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Join SMA Community Connections

(Official White House Photo by Pete Souza)

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www.curesma.org
Families of Spinal Muscular Atrophy is Proud to be Implementing a New Support Program for Newly Diagnosed SMA Families

Everyone at Families of SMA is extremely proud to be implementing our latest program for newly diagnosed SMA families. We have had several conversations regarding better ways to support families and those that are newly diagnosed. Thanks to Hillary and Keith Schmid, the FSMA Greater Florida Chapter and Audra and Alan Butler, we are excited to announce that Families of SMA has created a binder of information with specific resources for each state. These binders contain important information about SMA, as well as provide families with a list of available resources within their state. The binders can also act as an organized place for families to keep important medical information concerning their child.

We will be providing all newly diagnosed SMA families with this resource as soon as they contact FSMA.

Our goal is to connect newly diagnosed families with local chapters and other SMA families in their area as soon as they contact the Families of SMA National Office, as well as to provide them with important resources available in their state.

We would like to thank all of the Families of SMA Chapters and SMA families who have provided us with the important information included in this binder.

If you are aware of any resources available in your community or state, and would like to share it with other SMA families, please e-mail info@fsma.org.

Families of SMA

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.
Conference Overview

**Thursday, June 23, 2011**
- 9:00am – 5:30pm: Registration Open for all Conference Attendees
- 5:30pm – 8:00pm: Meet & Greet
- Relay Race with Researchers and Kids
- Disney Character Welcome (1 hour only)
- Carnival Games
- Ice Cream Social with Researchers

**Friday, June 24, 2011**
- 8:00am – 9:00am: Registration Opens - Continental Breakfast, Exhibitor and Vendor Tables
- 9:00am – 10:15pm: Kids Talk it Out (Kids Only - Ages 6 to 9)
- 9:00am – 10:15pm: General Session
- 10:30am – 12:00pm: Breakout Session #1
- 12:00pm – 1:30pm: Lunch on your Own
- 1:30pm – 3:00pm: Breakout Session #2
- 4:00pm – 7:00pm: Epcot Admissions
- 8:30pm – 9:30pm: Private Dessert Social Worldview Plaza Epcot
- 9:00pm: IllumiNations: Reflections of Earth

**Saturday, June 25, 2011**
- 8:00am – 9:00am: Registration Opens - Continental Breakfast, Exhibitor and Vendor Tables
- 9:00am – 10:15am: Kids Talk It Out (Kids only – Ages 10 and older)
- 9:00am – 11:00am: Sibling Workshop
- 9:00am – 10:25am: General Session
- 10:40am – 12:15pm: Breakout Session #3
- 12:15pm – 1:30pm: Lunch on your Own
- 1:30pm – 3:00pm: Breakout Session #4
- 4:00pm: Dinner and Activities on Your Own Convention Park Admissions
- 6:15pm – 8:15pm: Kids Movie and PJ Party

**Sunday, June 26, 2011**
- 8:00am: Full Breakfast Buffet
- 8:00am - 9:00am: Disney Character Visits (1 hour only)
- 9:15am – 11:30am: Closing General Session (Adults only)

**Breakout Session #1**
- Sharing your Type I Experience
- Sharing your Type II Experience
- Sharing your Type III Experience
- Grieving Families
- Grandparents Talk it Out
- Adults with SMA – Roundtable

**Breakout Session #2**
- IEP - Being Your Child’s Best Advocate
- Life Care Planning
- Pre-Genetic Diagnosis
- Orthopedic Management
- Toy Adaptation
- College Bound

**Breakout Session #3**
- Hands on Physical Therapy
- Healing The Grieving Heart - Part I
- Learning to Drive
- Good Nutrition for Oral Feeders
- Respiratory Care Choices for Type I

**Breakout Session #4**
- Yoga Therapy for SMA
- Good Nutrition for G Tube Feeders
- Medical Management of Adults with SMA
- Respiratory Care Choices – Type II
- What It Means to be a Teen on Wheels
- Healing the Grieving Heart – Now What? Part 2
- Fundraising Workshop

**Discover The Magic Of Disney**
2011 Annual SMA Conference, June 23-26, 2011
Walt Disney World Swan Resort – Lake Buena Vista, Florida

For more information and to register for the conference, see the FSMA website: [www.fsma.org/FSMACommunity/Conference/](http://www.fsma.org/FSMACommunity/Conference/)
Members of the Medical Advisory Council (MAC) attended two days of meetings on January 28th and 29th. This Council focuses on educating families, health care providers and the public about SMA; expanding SMA standards of care; and translating positive research results into clinical practice. Dr. Mary Schroth, a leading pediatric pulmonologist serves as Chair for the MAC. Mary is Associate Professor of Pediatrics and Director of the Pediatric Pulmonary Center Grant at the University of Wisconsin Children’s Hospital.

This productive meeting covered important SMA medical care topics including:

- The 2011 Annual SMA Conference workshops based on feedback and surveys from the previous year
- The agenda for the special Newly Diagnosed Program at the 2011 Annual SMA Conference
- Information packets for healthcare providers including primary care physicians to improve awareness and education on SMA care basics
- Discussion on improving Newly Diagnosed Information Binders for families
- New items for the FSMA Equipment Pool
- Legislative activities and funding that could impact care for SMA patients
- Topics for new SMA Care Series Booklets
- Future goals for the SMA Patient Registry
- Opportunities for the next area of research and studies for the clinical trial network Project Cure SMA
- Potential interactions with the next government initiative

The MAC is composed of experts in the following fields: Neurology (pediatric and adult); Pediatrics; Pulmonology; Pediatric Orthopedic Surgery; Pediatric Critical Care (NICU specialist); Physiatry (rehab medicine); Psychology; Genetic Counseling and/or Medical Ethics; Physical Therapy; Occupational Therapy; Diet and Nutrition; Respiratory Therapy; Nursing.

Families of Spinal Muscular Atrophy Announces Generous Donation from Radio Flyer to the SMA Care Package Program

Radio Flyer, Inc. donates 100 Pathfinder wagons to support the mission of Families of SMA.

Families of SMA is thrilled to announce the donation of 100 wagons to the Newly Diagnosed Care Package Program, valued at over $10,000. These wagons will be sent to all newly diagnosed type I families when they first contact FSMA.

These Radio Flyer wagons are so beneficial for transporting SMA infants, as it is important to keep these children horizontal. The wagons act as an easy way to transport them around the house, the yard, doctors’ offices, hospitals, stores, etc… SMA babies love to be pulled around in their wagons while moving comfortably from one location to another, as opposed to being picked up and carried frequently for feedings or diaper changes. Many SMA children will nap or watch their favorite television program in their wagons.

The first shipment of Radio Flyer wagons has already arrived at the Families of SMA National Office! Just two weeks ago, twenty-five brand new Pathfinder wagons were delivered representing just one of four shipments to be received throughout 2011.

When Antonio Pasin started Radio Flyer in 1917, his dream was to “bring joy to every boy and every girl”. Today, the Radio Flyer family continues that tradition by building safe, quality toys that spark imagination and inspire active play. From the original little red wagon to their current wagons, tricycles, scooters, and other ride-ons, their toys bring smiles to children and families around the world and create warm memories that last a lifetime.

Thank you Radio Flyer, Inc. for making such a difference in the lives of many SMA families!
Meeting President Barack Obama

By Dylan Cuevas

My name is Dylan Cuevas and I am seven years old. I have SMA. A couple of years ago the Make-A-Wish girl came to my school and told my Mom I could have a wish. My Mom told me to think of what I would wish for most. I see my Mom always trying to do things for SMA. I know she works hard for me and some of my friends. I really like President Obama. I told my Mom my wish was to meet President Obama and tell him about SMA.

We stayed at a really nice hotel. I liked all of the people there. They even put a Wii in my room for me. I went for a cool tour of the White House. I saw where President Obama watched movies. We went to the West Wing where President Obama has his office. We stood in a hallway and President Obama opened the door and my Mom helped me to shake his hand. His hand was really big, but he was careful not to hurt my hand. He introduced himself to my family. We went into his office. There was a big eagle on his carpet. He has a really big picture of Abraham Lincoln there too. My Mom was nervous I would crash into the President’s desk with my power chair. The President laughed and told my Mom not to worry. I laughed when he said that, because my Mom always worries. We took a lot of pictures with the President. I gave him something I wrote about SMA and my life. I also gave him a CURE SMA bracelet which he immediately put on his wrist. He gave me some cool pins and a coin. He talked to me about school and about SMA. He talked to my Mom and Dad. He thanked Arthur for being a good nurse. He asked Heather what she liked. The President also hugged Pop Pop. He had the Secret Service bring Bo the dog to meet me. That was awesome. Then he told me I was his good luck charm when he won the election since he won on my birthday. We then went on the lawn and saw President Obama leave on his helicopter. I really enjoyed being able to meet President Obama.
At one point in our journey with Gwendolyn, I couldn’t bring myself to fathom how it could be possible to live a more normal life given the challenges of SMA. But I vividly remember a comment from an SMA mom with a child much older than Gwendolyn. She said simply — “I can’t even recall exactly when, but at some point we just started living.” Her comment has always stuck with me. And although at the time I still couldn’t believe it, now it makes perfect sense. She was absolutely right. And at some point, we, too, just started living.

One of the more common questions we get from other SMA parents, especially newly diagnosed, is how we get out and about with Gwendolyn so regularly. To be fair we have weather and community on our side — we can literally walk 5 minutes out our front door almost 365 days per year to several parks, the beach, restaurants, etc. And purchasing a minivan and recently a conversion minivan has allowed us to travel more — especially since we transport Gwendolyn in her stroller with all of the equipment already secured on the stroller making things logistically much, MUCH easier. We also learned that Gwendolyn did better if she wore her bipap on walks (even though she didn’t always “need” it early on) — it helped her push her secretions out, relaxed her, and, therefore, meant less frequent and severe choking episodes, etc. which relaxed us. And then once we got to the destination, if she tolerated it, we had the option to take her off bipap. Despite logistics, probably the most important thing to realize is that we haven’t always been so mobile or comfortable taking Gwendolyn out. That took time. And it took going out to become more comfortable. We’re always extremely careful and mindful in weighing the risk and benefit every time we leave the house — even now — but it has been worth it!

Gwendolyn has always been a social child and she’s always made it crystal clear what she wants out of life — HER life. Sometimes those things are at odds with what we, as her protective parents, want — but it is her life. We’ve come to learn that while there are many things that we can’t control with Gwendolyn’s SMA, there are many, many things that we can. And finding ways to give her life experiences is one of those. So we’ve pushed ourselves over the last three years to accept aspects of Gwendolyn’s SMA, face and get over our constant fears, be creative, ask favors, and find ways to give our bright little girl as many of those life experiences as possible.

Now, this didn’t happen over night. Not even close. It happened slowly and to this day we have peaks and valleys with our confidence. When Gwendolyn is strong, we are more adventurous. When Gwendolyn has setbacks or normal SMA challenges, we retreat. That’s only natural given the reality of SMA. We also have a rule that we don’t do anything that doesn’t feel right to Victoria "and" me or is likely to create unnecessary stress. And if we try a situation and it just doesn’t feel right, to either of us, we leave immediately. But, and this is a big BUT, if an outing doesn’t go as planned, we try not to let that stop us from getting back up and trying it again in the future.

We started getting more mobile around Gwendolyn’s 11 month birthday when we got her JAZZ EASY S stroller. We started local, walking to our nearest park with a duck pond when no one else was there. Then we ventured to a coffee shop. And eventually we worked up to a restaurant — at off times. We continued to move out from there — and each time, Gwendolyn’s bright smile and eagerness to go and do and see pushed us to keep at it. We’ve learned to ask for favors (something we aren’t naturally comfortable with), but sometimes that favor makes all the difference and means Gwendolyn gets to have an experience we thought was not possible. And we’ve learned that almost every time we explain the special situation to a zoo or theater show or hotel…every one of them has been more than happy to help give Gwendolyn (and us) these opportunities.

With germs (and protecting Gwendolyn from them), that’s something that has definitely taken time to not feel constantly stressed about. But we plan
after, go on off times, and are extremely
diligent about creating a discreet safety
zone around Gwendolyn. Constant hand
washing and sanitizing is the norm — of
course. If Gwendolyn is going to touch
anything it’s wiped down before if possible
and her hands are definitely wiped down
afterward. We’ve even found ways to be
semi-discreet about doing that so
Gwendolyn’s fun isn’t interrupted. We’ve
also come to learn that Victoria and I are
really the weak links and biggest risk to
exposing Gwendolyn to germs as we are
the only ones that touch her
face/nose/mouth and suction her. We are
constantly washing hands, wiping hands,
and sanitizing before touching or
suctioning Gwendolyn or even
Gwendolyn’s things.

We know it’s not easy. We know it’s scary.
We know it’s daunting. But we’ve had so
many experiences with Gwendolyn that we
never thought we’d get the chance to do —
things that have truly enriched her life and
ours. And we don’t regret any of it for a
second! Pushing ourselves was the first
hurdle. And that has only benefited Gwen-
dolyn’s quality of life — and ours as we
continue to figure out how to live life with
SMA.

Here are some of my favorite experiences
we’ve had over the years—some simple and
some big adventures: Concerts at the park,
Monterey Bay Aquarium, Point Lobos
State Reserve, Avenue of the Giants, Disney
Playhouse Live, Halloween festivals,
playing with friends, 5,000 mile RV trip
from California to Mississippi to connect
Gwendolyn with her 104-year-old great
grandfather, birthday parties, sledding at
the Santa Barbara Zoo, Yo Gabba Gabba
concert, Sesame Street Live, sailing and
wine tasting, FSMA conference,
Disneyland and starting Preschool!

FSMA Donated Blankets in
Memory of Violet Wehrkamp

After my daughter, Violet
Madison Wehrkamp, passed
away on August 27, 2010, I
looked for support from the
SMA Community. While
surfing the internet one
morning, I came across the
Families of SMA Community
Connections and met
Stephanie Humes. Stephanie
and I exchanged our stories
and I learned that during her
pregnancy both her and her
husband found out they were
 carriers of SMA and they
suffered the loss of their child.
Stephanie and I related a lot
and became fast friends. When
I began quilting and started a
shop on Etsy called “Little
Flower Violet” making security blankets, Stephanie generously donated
fabric from her family’s textile company to my cause! With that donation
she also sent fleece and plush blankets to help raise donations. Her
generosity gave me inspiration.

When Violet was first diagnosed, we received a ridiculously huge box full
of wonderful items from Families of SMA and Violet treasured every item!
One in particular stands out to me- we received a handmade quilt from a
grandmother who has a granddaughter with SMA. Violet loved that quilt.
It was so colorful and soft and it meant so much to us for a family to
donate such a beautiful item in honor of their granddaughter to be used
by another SMA child.

With Stephanie’s permission, we agreed to donate the blankets she had
sent to me to be used in the Type I Newly Diagnosed Care Packages.
Stephanie’s family is also donating many more blankets in memory of
Violet to be used in these care packages. It was then that I realized my
talent of quilting could benefit another newly diagnosed family and bring
them some comfort during that difficult time. My husband’s aunt, Pat
Dunn, and I will be making handmade quilts and blankies to be included
in the Type I Newly Diagnosed Care Packages. The quilt we received in
Violet’s care package provided us with such comfort, that we hope we can
bring that to another family. So we will be continuously donating blankets
in memory of our daughter, Violet, to FSMA.

To Families of SMA and Stephanie Humes- Thank you so much for being
there for our family when we needed it most. We know that our Little
Flower Violet is smiling down on you all and we truly appreciate all the
good you are doing. We hope we can spread some of that good to another
family with our blankets made in memory of Violet.

Love,
Allison and Bill Wehrkamp and our Angel Violet of Effort, PA
Your family is officially invited to the 11th annual SMA Family Camp!! This year we are back in our beloved Cultus Lake, British Columbia location.

**Camp dates are July 19 – 24, 2011**

**Camping arrangements**
At SMA family camp, families show up with their own camping facilities, be it trailer, tent, motor home, etc. Some families arrange rental, a renter would have their camper set up and ready for them when they arrive. If neither of these are possible for you, but you’d still like to attend, please let me know, I have a few other tricks up my sleeve!!

**Location**
Cultus Lake, British Columbia is part of the beautiful Fraser Valley in South Western Canada. The camp is only 20 minutes from the Sumas, USA border. We have repeatedly camped in this cottage community vacation spot due to it’s perfect accommodations for our group. We have a wheelchair accessible playground with exclusive rental of an elementary school and it’s grounds. There is a wheelchair accessible bathroom with lift and tracking system, change table as well as a shower room. There is a full kitchen with stoves, ovens, refrigerator and freezers. The field we use is large and perfect for the camping as well as all the activities we have planned. We are a few short steps away from the lake shore, as well as all the amenities you could possibly need. Power hook up is available for those that need it.

**Activities**
We will have scavenger hunts, obstacle course, relay games, marshmallow wars, crafts, games, a fire pit, and lots of prizes. Everything we do is wheelchair accessible and inclusive for the entire family! The obstacle course is run by all members of the family in the SMA kid’s chairs (or a borrowed one), it’s a battle for the family with the best combined time. Every one gets awards and prizes in the end. We also walk for ice cream, have some beach time with a swim in the lake. The last 2 days will be the adventure camp part where volunteers come to take us all hiking, kayaking, bicycling with their amazing equipment. These people are an absolute gift with their experience and knowledge. Professional firefighters, nurses, ambulance attendants, search and rescue are just a few of their professions. For us, they mean we can have adventures that just aren’t possible without them. We’ll have shared meals with everyone taking a turn to cook.

**Cost**
The cost is very low, total cost per family will be under $100 all inclusive. I am still working out the kinks but am trying to reduce the cost to almost nil. Families will take care of their own transportation costs.

**Register**
Register by emailing Families of SMA Canada at fsmacan@telus.net to request a registration form or request more information.

**Promise**
I promise at some point you will laugh, cry and have some of the best times you will ever have had with your family. I promise your children will beg to come back year after year. I promise you will make memories you will hold as a precious treasure for the rest of your life. And I promise you will form bonds that will last the entire year round. You will leave with a sense of belonging, hope and pure simple joy.

That’s a big promise, but it’s an easy one, because I know what we do and what we have done. There’s something about this camp that is indescribable, you have to experience it, and it’s worth the effort to get here from where ever you are.

Come join the fun!!
Susi Vander Wyk
President
Families of SMA Canada
WaterWayBabies and Your SMA Child

WaterWayBabies is a safe, easy, and effective way to help your child maintain health through warm water therapy. You might have already noticed that your child loves the water. Water removes the forces of gravity and frees your child to move. Parents of SMA waterway babies love seeing increased voluntary movement by their child in the WaterWayBabies pool. The density of water supports arms and legs while the viscosity improves tone because moving in water requires more effort. With your child’s head supported safely above the water by the inflatable neck ring, every cell of your child’s skin is bathed with warm water. The skin, nervous system and muscles intercommunicate to provide maximum stimulation through the body-brain feedback system.

As the disease advances and muscle tone decreases, your child might need to lie flat to help with breathing. Using the WaterWayBabies neck ring in water, your child can be upright, which provides a huge psychosocial benefit to both child and parent alike, as well as to siblings and other family members. Water time is playtime and should always be a fun experience. Often siblings get in the WaterWayBabies pool with their little brother or sister, or stand by the side to visit and cheer their sister or brother’s movements. Even moms have climbed in the pool to share this special experience with their baby. (Very light ankle weights can be used to help maintain an upright position as tone decreases.)

Additionally, you will see over time that water therapy helps to maintain lung health, which is particularly important for children with SMA. With each breath, the chest wall pushes against the water’s density. The cough-gag reflex is supported, as well as attempts at vocalization, which are all signs of the interplay between nerves and muscles responding to healthy stimulation.

Digestion is also aided through improved peristalsis. Peristalsis is the process of wave-like muscular contractions by which food is moved through the digestive tract. Water exerts gentle pressure on the abdomen, which along with kicking the legs, helps to increase peristaltic action.

All therapies your child receives are valuable and important. WaterWayBabies gives parents a way to directly participate in their child’s therapeutic process. The pool comes with a water thermometer to ensure best temperature (92-94°F) and can be filled to different depths depending on the size of the child and goals to be achieved. Gentle weight-bearing on the bottom may be useful for older children with SMA Type II. The system should ideally be used daily for 20-40 minutes or a minimum of three times a week to accomplish best results. Play music, offer water toys, hold up a mirror and make it fun for the whole family. WaterWayBabies provides a holistic approach to therapy “work” combined with socialization and recreation.

Not everyone has access to aquatic therapy, but do take their neck rings to therapy sessions. While the neck ring supports the child, both the therapist’s hands are freed for interventions and exercises. The child and parent can repeat these exercises at home in the WaterWayBabies pool. Older children accomplish this in the bathtub or at a Y pool. (Most YMCAs have a warm water therapy pool.)

There is always spring break, summer vacations, or visits to grandma’s house with a pool or hot tub. Parents love the collapsibility of the inflatable neck ring for easy packing in their luggage. Using the device in the context of a family swim allows the SMA child and parent a sense of independence and freedom. The child develops self-identity despite having a disease that creates total dependence on others. Of course, an adult is immediately present within arm’s length at all times.

Spinal Muscular Atrophy is a neuromuscular disease and WaterWayBabies can’t change that. The WaterWayBabies System can positively impact your child’s quality of life. It is a proactive way to help your child maintain the best possible health.

So, get swimming! And have some fun! Go to www.waterwaybabies.com for more information.

Nancy M. Higgs, RN, President, WeeWaterWays, LLC
iPad Opens World to a Disabled Boy

By EMILY B. HAGER
Published: October 29, 2010, A version of this article appeared in print on October 31, 2010, on page MB7 of the New York edition.

