is our contribution?
Shortly after Jen’s diagnosis we gathered up a group of about 200 family and friends, ”Jenny’s Team”, and participated in the first New England Chapter “Fall - Walk & Roll” held by Michelle and Andrew Rollinson in memory of their daughter Rachel. They embraced us, and in short “drew us a life preserver!” Without a doubt, Michelle and Andy are a testament to the entire concept of family support and commitment to fundraising efforts and we are blessed to be able to call them amazing friends. Since then, we’ve become integrally involved with the New England Chapter and Jenny’s Team has continued to participate annually in numerous events that the chapter has held.

What do we like about FSMA?
The best thing about Families of SMA from a national perspective is their never ending pursuit of keeping families connected both with informational resources and personal connections through their annual conference. From a chapter perspective we can’t say enough about all the families that are involved and how significant they are to us in our daily lives with support, information and friendship.
Jim Rusche, Ph.D.

Who am I?
I am a scientist and administrator at a biopharmaceutical company, Repligen. My job is to help identify new opportunities to develop treatments for CNS diseases, especially those with no current treatments. I direct a small but dedicated group of scientists with the task of trying to design and manage all the parts of developing novel drugs.

I have spent 25 years trying to advance new therapies for childhood diseases such as Autism, Friedreich's Ataxia and Spinal muscular Atrophy.

Why did I become active in SMA?
My company has been keen to find areas where new scientific findings provide a chance for novel treatments to advance quickly. In attending a conference sponsored by FSMA, I became aware of the astonishingly fast progress made in the molecular understanding of the cause of SMA. At that meeting it became apparent that approaches to increasing SMN production could be a powerful therapy, and potential therapeutic molecules were being identified. This started a three year communication with FSMA to understand their program and provide feedback about what needed to be done to make this a successful therapeutic that could attract the resources needed for commercial development.

As a small company, we take a personal involvement in our programs. The combination of a large unmet need in SMA, a promising pre-clinical compound identified by years of good effort by FSMA, and the resources available at Repligen, there seemed to be a good match.

What is my contribution to SMA?
Last fall we licensed the quinazoline compounds from FSMA to advance these molecules and develop a potential treatment for SMA. I hope to coordinate the drug development operations that can advance this experimental drug through safety evaluations, manufacturing methods development, testing in non-clinical settings all in preparation for testing in patients. New drugs with novel protein targets are challenging to develop as there is no existing roadmap. My contribution is to create this roadmap for this compound and give it every chance to succeed to be an effective treatment for SMA.

What do I like about FSMA?
There are two aspects that drew me to become involved with FSMA. The people of the organization are bright, hardworking and upbeat, while being pragmatic of the difficult task of being involved in developing treatments for the patients they represent. The meetings held by FSMA for scientists and families provided me as a non-clinician an opportunity to see the faces of families that deal with SMA daily and make a strong connection for me that brought my personal goals and work goals together.

Shannon O'Brien

Who am I?
I am Shannon O'Brien from Chicago, IL. I have SMA Type III and was diagnosed at the age of 2 years old.

I am now 22 years old and a full-time student at University of Illinois in Champaign. I will be graduating this December with my Bachelor's in Speech and Hearing Science and hope to attend graduate school the following fall to get my master's in Speech Language Pathology.

Why did I become active in SMA?
When I was diagnosed twenty years ago a nurse at the hospital gave my parents a pamphlet about Families of SMA (no websites were around that long ago LOL) and my parents decided to contact this organization for more information. A few years after my diagnosis my family and I decided to attend our first SMA conference and have attended almost every conference since then.

What is my contribution?
I volunteer at the conference every year and look forward to meeting with my peers as well as with parents and grandparents of affected children. I think the adults appreciate understanding what their children are going through as well as relationships, what doesn't, and I get to learn from them as well.