OWEN CAIN depends on a respirator and struggles to make even the slightest movements — he has had a debilitating motor-neuron disease since infancy.

Owen, 7, does not have the strength to maneuver a computer mouse, but when a nurse propped her boyfriend’s iPad within reach in June, he did something his mother had never seen before.

He aimed his left pointer finger at an icon on the screen, touched it — just barely — and opened the application Gravitarium, which plays music as users create landscapes of stars on the screen. Over the years, Owen’s parents had tried several computerized communications contraptions to give him an escape from his disability, but the iPad was the first that worked on the first try.

“We have spent all this time keeping him alive, and now we owe him more than that,” said his mother, Ellen Goldstein, a vice president at the Times Square Alliance business association. “I see his ability to communicate and to learn as a big part of that challenge — not all of it, but a big part of it. And so, that’s my responsibility.”

Since its debut in April, the iPad has become a popular therapeutic tool for people with disabilities of all kinds, though no one keeps track of how many are used this way, and studies are just getting under way to test its effectiveness, which varies widely depending on diagnosis.

A speech pathologist at Walter Reed Army Medical Center uses text-to-speech applications to give patients a voice. Christopher Bulger, a 16-year-old in Chicago who injured his spine in a car accident, used an iPad to surf the Internet during the early stages of his rehabilitation, when his hands were clenched into fists. “It was nice because you progressed from the knuckle to the finger to using more than one knuckle on the screen,” he said.

Parents of autistic children are using applications to teach them basic skills, like brushing teeth and communicating better.

For a mainstream technological device like the iPad to have been instantly embraced by the disabled is unusual. It is far more common for items designed for disabled people to be adapted for general use, like closed-captioning on televisions in gyms or GPS devices in cars that announce directions. Also, most mainstream devices do not come with built-ins like the iPad’s closed-captioning, magnification and audible readout functions — which were intended to keep it simple for all users, but also help disabled people.

“Making things less complicated can actually make a lot of money,” said Gregg C. Vanderheiden, an engineering professor at the University of Wisconsin at Madison who has worked on accessibility issues for decades.

Representative Edward J. Markey, a Massachusetts Democrat, who wrote recently enacted legislation that will require mobile devices to be more accessible to users with disabilities, said approximately three-fourths of communications and video devices need to be adapted for blind and deaf people. “Apple,” he said in a statement, “is an outlier when it comes to devices that are accessible out of the box.”

The iPad is also, generally speaking, less expensive than computers and other gadgets specifically designed to help disabled people speak, read or write. While insurers usually do not cover the cost of mobile devices like the iPad because they are not medical equipment, in some cases they will pay for the applications that run on them.

In Owen’s case, his grandmother bought him a $600 iPad in August, and his parents have invested about $200 more in software. One day this summer, his finger dangled over the title page of
“Alice in Wonderland” on his iPad while his mother hovered over his shoulder in their Brooklyn home. Then, with the tiniest of movements, and thanks to the sensitivity of the iPad’s touch screen, Owen began to turn the pages of the book. “You are reading a book on your own, Owen!” Ms. Goldstein, 44, exclaimed. “That is completely wonderful.”

But while the sensitivity of the iPad’s touch screen makes it promising for Owen, it can be problematic for others, like Glenda Watson Hyatt, a blogger in Surrey, British Columbia, who has cerebral palsy. “When ‘flipping’ screens, sometimes I flip more than one screen,” Ms. Hyatt wrote in an interview conducted by e-mail. “Or I touch what I didn’t intend to.”

Still, Ms. Hyatt said that when she was having trouble chatting with friends at a bar recently, she pulled out her iPad to help communicate and felt normal. “People were drawn to it because it was a ‘recognized’ or ‘known’ piece of technology,” she wrote in a blog post reviewing the device.

At the Shepherd Center, a spinal cord rehabilitation clinic in Atlanta, some teenage quadriplegics have received iPads as gifts, but they do not work well for those who rely on a mouse stick — basically a long pen controlled by mouth.

“It wants to see a finger,” said John Anschutz, the manager of the assistive technology program at Shepherd. “It really requires the quality of skin and body mass to operate.”

For Owen Cain, whose disease is physical, not mental, the iPad has limitations, too. Moving his finger all the way across the keypad remains a challenge, and makes writing difficult. Ms. Goldstein said its versatility and affordability, though, were a boon. He has been experimenting with a variety of applications — Proloquo2Go, which allows him to touch an icon that prompts the device to speak things like, “I need to go to the bathroom”; Math Magic, which helps him practice arithmetic; and Animal Match, a memory game.

“If all you’re worrying about is ‘I can try this program, or I can try that program, I can buy that app or I can buy this app,’ and the investment is so much lower,” his mother said, “then our ability to explore or experiment with different things is so much bigger.”

When Owen was about 8 weeks old, his mother noticed his right arm drooping. It led to a crushing diagnosis: the motor-neuron disease known as spinal muscular atrophy Type 1. A 2003 New York Times article about spinal muscular atrophy said his parents had been told Owen would be “paralyzed for his life, which doctors predicted would last no more than about two years.”

Owen will turn 8 on Nov. 11. While his condition is not expected to worsen, he is extremely sensitive to infection and once nearly died of pneumonia; three specialized therapists and a nurse help keep him alive.

Though he cannot speak, his parents have taught him to read, write and do math. He has an impish sense of humor and a love of “Star Wars.” “He’s a normal child trapped in a not normal body,” said his father, Hamilton Cain, 45, a book editor.

Since he received the iPad, Owen has been trying to read books, and playing around with apps like Air Guitar. And, one day, he typed out on the keypad, “I want to be Han Solo for Halloween.”

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Families of SMA Offers a Record Number of Scholarships for Families to Attend The 2011 Annual Conference

Families of SMA is thrilled to announce that we have already given over 300 Conference Scholarships to SMA families so that they can attend The 2011 Annual SMA Conference this June in Orlando, FL. These scholarships were offered through both our Newly Diagnosed Conference Scholarship Program, as well as through our General Conference Scholarship Program. We received three times as many scholarship requests this year compared to previous years. Thank you to all of the individuals and groups who have provided donations and sponsorships for funding to allow this to happen.

Families of SMA has been hosting this conference for over 22 years. The conference will be filled with networking opportunities with other families, workshops, a memorable kids program, a relay race with the kids and SMA researchers and opportunities to interact with families and get first hand updates from the researchers. There are already over 1,300 people registered to attend this magical conference. We are expecting a record attendance of well over 1,500 attendees.
The research 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 later-stage drug discovery programs and clinical trials. FSMA research funding contributed to the results in 17 published articles in 2010.

Basic research allows us to solve critical unanswered questions in SMA biology. This information then reveals new and more effective ways of making SMA drugs which helps us build a robust and diverse SMA drug pipeline.

One useful metric 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 basic research that we fund indicates that our investments are leading to new and important discoveries about SMA.

In order to fund research at universities across the world, FSMA has a Research Grant Program that is administered by our Scientific Advisory Board (SAB).

There are three main research objectives of this Research Grant Program:

1) Learning basic biological information about SMA to enable more effective therapy development
2) Generating research tools to enable SMA research, drug development, and clinical trials
3) Identifying and then validating new and better ways of making SMA drugs

The overall goal for our basic research grant program is to identify seed ideas that will form the basis of full-scale industrial drug discovery programs.

Specific funding was provided from Families of SMA to the following 19 institutions which published these results in 2010:

- University of California Irvine
- The Ohio State University
- Rosalind Franklin University
- University of Utah
- University of Pennsylvania
- CBSquared
- University of Ottawa
- University of Milan
- University of Cologne
- Emory University
- Northwestern University
- Harvard University
- Cambria Biosciences
- The Ohio State University
- The Project Cure SMA Clinical Trial Network (which included work at University of Utah, University of Wisconsin-Madison Health Sciences, Wayne State University, Johns Hopkins Medical School, Ste. Justine Hospital, Northwestern University, University of Manitoba, and CBSquared)
Families of SMA Launches Next Phase of Drug Development Efforts for SMA and Considers 6 Projects for Funding

Families of SMA announces Request for Proposals (RFP) for new drug programs to develop therapies for Spinal Muscular Atrophy.

Families of SMA has made significant progress in advancing new therapies for SMA, starting with funding the first ever SMA drug program in 2000. The organization is now launching the next phase of therapeutic development work for SMA. FSMIA is aiming to fund two new preclinical drug development programs in 2011, with more to follow. These multi-million dollar collaborations will focus on innovative methods of developing novel therapies for SMA, including both biologic and small molecule approaches. These programs will be multi-year in scope with a typical duration of three years. The requested proposals will be reviewed by the FSMIA Translational Advisory Committee this spring.

In response to our October Request for Proposals (RFP) for new drug programs to develop therapies for Spinal Muscular Atrophy we received nine Letters of Intent for potential programs. Our Translational Advisory Committee (TAC) reviewed and then selected six of these for further consideration for funding. Each of these six applicants will now submit a full detailed proposal, which was due in February 2011.

Families of SMA has been investing in and advancing pre-clinical drug research since 2000, with a total investment of $17 million in this area. Over the last decade, our community has made great strides in this area, and currently there are a number of promising drug avenues for SMA emerging. This progress is also clearly demonstrated by the successful transition of several potential therapies to industry and government funding after early stage investment and research leadership by Families of SMA.

Drug development is a high risk with less than 10% of therapies that reach clinical trials ultimately receiving FDA approval. Our research model is based on advancing multiple opportunities at once, and then incentivizing and encouraging companies and the government to fund activities in later clinical stages. Having multiple “shots on goal” gives us the best potential for reaching our goal of a treatment and cure for SMA.

FSMIA has made significant progress in the area of discovering and developing new therapies for SMA. To date we have funded and advanced five such ventures:

1. Since 2000, with an investment of $13 million, the Quinazoline Compound to increase production of the back-up SMN2 gene, which was licensed to Repligen in 2009 for clinical development and is now in preparation to file for approval to start clinical trials. This new drug candidate recently received the first ever Orphan Disease Designation from the FDA for SMA.

2. Since 2003, the Oligonucleotide Program at University of Massachusetts, which identified an important therapeutic strategy using genetic material to modify the splicing of the back-up SMN2 gene. This discovery was recently licensed to ISIS Pharmaceuticals, who now leads the clinical development program.

3. Since 2003 with an investment of $2 million, the MotorGraft Cellular Therapy Program at California Stem Cell Inc., University California, Irvine and Johns Hopkins, which completed the first ever pre-Investigational New Drug Meeting with the FDA for SMA.

4. Since 2004 with an investment of $2 million, the Tetracycline Program at Paratek Pharmaceuticals to correct SMN2 splicing, which is now being funded in part from a multi-million dollar award by the NINDS.

5. Starting in 2010, the Gene Therapy Program at Nationwide Children’s Hospital in Ohio, to replace the entire SMN1 gene.

As demonstrated by the projects described above, one of the long term goals at FSMIA is to fund and de-risk early stage drug discovery programs for SMA. At the very earliest stages of drug development, programs have a less than 1% chance of FDA approval. This inherent risk along with low potential for profit because of the small patient population has traditionally hindered industry from working on orphan diseases.

FSMIA has actively reduced the barriers to early stage SMA drug discovery programs by providing: 1) early seed funding, 2) access to tools and reagents, 3) expert SMA advisors, and 4) established clinical trial protocols and networks.

The FSMIA rational for providing these incentives to industry to work on SMA drug discovery is to build a large and diverse therapeutic pipeline. Through this new RFP, FSMIA will continue its long-term commitment to investment in this area. This next phase of SMA drug development will build on our success of advancing five programs over the last ten years, and rapidly create a broader SMA therapeutic pipeline.

The selection of the most promising projects will be governed by the FSMIA Translational Advisory Committee (TAC), which is made up of experts from multiple facets of drug development. The use of the TAC to select drug programs for funding fits perfectly with the overall FSMIA research funding model, which is based on the need for expert and independent prioritization and oversight of research projects. This approach ensures that FSMIA funds only the most promising research, and that funded projects are run in a professional and efficient manner under the guidance of world-class experts.
Study with Funding from FSMA Shows a Muscle Specific Intervention Improves Phenotype in a Mouse Model of Spinal Muscular Atrophy

Dr. Charlotte Sumner and colleagues at Johns Hopkins University published a study in the journal Human Molecular Genetics showing improvement in survival but not motor function in a severe model of Spinal Muscular Atrophy by increasing the levels of the muscle modulator Insulin-like growth factor 1 (IGF-1).

Spinal Muscular Atrophy (SMA) is an inherited motor neuron disease caused by the mutation of the Survival Motor Neuron 1 (SMN1) gene and deficiency of the SMN protein. Severe SMA mice have abnormal motor function and small, immature myofibers early in development suggesting that SMN protein deficiency results in retarded muscle growth. Insulin-like growth factor 1 (IGF-1) stimulates myoblast proliferation, induces myogenic differentiation, and generates myocyte hypertrophy in vitro and in vivo.

The authors hypothesized that increased expression of IGF-1 specifically in skeletal muscle would attenuate disease features of SMA 7 mice. SMA 7 mice overexpressing a local isoform of IGF-1 (mIGF-1) in muscle showed enlarged myofibers and a 40% increase in median survival compared to mIGF-1 negative SMA littermates (median survival = 14 vs. 10 days respectively, log rank p=0.025). Surprisingly, this was not associated with a significant improvement in motor behavior. Co-treatment with the histone deacetylase inhibitor, trichostatin A (TSA), resulted in a further extension of survival and improved motor behavior.

The authors suggest that these results show that increased mIGF-1 expression restricted to muscle can modulate the phenotype of SMA mice indicating that therapeutics targeted to muscle alone should not be discounted as potential disease-modifying therapies in SMA. IGF-1 may warrant further investigation in mild SMA animal models and perhaps SMA patients.

This work also supports the general idea of pursuing combination therapies, each targeting different mechanisms, in the treatment of SMA.

Muscular Dystrophy Association Invests $1.4 Million to Help Advance the Families of SMA Quinazoline Drug Program for Spinal Muscular Atrophy at Repligen Corporation

The MDA has committed to invest funds in the FSMA Quinazoline Program at Repligen Corporation to assist in advancing the program to an IND filing with the FDA.

FSMA began the Quinazoline, or DcpS inhibitor RG3039, program in 2000 at the very initial stages of drug development, when risk is the highest. It was the very first industrial drug program for SMA ever done. FSMA fully funded the program until 2009, when our investments of over $13 million provided the positive results to leverage larger funding amounts for clinical development from Repligen Corporation.

Repligen Corporation is now responsible for coordinating and funding the clinical development phase of the program. This current MDA grant is the second outside funding award obtained for this particular program. In 2009, Christine DiDonato of Northwestern University received a NIH grant using data obtained with FSMA funding to support mouse model studies on this compound.

The follow-on investments made by the government, the company Repligen, and now the MDA in this particular program help demonstrate the value and success of the FSMA model and its scientific expertise.

One of the goals at FSMA is to fund and de-risk early stage drug discovery programs for SMA to the point that other groups are willing to invest. At the earliest stages of drug development, programs have a less than 1% chance of FDA approval. This inherent risk along with low potential for profit due to a small patient population, has traditionally hindered industry from working on orphan diseases. FSMA has actively reduced the barriers to early stage SMA drug discovery programs by providing: 1) early seed funding, 2) access to tools and reagents, 3) expert SMA advisors, and 4) established clinical trial protocols and networks.

In keeping with our commitment to build a robust drug pipeline for SMA, in order to mitigate the inherent risk associated with even the most promising approaches, FSMA recently released a Request for Proposals for new preclinical drug discovery programs.

Partnerships between non-profits, the government and companies are a very effective way to share the risks of developing rare disease treatments. This FSMA approach also enables the correct expertise for a particular stage of development to be brought into a program.
The California Institute for Regenerative Medicine (CIRM) Awards iPierian $5.6 Million to Advance a Spinal Muscular Atrophy Drug Program

The California Institute for Regenerative Medicine, the state stem cell agency created by Proposition 71, approved funding for 19 awards worth $67 million in its second round of awards designed to move good ideas out of the lab and into the clinic. This includes a small molecule drug program for SMA at iPierian. The funded projects are expected to either result in a candidate drug or cell therapy or make significant strides toward such a candidate, which can then be developed for submission to the FDA for clinical trials.

iPierian’s project is designed to identify small molecules that increase the expression of the SMN protein in Spinal Muscular Atrophy patients in motor neuron cells derived from iPS. It was the only for profit venture funded by CIRM and will receive more than $5.6 million for the SMA project. The iPierian award will be in the form of a loan, while the other awards are grants.

iPierian is a pioneering biopharmaceutical company that is taking the cutting-edge technologies of cellular reprogramming and directed differentiation to a new level to harness the power of induced pluripotent stem (iPS) cells to advance the understanding of human diseases and accelerate the discovery of more effective therapeutics for patients.

iPierian has built one of the most qualified teams of stem cell scientists in the world, combining the expertise of the founding scientists of what was formerly iZumi Bio with internationally-renowned scientists from top institutions such as the Harvard Stem Cell Institute and University of California San Francisco, among others. iPierian is the first company to apply cellular reprogramming and directed differentiation to cells that are derived from patients representing a broad spectrum of diseases.

Dr. Lee Rubin, a member of the FSMA Translational Advisory Committee, is a scientific founder of iPierian and a Professor at the Harvard Stem Cell Institute.

Trophos Initiates Pivotal Efficacy Study of Olesoxime in Spinal Muscular Atrophy

Trophos SA, a clinical stage pharmaceutical company developing innovative therapeutics from discovery to clinical validation for indications with under-served needs in neurology and cardiology, announced today the initiation of the pivotal efficacy study of olesoxime in the rare, neurodegenerative condition, Spinal Muscular Atrophy (SMA).

The study is substantially funded by Trophos’ partnership with the Association Française contre les Myopathies (AFM) (see the release from March 19, 2009 for more information on this program). The trial protocol has benefited from the EMA Protocol Advice procedure. Efficacy results are expected in 2013.

Olesoxime (TRO19622) is the lead compound of the Trophos’ proprietary cholesterol-oxime compound family of mitochondrial pore modulators.

Would you like your primary care doctor or other medical professionals to receive information on SMA? If so, e-mail membership@fsma.org with the contact information.
The Alabama Chapter held its 8th Annual Walk-n-Roll to Cure SMA on Saturday, October 30, 2010. We had a great turnout! Over 225 people attended and we raised over $30,000! We walked two laps around Snow Hinton Park. There was entertainment for all ages. The silent auction consisted of donated photos, paintings, sports memorabilia, themed baskets, movie tickets, restaurant gift cards, vacation packages and more. The auction alone raised over $6,000. The kids enjoyed the playground, a blow-up bouncer, face painting, a clown who passed out balloons, carnival games and the University of Alabama's “Big Al”. For lunch, we dined on hamburgers and hot dogs. The nice weather set a wonderful backdrop to honor and remember our precious children with SMA. Mark your calendars for the 2011 Alabama Walk-n-Roll set for Saturday, October 29th!

USA Triathlon will host the 2011 Collegiate National Championship and Sprint Triathlon in Tuscaloosa, AL on April 9, 2011. Jason Patrick, father of 4 year old Logan Patrick, SMA Type I, will compete with eight of his coworkers as a part of Team Logan in the Sprint Triathlon. The Sprint consists of a 750 meter swim in the Black Warrior River, a 12 mile bike and a 5K run. The money Team Logan raises for the event will be donated to Families of SMA.
Alaska Chapter

The Alaska Chapter held its first fundraiser on November 14, 2010 in Anchorage, Alaska! Over 20 people came together for the inaugural Bowl-a-Thon and bowled their way toward finding a cure for SMA. This event was a great success for our chapter and was a fun way to raise awareness about SMA. We raised over $1,800 at this event! Participants requested that we host another bowl-a-thon next year with prizes like ‘most improved bowler’. We are so looking forward to it! Thank you to everyone who came out and participated. Also, a big thank you to Jeanine Firmin and Therese Tamarra for all of your hard work putting the Bowl-a-Thon together. Your energy and support made the fundraiser such a fun and successful event!

It has been an eventful few months for the Alaska Chapter. It finally feels like we are organized and moving forward toward accomplishing FSMA’s goals and objectives. Plus, the Alaska Chapter is exceeding our goals to integrate with the local communities by reaching out to doctors and medical entities and coordinating with local agencies like the Muscular Dystrophy Association of Anchorage. Not only are we busy spreading the word about SMA, we are also preparing for our second fundraiser! We are planning a mid-April Spaghetti Lunch for downtown Anchorageites with a Spaghetti Dinner to follow in the surrounding town. If any of the other chapters have had success with this type of event, please contact Meghan Lowber at Alaska@fsma.org with your pointers. Any guidance is greatly appreciated.
The 5th Annual Arizona Walk-n-Roll was held on November 21, 2010 at Chaparral Park in Scottsdale, Arizona. Over 300 individuals attended the walk this year. We started the day with clear, sunny skies, which turned into clouds and rain following the walk. It’s hard to believe it rained in Arizona, especially in November! We took a one mile walk around the beautiful lake where signs showcased 25 of our amazing children. A wonderful DJ, Bubbles the Clown and the Phoenix Suns Gorilla entertained our group. We had lots of games and activities for the children to participate in, as well as some amazing raffle prizes! We raised over $26,000 to help support research and find a cure for SMA!

WE HOPE YOU CAN JOIN US FOR ONE OR MORE OF OUR UPCOMING ARIZONA CHAPTER EVENTS!

**KDK Golf Tournament**
Friday, May 6 at 1:00pm
Western Skies Golf Club
1245 E. Warner Rd.
Gilbert, AZ 85296
kdksmash.com/default.aspx

**Family Meet & Greet**
Sunday, July 10 at 4:00pm
Sweet Tomatoes
9029 E. Indian Bend Rd.
Scottsdale, AZ 85250

**Family Meet & Greet**
Saturday, September 10
at 4:00pm
Islands
12811 N. Tatum Blvd.,Suite A
Phoenix, AZ 85032

**Northern California Chapter**

Rain in California? Yes it did! But we still had about 115 enthusiastic people come out and walk in the rain at our Walk-n-Roll! On October 24th, we gathered in Golden Gate Park in San Francisco, CA and walked from Peacock Meadow down to John F. Kennedy Drive to a gorgeous waterfall before returning to our site. The park was beautiful, even in a storm. We enjoyed entertainment, a raffle, snacks and lunch before we all headed home—wet, but happy. While our attendance was down, we still raised over $30,000 for Families of SMA to help find a cure for Spinal Muscular Atrophy.
Thank you to all who attended and supported our 4th Annual Southern California Walk-n-Roll on Sunday, November 7th. We far exceeded our expectations with over 800 attendees, and more than 33 teams of walkers. Through all of your amazing fundraising efforts, we raised over $75,000!

Despite the threat of rain, it was a wonderful, clear morning. Jim Roope, the LA Correspondent for CNN Radio, was the emcee and Vice Mayor of Burbank, Jess Talamantes, welcomed our walkers. The Burbank Firefighters Association Local 778 sent Firefighter Bruce Smentek with a big red fire truck for the kids to explore along with gifts for our children with SMA. The Burbank Police Officers Association sent Officer Sam Anderson to greet the children with a special police vehicle.

Over 11 activity tables were set up for the children. Local high school students from Providence High School and St. Francis Xavier Parish were on hand to greet the children and run the games.

The In-N-Out Burger Truck served up burgers as the walkers came in while Jim Roope and actor Dan Robbuck (Leslie Artz from LOST) along with Zeke, Lilly, Dominick and Luke called the raffle winners.

From start to finish, the day was run by volunteers, and if not for them, this day would not have been possible. Thank you to our teams for your attendance and all of your fundraising efforts. We are all working towards the same goal and every dollar raised will make a difference. Thank you to all of our sponsors, and a big thank you to Rosie Roope for organizing the Walk-n-Roll.
Five sixth grade students from St. Mary School in Bethel, Connecticut raised over $300 to give to Families of SMA. Mary Biasetti, Danielle Marcone, Gwenyth Stuard, Rosanna Lifrieri and Isabel Kent sold handmade friendship bracelets and beaded necklaces at the St. Mary Craft Fair and Christmas Gala. “Working together was fun,” said Isabel Kent, whose cousin, Cubby Wax, was diagnosed with SMA at four months old. “And knowing we raised money towards a cure is even better.”

Liberty Life Center hosted a Christmas Party for the South Florida Chapter. Members of the church donated gifts for the party and attendees were greeted by a special guest – Santa!

The Greater Florida Chapter ended 2010 with two of our biggest events, raising much-needed awareness for SMA and funds for a cure!

A Walk in the Park:
Imagine a stroll through the park and the variety of food, entertainment and activities that you would encounter. From hot dogs to cotton candy, music to lawn bowling, you could find all of this and more at Wekiva High School’s first-ever A Walk in the Park community fundraising event on Saturday, October 16, 2010, in Apopka, FL. The high school’s Do Something club hosted the event, which was organized by senior Audrey Winkelsas, who has SMA Type II, and was sponsored by other Wekiva clubs and organizations. In addition to featuring a variety of food and activity stations that were fun for the entire family, the event featured a “Tree of Knowledge” where everyone was invited to learn more about SMA, and a “Purse Snatch” where exciting auction items were available for purchase or bid. This interactive and innovative event raised $3,600 for FSMA.
**Second Annual Walk-n-Roll:**
The FSMA Greater Florida Chapter’s Walk-n-Roll on Saturday, October 23, 2010, was a great success. More than 300 people attended the beachfront event on a beautiful sunny day at Ft. Desoto Park in Tierra Verde, FL. We raised over $23,000 for the fight against SMA and exceeded our fundraising goal! We kicked off the walk with the song “Beauty in the World,” which reminds us of all we have to cherish in this life and has become our chapter’s theme song. As participants walked and rolled throughout the scenic one-mile course, they were met with 27 signs honoring our chapter’s beautiful SMA angels and warriors. After the walk, kids were entertained with music, clowns, face painters, pumpkin painting, the Chick-fil-A cow and games. Adults shopped at craft tables and donated for raffle prizes. The top three biggest teams (Andrea’s Army, Andy’s Army and Team Abby) and the top five fundraising teams (Andy’s Army, Team Abby, Andrea’s Army, Team Chloe and Team Taylor) were honored with special prizes. It truly was a day to remember!

On February 16, 2011, Chapter Vice President Audra Butler made a presentation to the lab technicians at Genzyme Genetics in Tampa, FL, helping them to connect the work they do every day in the lab with real people. The presentation explained the devastating impact of an SMA diagnosis on a family, what life caring for a child with SMA is like, and the importance of SMA carrier and prenatal testing. The Greater Florida Chapter hopes to continue our relationship with Genzyme through other presentations and sponsorship opportunities.

The Greater Florida Chapter is thrilled to announce that the Tampa Bay Rays Major League Baseball team has invited our organization to be their charity of the day on July 17, 2011. The Greater Florida Chapter is selling specially priced tickets for our FSMA section. Plan to join us at our SMA Day with the Rays as we take on the Boston Red Sox at 2:05pm at Tropicana Field in St. Petersburg, Florida. Visit www.fisma.org/greaterflorida for more information.

We also are looking forward to other great events planned for 2011, including Bike Night at Quaker Steak & Lube in March, our annual Family Fun Day in May and our Third Annual Walk-n-Roll in November. We are extremely excited and pleased to have the 2011 SMA Families and Professional Conference here in Florida, and we look forward to greeting our extended SMA family in Orlando this June.
**Georgia Chapter**

Two Georgia Chapter Officers, Ashley Jones and Ashley Manross, spoke at Children’s Healthcare of Atlanta this past fall to help medical professionals better understand the personal and medical side of SMA. The conference had over 100 attendees including respiratory therapists, physical therapists, pulmonologists, nurses and more. They hope to be a part of another conference this year in August for SMA Awareness month.

The GA Chapter is planning a Walk-n-Roll event this summer which will be held in midtown Atlanta. Look for details about the event in the next issue of Directions.

We were honored to be included in the 1st Annual 5K Eat ‘n Run in Columbus, GA on March 26, 2011. The event was held in honor of Caleb Merriken and Sullivan ‘Sully’ Rossmiller. Thanks to Kari and Kanaan Merriken and the Rossmiller family for including us in this great event!

**Illinois Chapter**

We have several events coming up in Illinois in the next few months. We hope you can join us for any or all of them! Please visit the Illinois Chapter Website for more information about these great events: http://www.fsma.org/illinois.

**WE HOPE YOU CAN JOIN US FOR ONE OR MORE OF OUR UPCOMING EVENTS!**

**The 3rd Annual Bowl-a-Thon in Memory of Zachary Brian Deutschle**

May 14, 2011
1:30pm–4:00pm
Parkside Lanes
34W185 Montgomery Road
Aurora, IL

**Tee Off with the Drive to Cure SMA in honor of Ryan Manfre**

May 21, 2011
Gleneagles Country Club
13070 McCarthy Road
Lemont, IL

**2011 Illinois Chapter Walk-n-Roll**

June 12, 2011
Independence Grove
Libertyville, IL
Iowa Chapter

The Iowa Chapter raised over $20,000 for Families of SMA at the Beaverdash this year. We are so thankful to those who have supported this event over the past 14 years.

The 14th Annual Beaverdale Beaverdash took place on September 18th. We always expect a big crowd early that morning. This year, however, the forecast called for rain...and rain it did. Amazingly, the rain let up for the hour and a half that our run took place. It was quite the miracle that allowed all of our SMA kids to be outside for the Beaverdash.

We had a great turnout of chapter members and always enjoy getting our families together. Despite the rain, we had over 800 people sign up for this year’s event. Although not everyone braved the rain, we had a much bigger turnout than we had expected.

Kansas City Chapter

On October 2, 2010, the Kansas City Chapter of Families of SMA held its 10th Annual Cure SMA Race-n-Roll in Roeland Park, Kansas. Even though we had to make a change in the location, we had more participants than ever as well as our largest number of teams in attendance! We had over 600 runners, walkers, rollers, friends and family who crossed the 5K or One Mile finish line! After the run, everyone enjoyed the crowd favorite “Kid’s Dash” as well as food, drinks, a raffle and games.

A big thanks to all of our SMA Family Teams who showed their support. This year, each team had a team name as well as a special team color which made for a rainbow on the race route! This year’s teams are listed below. We also want to thank all of our dedicated volunteers who help us year after year, especially Gardner-Edgerton High School and Shawnee Mission East High School volunteers.

We had a great day and the event was a huge success! We all came together to make a difference and we raised $41,000! This year’s teams are listed to the right.

Team Sam * Groovy Gibbs Girls * Lindsay’s Trailblazers * Brett’s Buddies * Hunter & Cody’s Crusaders * Charlie’s Crew * Kennedy’s Krusaders * Peter’s Posse * Hope For Sam

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Our First Annual Jazz n Jam was a huge success! We had over 300 participants including over 30 Jazzercise instructors. Celebrity choreographer Tim Roberts joined us from the East Coast to lead our last hour, which was unbelievable. We danced for over three hours to raise awareness and funds for SMA. Parkview Baptist’s Jump Rope Team did an amazing demonstration as did the Junior Jazzercisers from St. Francisville. The morning was amazing! We raised over $32,000. Next year’s event will be held January 28, 2012 at Louisiana State University.

Michigan Chapter

Ken and Cindy Armbrustmacher of the Michigan Chapter of Families of SMA held their 7th Annual Flippin’ for a Cure Hamburger Night at the VFW Post 4090 in Portland, Michigan. We served approximately 450 hamburger and fry baskets and raffled off over 100 donated items throughout the evening. We raised $4,500 as well as lots of awareness for SMA.

The Spitzley family of Westphalia, Michigan held their annual charity auction at the family Christmas party. Many rare items were bought and sold to family members. The Spitzley’s donated half of the proceeds from the auction, $370, to Families of SMA in honor of their great-granddaughter Mallory Armbrustmacher.

SAVE THE DATE

Michigan Chapter’s 5K Run, Walk-n-Roll & Family Fun Day
Saturday May, 7 2011
8:30AM
Hawk Island Park
1601 East Cavanaugh
Lansing, MI 48910
September 12, 2010 was a picture perfect day in St. Paul, Minnesota. Volunteers arrived early to a beautiful sunrise and the aroma of fresh coffee and hot chocolate. They worked hard to set up the pavilion at Lake Phalen before registrants started to arrive. We spent a considerable amount of time taking pictures before the “Ready, Set, GO!” to start the 5K around the lake. As usual, our kitchen crew was ready with hot dogs, chips, nachos, etc. as the walkers came in. The day was so nice that we had the cake walk/roll outside. We also had informational materials available and merchandise for sale. It is a joy to see the teams come each year joined by their friends and family in colorful T-shirts. This year we had nine teams who together raised almost $23,000. Thank you all for your participation and volunteer support.

The Minnesota Chapter had a very successful Spaghetti Dinner Fundraiser on November 28th. It was our first event of this kind, and we served about 150 people. We had expected to have a small bake sale, as well as a silent auction. The Mevissen family supported the fundraiser more than we could have hoped for. They brought many baked goods and an overwhelming number of silent auction items. We raised $1,600 and had a great time socializing. We hope to make this an annual event for the Minnesota Chapter. We are making plans to have a Pancake Breakfast in the spring. Please look for more information about this event.

Jessica Wosika, granddaughter of Wanda Wosika, is a member of United Special Sportsman’s Alliance. The USSA, Inc. is an organization that specializes in sending critically ill or disabled youth and disabled veterans on the outdoor adventure of their dreams! Jessica’s dream was to shoot a Buck like her Daddy and Papa. Jessica was picked in June to go to the American Adventures Ranch in West-Central Wisconsin. Rick Vojitk, the owner of the ranch, donates three hunts per year through the USSA, Inc. Jessica left for American Adventures Ranch with her dad, Chris Wosika, and Nana, Wanda Wosika. Jessica stayed in the Deer Cabin with the rest of the hunters and went out a couple of times to get the feel of the handicap blind she would be shooting from. Near the end on Jessica’s last day, a big buck walked out. Jessica spotted it and pointed to it. With a little help from her dad, Jessica shot! It was amazing! Everyone cheered and Jessica was shocked at what had just happened. Jessica shot a 13 pt. Buck, beating her dad and Papa in bagging the largest Buck!
Lyncht School Walk for a CURE for SMA

The Lynch Elementary School 5th Graders chose Families of SMA for its Community Service project this year in honor of fellow classmate, Katie Mirabile who has SMA Type II. Their walk, along with raffle, silent auction, bake sale and kids’ activities, raised over $31,000 for Families of SMA!

Birthday Wishes for FSMA

Winchester resident Elle O’Connor shared her birthday wish with FSMA. This year Elle asked for donations to be given to Families of SMA instead of receiving birthday gifts. She raised $240 for FSMA.

Grant Schilling and William Johnson’s Birthday Party

Grant Schilling and William Johnson are two extraordinary 11 year olds. On October 30, 2010, they threw a combined birthday party, but instead of asking for gifts, they asked their friends to donate to Families of SMA – New England Chapter. About 70 5th graders gathered in the Schilling’s garage that night to make a difference for their friend and raised $3,900!

Johnson’s Golf Tournament

It took a hearty golfer to make it out to the course for the 4th Annual Fall Classic for FSMA in honor of William Johnson. Clearly the check to mother nature must have gotten lost in the mail, as she decided to rain on our parade. Despite a smaller, very damp crowd, everyone’s amazing support enabled us to raise over $37,000 for Families of SMA. Our family continues to marvel at how our community rallies behind us to find a cure for William and all who deal with the demon of SMA. Our deepest gratitude to everyone who made this soggy, albeit memorable, event possible.

Cubist Bake Sale

The Information and Business Solutions Department at Cubist Pharmaceuticals hosted the 2nd Annual Bake Sale and Silent Auction on December 17, 2010. This year, the IBS Department was joined by friends across many departments at Cubist, former members of their department who came back to Cubist for the day to help out, and friends and family of IBS team members who just wanted to pitch in by baking or donating an auction item. It was wonderful to exceed last year’s fundraising and collect over $4,800 in donations!

This event is held in honor of Macarthur Sohl, whose mother, Kate Sohl, is a member of the department. Macarthur is three years old and has SMA Type II. He also attended this year and had a wonderful time cruising around the offices and cubes in his wheelchair.

Shamrocks for SMA

Courtney and Paul Davidopoulos organized Shamrocks for SMA on Friday, March 4, 2011 at the Claddaugh Pub in Lawrence, Massachusetts. The night of pre-St. Patrick’s Day cheer was held in honor of their son Matthew. The night included live entertainment, prizes and fun. Nationally recognized Irish band, Inchicore, opened the evening and we capped things off with local fan favorite ‘Courduroy’! The event raised about $10,000 for Families of SMA.

TAKE A LOOK AT UPCOMING NEW ENGLAND CHAPTER EVENTS:

On Sunday, April 10, 2011 from 1:00–3:00pm, we will have a Family Ice Cream Social with live entertainment for the kids. It will be held at Hibernian Hall in Watertown, Massachusetts. Admission is Free!

The 11th Annual Cure SMA Walk-n-Roll will be held on May 14, 2011 at Wompatuck State Park in Hingham, Massachusetts from 9:00am to 12:00pm. This is a great fundraiser and fun family event. You can register now for the walk at http://www.fsma.org/newenglandwalknroll2011
South Jersey – Delaware Chapter

Join us for the 6th Annual Steven’s Walk to Drum Out SMA on May 14, 2011 at Newton Lake Park in Haddon Township, NJ. Zumba Away SMA will be held on Friday, June 3, 2011. Check out our chapter website at www.fsma.org/southjersey for more information about these great events. Our chapter is also planning a Family Fun Day which will be held at Wicked R Western Ranch this summer. Please check our chapter website for the date.

The Fall brings back two annual events: Steven’s Swing for a Cure Golf Tournament will be held on September 23rd at Jonathan’s Landing in Magnolia, Delaware. The Kingkiner family, along with some other local families, will hold their annual Hula Hoping Walk-n-Roll for a Cure in New Jersey. The date is yet to be determined.

Greater New York Chapter

A Night of Comedy for FSMA in honor of Greyson Erwin was held on October 14, 2010 at Governor’s Comedy Club on Long Island. We had a great turnout, and every comic was amazing. We also had a silent auction and raffle. A fun night was had by all and we raised over $20,000!

Michele Erwin organized a Macy’s Shop for a Cause day for Families of SMA. Participant’s purchased $5 shopping passes and received 25% off of all of their purchases on October 16, 2010. We sold over 170 shopping passes and raised over $1,800 for Families of SMA.

We would like to thank Angela’s House and specifically Bob Policastro for organizing A Night for the Cure. Our chapter participated in this event with over 15 other rare diseases in the Long Island, New York area. Thank you Angela’s House for donating over $900 to our chapter. We would also like to thank Brittany Cleere and the Cleere Dance Project for hosting the Zumbathon for SMA which raised over $400 for our chapter. The Greater NY Chapter also marched in the 2011 Rockville Centre St. Patrick’s Day Parade again this year.

For the third time, the Erwin Family organized Team Families of SMA for the 2011 NYC Half Marathon. This year, for the first time, Families of SMA was an official charity partner for the event. The NYC Half Marathon is the most competitive and popular half marathon in the United States with over 35,000 applicants. Families of SMA is honored to partner with New York Road Runners and be included as a charity team. Team Families of SMA consisted of 20 runners who each raised over $1,000.

If you are interested in hosting your own fundraiser, please contact us at 866-774-9533 or email jnjmoyer@comcast.net and we will help you get started. Happy Spring! Together we will find a cure!
UPCOMING GREATER NEW YORK CHAPTER EVENTS:

Please save the date for our first **Golf Outing** which will take place on Monday, July 18, 2011 at Hudson Hills Golf Course in Ossining, New York.

Also, please save the date for our 4th Annual **SMA Awareness Day** with the New York Mets on Sunday, August 21, 2011. More details to come on this event in the upcoming months.

Our 7th Annual **Walk-n-Roll to Cure SMA** will be held on Saturday, September 17, 2011 in Long Beach, New York. This year’s walk will be in memory of Keira Sweeney. To register for the walk, please visit www.fsma.org/gnywalknroll2011.
Planning for the 8th Annual Walk for a Cure is underway. The event is scheduled for August 6th at Beaver Island State Park on Grand Island, New York. As in years past, the event will be co-chaired by State Senator George Maziarz and KISS 98.5 DJ Nickolas Pickolas.

This year, with the help of the Faso Family, we have established committees to head each portion of the walk. Each team will be dedicated to making sure everything is in order on the day of the event. Team leaders will be designated by special T-shirts. These new procedures should help add to our success. Thank you, Ron, Lori and Paula.

Kudos to Bailey Walter, a 4th grade classmate of Kale Shiesley. She sent 200 letters to her friends and relatives regarding the walk. She has already received many responses. She also raised several hundred dollars for Families of SMA in Kale’s honor by selling wrist bands.

We would like to extend an invitation to anyone in our area to help with the Walk-n-Roll this year. We always need help setting up on the day of the event and would welcome any ideas or suggestions.

Cincinnati FSM A Walk-n-Roll 2011
The 8th Annual Walk-n-Roll will take place April 30, 2011 at the Cintas Center, Xavier University. We are looking forward to another successful walk. We can use more volunteers to help. Please contact Beth Lockwood at 513-947-0161 or email her at bethml@fuse.net. See everyone in the spring!

Halloween Skating Party
For the past five years, the OKI Chapter has held a special Halloween party at Skatetown USA in West Chester, OH for SMA families and all supporters. The skating rink allows SMA children, in their power chairs, to skate around the rink for more than one hour without public participation. SMA children thoroughly enjoy the excitement of the rink and music, and some even wear skates although in their power chairs. All wear their special Halloween costumes. Following the skating, participants bond over pizza, pop, and desserts. The Halloween Party is a highlight for OKI Chapter families. It should be mentioned that this year’s costumes were the greatest!

Power Soccer in Cincinnati
Power Soccer started in Cincinnati this year. A demo and clinic was presented by the team from Indianapolis. It was an awesome day to see them show off their skills and teach us how to use the equipment. After that, we recruited players from our area. Power Soccer will resume in April. We are in need of more participants six years old and older. Also if you are interested in helping, please contact Beth Lockwood at 513-947-0161 or bethml@fuse.net.

Thank you to Michelle Vickers for raising $130 by having a 31 Purse Party fundraiser for SMA!
Walk-n-Roll
Our 3rd Annual Walk-n-roll at Greenlake was a great success! Almost 200 people attended and we raised over $8,700. We had good weather again this year and everyone enjoyed their walk around the lake. Plans are already underway to continue to grow our walk this year.

Stacy McBride Collections Jewelry Fundraiser
On November 13th, Kelly Hargrave hosted a Stacy McBride Collections jewelry party. Thirty friends and family attended the event put together by Stacy McBride consultant, Rebecca Sorter, to benefit Families of SMA. They enjoyed good food and lots of fancy jewelry. Everyone was able to get some early holiday shopping done! Through the party and online sales, Kelly and Rebecca raised $500 for FSM. It was a really fun party for a good cause and plans are already set for next year.