What do I like about FSMA?
Families of SMA is an amazing organization that offers so much support for families! Whether it is sending out care packages or information packages to newly diagnosed families, or lending equipment from the equipment pool, they are always supporting families. I am very fortunate to be a part of a caring organization that keeps us connected and current both on the research front as well as the day to day living issues we face.
Louise Simard, Ph.D.

Who am I?
I am a research scientist and geneticist who has sought to find ways to translate basic understanding of SMA to practical outcomes for SMA families.

Why did I become active in SMA?
My interest in SMA was spurred by my neurologist colleagues at a time when the gene responsible for SMA had not yet been identified. The neurologists baited the hook, Families of SMA reeled me in!

What is my contribution?
As a geneticist, I have contributed by meeting families and talking genes and genetics, and by aiding in the transfer of DNA tests from a research lab to a diagnostic lab setting that makes these tests available to SMA families. I am the lead author that created the Genetics of SMA booklet for Families of SMA.

What do I like about FSMAS?
There is no doubt in my mind that the great strides we have made in SMA research would not have been possible without the support of Families of SMA. It is the SMA families that inspire me by their selfless commitment to finding a cure for SMA. As such, families and researchers have taken on this journey and challenge together.

The Sutker Family

Who are we?
We are the Sutker family from Columbia, Maryland: Steve, Julie, Noah (age 9), Quinn (age 7), Dylan (age 2) and Wyatt, our hero who passed away in 1999 from SMA Type I at 5½ months of age. Wyatt's wisdom and curiosity have been the inspiration and guide for our ongoing involvement with the SMA community. SMA will always be a large part of our family and has instilled in our children a sense of pride, compassion, and understanding as well as the necessity of reaching out and standing up to make a difference in the lives of other people.

Why did we become active with FSMAS?
At 9 weeks Wyatt was diagnosed with SMA Type I. Shocked and devastated we searched for help. We soon realized, at the time, a significant lack of awareness in the medical community about the toll that SMA Type I takes. At Wyatt's passing we promised him that his short sweet life would not be in vain.

What is our contribution?
We founded the Wyatt Kyle Sutker Foundation, Ltd. in 1999 and have raised over $300,000 to support SMA research and increase awareness in the public and medical communities. We have partnered with Families of SMA to provide scholarships and care packages and have sponsored a luncheon and entertainment at the annual FSM conference for the past 8 years.

What do we like about FSMAS?
The Families of SMA organization impressed us from day one. They were our go-to source for unanswered questions and provided unprecedented abilities to actually access physicians, specialists, and scientists working together with us, not just for the families facing SMA. We make a point each year to attend the annual FSM conference with our children so that they can begin to really "know" their older brother, understand what SMA means, and feel the energy that this amazing community exudes. Thank you Families of SMA and may the next 25 see even more advancements in our fight against SMA.
The Potter Family

Who are we?
We are the Potter family of Massachusetts. Mark & Laurie, Murphy (5 years old), Anders (2 years old), and Marshall (forever 4 months & 6 days old).

Why did we become active with FSM A?
Almost immediately after Marshall died in December of 2002, we began fundraising for Families of SMA. In the beginning, it was a survival mechanism for us. We needed something to occupy our minds and our hearts to get through each day without our son. We began attending local events and met many other families who had also been touched by SMA. Years later, we continue to do what we can to help Families of SMA so that they in turn can continue to help others.

What is our contribution?
We try to work behind the scenes as much as we can. We try to offer as much local support as we are able to. Through our generous helpers and sponsors, we have purchased toys for the children’s rooms at the conference. We have also been known to purchase equipment for families such as toilet seats and car beds, wheelchairs, lifts for vans, portable battery units, positioning devices, etc. On a rare occasion we have funded funeral and burial services. We also answer the phones for the New England Chapter of SMA, and frequently speak with parents of the newly diagnosed, and those who have been recently bereaved. Most recently, along with the Reilly family (also of Massachusetts), and under the direction of the Strong family of California, we were able to make a sizable donation toward the efforts of Dr. Keirstead’s stem cell project. Even though our own son has been gone for quite some time, that cure is still so important to us! We continue to do what we can to support research and prevention of SMA.