The 3rd Annual Pacific Northwest Chapter Walk-n-Roll

Penny Wars Fundraiser
Rozie McClay has worked for Washington State for the past nine years, but started working in a new agency on April 1, 2010. Everyone at her new job has been tremendously supportive of the SMA cause. This year, they offered to have Families of Spinal Muscular Atrophy as the charity recipient of their annual Penny War Fundraiser. The 2010 Washington State Combined Fund Drive Penny War raised $400 for FSM. The war was a competition between four Department of Retirement System teams. All pennies collected were worth one point. All other coins, cash or checks were negative points. Rozie’s department won the penny drive with 6,430 points. All of the other departments ended up in the negative. Rozie’s daughter Kiley had fun giving out the winning trophy at a wrap-up on October 29, 2010.

Wreaths for Hope
John & Sybil Kuhn held a wreath making fundraiser in November. They raised almost $1,400.

Potluck Play Date
We had a potluck play date on March 27th in Tacoma, Washington. A representative from Permobil was there to talk about becoming an informed consumer, advocacy and how to find the right medical equipment. Dr. Susan Apkon, a rehabilitation physician at Children’s Hospital who sits on the Medical Advisory Committee for FSM, also joined us to meet with Chapter Families. It was a fun time for the kids and a great opportunity to meet some new families who have joined our chapter.

Do you want to see your Chapter updates in the next issue of Directions?
Please send submissions to our Chapter Coordinator, Sarah Hunsicker at chapters@fsma.org

Kiley McClay giving out award to the winner of Penny Wars
Pennsylvania Chapter

Greetings from the Pennsylvania Chapter!

With the addition of five new families to our Chapter, we are rapidly expanding our ability to spread awareness and fundraise to ultimately CURE SMA! We are extremely grateful for the commitment to this mission from our newest members: the Hernandez Family, the Morales Family, the Peters Family, the Reilly Family and the Wehrkamp Family.

Along with our continued fundraising efforts, we are also focusing on providing the BEST SUPPORT to our SMA children and families. By hosting quarterly Chapter Meetings, our local SMA Community has united to fight this horrendous disease.

We cannot thank our amazing families enough for ALL THAT THEY ARE DOING! Here is a glance at what we have accomplished and what's on deck for 2011:

**Turkey Trot**

Each year the students, faculty, staff and parents of the New Hope Solebury Lower Elementary School come together for their annual Turkey Trot. The Turkey Trot is a mini walk-a-thon in which students learn the importance of fitness, but also about how they can help support individuals within their community.

This year, on November 10, 2010, the 10th Annual Turkey Trot was held in honor of two students who live with SMA; Matthew Reilly and Jake Saxton. Thanks to the generosity and kindness of the students, parents and faculty, $1,800 was raised for Families of SMA.

It was a beautiful day! The children learned about SMA, walked and rolled in support of their friends and together chanted: “CURE SMA!!”

The local paper covered and photographed the event, and as a result, a local woman with SMA read about the work of these kids. She wrote asking the school to let the children know that “This Thanksgiving . . . she was thankful for THEM!”

As their motto states: “New Hope Solebury Lower Elementary School is a very special place to learn and grow.”

**Sarah’s Read-a-Thon for SMA**

This was Sarah’s second year hosting her Read-a-Thon for Families of SMA in honor of her friend, Jake Saxton. Last year Sarah asked close friends to join her in raising over $800 for FSMA.

This December, Sarah was hoping to spread even more SMA awareness. Armed with her poster board and information about SMA, she asked her teacher if she could present her idea to her classmates. When the Principal heard of Sarah’s mission, she asked Sarah to present it to the entire student body. Sarah recruited over 40 readers and asked them to set a goal for the amount of pages they could read in the month of December. She then encouraged them to ask family and friends to sponsor them for each page they read.

Over 10,000 pages were read collectively and $2,500 was raised for Families of SMA. Most importantly, Sarah raised awareness about SMA throughout her entire school! She is a true friend and an amazing SMA fighter. We are lucky to have her on our team. Thank you to Sarah and the New Hope Solebury Upper Elementary School!

**Clubhouse Vendor Sale**

Barbara Perre, grandmother of Pete Henkel, who has SMA Type II, has been an active fundraiser for the PA Chapter since its inception. Whether it is organizing the raffle at the annual Walk-n-Roll or collecting donations in our neighboring state of New Jersey, she always supports our mission.

Recently, Barbara organized a small Vendor Sale at her Clubhouse and raised $375 for SMA research. Thank you Barbara for all you do!
CHAPTER updates

Pennsylvania Chapter Cont.

FUNDRAISING BY SWEET BABY ZANE

Honoring the memory of their 5½ month old daughter, Zane, Hillary and Keith Schmid established Sweet Baby Zane. The mission of Sweet Baby Zane is to educate people and to bring awareness about Spinal Muscular Atrophy, raise money that is to be donated to SMA charities who support other families and research, as well as, to be a part of the SMA Community determined to find a CURE for SMA. For more information, please visit www.sweetbabyzane.com.

Real Estate for a Cause

Real Estate for a Cause is a commitment by Hillary’s sister, Kristen Kearns, and her colleagues, Lucy Rhodes and Ron Bradley to donate a portion of profits from their Real Estate transactions to fight SMA. In 2010, over $8,500 was donated to Families of Spinal Muscular Atrophy (FSMA) and The Gwendolyn Strong Foundation.

Big thanks to this amazing team! Your incredible generosity is making a difference.

Philadephia Marathon

In preparation for the Philadelphia Marathon, Hillary’s friend, Gene McHale, approached her and offered to RUN FOR SMA. On Sunday, November 21, 2010, Gene ran the Philadelphia Marathon honoring the memory of Zane Schmid. He collected pledges from supporters and raised over $5,500. Way to go Gene!

The Hope Car Bed

Families of SMA is ecstatic to offer families the brand new Hope Car Bed, now available in the FSMA Equipment Pool. This was made possible through generous funding from the Schmid Family and their organization, Sweet Baby Zane. These amazing car beds are funded in memory of their sweet daughter Zane. Thank you Hillary, Keith, Avery and Zane for allowing FSMA to provide support.

Corporate Donation from VeriSigns

Derek Schmidt, devoted uncle to Jocelyn Paige Lee, never misses a Chapter Meeting which is pretty impressive since he drives over an hour from Delaware on behalf of his niece, who lives all the way in North Carolina! He is actively involved in the Jocelyn Paige Lee Foundation, which supports the care of his niece and also funds SMA research through donations and two annual fundraisers. (See below in “Upcoming Events”)

In 2010, Derek donated $1,475, which was matched by his company VeriSigns, for a total of $2,950! Thank you Derek for ALL that you do to support the FSMA mission.

Lukie’s Fall Fest

We were blessed with another absolutely perfect day for the 7th Annual Lukie’s Fall Festival. The weather was beautiful, we had the largest attendance to date, and we were busy from start to finish. Our opening ceremony was filled with prayers, love, and memories. We released balloons and lit candles in memory of Lukie, all the SMA Angels, and all the SMA Heroes. Many families came out to enjoy the food, fun, and games. We had performances by bag pipers, clowns, musicians, singers, cheerleaders, and a show choir. The local fire department brought their fire safety house for the kids to explore. We also had a huge raffle with nearly 100 items.

The festival honors the memory of SMA angel Lukie Maida who would have been ten years old this past June. The festival, which is hosted by the Maida every fall in Pennsylvania, has become a celebration of his life, spirit and of hope for the day that we find a cure for SMA.
Fundraising by Little Flower Violet

On August 27, 2010, Violet Madison Wehrkamp lost her life to SMA at just six months old. Since her passing, her parents, Bill and Allison Wehrkamp have fought tirelessly to help raise awareness about SMA through their website www.littleflowerviolet.com.

Little Flower Violet provides information about SMA, the story of Violet’s life and battle with SMA and has a store where you can purchase items for which proceeds go to raise awareness and continue research for a cure.

Little Flower Violet “Hair Clips and Cuddle Blankets”

In December of 2010, Allison Wehrkamp began designing beautiful felt hair clips, hair bands, and pins. She expanded her collection to include Cuddle Blankets, in boy/girl patterns, as well as a line dedicated to children affected by SMA. 100% of all the proceeds from her sales are donated to SMA research. Her items can be purchased on ETSY.COM, the popular website of handmade goods.

To date, Little Flower Violet has donated $1,000 from the sale of these beautiful items. What unbelievable progress in such a short amount of time. Please visit www.etsy.com/shop/littleflowerviolet and get a head start on your Spring accessories.

“SMAzes” Maze Activity Books

The Wishmakers, a charity organization in Pennsylvania that harnesses the power of music and art to foster the spirit of giving, chose SMA as their charity project this year. In August 2010, The Wishmakers co-founder Gary Wehrkamp lost his 6-month-old niece Violet Madison Wehrkamp to SMA. Gary and The Wishmakers created children’s maze activity books and are selling them to raise money for Families of SMA. They’ve held a number of events where the books have been on sale. The books can also be purchased online at www.thewishmakers.org. To date, The Wishmakers have raised almost $1,600 for Families of SMA in memory of Little Flower Violet Wehrkamp.

Donations Honoring Violet’s First Birthday

February 18, 2011 was a very special day for the Wehrkamp Family:

“This is my daughter, Violet’s first birthday. And while she may be celebrating it in Heaven we know she is looking down upon us all. Today we will not focus on the fact that she passed away, but we will celebrate her life. She was a beautifully unique little girl who had such a personality… She affected the lives of many people. She had an old soul and taught us so much about ourselves and others. We love you “Girl Face” and we will ALWAYS remember you as our daughter and the joy you brought to our lives. Thank you for blessing us with your love.”

In honor of Violet’s birthday, Allison and Bill Wehrkamp started a gift registry page on curesmsa.org. Between the contributions made online and checks given to Allison and Bill, over $2,500 was donated to Families of SMA in memory of Violet.
Pennsylvania Chapter Cont.

**LYLA MERTZ FOUNDATION**

**Fundraising by The Lyla Mertz Foundation**

The Lyla Mertz Foundation, Inc. and Team Lyla were created by Steven and Jennifer Mertz, in memory of their daughter, Lyla J. Mertz. Their mission is to help create community awareness, fund research, and help families who have been affected by Spinal Muscular Atrophy (SMA).

**Dance Away SMA**

Although we wrote of this event in the Fall Edition of Directions, we hadn’t yet received the full report on the night’s success. So here goes…

In October of 2010, the Lyla Mertz Foundation hosted the First Annual Dance Away SMA, an event to celebrate the life of Lyla. Supporters of Team Lyla gathered at Frieden’s Fire Company Social Hall in Slatington, Pennsylvania and enjoyed great food, a Chinese Auction, and music by “The Chas Band”. The night was a huge success, raising over $6,000 for Families of SMA! Check out the FSMA website or www.teamlyla.org to take a peek at the wonderful video commemorating this great effort!

**Bags For Lyla**

Not-for-Profit “Bags for Lyla” is an ongoing fundraising effort by Jen Mertz. These beautiful purses are handmade by Lyla’s friends and family. They currently offer six types of bags, all of which are named after Lyla’s Care Team during her stay at the Lehigh Valley Hospital. Each bag has a tag with a ladybug button that says “Bags for Lyla” on one side and “Love you Little Angel” on the opposite side.

Recently, Jen has added “Bags for Lyla Jr.” to the collection for little girls. And this Spring, look for the newest line of matching “Mommy and Me” bags!

To date, $1,800 has been raised to fight SMA! Look out Kate Spade!

**Silpada Jewelry Party**

In January 2011, Jen Mertz’s cousin, Robin Hagy hosted a Silpada Jewelry Party Fundraiser in honor of Lyla Mertz. Shelly McCann, a Silpada consultant and Robin’s good friend, sold her jewelry and donated a portion of all her commission to the PA Chapter of FSMA. Huge thanks Shelly and Robin! Everyone had a fantastic time. And the total funds raised exceeded $1,180! Great jewelry! Great success! And most important, a Great Cause!

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**8th Grader Dorian Harvey writes about SMA**

Last November, Mr. Fogarty’s 8th Grade Religion Class at Waldron Mercy Academy was given an assignment…write about what it means to “Spread the Good News” today. Dorian Harvey, goddaughter to PA Chapter President, Karen McRory-Negrin decided to highlight the work done in the local FSMA Chapter.

Although she knew Abigail Negrin and had attended the Annual SMA Walks, she set forth gathering her facts. Dorian interviewed Karen about running the local Chapter, and the work that is devoted to organizing the Walk, supporting families and spreading awareness. She researched the disease to learn how it affects those stricken, as well as their families.

Dorian taught her class the importance of our organization’s ability to remain positive in the face of huge challenge. She wrote that in our work, we are “a great role model for never giving up, and keeping the faith.” It is “through actions and words” that we can fulfill the “command of spreading the Good News.”
Huge thanks to all our families and friends who work tirelessly to help us in our mission to CURE SMA!

In Friendship,
The Pennsylvania Chapter of FSMA

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<tr>
<th>Event Name</th>
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<tr>
<td>Emmy’s Crop for a Cure</td>
<td>March 12, 2011</td>
<td>Brandy Baugher, Hanover, PA</td>
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<td>Steak and Hoagie Factory Coupons</td>
<td>March–April</td>
<td>Chris Cooter, Horsham, PA</td>
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<td>Jocelyn Paige Lee Benefit</td>
<td>April 16, 2011</td>
<td>Derek Schmidt, Bear DE</td>
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<td>Malvern Blooms Family Festival</td>
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<td>SMA Motorcycle Ride</td>
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<td>Jocelyn Paige Lee Golf Tournament</td>
<td>May 14, 2011</td>
<td>Derek Schmidt, Lochsberg, NC</td>
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<td>8th Annual Chapter Walk-n-Roll</td>
<td>May 15, 2011</td>
<td>PA Chapter Event, Philadelphia, PA</td>
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<td>Summer Fair Fundraiser</td>
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<td>Jen Mertz and Alison Wehrkap, Lehigh Valley, PA</td>
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<td>Phillies Game &amp; SMA Awareness Night</td>
<td>June 14, 2011</td>
<td>PA Chapter Event, Philadelphia, PA</td>
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<td>Lukie’s Fall Fest</td>
<td>October 8, 2011</td>
<td>Tara and Joe Maida, Pen Argyl, PA</td>
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Thank you to everyone who participated in our 11th Annual Cure SMA Walk-n-Roll & Run on September 11, 2010. With your help and contributions, we surpassed our goal by raising over $40,000 making this our most successful walk to date! Please Save the Date for next year. Our 12th Annual Cure SMA Walk-n-Roll & Run Across America will take place on September 10, 2011 at Clement Park in Littleton, Colorado.

A conference on “Recent Advances in Pediatric Neuromuscular Disease with an emphasis on Spinal Muscular Atrophy” was held February 4, 2011, at Children’s Hospital in Denver. It was attended by pediatricians, family practice physicians, mid level providers, specialists, genetic counselors, occupational therapists and physical therapists. The Rocky Mountain Chapter had a booth to answer questions about the local chapter.

The Rocky Mountain Chapter held its annual Gala on March 12, 2011, at the Merchandise Mart in Denver, Colorado. More information to follow in the next issue of Directions.

On Friday, December 10th, country stars and hit songwriters came together in Hermitage, Tennessee to play an all ages show benefitting Families of SMA – Tennessee Chapter. Performers included Trent Tomlinson, Ken Mellons, Rich Fagan, Zack Lyle, Gary Hanna, Warren Silvers and many more. Nashville songwriter Kevin Barton, SMA Type II, was the lucky winner of an autographed guitar in the silent auction. In total, the event raised about $1,500 for Families of SMA. A big thank you to Warren Silvers for organizing this great event, and to all performers and attendees for your support of Families of SMA.

The Tennessee Chapter held their 8th Annual Comedy for a Cure this past October and raised over $32,500! We were honored to have Kenneth Hobby join us. The weather was perfect, allowing us to use the museum courtyard to display the silent and Chinese auction items. With the city lights as a backdrop and the music of an impressive jazz quintet, The Green Fleece (University of Tennessee students David Platillero, Brandon Neal, Matt Nelson, Luke Bowers and Marquis McGee) the evening was off to a great start. Pianist Neil Jochman performed as diners had the opportunity to catch up with old friends and welcome new supporters. We were very fortunate to have these accomplished, young musicians share their talents with us.

After dinner, comedians Leanne Morgan and Henry Cho brought down the house. The event would not have been such a success without the help of our volunteers who secured items for the auctions, donated items and services, helped prepare the museum space, ran the check in and check out, and most importantly, gave of themselves.

April 25, 2011 is the date for the 8th Annual Golf Tournament For a Cure at Gettysvue Country Club. It is a four person scramble event with food, beverages, prizes and auction items. Visit www.fisma.org/tngolfclassic2011 for details.
Wisconsin Chapter

The Wisconsin Chapter has been busy hibernating and keeping all of our kiddos healthy this winter. In December, Dr. Mary Schroth and Karen Patterson, PT, MS, PCS, came to talk to the therapists from New Berlin Therapies and Southeastern Wisconsin. The therapists each paid $10 for admission and donated the money to Families of SMA. It was a great event which included sessions with the therapists and a Q&A for the families.

New Berlin Eisenhower and New Berlin West, cross town rival girls basketball programs in New Berlin, Wisconsin, teamed up on January 5, 2011 to “Shoot to Cure SMA.” Teams from both schools sold T-shirts to friends and family, as well as the boys basketball teams, to raise a total of $2,000 for Families of SMA. The game was played at New Berlin West High School with special guests Reagan Imhoff, Braden McCarthy and Jackie Hoffman there to cheer on our teams.

In April, we are welcoming Josef Fleischmann, along with his mother, from Germany as an exchange student. Josef has SMA and is very excited about coming to Wisconsin and attending Sussex High School. He will also be spending part of his time with the Meyers in Madison. We were so happy to find an SMA family to host Josef and his mother thus enabling him to have a well-rounded experience.

Everyone in Wisconsin is looking forward to the conference in Florida (and finally some warm weather!). We can’t wait to be with our SMA family again.

We will keep everyone updated as we plan our summer fundraisers and festivities.

Do you want to see your Chapter updates in the next issue of Directions?

Please send submissions to our Chapter Coordinator, Sarah Hunsicker at chapters@fsma.org
**CHAPTER info**

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<th>Chapter</th>
<th>Address</th>
<th>Phone Numbers</th>
<th>President</th>
<th>Email</th>
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<tbody>
<tr>
<td><strong>Alabama Chapter</strong> (since 2005)</td>
<td>PO Box 71918, Tuscaloosa, AL 35407 (205) 979-6493</td>
<td>Rhyann Granger, President <a href="mailto:alabama@fsma.org">alabama@fsma.org</a></td>
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<td><strong>Alaska Chapter</strong> (Since 2010)</td>
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<td>Meghan Lowber, President <a href="mailto:alaska@fsma.org">alaska@fsma.org</a></td>
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<td><strong>Arizona Chapter</strong> (since 1997)</td>
<td>PO Box 43861, Phoenix, AZ 85080 (602) 314-4902</td>
<td>Angel Wolff, President <a href="mailto:arizona@fsma.org">arizona@fsma.org</a></td>
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<tr>
<td><strong>Northern California Chapter</strong> (since 1998)</td>
<td>PO Box 9014, Santa Rosa, CA 95405 (707) 571-8990</td>
<td>David Sereni, President <a href="mailto:ncalif@fsma.org">ncalif@fsma.org</a></td>
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<tr>
<td><strong>Southern California Chapter</strong> (since 1999)</td>
<td>1070 E. Orange Grove, Burbank, CA 91501 (818) 846-6589</td>
<td>Rosemary Roope, President <a href="mailto:socalif@fsma.org">socalif@fsma.org</a></td>
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<tr>
<td><strong>Rocky Mountain Chapter</strong> (since 1998)</td>
<td>PO Box 1913, Arvada, CO 80001 (970) 349-0481 or (877) 591-4023</td>
<td>Marynell Larson, President <a href="mailto:rockymt@fsma.org">rockymt@fsma.org</a></td>
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<tr>
<td><strong>Connecticut Chapter</strong> (since 2003)</td>
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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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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 Alaska and Georgia.

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.

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.
Dr. George Mentis of Columbia University, the first recipient of the FSMA Audrey Lewis Young Investigator Award, published a study in the prestigious scientific journal Neuron implicating sensory synapse defects in a mouse model of SMA.

Cell Press issued a press release describing this potentially groundbreaking work. An excerpt is below:

The study, published by Cell Press in the February 10 issue of the journal Neuron, suggests that therapeutic strategies designed to improve communication at these spinal synapses might help to slow or prevent the progression of the disease and should be further explored.

Amyotrophic Lateral Sclerosis (ALS) and SMA are human motor neuron diseases characterized by degeneration and death of motor neurons and the muscles that they innervate. Most research on motor neuron diseases has focused on the communication, or synapse, between the neuron and the muscle. However, because these motor neurons originate in the spinal cord and rely on inputs from sensory neurons as well as other neurons from different regions of the brain and spinal cord, it is possible that upstream events might contribute to disease pathology.

Using a mouse model of SMA that exhibits many of the features of human SMA, Dr. Mentis and colleagues studied synaptic connections between sensory and motor neurons in the spinal cord. “We found that communication between the sensory and motor neurons that make up the stretch reflex, which is known to be important for motor function, showed massive and progressive failure early in the disease process,” says Dr. Mentis. The functional deficit mirrored the pattern of muscle weakness in human SMA patients. The researchers went on to show that a drug that has been shown to improve motor function and increase survival of SMA mice improved the sensory-motor circuitry.

“Collectively, our findings suggest that spinal circuit dysfunction is one of the earliest and most pronounced pathological features of the disease and therefore may contribute significantly to the loss of motor function that characterize both mouse models and human SMA patients,” concludes Dr. Mentis. “Our data also support the potential therapeutic use of drugs to improve synaptic function, which is likely to be a key factor in the restoration of normal motor function in this disease.”
Multiple Presentations on Spinal Muscular Atrophy at the 2010 Society for Neuroscience Meeting

The 40th Annual Society of Neuroscience Meeting was held November 13 to 17, 2010 in San Diego, California. Over 31,000 neuroscientists were in attendance to hear about the latest developments in the field. The meeting included several dozen presentations on Spinal Muscular Atrophy.

About 30 presentations were given on SMA at the 2010 Society of Neuroscience Meeting, on both basic and drug development research. In the basic research area, talks were given by many of the leading labs in the field.

Presentations were also given on several of the leading therapy programs for SMA. These included presentations from ISIS Pharmaceuticals and their collaborators at Genzyme on their Oligonucleotide program, Repligen Corporation on their small molecule Quinazoline program, and the Kaspar lab in Ohio on SMA Gene Therapy, and from Genzyme Corporation on SMA Gene Therapy.

In addition, SMA advocacy groups, including Families of SMA, MDA, SMA Foundation, and FightSMA, held an official satellite symposium focused on SMA at SfN, entitled “Nucleic Acids to the Rescue: Gene and Antisense Oligonucleotide Therapies for SMA” to help raise awareness about the disease among neuroscientists.

FSMA Requesting New Basic Research Grant Applications for 2011 Funding

FSMA is pleased to announce that we are accepting new basic research grant applications for 2011 funding.

FSMA has been funding basic research since our inception in 1984, and has invested over $25 million in this area. Our basic research grant program has funded 140 projects at 70 institutions around the world.

In this current grant solicitation, we are encouraging applications on novel projects that will enhance our understanding of SMA disease pathology and contribute to developing new therapeutic approaches for SMA.

Basic research provides fundamental information about what is going wrong in SMA at the cellular, molecular, and biochemical level. This information provides seed ideas for making the most effective SMA drugs.

Our basic research program is governed by our Scientific Advisory Board (SAB). The SAB carefully reviews all grant applications and makes sure that we fund only the best research. Reviews are based on quality and relevance to the FSMA research mission of creating a treatment and cure for SMA.

Continued investment in basic research, leading to a greater understanding of the exact nature, causes and consequences of SMA, is key to ensuring the most effective SMA treatments can be identified and developed as quickly as possible.
California Stem Cell Inc. Files IND to Commence Phase I Clinical Trial in Spinal Muscular Atrophy

In December, California Stem Cell, Inc. (CSC) and Families of Spinal Muscular Atrophy (FSMA) announced that CSC has filed an investigational new drug (IND) application with the U.S. Food and Drug Administration (FDA) for approval to commence a Phase I safety study on a jointly-developed stem cell-derived motor neuron transplantation therapy for Spinal Muscular Atrophy (SMA) Type I.

SMA is the leading genetic cause of death of infants. It is a disorder that results from a chronic deficiency in the production of the SMN protein, which is essential to the proper functioning of the motor neurons in the spinal cord. SMA is typically marked by the deterioration of the muscles that control crawling, walking, swallowing and breathing. Approximately 1 in every 6,000 babies born is affected. 1 in 40 people, or approximately 7.5 million people in the U.S., are genetic carriers. SMA Type I, the most severe form of the disease, progresses very rapidly and is often fatal in the affected infants. To date, there are no treatments for this disease.

CSC, a leading stem cell therapeutics company, has developed a stem cell-derived motor neuron transplantation therapy, MotorGraftTM, for the treatment of SMA Type I. Pre-clinical studies completed in collaboration with the Hans Keirstead Research Group at the University of California, Irvine have shown functional benefit and safety in animal models. CSC’s MotorGraftTM was granted orphan drug status for treatment of SMA by the FDA in late 2009.

Filing of this application is the first step in a multi-phase clinical development pathway aimed ultimately at approval of a novel therapy. The approval process for cutting-edge therapeutic approaches such as cell products may present unique regulatory challenges compared to conventional drugs, so companies and the FDA must work in close partnership to ensure safety and efficacy of these first in-human products. A cautious regulatory approach has been the norm in cell therapy applications submitted to date in other disease areas.

The proposed trial is to study the safety of MotorGraftTM and the surgical procedure required to deliver these cells directly into the spinal cords of patients with SMA Type I and will enroll a very limited number of patients.

The response by the FDA was to place the proposed MotorGraftTM trial on clinical hold. A clinical hold is an order that the FDA issues to a sponsor to delay a proposed trial. Clinical holds are not uncommon, especially in cases of novel treatments such as this one. Similar holds were issued by the FDA to each of the previous applications for pluripotent stem cell therapeutics, such as those submitted by NeuralStem (ALS trial), Geron Corporation (spinal cord injury trial) and Advanced Cell Technology (macular degeneration trial), and all have since been lifted and advanced to clinical trials.

The FDA completed a thorough review of the entire IND application and provided CSC with comments, questions and recommendations. Specifically, they have requested the completion of an additional species animal study to further ensure safety, and completion of ongoing SMA animal studies to provide more data on the link between neuronal sparing and functional benefits. CSC believes it can provide this information in an expeditious manner and will work closely with the FDA to facilitate review of the additional information and to release the clinical hold.

About California Stem Cell, Inc.:
California Stem Cell, Inc is a privately held company focused on the manufacture of high-purity human cells for therapeutic development and screening applications. Since its founding in 2005, CSC has developed and has intellectual property surrounding methods for scalable production of human motor neurons, neuronal progenitors, cardiac cells and liver cells at its Irvine, California facility. CSC is currently developing stem cell-derived therapies for Spinal Muscular Atrophy (SMA), Amyotrophic Lateral Sclerosis (ALS) and spinal cord injury.

Website:
http://californiastemcell.com
Families of SMA is pleased to announce that we have added three new members to our Scientific Advisory Board. They include Rashmi Kothary, Ph.D. of the Ottawa Hospital Research Institute, Samuel Pfaff, Ph.D. of the Salk Institute of Biological Studies, and Mark Rich, M.D., Ph.D. of Wright State University.

Rashmi Kothary, Ph.D.

Dr. Kothary is an Associate Director and Senior Scientist at the Ottawa Hospital Research Institute and a Professor at the University of Ottawa. Dr. Kothary works on understanding the importance of the cytoskeleton in neuromuscular disorders such as SMA. Dr. Kothary has a keen interest in modeling disease pathology in mice and has developed an intermediate mouse model of SMA. He also holds the University Health Research Chair in Neuromuscular Disorders.

Samuel Pfaff, Ph.D.

Dr Pfaff is an Investigator of the Howard Hughes Medical Institute and Professor at the Gene Expression Laboratory at the Salk Institute for Biological Studies in La Jolla, California. The Pfaff laboratory focuses on the development of motor neurons. Of special interest to him is how motor neurons form and make connections between the spinal cord and muscles in the body, and how these connections relate to spinal cord injuries and to degenerative diseases such as ALS, SMA and post-polio syndrome. In 2009, his group at the Salk Institute was awarded a $11.5 million grant by the California Institute for Regenerative Medicine (CIRM) for translational research focusing on developing a novel stem-cell based therapy for Amyotrophic Lateral Sclerosis (ALS).

Mark Rich, M.D., Ph.D.

Dr. Rich is an Associate Professor in the Department of Neuroscience, Cell Biology, and Physiology at Wright State University. He completed a medical fellowship in neuromuscular disease and spends about 10% of his time with neuromuscular patients in clinic. His research laboratory specializes on synapse physiology at the neuromuscular junction in mice.

The SAB performs two main functions at FSMA. First, SAB assesses all research grant applications to ensure that we fund only the best research. FSMA has been funding basic research since our inception in 1984 and has invested over $25 million in this area, as well as another $25 million in clinical and drug discovery research. Specifically, our basic research grant program has funded 140 projects at 70 institutions around the world.

The second function of the SAB is to organize the scientific content of the Annual SMA Research Group Meeting. This is the largest SMA focused scientific conference worldwide, which included over 100 scientific presentations in 2010.

The SAB plays a key role in developing the FSMA research strategy. Continued investment in basic research, leading to a greater understanding of the exact nature, causes and consequences of SMA, is key to ensuring the most effective SMA treatments can be identified and developed as quickly as possible.

Over the last 25 years FSMA basic research funding has contributed to many critical SMA breakthroughs, including the following:

- Mapping and cloning of the SMA gene, SMN1
- Identification of the SMN protein and its roles in the cell
- Discovery of the back-up SMA gene, SMN2 that provides a unique and straightforward approach to developing a treatment
- Development of animal models to better understand SMA disease pathology and to test SMA drug candidates
- Determination that HDAC inhibitors can enhance SMN2 gene expression
- Identification of the nucleic acid sequence being used to correct SMN2 splicing by ISIS Pharmaceuticals

Families of SMA sincerely thanks Drs. Mark Gurney, Steve Strittmatter, Louise Simard and Christopher Spancake, all of whom recently retired from our SAB after at least five years of service. We very much appreciate the time, expertise, and dedication that each donated to FSMA and our mission.
Turning Pop-Up Pages for Cecilia
On each lettered page from alligator to zebra a flap uncovers
behind green grass, or bush, or tree a jungle creature that sometimes wins her twinkle of recognition, her ghost of a grin.

Prone on that high hospital bed she lies and listens and stares and waits for revelation on each propped page.

None but the giraffe whose arching neck and nibbling mouth can reach the tallest leaves will earn her wide and crooked smile.

Previously published in The Litchfield Review.

First Sonnet for Cianan
When life becomes a synonym for year, what words can hold an infant for all time? Will our next generations ever hear of how he loved to laugh at silly rhymes, at books like Jamberry, Pooh, and Brown Bear? The way balloons above his bed beguiled him, or how bubbles, translucent spheres ephemeral as hope, would win his smile? And when his cousins, older now than he will ever be, ask why he had to die, what answer but that faith and memory surround a loss, though neither satisfies. In just a year, swift as a falling star, his life would pass, a radiant meteor.

Previously published in The Litchfield Review.

These poems are from Shelia Murphy’s View From a Kayak in Autumn, chapbook, in memory of her grandchildren, Cecilia and Cianian Murphy. All proceeds from the chapbook are going directly to Families of SMA. Please visit http://www.fsma.org/Fundraising/Merchandise/ to purchase your copy!

Dear FSMA,
Please find enclosed a check for $550.
When my husband, Gordy Wuethrich, passed away suddenly from a heart attack on December 13th, I knew right away he would want memorial donations to go to FSMA. Our daughter, Michele, was age 11 when she passed from SMA. I am comforted to know her Daddy is in Heaven with his SMA angel now.

Thank You,
Deb Wuethrich
IN MEMORIAM

Jeremiah Hinkle
July 18, 2010 – November 1, 2010

Our sweet baby Jeremiah was born four weeks early on July 18, 2010. Six weeks after Jeremiah’s birth, he became floppy and began belly breathing. We took him to his pediatricians office, they then sent us to the ER. At the ER it was determined that Jeremiah would need to go to UNC Children’s hospital for further testing. There were so many possible diagnoses that were causing Jeremiah to be floppy and having to be put on a ventilator. As the first week passed, we still had not been given a definite diagnosis; it had been such a rollercoaster ride. It wasn’t until the third week of him being in the PICU that SMA was brought up. Our hearts were crushed when we learned that he had all the signs of SMA Type I. By the fourth week the test results were in and it was in fact positive for SMA.

We had contacted Families of SMA and you all were wonderful to send out information packets and a care package for us. We had never heard of SMA until Jeremiah was diagnosed. After Jeremiah spent 37 days in the PICU we brought him home under hospice care. Throughout all of this Jeremiah continued to be very bright eyed and could even hold a conversation with his eyes. His big brother Noah was ecstatic to have his little brother home. We were able to spend two wonderful weeks home with Jeremiah. On November 1, 2010, Jeremiah earned his angel wings. We have been told many times that Jeremiah has touched more lives than we will ever know.

Nathalie and JR Hinkle of Spring Lake, NC

IN MEMORIAM

Maggie Grace Lagana
October 7, 2009 – February 3, 2010

IN MEMORIAM

Jonas Mathie Coleman
December 02, 2007 – November 18, 2010

IN MEMORIAM

Rebeckah Marie Courdt
March 5, 2007 – November 14, 2010
“Little Angels”

When God calls little children
to dwell with Him above,
we mortals sometimes question
the wisdom of His love.
For no heartache compares with
the death of one small child
who does so much to make our world
seem wonderful and mild.
Perhaps God tired of calling the aged to His fold,
so He picks a rosebud before it can grow old.
God knows how much we need them,
and so He takes but few
to make the land of Heaven
more beautiful to view.
Believing this is difficult
still somehow we must try:
the saddest word mankind knows
will always be “Goodbye.”
So when a little child departs,
we who are left behind
must realized God loves children-
Angels are hard to find.

Baby Wyatt joined the angels, but
left us with so many cherished
memories. From the “Good
morning, Mommy” smile he
flashed from his crib at 5:00am,
to his nighttime ritual of falling
asleep with one hand on Daddy’s
shoulder, our sweet Wyatt
brightened our lives with his
love. Nobody looked cuter
covered in sweet potatoes or all
suds up in the tub talking smack
to “that baby in the mirror.” In
his short life, Wyatt did many things. He played with a
penguin, pet a giraffe, rode a horse, cruised on a four-wheeler,
read several books, sat on Santa’s lap and painted hand-print
turkeys. We picture Wyatt as happy- if not happier- in heaven
than he was on his cherished changing table. We’ll remember
his sneaky sly little grin and his tasty chubby chins as we hold
on to his spirit forever.

Love,
Paula Lavigne and Chris Arnold of Omaha, NE

Haley Mitchell made a lasting impression on everyone she came in contact
with. While her physical challenges were overwhelming, her positive attitude
and spirit more than compensated for them. She touched many hearts in her
short life with her unmistakable lessons of patience, tolerance and happiness
under adverse circumstances. She left the children of our community with the
ability to look past one’s disabilities to see the beauty within.

We will treasure the wonderful memories that we made with Haley. We are
proud to be her parents and sister and to have observed the impact and inspira-
tion she provided to others. We are humbled by the care and compassion
offered from our friends and community and consider it a reflection of the love
that Haley shared with us all.

Thank you for your expression of sympathy after the loss of our beautiful
Haley.

Jeff, Val and Kelsie Mitchell of Elizabeth City, NC
“Calling All Angels”

The heaven appear so much brighter tonight
As another sweet angel has just taken flight
Leaving behind many hearts that won’t heal
And a mother who’s pain and sorrow we feel.
Calling all angels, come hear this plea
Please guide this child into eternity.
When a hero falls, it affects us all
In ways we can’t explain.
The hopes, the dreams, what the future brings
Is challenged once again.
Calling all angels, please calm my fear
Help me understand why he’s no longer here.
To live this life is no easy task
Our beliefs are queried, why we ask,
Does God need so many angels to be at His side?
Leaving family and friends on an emotional ride.
Calling all angels, please help to heal
A heart that is broken, a faith I can’t feel.
How do I tell the child I love
That another friend is in heaven above?
I choke down the sobs, my eyes fill with tears
As I do my best to abolish his fears.
Calling all angels, please help him to see
That children are dancing and running free.
We get through the day the best that we can.
Knowing that this will happen again.
We hope, we pray, we just wait to learn
A cure has been found, for which we all yearn.
Calling all angels, allow us to dream
Of ending the pain this disease can redeem.
(Excerpt from an SMA child’s CaringBridge website)
We love you Angel Trevor.
Sarah Broton of Fort Ripley, MN

IN MEMORIAM
Trevor James Broton
November 27, 2007 – January 12, 2011

IN MEMORIAM
Mackinley Hardison
January 31, 2009 – November 24, 2010

Mackinley’s life was much too short; yet he touched so many lives in his brief stay with us here on earth. He taught his loved ones to focus on the important things in life, to live life to the fullest no matter our circumstances, and to believe in miracles. Mackinley has his miracles in heaven. We pray that a cure will be found for this devastating disease. Thank you FSMA for your support and guidance.

Mackinley’s Family of Clinton, NC

IN MEMORIAM
Andy Butler
January 8, 2009 – June 4, 2009

January 8, 2011, marked angel Andy Butler’s second birthday in heaven. On that special day, our family gathered at Andy’s resting place, where we released 24 balloons - one for every month since he was born. Each balloon had a special message written on it from a member of the family - Mommy, Daddy, his little sister Lucy, his grandparents, aunts, uncles and cousins. We will continue to celebrate his life, remember all of the joy he brought to ours and keep his legacy alive in our hearts.

We love you always, Andy.
Love,
Mommy, Daddy and Lucy Butler of Land O’ Lakes, FL
Reece Miller Elliott was born July 20, 2010, which was also his sister Daisy’s 3rd Birthday. He was born 9 pounds 2 ounces and looked so perfect and strong. In the first few minutes of his life our little dream was shattered as the doctor immediately knew all was not well. We never imagined what tragic fate lay ahead for him.

Reece was only with us for seven short weeks, but he touched everyone’s hearts that had the privilege to meet him each second with love and strength. Although he was limited in his movements he made up for it with his big blue eyes. At first we prayed things would be OK. None of the doctors were sure what was wrong, but the one thing people kept mentioning was “SMA- Spinal Muscular Atrophy.” It meant nothing to me, but after a week in the hospital I came home for the night and read up on this condition on the Internet. My heart broke; deep down I think I knew that night that this was what he had, even though I prayed and prayed it wasn’t. On August 12th our worst fears were confirmed when Reece was diagnosed with Spinal Muscular Atrophy Type I, a disease that I had never heard of. All of our tears, prayers and hopes were not answered and the awful truth of his illness hit me like a ton of bricks, however, we knew we still needed to be strong for him.

Most of Reece’s short life was spent in hospitals, at first Belleville General and then Sick Kids in Toronto, where he was diagnosed. While in the hospital Reece had an MRI which really knocked his energy, and we were then asked to make the heartbreaking decisions on what we would do to keep Reece alive. I never imagined having to make such a decision on whether to keep my baby alive or help him to die. We decided that he was suffering enough and that whatever we did he would die anyway before he was two, and that all he was feeling was pain, so we decided not to resuscitate him or prolong his life.

We had Reece at home for two weeks before he started to deteriorate. He was struggling with his breathing and again he had pneumonia on his lungs. He was also sweating a lot, and beginning to look grey, which was a sign that his body was struggling. He was admitted back into the hospital for three days; he stopped breathing twice and we assisted him with his breathing and then decided enough was enough, even though we thought we would have him longer than we did, he was just so weak. On Tuesday night again he started to struggle to breathe, only this time when we were ready for the end he suddenly picked up and his face became full of color. We decided that he was struggling every time he ate so we stopped his feeds and gave him water to keep him comfortable. He was also on medication to keep him out of pain. The next morning his sister, Daisy, came to see him before she went to daycare and he opened his eyes as soon as he heard her voice and as weak as he was, he gave her a little smile and fell back to sleep. That morning at 11am he fell asleep in his mommmy’s arms, peacefully just like any baby would; it’s just he never woke back up. He looked so peaceful and out of pain.

In his short time Reece developed a very strong love for his sister. His eyes would light up when he would see her in the mornings and he would watch her so proudly playing. She would help bathe him, help change him and she was so proud to be his big sister. Reece was named after his sister’s love of Reese Pieces and it is so cruel the bond between them that was not allowed to develop on Earth. Reece left Daisy a pair of Angel wings and when she is sad she wears them and can be close to our angel.

There must be some purpose in why our baby was taken so fast, but we were lucky to have enjoyed some time with him and were able to take him home. The name means “Runner” and this is something he could never do on Earths, so hopefully he is running free in Heaven. This is why I have set out to raise money for CURESMA by organizing a local run in Belleville, Ontario in July and also running the Toronto Waterfront Marathon.

I have felt every emotion possible the last few months: anger, sadness, jealousy, but most of all blessed, that we were touched by this angel who was sent to us by God to bud on Earth, only to bloom in Heaven.

He was such a beautiful happy baby, and even though I was robbed of my baby, Heaven gained an angel. I know my mom is in heaven looking after Reece until we meet again. He is in peace and feels no pain anymore, which was our main wish for him. He passed quickly and peacefully in my arms and his spirit will always remain with me and a part of my heart went with him.

By: Mom, Karen Walsh of Ontario, Canada
“A Beautiful Life”
A beautiful life that came to an end, she died as she lived, everyone’s friend. In our hearts a memory will always be kept, of one we loved, and will never forget.

Love,
Joanna McLaughlin, proud mom of Angel Isabella, SMA Type I of Norwalk, CT

LUKIE’S LOVE
A little angel baby graced our lives for a short time, but our hearts forever. His big brown eyes entranced you; his smile melted your heart. His light coos an angels whisper, his body weak from his disease, but his spirit strong with love. This little man taught many people, lessons about love, strength and compassion. Lukie enjoyed the little things in life: his binkie, his red baseball hat, Mickey Mouse and a good meal. He loved to sit in his bouncy chair and watch his big sister, Kadyne, play with his cousins or hold his hand out to touch a cat walking past. He loved to be cuddled and held by mom and dad, and dad even taught him karate moves. Not a day goes by that we don’t think about our “Baby Boy”. Sometimes it feels like it was only yesterday he was here with us. Luke is our Special Guardian Angel who watches over us from Heaven. We know he is with us, “Forever in our Hearts.”

Joseph and Tara Maida of Roseto, PA

IN MEMORIAM
Isabella Nicole Kurek
December 26, 2003 – October 13, 2010

IN MEMORIAM
Isabella Nicole Kurek
December 26, 2003 – October 13, 2010

IN MEMORIAM
Luke Anthony Joseph Maida
“Lukie”
June 12, 2000 – December 8, 2000

IN MEMORIAM
Coby Kulis
September 22, 2010 - February 27, 2011
FSMA:
I really wanted to do something extraordinary to help raise awareness of SMA. I have done some investigating and I would love to share anything about SMA and how you can donate to help on any news site. I then figure at least some people will gain awareness. I would hope a larger news network would pick up on the concept of SMA families sharing their stories and what SMA is.