What do we like about FSM A?
The one thing that sticks in our minds is how each and every family is held in high regard and remembered by everyone involved with FSM A. We have always been people with names, not a number or just another case of a family whose baby has SMA. Each family has been embraced and supported. That was a time after Marshall had been diagnosed that I called the national office for something and spoke with someone there. Utopia means that they had any knowledge of us at all. I said into the phone “hello, my name is Laurie Potter” and the response on the other end of the line was “Oh, you are Marshall’s Mom”. I was surprised to say the least. Yes, I was Marshall’s Mom! And 7 years later, to everyone at FSM A, we aren’t just Laurie and Mark Potter. We will always be Marshall’s Mom and Dad.

Brunhilde Wirth, Ph.D.

Who am I?
Brunhilde Wirth is full-time professor and chair of the Institute of Human Genetics in Cologne, Germany and group leader of the Neuromuscular Research Group.

Why did I become active in SMA?
I became a group leader at the Institute of Human Genetics in Bonn, Germany in 1990 and decided to start working on SMA soon after the gene locus has been linked to the chromosome 5q13.

What is my contribution?
Our group has been working on SMA for 20 years now. Our major contributions to the research field include the following discoveries:

• Narrowing down on the SMA region which contributed to the final identification of the gene;
• Identification of discordant SMA families, e.g. of asymptomatic individuals carrying SMN1 deletions;
• Identification of a strong correlation of the SMA phenotype with the SMN2 copy number;
• Identification of several important drugs that upregulate SMN2 such as valproic acid, SAHA, LBM89 and M344;
• The first pilot clinical trial with valpoate in SMA patients to prove that VPA can upregulate SMN levels in vivo;
• Identification of responders and non-responders to VPA in SMA patients;
• Identification of the first full protective SMA modifying gene, called plastin 3.

What do I like about FSM A?
Families of SMA is a real family for researchers also. By organizing and supporting the SMA International Annual Meetings, FSM A has contributed to and promoted connections between researchers, which are essential for successful collaborations. Based on these meetings, many of us know each other and are good friends for many years now, which makes a big difference in the research area. FSM A supported and funded almost all of the main contributions in the field and this is unique and fantastic.
A Day On Set

By Rozie McClay

We had an amazing time on the set of Extraordinary Measures last May! Our scene was shot at the Nike headquarters in Beaverton, Oregon. Right from the start we were treated like actors and not extras. Everyone on set really wanted Kiley to have a very special day, and she did. The movie is based on a true story about the Crowley family who have two children with Pompe’s disease. The dad, John Crowley, quits his job and starts a biotech company with a scientist who is on the verge of finding a treatment for Pompe’s. The dad is played by Brendan Fraser, the mom by Keri Russell, and the scientist by Harrison Ford. In our scene we represent a Pompe family who are meeting the scientists trying to cure their children. At the time we were a couple of weeks from going to our 4th Families of SMA conference in Cincinnati. It was like art imitating life for us as we are very familiar with the importance of our SMA kiddos meeting the SMA researchers.

We did not get to meet Harrison Ford, darn it. We did, however, get to spend the day with Brendan and Keri. They could not have been any nicer. Kiley was sitting right behind Keri and they chatted during filming breaks. Brendan would come and chat with us all, during down times. Both were interested in hearing about our experiences fighting for a cure for SMA. Kiley had her service dog Billy III on set. He made a lot of Hollywood friends too. Brendan jotted down information about Canine Companions for Independence since he has a son with Autism.

We went with a group of family and friends on the opening weekend to see the movie. We were thrilled to see a great shot of our little Miss Kiley on the big screen! We had to let everyone else in the theatre know what all the happy yelling was about. If you haven’t seen the movie already I don’t want to ruin the ending, but it is one that all of us fighting SMA can especially appreciate!