I too have lost my sister, Emily, to SMA, and it’s the only thing that you can do to help fight it. The chances are slim but I have hope; I would love to honor my sister and all the other innocent children fighting SMA, and how they touch us all.

This has probably been submitted to you many times before, but I am determined we can do something and get someone’s attention because so many have no clue what the #1 genetic killer of babies even is. We need to do something.

Thank you for your time,
Sarah Coddington, age 13, of Uniontown, PA

Below is a paper Sarah wrote for her school:

There are four things in life you can never get back…the stone, once it’s thrown; the word, once it’s said; the occasion, once it’s missed; and the time, once it’s gone. And we all know that the time Emily was here with all of us was special and touched all of us. She had something special that no one else could ever come close to, which is why we all had that one special time with her, whether it was holding her for the first time, seeing her smile, or just spending time with her.

When she was born we all knew she was special, not like any other baby. We loved her even before she was born, but the first time we saw her it was obvious she belonged, an angel sent to Earth.

When she was diagnosed with SMA it shook us all, and never seemed to stop shaking us. But as time went on, Emily taught us one of the most important lessons in life, to live every day to the fullest and do not focus on the future because you cannot, no matter how hard you try, plan the future.

Her ear to ear, toothless smile could light up a whole room in seconds. Brightening up your day was her specialty. No matter what kind of day you were having, as soon as you walked into that room where she was playing and she looked up and flashed you a grin, your day instantly got better. Her giggle would make you laugh along with her, as you shared a precious moment with her.

Though she often got colds and was sick, she never seemed to let it bring her down or anything else in that matter, which is something we all can learn from. She visited the hospital many times over sickness but she just thought of it as a new place to play. It wasn’t fun being sick but she still fought through it and made the best of every single day.

Her little body, so perfect and little, made you wonder how something so small could touch so many people. Her blonde hair is still a mystery to us, but it fit her in a way. Her hands so small, and also stinky, which is what brought on one of her nicknames, Cheese Hands, which even she giggled about. Her nose, orange at times, but still so perfect. Emily had the chubbiest cheeks you would ever see, you just wanted to squeeze them. She had hair that only parted one way all the time and it stuck up all the time, so she was given another nickname, Jimmy Neutron. Her body was perfect in every detail right down to her long eyelashes, and tiny fingernails.

She often enjoyed her yellow balloon, her pinwheel, her animal wheel and anything or anybody else she could play with.

She slept by mommy’s side every night, feeling safe and comforted there. Anytime she went to sleep or took a nap...
her little hand always wound up planted right on your nose. It was her way of knowing you were always right beside her.

Emily possessed a power greater than any other, the key to happiness and a heart full of love. She knew the love that all of us felt for her. She was very blessed to have so many people love and appreciate her. But she, not being the only one blessed, the ones who really were truly blessed, the ones who really were truly blessed to enjoy such a wonderful perfect little girl, was us. She was truly an angel, alive on earth and sent to be loved and filled with hope.

There is no doubt our little angel is in heaven now, crawling and walking, discovering her new feet and looking down smiling upon all of us. She is free of suffering and can now not only walk, but fly.

Love, Sissy, Sarah
February 28, 2010

“My First Christmas In Heaven”
I see the countless Christmas trees around the world below
With tiny lights, like Heaven’s stars, reflecting on the snow
The sight is so spectacular, please wipe away the tear
For I am spending Christmas with Jesus Christ this year.

I hear the many Christmas songs that people hold so dear
I hear the many Christmas songs that people hold so dear
But the sounds of music can’t compare with the Christmas choir up here.

I have no words to tell you, the joy their voices bring,
For it is beyond description, to hear the angels sing.
I know how much you miss me, I see the pain inside your heart
But I am not so far away, We really aren’t apart.
So be happy for me, dear ones, You know I hold you dear.
And be glad I’m spending Christmas with Jesus Christ this year.

I sent you each a special gift, from my heavenly home above.
I sent you each a memory of my undying love.
After all, love is a gift more precious than pure gold.
It was always most important in the stories Jesus told.

Please love and keep each other, as my Father said to do.
For I can’t count the blessing or love he has for each of you.
So have a Merry Christmas and wipe away that tear.
Remember, I am spending Christmas with Jesus Christ this year.

Love, Sissy, Sarah
February 28, 2010

IN MEMORIAM
Jacob Slaymaker
June 29, 2003 – December 18, 2010

IN MEMORIAM
Jaelynn M. Martins
January 22, 2008 - June 9, 2009

IN MEMORIAM
Kevin James Lintz
July 26, 2010 - December 21, 2010
Dear FSMa,

I am an eighty-three year old widow. I’ve been a widow for twenty-four years; I had a very devoted husband who died of a very fatal cancer in February of 1987.

God in his love gave us four babies who died. They were victims of SMA. Our first baby boy was born in February of 1948 in Augustana Hospital in Chicago. He lived three months and died at Children’s Memorial Hospital in Chicago. I was twenty years old and George was twenty-two. I had never been to a funeral before, but we had friends that helped us lots. His name was George Henry, Jr.

God gave us a daughter in March of 1949 and she currently lives in South Washington. Our third child, Ruth Margaret was born in January of 1951 and lived until August 1951 where she passed away at home. My sister, who was a nurse, lived with us and helped us care for her. We took her to Billings Hospital in Chicago for an evaluation. I nursed all of our SMA babies until they lost their sucking ability; after that, we fed them ourselves.

We were then blessed with four healthy babies in 1952, 1954, 1956 and 1958.

In November of 1962, our Deborah Joyce was born at Elmhurst Hospital. She lived six months and passed away at Elmhurst Hospital. In 1964, our Elizabeth Joy was born in Elmhurst Hospital and lived eighteen months and passed away at home.

Our four SMA babies were very loved and cared for. They were very bright and smiled a lot. We did feel alone a lot because most people I believe didn’t even want to see them. George and I are Christians and depended on that to help us with all of our babies. Our family will never forget them. God gave them to us and in his time chose to take them to Heaven. I’m sure my family is stronger and more compassionate because we were blessed with our babies here, and now in Heaven. He doesn’t make mistakes.

It would be so wonderful if there was a cure for SMA.

Mary A. Enders of Melrose Park, IL

PS. I have 21 grandchildren all healthy and 22 great-grand children.
LOVING memories

IN MEMORIAM

GRAYSON MICHAEL COATES
June 16, 2010 - September 4, 2010

IN MEMORIAM

SOPHIE FREDERICK
August 16, 2010 - October 24, 2010

IN MEMORIAM

NAOMI VIRGINIA
November 20, 2008 - March 4, 2009

IN MEMORIAM

ISAAC JACOB WALTERS
July 18, 2010 - December 28, 2010

IN MEMORIAM

ANNE GRIMES
October 13, 2009 - August 6, 2010

IN MEMORIAM

GRAYSON MICHAEL COATES
June 16, 2010 - September 4, 2010

IN MEMORIAM

Hu Zi

IN MEMORIAM

VANESSA LLENE VASQUEZ
June 8, 2010 – December 1, 2010

IN MEMORIAM

DESMOND LUKENBACH
May 19, 2010 – December 8, 2010
The Turnbull kids

Sydney Utzat

Allegra Johnson Keys

William, Matthew and Abby Johnson

Danielle Pruitt

Reagan Imhoff

Brett Kingsley

Courtney Rosas

Liadan and Keenan Conner-Park

Murphy and Anders Potter

Briahnna Johnson

The Abraldees

Mikey, Hope and Noelle Hazel

Angel Faye Young

Colin and Casey O’Neil

Lizzy Hallam

Wyatt and Jack Tranby

Braelyn and Tambryn Campbell

www.curesma.org
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.

The Genetics of Spinal Muscular Atrophy
Confused about genes, proteins, DNA and how SMA is diagnosed?

Read this helpful pamphlet. It includes definitions, explanations and diagrams from genetics expert Louise Simard, Ph.D. and the FSMA Medical Advisory Council.

Patient Services & Family Support
This booklet has details on the following Families of SMA programs:
1) Programs For Newly Diagnosed Families:
   • Including our special Type I programs such as: Care Packages; Sheep Skin Blankets; Radio Flyer Wagons; Dinners; and Home Support.
2) Families of SMA Equipment Pool.
3) Medical Care.
   • Including the “Ask the Expert” Service.
4) Daily Living.
5) Local Support.
6) How to Keep up to Date.
7) The Annual SMA Conference:
   • Including the FSMA Newly Diagnosed Conference Program.

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?

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.

Two New Care Series Publications Coming Soon!
The Families of SMA Medical Advisory Council (MAC) 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.
New Event Website Upgrades

Quick and Easy Way to Invite Donors
- Families of SMA has recently added a feature to our event websites which allows you to upload e-mail contacts directly from your address book (Gmail, Outlook, Yahoo!, and a number of other programs are supported). Thanks to this brand new feature, it takes just a few minutes to share your story with all of your friends and family, when fundraising with a Gift Registry Page, or for an event on our events Calendar.

Use Social Media to Share Your Page
- In the top right corner of your personal fundraising page, click on these buttons to post a link to your page on Facebook, Twitter or other social networking sites. This is another fast, easy way to share your story with friends and family members, and to ask them to support your efforts to raise money for a cure for SMA.

Also New This Year
- Gifts made to an event or to a personal fundraising page can now be made in honor or memory of a loved one.
- An easy drop-down list is available as a search method to find the teams registered for an event.
- Event scrolling boxes now list both names associated with a donation, when applicable.
- Donors can mark their contributions as “Anonymous” and remain anonymous on all event pages and personal fundraising pages throughout the website.
- Participants are able to post their offline cash and check donations to appear online in their personal, team and event totals, to showcase their fundraising success.

Fundraise Online with a Personalized Gift Registry Page

Families of SMA wants to help you raise funds for Spinal Muscular Atrophy as easily and effectively as possible. Because of this, on the Families of SMA website, in addition to our events calendar, we offer the capability to start your own personal Gift Registry Webpage. Gift Registries are a great way to set up an individual fundraising page that is not connected to a larger fundraising event. For example, if you were to create a Birthday Gift Registry, instead of family and friends buying you birthday presents, they can make a donation to support the mission of Families of SMA. This is the best way to get the people close to you involved in helping to develop a treatment and cure for SMA!

Gift Registries help to facilitate your own individual fundraising efforts, while allowing you to add a personal touch with words and photos. Setting up a registry takes only a few minutes. To find out how, please visit www.curesma.org/Fundraising/GiftRegistries. To see some of the successful gift registries that have been created over the last few months, please visit the Fundraising Stars section of this newsletter!
Promotional Materials from Families of SMA
Make Planning a Fundraiser Easy and Fun

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
- Families of SMA “Results & Progress” flyer
- New FSMA Bracelets
- Donation tags
- Plastic event bags
- Donation Cards
- Promotional Tips
  - Balloons
  - Purple & Orange Golf Tees
  - Tattoos
  - Magnets
  - Coin Canisters
  - And more!

Are you interested in hosting a fundraiser? Families of SMA has manuals, sample booklets and dedicated staff to help you through the entire planning process. Please feel free to contact us anytime at fundraising@fsma.org to get started today!

Event Website Updates

- Customized Banner
- Widget & Video Integration
- Progress Bar & Amount Raised
- Scrolling Lists Showing Donors and Fundraisers
- Register & Donate Buttons

In Honor/Memory of ________________________
Donated by ________________________
Help find a cure for Spinal Muscular Atrophy
www.curesma.org

Families of SMA
www.curesma.org
800-886-1762

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I want to make a donation in the amount of $ __________

Donor Name

Donor Address

Donation made in honor/memory of ________________________________

Notice of Donation–Name & Relationship to affected individual ________________________________

Notice of Donation–Address ________________________________

Payment Method

☐ Check ☐ Money Order
☐ VISA ☐ Mastercard ☐ Discover
☐ American Express

Credit Card # _______________________________________

Expiration Date & 3 or 4 digit Security Code ____________________________

Name on card _______________________________________

Signature _______________________________________

Return form to FSMA Donations, 925 Busse Road, Elk Grove Village, IL 60007 or FAX to 847.367.7623
Malukos spent time as kids. In 1996, a new and deeper passion went into the event when one of our best friend’s son, Tyler Hernandez, was diagnosed with Spinal Muscular Atrophy, the number one genetic killer of children under the age of two. We learned that there are some 20,000 children in the U.S. with SMA today and most of them will not see their second birthday. The Malukos changed the beneficiary to FSM to help children like Tyler. We truly care about winning this battle and it is our desire to make a “small” impact by raising money in a fun way for research in development of a cure.

The Maluko’s have held 18 Golf Tournaments in the past 20 years. The last 12 for SMA have raised between $20,000 and $30,000 per event. This year we exceeded $30,000 in a tough economy, reaching $36,790.

Tyler is a freshman at Tampa Jesuit High School and is one smart kid. Carlos Menendez, Tyler’s Godfather and I love watching him roam the tournament talking to the players that attend. Tyler’s positive attitude, great sense of humor and kind heart is the true inspiration behind the Maluko’s.

We are humbled that we can make a small difference.

Thank you,
Chris Leto and Carlos Menendez, Event Organizers
Tampa, FL

Please Note: The amounts raised and shown on the following pages are totals as of March 1, 2011, and may differ from current fundraising totals by the time you receive this newsletter.
Savannah Sue Norton was diagnosed with SMA Type I in June of 2010. Since then, friends and family members of Paul and Sheree Norton, Savannah’s parents, have held multiple fundraisers in her honor. The fundraisers have all been extremely successful and a total of $28,113 has been raised for Families of SMA, in Savannah’s honor.

On November 7, 2010, Emily Scoville, Savannah’s cousin, organized a benefit called All You Need is Love at the Dallas, Texas House of Blues. The night included dance, live music, live art, celebrity appearances, face painting and a silent auction. Comedian Justin Foster was the host for the evening, and all of the arts were brought together with music from all genres along with some extremely talented dance performances. Altogether, the benefit raised $15,662 for FSMA!

On Saturday, November 20, 2010 a booth was set up for a cure for SMA, benefiting Savannah Smiles-Savannah Sue Norton. The booth was at Bonnie Holland Elementary School in Katy, Texas where Savannah Norton’s brother, Blake, attends 5th grade. There has been so much support from BHE and the families that live in the same community as Savannah’s family, Seven Meadows. Brooke Lamb, a 3rd grader at BHE, came up with the idea of Mani-CURES for Savannah Sue. She and lots of friends painted nails and raised money to find a cure for SMA.

Meridith Struble, a close friend of Paul and Sheree, helped get a group of runners together to create the Savannah Smiles team at the USA FIT Marathon in Sugar Land, Texas on January 16, 2011. Together, the team raised $12,072 for Families of SMA, and ran for Savannah “turning miles into smiles”. In addition, Lori Needham started a gift registry page on curesma.org to raise funds for the Marathon as well. She was able to raise a total of $379 for the event, bringing the total to $12,451.

About four years ago, Kyra Scadden began collecting pennies in an effort to raise money to help find a cure for her friend Angie Lee’s disease, Spinal Muscular Atrophy. In 2006, the fundraising efforts turned into an annual Garage Sale event, drawing thousands of dollars. This year’s Garage Sale for a Cure was held in Naperville, Illinois on September 25, 2010. The goal for this year was $14,000, and they were able to surpass that goal by raising $20,200!

Most second graders would be intimidated by a girl in a wheelchair, but when they met, Angie made Kyra feel comfortable enough to approach her and explain her disease. The girls’ friendship also quickly led to another between their moms, Kris Scadden and Kim Lee. The girls are now in middle school, and their friendship is stronger than ever. A large group of kids went to the Hilltopper dance recently at Hill Middle School, and they all wore the fundraiser t-shirt that reads, “Kyra’s Idea, Angie’s Hope”. They all danced as a group with Angie in the middle.

Kris and Kim began conversations regarding this year’s Garage Sale back in February 2010. Kim says that her favorite part of the sale is not the money raised, but the encouragement they are able to provide to other families with children who have SMA. Many of those families now come to the Garage Sale to see how Angie is thriving, and gain personal hope for their own children.

Kris and Kim shed tears of happiness and appreciation for all the support they have received to make the garage sale successful. One neighbor, Martha Baker, provided the connection for an amazing rock concert right on Amble-side Circle in Naperville, Illinois. Mr.
Andrea Nelson Meigs of Los Angeles, California, started a gift registry page on curesma.org in memory of her daughter, Alexandra Meigs. The registry was set up to remember Alexandra’s 3rd birthday, which would’ve been on October 24, 2010. Through the registry page, Andrea raised $14,240 in Alexandra’s memory.

Savanna’s Rush for a Cure was held on October 16, 2010, and raised a total of $10,619 for Families of SMA. This Walk-n-Roll is organized annually by Mindy and Tim Rush, in honor of their daughter Savanna, in Saginaw, Texas.

On February 1, 2006, we welcomed a bouncing 8 lb. 4 oz. baby boy named Joseph Blaine into our family. We were on top of the world. Little did we know that just eight short weeks later our happy world would come crashing down around us. When Joseph was just about two months old we noticed that something did not seem quite right. We were referred to one of the leading children’s hospitals in the nation, Duke University, to have a neurological consult. Before we could even make that appointment we found ourselves sitting in the emergency department because Joseph had developed pneumonia. In less than 24 hours we had the devastating news that Joseph had Type I SMA or Werdnig-Hoffman’s Disease. What a whirlwind our lives turned into in the days to come. We went from having a perfect baby to a terminally ill one. Even though we found ourselves with a lot of questions we were fortunate to have a wonderful resource in the staff at Duke that helped us to learn about SMA and we were welcomed to Families of SMA with open arms. The care packages and information that came in the days after Joseph’s diagnosis helped us to better understand SMA as a disease and how to cope with having a sick child. For the next three months we were able to have few hospital visits and were able to keep Joseph at home as much as we could. Our little boy got his wings on July 1, 2006 at the age of 5 months.

After Joseph passed away we thought long and hard about a way to keep his memory alive and to help the two organizations that were such a great resource to us in our time of need. The First Annual LittleMan Memorial “Shoot the Links for a Cure” Golf Tournament was held in June of 2008. The first tournament consisted of 18 four-man teams and a silent auction. Over $12,000 was raised at our event. The proceeds from the tournament were divided among Duke Children’s Hospital and Families of SMA.

The 2nd Annual LittleMan Memorial Golf Tournament was held on June 20, 2009. We were excited that the tournament had grown to twenty two teams in only our second year! The Friday night before the tournament we held a cornhole tournament at the golf course to help kick off the weekend’s activities. We were excited to be raising money yet again for two wonderful organizations. Little did we know that we would be in need of one of them once again. Our daughter Haley, who was born in 2007 at Duke, was accidentally run over by a golf-cart that Friday night. We found ourselves sitting in the emergency department at Duke again with one of our children. Haley suffered a fractured skull and had many bumps and bruises. We missed the golf tournament but were happy to hear that it was again a success. We raised over $10,000 for FSMA and Duke Children’s Hospital. Haley was released from the hospital that Sunday with follow-up visits to the Children’s Hospital for the next few months. She is now a happy, healthy three and a half year old that is full of energy.

The 3rd Annual LittleMan Memorial Golf Tournament was held on June 19, 2010 in Macon, North Carolina, and to date was our most successful one. Just over $16,000 was raised, with $7,805 going to Families of SMA. The weekend activities included a dinner for our sponsors and players followed by a live auction. The live auction was a hit with items donated from various celebrities and athletes. The tournament was at full capacity with twenty four teams. One of Joseph’s doctors, Dr. Jeremy Baker, flew in from Texas to participate in the tournament.

Please Note: The amounts raised and shown on the following pages are totals as of March 1, 2011, and may differ from current fundraising totals by the time you receive this newsletter.
The 4th Annual Little Man Memorial Golf Tournament will be held on June 17 and 18. Activities for Friday night will include a dinner for sponsors and players followed by a live auction. Saturday’s event will kick off with the first flight teeing off at 8:00 am followed by the second flight at noon. There will be a silent auction as well.

One special item that is included each year at the tournament is a Radio Flyer wagon. Joseph was given a Radio Flyer wagon shortly after his diagnosis through the Tumbleweed’s Wagon Fund for FSMA honoring the memory of Braden (Tumbleweed) Ray Campbell. Joseph loved rides in his wagon. Each year the date of the tournament is painted on the wagon. It is one of the most sought after items at our event.

It is an honor to help raise awareness of SMA and to honor the memory of Joseph by hosting this event each year. We are looking forward to a bigger, better tournament in 2011!

Blaine and Joanne Reese
Macon, NC

The Grimes Family, Eddy, Nicole and Garrett, held multiple fundraisers over the past few months for Families of SMA, in memory of their forever nine month old girl, Annie, SMA Type I, who passed away in August. Read the excerpts below, written by Nicole, Annie’s mother, to find out more about each of their fundraisers. Also, visit the Kids Corner section of this newsletter to read about yet another fundraiser they organized at their son’s school, and other schools in their area, called Hats on 4 Annie. Including the Hats on 4 Annie event, the Grimes family has raised a total of $7,037 for Families of SMA!

All three Zaxby Restaurant locations in Bowling Green, Kentucky participated in Dine 4 Annie on October 21, 2010. Zaxby’s donated 10% of the sales from that night to FSMA in memory of Annie Grimes. Zaxby’s raised $850 from sales and also made a matching donation for a total contribution of $1,300! Thank you Zaxby’s for such a
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1-800-886-1762

FUNDRAISING stars

wonderful event, and for your support! Also, a special thank you goes out to Kathy Barton and Amanda Phelps for organizing and marketing this event for us.

Thirty-two “serious” scrapbooking divas got all dressed up in their pink pj’s and enjoyed a great ice cream party to raise SMA awareness... 4 Annie! Thank you Janet Kay Brown for suggesting this great idea at this year’s retreat! The ladies of the Taylor Christian 6th Annual Ladies Scrapbook Retreat were a huge support and raised $385 for Families of SMA in memory of angel Annie Grimes!

The Celebrate Annie & Raise SMA Awareness Event was held on what would have been Annie’s first birthday, October 13, 2010. Our focus for this event was to celebrate her life and thank those in our community who had shown us so much support during her illness and passing. We did not ask for donations on this day, but did have some generous gifts in her memory. During this event, we did sell t-shirts and bracelets, which are still forth going. Please accept these donations of $300 in Annie’s memory. Thank you for all your support during this time. It was a tough day to face, but remembering her with friends and family made all the difference.

Please find enclosed donations from our sales of www.4AnnieGirl.com bracelets! These hot pink bracelets have been a great way for us to help raise awareness for SMA with 100% of the proceeds benefiting Families of SMA. These bracelets were sold from October 2010 to present and sales still continue today. We are honored to enclose the following proceeds of $884 in memory of Annie! Pictures of the bracelets can be found on the main page of our website.

The 2010 Strike Out SMA Bowl-a-Thon was held in Warren, Michigan on October 9, 2010. Lynsi Welsh organized the event in honor of her daughter, Alyssa Welsh, and raised $5,719 for Families of SMA!

The First Annual Help Landon Hunt for a Cure Walk-n-Roll was held on November 6, 2010 in Timpson, Texas. Debra McLeroy organized the event in honor of Landon Parks. It raised $5,198 for Families of SMA!

The Bingo Breakfast is a charity event that Alexandra Betancur put together to spread awareness about SMA and raise funds for a cure. She has a daughter with SMA Type III, Valeria Valdez, who is no longer able to walk unassisted.

The response of all Alexandra’s friends made it possible to have more than 60 ladies playing bingo for a good cause! The breakfast was held in Sao Paulo, Brazil, in November, and raised $5,000 for Families of SMA.

Brazil Bingo Breakfast

The Grimes Family; Eddy, Nicole and Garrett
Bowling Green, KY

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Dear Families of SMA,

Fourteen years ago my brother, Joshua Michael, was born with SMA. Tragically, Joshua passed away as an infant. Since this time, my family has supported FSMA in raising money for SMA research. As part of my Bat Mitzvah, I encouraged my family and friends to donate money to FSMA in memory of my brother. I also did small projects, such as shoveling snow from driveways, to raise money. Please accept a personal donation of $585 from these efforts and from the gift money that I received from family and friends. Altogether, Families of SMA has received $4,148 from the Bat Mitzvah. I hope that all of these donations bring us closer to a cure so other children won’t have to suffer from SMA.

Sincerely,
Rebecca Gordon, daughter of Dave and Carolyn Gordon
Rockville, MD

Skybrook Golf Course in Huntersville, North Carolina hosted The Rusty Rudder’s 1st Charity Golf Tournament for Families of SMA. It was a beautiful day that hosted over 140 golfers.

Brielle and Brooke Kennedy, who live with Spinal Muscular Atrophy (SMA) Type II, stole the hearts of many in the Charlotte, NC region. Both Eric Paul and Brian Johnston of The Rusty Rudder Management Staff, knew they had to do something to help. They both met the girls earlier in the year at a casino night fundraiser for the girls, hosted by Hendrick Motorsports, and they wanted to do everything they could to help find a cure to this devastating disease. Eric and Brian rallied the community and vowed to raise money and awareness for SMA. A golf tournament seemed like the perfect fit and away they went to the drawing board, and on September 13, 2010, they held their first ever charity golf tournament.

“We knew we had a lot to do in a short period of time, but we’d do anything we could to help these two sweet little angels”, said Eric Paul, Owner of The Rusty Rudder. The ladies and gentlemen that participated teed off to a shotgun start, captain’s choice format and finished up around 4:00 pm. After golf, a reception was held back at The Rusty Rudder with complimentary food, cocktails, friends and family. “We couldn’t have asked for a better turnout the first time and we can’t wait to start planning again for next year”, said Brian Johnston, General Manager of The Rusty Rudder. Kristin Balzer’s team won the tournament and bragging rights for next year. “The Rusty Rudder is a great place to work and my father and his team were thrilled to participate and can’t wait to defend the winning title until next year”, said Kristin Balzer, bartender at The Rusty Rudder. If you are ever in the Cornelius area of Lake Norman, NC, home to many superstars of NASCAR, please be sure to stop in at The Rusty Rudder and say “hi” to Eric and Brian!

Altogether, The Rusty Rudder Golf Tournament raised $4,000 for Families of SMA!

Eric Paul of The Rusty Rudder and Christen Tinsley of Hendrick Motorsports and Friends of Brielle and Brooke Kennedy
Charlotte, NC

Please Note: The amounts raised and shown on the following pages are totals as of March 1, 2011, and may differ from current fundraising totals by the time you receive this newsletter.
The 3rd Annual Cody Munz Memorial Golf Scramble was held September 11, 2010 in Fishers, Indiana. We began holding this event after the death of our son in 2008. In addition to golf, we also held a silent auction to help our cause. This year, we raised $3,200 and in the last three years we have been able to raise over $10,000 total. This fundraiser has been a great way for us to keep our son’s memory alive, raise awareness and help find a cure for SMA so others will not have to live with this devastating disease.

Rhonda and Matt Munz
Zionsville, IN

This past fall we held our 6th Annual Lily Kennedy Memorial Golf Outing at Iron Masters County Club in Roaring Springs, Pennsylvania. It was sponsored by St. Francis University Social Work Club under the direction of Dr. Mark Lynch and Professor Suzanne Black. It was a beautiful day of golf, with sunshine and just enough of a fall chill in the air to keep the golfers and volunteers energized. Eighteen teams comprised of 72 golfers participated in golf and a Chinese Auction that followed. As usual, no one walked away empty handed. There were lots of prizes, awards and good food to be had by all! Personally, I think what touches my heart the most, aside from the new faces we see each year, is those familiar patrons who come out to support our cause each year through rain storms, sunshine or wind.

A special, “THANK YOU”, for the spectacular efforts from the St. Francis student volunteers and the tireless continued devotion of Dr. Mark Lynch and Mrs. Suzanne Black who organize this event each year. Because of their work, we raised over $3,000 to further SMA research. I am looking forward to another great event next October 2, 2011 and spending the day with our SMA family and friends.

Peace and blessing,
Heather Kennedy
East Freedom, PA

Lily Kennedy Memorial Golf Outing

Thank you for contacting us concerning Families of Spinal Muscular Atrophy. On behalf of Bloomberg, I am pleased to let you know that $2,500 for winning the “Find Time” Scavenger Hunt was sent electronically to the organization’s financial institution on December 28, 2010, in memory of previous Bloomberg employee, Dianne Pollie Nuell.

It is our pleasure to recognize Ms. Erica Jones’ (current Bloomberg employee) involvement and support of Families of Spinal Muscular Atrophy’s important research programs identifying the causes of and effective treatment for motor neuron diseases as well as providing a support system for families affected by this disease. We are proud to be a part of this initiative and commend Erica on your efforts.

Sincerely,
Erana Stennett
Bloomberg L.P., New York, NY

Families of SMA,

Our team at Shine Salon is grateful for your organization. Every year we host a Families of SMA Cut-a-Thon in honor of Cubby Wax. This
Fundraising stars

year we were able to raise $2,355. We thank you so much for making this all possible. You are all appreciated.

Love,
The Shine Salon Team
Ridgefield, CT

Dear Families of SMA,

Enclosed are donations to SMA in the amount of $2,230. These donations were raised by our daughter Caroline Genster and her classmates, Holly Brautigan, Molly McCarthy and Olivia Mullen as a community service project at their school in Seattle, Washington, Assumption of St. Bridget. Contributions were made by school families, friends and family members. Thank you for your great work on behalf of families affected by SMA. We are grateful.

Joe, Alisa, Caroline and Nora Genster
Seattle, WA

More than 25 students and supporters participated in Alpha Tae Kwon Do Academy’s 8th Annual Night of 1,000 Kicks on December 29, 2010 in memory of Rachel Rollinson. This year, the event raised more than $2,075 for Families of Spinal Muscular Atrophy. Before the kicking began, Renshi Andrew Rollinson thanked the participants for their help.

“This fundraiser is really worth it because of the work being done to cure SMA,” Rollinson said. “They are going to find a cure, and we’re going to see it happen. And every time we do something like this, whether we raise $1 or $1,000; that helps.”

For every 100 kicks, Andrew would pick someone from the crowd to break a board. It was good to break it up a bit... plus lots of fun.

Many hugs and here’s hoping for a cure in 2011!

Michelle and Andrew Rollinson
Chelmsford, MA

Families of SMA,

The enclosed check for $1,838 is a donation for FSMA from the students, faculty, and staff at Falmouth Academy, a small private day school located in Falmouth, Massachusetts. The funds came from a coin challenge held on our campus last month. The students chose to send the funds collected from this challenge to FSMA, to support the valuable work your organization is doing in SMA research and in helping SMA families.

We wish you success in your important endeavors, and we hope you have a very happy holiday season.

On behalf of everyone at Falmouth Academy,

Dr. Audrey Meyer, Class Advisor and Teacher, Falmouth Academy
Falmouth, MA

Dear Families of SMA,

Enclosed please find checks from our Trivia Night and also a picture of the ladies from the Phi Tau Omega sorority. They have been loving their trivia for the last few years. Brittany Carpenter was a special guest at our trivia this year. Together we raised $1,683. Hope this helps with research for the children.

Sincerely,
Kathy Goodyear
Saint Louis, MO
Mommy’s Marathon for Constantine’s Cure. I got the idea for the name while I was running last winter in the ice and slush of Vermont. I guess I subconsciously decided that I was going to run a marathon after spending lots of miles trying to figure out a way to make a difference and fight SMA. I have always been a runner, but by no means a marathoner. I wanted a challenge that would make people know what an SMA parent would do for their children, and really feel like I was FIGHTING this disease by raising money for a cure as well as awareness for SMA.

Our son, Constantine, is three and is the most amazing little boy. He was diagnosed at eight months old with Type II SMA, just one week after we found out we were pregnant with his little sister, Aurelia. Our family thrives off our kids’ happiness and our hope that someday SOON there will be a cure or a treatment for SMA. We hope that by putting our family’s story out there and our passion to find an end to SMA we will inspire others to make a difference too.

You can check out my blog at constantinescure.blogspot.com to see the weekly updates I wrote while training for the marathon. I ran the Manchester City Marathon in November 2010. It was cold and definitely very challenging, but I ended up raising $1,500 for FSMA to fund research and another $700 for Constantine’s medical fund. We were also in three newspapers which helped to get the word out about SMA. We were thrilled with the results and that all the hard work paid off. We are excited to get planning our next fundraiser to cure SMA!

Lucianta Salce
Hillsborough, NH

Dear FSMA,

Although we had bad weather everyone seemed to have a great time at our Golf Tournament. We are delighted to donate $1,495 in memory of our son Matthew this year. I hope you will find this money helpful.

Thank you for all of the extra goodies you sent for our gift bags. Everyone loved receiving gifts and it was so nice for them to get more information on SMA.

I look forward to helping in the future as this means so much to myself, my family, and my friends.

Thanks again,
Ashley deBeaubien
Bay City, MI

In December, Dave Jaworski of Fitchburg, Wisconsin, started a Holiday gift registry page on cureSMA.org, asking for donations instead of holiday presents. He was able to raise a total of $1,400 through the page, for Families of SMA.

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donations. If they didn’t last eight seconds, ALL the donations collected would be given to FSMA in Addison’s name.

During the rodeo, there was information on Addison and SMA distributed to all attendees. There were donation cans set up around the arena, and the Bull Fighters also went around and asked the crowd for donations for FSMA. Addison was even led on a horse out into the center of the arena while the announcer read about SMA and Marshall, but his parents handled them gracefully. As a result, Max became increasingly excited about his project. With gusto, he decorated a donation box for his party and invited his closest family members, friends, and classmates and raised an astounding $500! I am a firm believer that children learn what they live. Just look at what Max has been able to learn, because his parents have enabled him to live it.

It is our pleasure, through Marshall’s Miles, to match the donations from Max’s birthday party. Please accept these checks, totaling $1,000 toward the purchase of new car beds for Type I SMA families. We are all honored to have been a part of Maxtin’s Birthday Project!

With much hope for the future,
The Potter Family & The Estey Family
Douglas, MA & Londonderry, NH

On July 31, 2010 Byron Bank and Chemical Bank presented the 6th Annual Byron Center 5K Run/Walk and Kids’ Fun Run. Both Chemical Bank and Byron Bank are committed to West Michigan and its residents. Consistent with that commitment, this event pays tribute to the benefits of a healthy lifestyle while supporting worthwhile causes.
Tim Potjer, of Byron Center, Michigan, has a daughter, Sydney, with SMA. He is a customer and friend of Byron Bank and an active member of the Byron Center community. We are happy to donate $1,000 to Families of SMA in honor of the Potjer Family.

This year’s event resulted in a record turn-out of over 1,200 runners and walkers! Race proceeds went to a group of very worthy beneficiaries: the cross-country programs at Byron Center High School and South Christian High School, Families of Spinal Muscular Atrophy, the A-T Children’s Project, Kent County CERT and the Michigan Vietnam Veterans.

Jodi Sevigny
Marketing Manager, Chemical Bank
Byron Center, MI

Randy & Vickie Whited of Lebanon, Tennessee, started a gift registry page on curesma.org in memory of their granddaughter, Alana Whited, who passed away in September 2010. They were able to raise a total of $921 in her memory.

Dear Families of SMA,

A dinner was held in honor of Kelley Patterson on August 13, 2010 to help support SMA. Our organization, Azusa Fraternal Order of Eagles, is a non-profit organization raising money for local communities and its families.

The dinner/raffle was hosted by one of our members to support her granddaughter who was recently diagnosed with SMA.

The dinner/raffle raised $840. Please accept the enclosed check, in hopes that we all can make a difference to find a cure for all those involved.

Thank you,
Azusa Fraternal Order of Eagles
Azusa, CA

Randy Schroeder of Medford, New York, started a gift registry page on curesma.org in memory of Deirdre Abraldes. On October 10, 2010, Ryan, John Schroeder and Chris Foy participated as a relay team in the Cedar Beach Triathlon. The race consisted of a ½ mile swim, 15 mile bike ride, and 3.2 mile run. Together, they were able to raise a total of $525 through their fundraising efforts.

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Families of SMA,

Enclosed please find donation checks totaling $502 from our annual Costume Crusade at The Village Learning Center (formerly Tutor Time of Brandon). Funds were raised from basket raffles and silent auctions.

Sincerely,
Joseph Miller, Owner
Brandon, FL

Friends and Family of Eden Cheslock, our Altoona, Pennsylvania Committee, participated in Friends Helping Friends Day at Boscov’s Department Store in Altoona, PA. We did this in honor of my granddaughter, Eden Cheslock, of Dover, Delaware.

Every 501(c)3 non-profit organization was eligible to participate. The organization was supplied with $5 tickets to sell to friends, neighbors, etc. Everyone who purchased a $5 ticket received a 25% discount shopping pass for purchases made only on Friends Helping Friends Day (which was October 5, 2010). Shoppers holding a pass were also eligible to win fabulous door prizes including shopping sprees or merchandise items. The organization keeps the entire $5 on each ticket sold.

Our committee had a table at Boscov’s on the day of the event (Oct. 5) as well as July 30 and September 25 to sell the shopping passes. We sold 67 passes. We also handed out SMA materials and sold wristbands and received some donations, raising $412.

I have added $64 to our amount which our daughter Nicole Cheslock, (Eden’s mother) of Dover, DE gave me which they collected in donations at Dover Downs in Delaware, in August (SMA Awareness month). This brings our total amount raised to $476.

Jeanette Foor
Altoona, PA

Dear FSMA,

We are pleased to be sending you these checks totaling $423 in honor of our daughter, Chloe Ochoa! This past Christmas we wanted to do a fundraiser to raise money for SMA research, so Chloe drew a beautiful picture that we made into Cure for Chloe ornaments to sell! With the support from our family and friends we were able to raise $423 for FSMA by selling these ornaments! We want to thank you for all the hard work you do by helping to find a cure for Chloe and so many other amazing SMA children!

Together we will find a cure!
The Ochoa Family, Kathleen, Jake, Chloe and Tyson
Homewood, IL

Candles for SMA (www.candlesforsma.com) was created by my husband, Greg, and myself (SMA Type III), with the goal in mind of joining the many other wonderful families and organizations that have raised money to help find a cure and spread awareness. Every one of our hand-poured, pure soy wax candles benefit the cause ranging from 20% to 100% of the proceeds. Currently we have 8 oz. tins, votive candles, and tea lights with nine scents to choose from. New products are in development such as the SMA Awareness Candle and Personalized Pillars along with new scents being tested. We started taking orders in October 2010 and have donated $420 total! We are excited to see what next year brings us!

Making these candles has been great for me personally. Unable to work outside of the home, I have searched for many years trying to figure out something that I was physically able to do that could make a little money. It is perfect for me. I can take my time, rest if needed, be creative, and feel good about giving back. It has helped me to accept my disease instead of trying to hide it. Bringing awareness to SMA is very important to me now. We are getting a great response from people and the support we have received means a lot to us.

If you love candles or know someone who does, please tell them about Candles for SMA, made by a SMA family! You can also follow us on Facebook!

Melissa Woods
Dixon, IL

Sheila Murphy and her husband Russ have lost two beloved grandchildren, Cianan DeWeer Murphy (June 21, 1997 – May 19, 1998) and Cecilia Lehan Murphy (April 26, 1999 – July 13, 2000), to SMA Type I. Their son Brian and daughter-in-law Silvia coordinate the Annual FSMA New England Chapter Walk-n-Roll in Hingham, Massachusetts. With their other children, grandchildren and numerous family members, they support that event, which was begun by Silvia in May 2001, the year after Cecilia died. In June of 2008, Sheila and her daughter Siobhan helped Silvia supervise a children’s playroom at the FSMA
conference in Boston. For 13 years, FSM A has been a powerful help in her family’s journey of loss and love.

As a retired English teacher, a published poet, and a teacher of memoir writing to senior citizens, Sheila longed to contribute to FSM A with words. When she was given the opportunity to publish a chapbook of her poems, she decided to organize the collection around a core group of poems about Cianan and Cecilia, to dedicate the book to their memory, and to donate proceeds from sales to Families of SMA.

In 2010, her poetry readings at art exhibits and libraries have resulted in donations of $400 to Families of SMA. In addition, she has donated copies of View from a Kayak in Autumn for sale on the Merchandise page of the SMA website.

Her book is a grandmother’s memoir in poems, arranged chronologically, that links to five generations of her family. The poems witness her belief that love, in families, is generational, and that even children whose lives are cut short remain forever in memory. Her intention, in rendering the lives of her two grandchildren and their enduring place in her family, is to honor all families whose lives are touched by SMA.

The first two poems in her book focus on works of art, and reinforce the idea of generational family bonds. In addition to poems about Cianan and Cecilia at the center, recurring places and people important to their life stories. In honoring the lives of two babies who died of SMA, she portrays the beauty and value of those brief lives, and the ways that faith, and memories of loved ones, can help sustain us in our life journeys.

To read some of the poems found within Sheila’s book, please visit the memorial section of this newsletter.

Upper Cumberland’s First Annual SMA Family Day in Memory of Bentley Bassamore was held on October 2, 2010. Crossville’s Centennial Recreational Park, where we held the benefit, now displays a “Bentley’s Butterfly Garden” plaque, a butterfly garden bench and butterfly bushes, all donated by us. We will also be planting a willow on his birthday in May.

Thanks to the following individuals, the benefit was a great success: those who brought their vehicles to the car and truck cruise-in, the Crossville City Police Department and Fire Department who came by to share their time with the children and families, the park for all their help, the personal and business sponsors in the community, Jennifer Keck and her sister, Sarah, Kathryn Kopp; Bentley’s grandmother, Michael Bassamore; Bentley’s uncle, Michael Watson and girlfriend, Mil, and most importantly, Joseph Bassamore, the father of Joseph “Bentley” Bassamore, who knows the daily sorrows of losing a child to SMA, but is hoping to raise awareness in his area so one day, relief for other children and their families will be found. Altogether, the event raised a total of $400.

Kathryn Kopp
Crossville, TN

Dear Families of SMA,

For the past four 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 six this past year. Unfortunately, SMA Type I took their lives way too soon (Owen at 11 weeks; Grant at 15 weeks).

Jeanette Arnold, Pampered Chef Consultant, has once again donated her profit from the sales ($150), the Pampered Chef Company ($153) and a $50 cash donation from my boy’s Great Aunt totaling $353 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, OH
Dear Families of SMA,

The Orange County Mustang Club is donating $295 to SMA. We have two car shows a year and each show has an opportunity drawing with half of the money going to SMA.

Kennedy always gets to pull the winning number and award the prize. My grandson, Kennedy Montoya, has Type II SMA and is seven years old. He is doing very well. Thank you for all you do to benefit the families.

I’m very proud of The Orange County Mustang Club. They have made Kennedy their mascot and include him in all their activities.

Thank you,
Renee King
Garden Grove, CA

On February 3, 2011, Sherry Crossley hosted a Premier Designs High Fashion Jewelry Party in honor of Brielle & Brooke Kennedy, SMA Type II. The event was held in Mattawan, Michigan. She organized a fun night out with the girls, to let them shop for some beautiful jewelry! In return, she was able to donate a percentage of sales to Families of SMA, totaling $285!

Dear FSMA,

Once again, Charlie wanted to ask for donations instead of presents for his birthday. Charlie’s 7th Birthday Party raised $282 this year, but we know that at least three other school friends donated on-line. He invited his classmates to a skating party again this year and it was a lot of fun. Charlie never ceases to amaze us. He is such a wonderful son and we are truly proud of him.

Thanks,
Kim and John Sykora
Leawood, KS

Sean and Karianne Brown of Cincinnati, Ohio started a gift registry page on curesma.org for their son Liam’s first birthday on February 12, 2011. Liam’s Auntie Caitie has SMA. Their family was able to raise a total of $275 for Families of SMA.

Families of SMA,

Runners With A Reason, Inc. is a non-profit organization that helps its runners find a personal reason that motivates them to run and become life-long runners. Besides the thrill of running and competition, each runner’s “reason” keeps the runner motivated to train each week and pushes the runner to complete either a half or a full marathon. In addition, each runner then raises money on behalf of Runners With A Reason and the runner’s “reason” for running.

Stacie Swanson successfully ran the 33rd Annual Lincoln National Guard Marathon on May 2, 2010. Her “reason” to run was to raise money to support Families of SMA. As a result of her efforts, she raised $221 in support of your cause.

The runners associated with Runners With A Reason raised more than $51,000 as they trained for the Lincoln Marathon. Plans are already underway to recruit more runners in 2011.

Sincerely,
Britt Ehlers
Lincoln, NE

Please Note: The amounts raised and shown on the following pages are totals as of March 1, 2011, and may differ from current fundraising totals by the time you receive this newsletter.
Dear Families of SMA,

My name is Danielle Molln. I work as an X-ray Technologist at Perry Memorial Hospital in Princeton, Illinois. In May, our Perry Pride Committee decided to try a new activity for hospital week this year. The activity challenged any hospital employee to be a “superhero” and raise money for the charity of their choice. Although some money had to go back to the committee for expenses, the rest went to the charity of choice. The top winners who raised the most for their charity received a pie in the face by someone who donated money toward their charity. I chose to be active in this event picking Families of SMA as my charitable organization.

My husband and I are friends with Monica and Jason Shofner, who also live in Princeton. Their seven year old son, Nolan, has SMA and they are members of your organization. Nolan is a wonderful funny little boy and is well known in our community. People know Nolan. We can see him, talk to him, and see that Nolan and his disease are real. People realized that by helping children across the U.S. they were also helping a little boy here in our own community.

As one of the top winners, I prepared for a pie in the face. I invited Nolan, his brother Blake, Monica and Jason to the pie throwing event. The person who was supposed to throw the pie agreed to help Nolan throw the pie at me instead. He picked out all the toppings and got to decide how much whipped cream to use. He had a wonderful time throwing the pie and his parents said he talked about it for days. On behalf of myself

and everyone who donated to my superhero charity, I would like to give this check in the amount of $200 to Families of SMA and dedicate it to Nolan Shofner, the SMA friends he has made over the years and all the children and their families who are or have struggled with this horrible disease.

Sincerely,
Danielle Molln
Princeton, IL

Families of SMA,
Enclosed please find checks that total $195. They are being given to aid in research to fight SMA. We raised this money because our friends, Deb and Len Aizenstein, have a little boy, Matthew, who has SMA Type I. We are hoping and praying he will find help to cure this devastating disease.

Sincerely,
Carol Kalvig
Hoffman Estates, IL

Muscular Atrophy, and I have seen how their lives have been affected. I found that Families of SMA was a great charity that would benefit people like Heather and Jessica. I talked to my friend Andrew Graham, who is good friends with my cousin’s family as well, and we planned for the event.

The name we gave the softball game was called the Summer Softball Classic. I decided that we were going to raise money for the game through selling t-shirts. Graham, who is a graphic design major at LaRoche College, designed the logo for the Summer Softball Classic, and we used the Families of SMA logo on the back of the t-shirt. We talked to some friends and got about 18 people to play. We knew that people would want an extra incentive if they were to win, so we bought a giant bucket as the trophy and named it simply “The Bucket”. It is intended that the winning team writes their names on “The Bucket”, and that there is enough space leftover so that we can continue to do charity sporting events in the future.

The game itself took place on Sunday, August 8, 2010 at Baldwin High School in Pittsburgh, Pennsylvania. We also bought and sold Rita’s Italian Ice, and any profit that was made through that also was donated. I was the manager of the blue team and Graham was the manager of the red team.

The game was awesome, even though it almost didn’t happen because the security guard came down to kick us off the field. We were able to negotiate a compromise so that we could play the game. In the end my team won. The picture attached is the only picture we were able to take and it is a picture of my team with “The Bucket”. We were able to raise $150. It wasn’t a ton of money, but I figure every little bit helps in some way. We also wanted to say thank you for what you do for so many people, and are more than happy to help in any way we can.

Justin Tomko
Pittsburgh, PA
Dear Friends,

Please accept our gift of $115 in honor of Colby Russ.

We have collected this money as a result of our 2010 Casual 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, Spirit Committee Member, Greater Clark County Schools Administration Building Jeffersonville, IN

Dear Families of SMA,

This $100 is being donated by Rock Patullo. His job is in Homeland Security. During the year, whenever any of the team says an inappropriate word the individual puts a "dollar in the jar". Rock had a hundred dollars worth of OTPS! He is a friend of mine and wanted to donate it to FSMA. My grandson, Kennedy Montoya has SMA Type II, is seven years old, and is doing well. His family was at the last conference… in fact we received the last newsletter today and there was a beautiful picture of him. Thank you for all you do.

Renee King
Garden Grove, CA

Peggy Ann Foor of Bonita Springs, Florida, raised $70 at her Premier Design Jewelry Fundraiser in December, 2010. She held this fundraiser in memory of her children, Crystal, Cori and Sunshine.

FSMA,

Holy Trinity Lutheran School has selected your agency as the recipient of a portion of our offerings collected at our weekly chapel services. We have raised $66 in honor of Annie Grimes. We pray that these funds will be helpful as you provide valuable service to our community. We are privileged as God’s children to serve our community together and pray that God will continue to bless our efforts to the furthering of His kingdom.

Serving together,
Bill Hiskey, Director, Holy Trinity Lutheran School
Bowling Green, KY

Dear Families of SMA,

Despite our efforts and good intentions, our pumpkin crop did not do well again this year. However, we had a few pumpkins to sell, and also have some friends who donated in Lainie’s memory in honor of her birthday, totaling $60. Please accept this money with our deepest gratitude for the work you do.

Love,
Lewis Center, OH

I am Marley Robinson’s grandmother. Enclosed is $25 Anne Mowell gave me for knitting a doll’s sweater. Thank you for all the work you do to improve the quality of life for these individuals.

Angie Robinson
Groton, CT

Dear Families of Spinal Muscular Atrophy,

The employees of Concurrent Technologies Corporation (CTC) participated in a Denim Day on August 20, 2010. Denim Day is a fundraising event where employees are permitted to wear denim to work in exchange for a $5 contribution to a designated charity organization. We are pleased to be able to donate the proceeds from this event to Families of Spinal Muscular Atrophy. Enclosed please find a check for the amount of $10.

Sincerely,
Cheri Wilson, Office Administrator, Concurrent Technologies Corporation Johnstown, PA

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KIDS corner

Limited By Kevin Schaefer of Cary, NC (age 17, Type II)

Weighted down by my limitations
Freedom captivates my heart.
Invokes its spirit into the deepest corners of my being;
But I am limited.
The four wheels that confine do not limit me,
Nor the muscle weakness I’ve always known.
What limits me is a world blind to its surroundings.
This $54 donation is from my eight year old son, **Liam**. We keep a tie-dyed soup can in the kitchen where we throw all our loose change and bills. When it is full (sometimes takes a week, sometimes a month!), we cash it in and write a check to the charity of our choice. It was Liam’s turn to choose last month and he knows about FSMA because Mama was writing press releases for your group and talking about hope a lot! He chose FSMA all on his own. Of course I cried. Awareness is the beginning of service!

Laura Franzen  
Itasca, IL

Happy New Year to Families of Spinal Muscular Atrophy,

The children in my **4th grade Sunday school class** did a project about charities. I gave each student $5 as their Christmas gift. In turn, each student gave a short report on their favorite charity. After all the reports were presented, the students had a choice of donating their $5 or keeping it. **Ashlyn** did her report on Spinal Muscular Atrophy and chose to donate her $5 to your worthy cause. Her presentation convinced **Natalie** to donate her $5 to SMA also. You might find it interesting to know that Ashlyn’s sister died of SMA. Natalie’s sister died in 2010 so she could relate to Ashlyn’s loss and showed her support by donating her $5. I’ve decided to support Ashlyn and Natalie by adding to their donation, totaling $20.

Thank you,  
**Karen Beaver**  
Lancaster, PA

Dear FSMA,  
Enclosed you will find donations from the staff of the **Oldham County Libraries** in Oldham County, Kentucky given on behalf of our son, **Connor Deluca**. Connor is four years old and has Type II/III SMA. He is a frequent visitor to the library where they always make us feel loved. Connor’s grandmother, **Kay DeLuca**, works as a librarian there and in lieu of Christmas presents to her they generously chose to make donations to your amazing organization. The donations total $165. We are so grateful to them for their remarkable kindness and to you for all your support to families like ours.

Sincerely,  
**Kristen DeLuca**, Mother of **Connor**  
Louisville, KY

Families of SMA,  
Enclosed please find a check for $140. I shared information about the annual campaign with my class and several of them wanted a bracelet. I did not read it very well, but told them that anyone who donated any amount would get a bracelet. I had 14 out of 21 students donate, one only two cents, but she was lucky to find that. I hope I can get 14 bracelets sent to **Delhi Elementary School**, in Jerseyville, Illinois for each of my students.

Thanks,  
**Kay Wittman**, Jerseyville, IL

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**Garrett Grimes**, big brother to SMA angel Annie, started Kindergarten on August 3, 2010. A new school, a new teacher and they welcomed him with open arms. Little did his peers know that he would lose his baby sister Annie to Type I SMA on August 6, 2010. **Potter Gray Elementary** immediately reached out to our family after knowing us for only three days. They were ready to support our efforts in raising SMA awareness… 4 Annie! On September 24, 2010, students, teachers and staff participated in a Hats On 4 Annie event where they were allowed to wear their favorite hat to school for a donation of $1 or more. It was a HUGE success!

Due to their excitement, seven other local schools decided to participate, reaching over 4,000 students! Students brought us their entire piggy bank savings, special gold coins and even their birthday money! These students truly touched our hearts with their generosity. We were very honored in submitting nearly $3,000 in Annie’s memory to FSMA! A big thank you goes out to **Potter Gray Elementary, Bristow Elementary, Briarwood Elementary, Richardsville Elementary, Warren East Middle School, Drakes Creek Middle School, Warren East High School and Foundation Christian Academy**. Visit www.4AnnieGirl.com for more info and photos.

**The Grimes Family, Eddy, Nicole & Garrett**  
Bowling Green, KY
My name is Mallory Armbrustmacher and I live in DeWitt, Michigan. I have Spinal Muscular Atrophy Type II. I have been swimming competitively for six years and have also been part of the DeWitt Area Swim Team and the DeWitt Junior High Swim Team. This year I am a freshman at DeWitt High School and am on the Girls Varsity Swim Team. I’m not quite as fast as all the other team members, but I always try my best and push myself to go faster. The girls on the team and my coach have been very supportive of me. Whenever I am swimming all of my teammates are cheering me on and the whole crowd is on their feet cheering for me. This season I have improved my swimming a lot. I dropped 2:09.49 this season and my best time for the 50 freestyle is 3:10.78.

I don’t let my disability get in the way of me doing what I love to do. I would encourage everyone with a disability to swim or do another sport that they love. Swimming is great exercise for me and when I’m in the water I feel as if anything is possible. You should never let anything hold you back from shooting for your goals.

This is a letter I received at our awards banquet from Governor of Michigan, Jennifer Granholm:

Dear Coach Brace:

Congratulations to you and the DeWitt High School Girl’s Swimming & Diving Team on a successful 2010 season.

Coach, thank you for your commitment to academic excellence and sportsmanship, and for teaching the importance of acceptance and compassion to your team. These values will not only make your swimmers better athletes, they will also make them better students and citizens.

To the young women on the Girls Swimming & Diving Team, I applaud you on your performance this year; and I understand there is one team member who is deserving of special recognition for her unquenchable spirit and gritty determination in the face of great personal challenge. Ms. Mallory Armbrustmacher is a powerful representative of the countless talented, determined, and courageous young people living full and rewarding lives despite disabilities. Mallory, you are an inspiration to us all. I wish you the very best as you continue on with your education and other athletic pursuits.

Again, congratulations, everyone, and please accept my heartfelt best wishes for the continued success of the DeWitt High School Girl’s Swimming & Diving Team.

Sincerely yours,

Jennifer M. Granholm
Gwendolyn Strong and Hayden Calaforie at Disneyland

Santino Delfino and Sister Alexandria

Savannah and brother Brett Norton

Max High

Logan Patrick

Madison Wolff with sister Ella

Jolie Ava Dziubela

Savannah Rush

Sydney Horak

Sofia Santana

Sydney Potjer

The Adams’s

Troy, Anthony and Jamie Lino

Veronica Rose St. Onge
NIH Funding for Spinal Muscular Atrophy Research Up 60% Since 2008

The National Institutes of Health (NIH), the federal government’s medical research agency, released its most recent estimate of funding for disease categories which indicates that its base funding levels for SMA-related research has increased from $10 million in fiscal year 2008 to $16 million in fiscal year 2010. An additional $3 million in one-time funding was provided to SMA-related projects in fiscal years 2009 and 2010, respectively, through the American Recovery and Reinvestment Act (ARRA).

Some of this increase in federal resources devoted to SMA-related research is the result of the success of a two-pronged, long-term strategy of Families of SMA to provide seed funding for critical drug discovery programs in order to leverage federal (and private) resources, and to raise awareness of SMA and SMA-related research among federal policymakers through advocacy and grassroots efforts.

Several recipients of NIH funding in fiscal year 2010 received their initial seed funding from Families of SMA. For instance, NIH supported two projects related to the Quinazoline Program to treat SMA, now being developed by Repligen Corporation and two projects related to the Tetracycline Program to correct SMN2 splicing, including $1 million in funding in 2010 to Paratek Pharmaceuticals from a five year multi-million dollar award.

The initial seed funding provided by Families of SMA played a critical role in positioning these four projects to receive highly-competitive NIH research dollars for the first time. Leveraging our initial seed money into greater industry or government investment is a key goal at FSMA.

Additionally, the NIH funded two grants in fiscal year 2010 to support the Families of SMA Annual Research Conference.

Going forward, continued growth in government funding for SMA-related research projects is contingent upon Congress providing adequate resources to the NIH. The House of Representatives recently passed a bill (H.R. 1) that would cut the NIH budget by more than 4% for the remainder of fiscal year 2011.

While the current increases in SMA research funding by the NIH are positive developments Families of SMA is working closely with its allies in the disease advocacy community to urge Congress not to cut NIH funding in the future. If you would like to contact your Members of Congress to encourage them to support NIH funding, you can reach them by calling the Capitol switchboard at (202) 224-3121, or by going to https://writerep.house.gov/writerep/welcome.shtml or http://www.senate.gov/general/contact_information/senators_cfm.cfm.

SHARING photos

Rachel, Connor and Mariel Negrin
Ryan Manriquez Halloween 2010 Convict
Savannah Norton
NIH Holds Conference on Spinal Muscular Atrophy Drug Development

The NIH held a conference in Bethesda, Maryland October 27th to 29th to assess the state of Therapy Development in Spinal Muscular Atrophy. The overarching goal of the meeting was to identify bottlenecks in the drug development process and begin to discuss possible solutions to address them.

The meeting gathered leaders from the advocacy community, from government such as the NIH and the FDA, from the pharmaceutical and biotechnology industry, from SMA researchers, and from SMA clinicians to dialog on SMA drug development from the earliest stages, such as assay development, to late stage clinical trials needed for FDA registration.

The intent of the meeting was to identify barriers to drug development, rather than to highlight specific therapies. Therefore, working groups were convened prior to the meeting to discuss potential areas for bottlenecks and then present their findings during the meeting. Working groups were organized to cover the following topics:

- Working Group 1: Available Assays, Validation and In Vitro Screening Tools for SMA Targets
- Working Group 2: Animal Models of SMA and Their Appropriate Use in Therapy Development
- Working Group 3: Decision Making in Therapy Development for SMA—Scientific, Corporate, and Regulatory Perspectives
- Working Group 4: Endpoints and Biomarkers for Clinical Trials
- Working Group 5: Proof-of-Concept Trial Design and Conduct
- Working Group 6: Small Molecules
- Working Group 7: Biological and Antisense Oligonucleotide Strategies

During the working group’s presentations, several drug candidates for SMA being advanced by companies and academic groups were mentioned. These included those of Trophos, Repligen Corporation, California Stem Cell, Inc., ISIS Pharmaceuticals and OSU.

Several early stage programs were also discussed, including those at Paratek Pharmaceuticals, iPierian, PTC, NINDS and those in the laboratory of Drs. Elliot Androphy and Gideon Dreyfuss.

Many Families of SMA funded researchers and clinicians attended and participated in the meeting, along with Jill Jarecki, PhD, FSMA Research Director and Kenneth Hobby, FSMA President. Dr. Jarecki participated as a member of the small molecule working group.

Drug discovery is a difficult venture, as evidenced by the fact only one highly effective drug is approved for all neuromuscular diseases, and this inherent difficulty was highlighted in the meeting findings. As was intended, the meeting identified multiple barrier points for our community to address. These included the following:

- How do we efficiently advance newborn screening for SMA? Research shows that all SMN based therapies will work better the earlier they are given.
- Is the clinical trial infrastructure ready to support the impending trials of new drugs over the next several years? How do we fund a US-wide clinical trial network and supporting infrastructure?
- Do we have adequate clinical trial endpoints and measures to effectively test new drug therapies? What do we have to do to make them ready for use in the eyes of the FDA?
- Are we ready to enable clinical trial recruitment in a fast manner?
- How do we work together to advance drug development in the most efficient way possible? In orphan drug disease, this often will take multiple parties coming together, including academics, industry, government and advocacy.

An official written summary of the meeting will be released in the next few months.
Dear Families,

Thank you for all you have done to increase awareness and attention towards Spinal Muscular Atrophy (SMA). As most of you are aware, this has been an eventful year in the U.S. Congress; national health care and research priorities have been prominent on the radar screens of lawmakers. The significant visibility that you have brought to SMA through outreach to policymakers has yielded significant research and policy momentum for our community. Since it has been several months since we last provided a joint update on such activities, we wanted to take a moment to inform you about recent and upcoming government-sponsored, SMA-related research conferences and to provide an update on the SMA Treatment Acceleration Act (H.R. 2149 / S. 1158).

This fall, several landmark federal research meetings are being conducted to address critical regulatory and therapeutic development opportunities in SMA. In September, the Food and Drug Administration (FDA) and the National Institutes of Health (NIH) jointly hosted a research conference focused on Antisense Oligonucleotide Therapies.

With regard to the SMA Treatment Acceleration Act, despite our best efforts and the unbelievable show of support by families across the nation, the current political climate in Washington makes it highly unlikely that the bill will pass this year.

After extensive conversations over the past several weeks with senior staff persons and key Members of Congress who serve on the congressional committees with jurisdiction over the bill, it has become clear that very few, if any, public health bills such as the SMA Treatment Acceleration Act will move through Congress during the lame-duck session set to begin on November 15. Furthermore, those bills that may move have been revised considerably and we believe that weakening the SMA Treatment Acceleration Act is unacceptable to our community and is too high a price to pay in order to achieve a symbolic gain.

While we are all disappointed by this realization, we want you to know the following:

1. Even if the bill, as expected, does not pass in the lame-duck session, the overall effort to push the legislation forward has had an incredibly positive impact; it has dramatically raised awareness of SMA among lawmakers and is directly responsible for the increasing attention SMA is receiving from the National Institutes of Health (NIH).

2. We will work with our champions on Capitol Hill to evaluate and introduce a new version of the Act in the next (112th) Congress, while continuing to stay in close contact with key Members and their health staff in case circumstances change before the end of this year. Looking ahead, we will review the clinical research landscape and work with legislators to craft legislation for the 112th Congress that addresses the specific needs of the research community.

While it is unlikely that the SMA Treatment Acceleration Act of 2009 will pass in the coming weeks, we believe that this is a time to celebrate the remarkable efforts of the entire SMA community in driving forward the Federal Government’s interest in SMA research. The bill has had a tremendously positive impact to date. Your efforts in securing 118 cosponsors in the House and 21 cosponsors in the Senate are responsible for the opportunities that are emerging to engage the NIH even more deeply in the effort to find a treatment for this disease.

We continue to be eternally grateful to you for your efforts and hope that you will remain energetic, engaged, and hopeful as we continue in our legislative and governmental efforts. Thank you for all that you do. We would not have achieved so much without your personal contributions and outreach to Congress and we have much to be proud of.

Thank you again for your help for all those with SMA!

Sincerely,

Kenneth Hobby
Families of SMA

Martha Slay
Fight SMA

Annie Kennedy
MDA

Cynthia Joyce
SMA Foundation
The Story of Angel Faye Young

After 17 weeks of strict bed rest to keep me safe, my mommy gave birth to me on January 19, 2010. I weighed six pounds and five ounces. I even received a nine on my APgar score. Mommy and daddy said I was the most beautiful baby that they had ever seen, and daddy added that I was perfect, just what he always wanted. I had completed our family; I have a brother, Joshua who is 20 years old, so you can see that my family; I have a brother, Joshua who is 20 years old, so you can see that mommy and daddy have been waiting on me for quite some time. The doctors checked me over at the hospital and gave me a clean bill of health. Two days after I was born, I went home to start my life with mommy and daddy. They said I was their dream come true, one dream that they thought would not come true, but look, miracles do happen, I’m here!

When I was about four months old my mommy started to worry about me. I wasn’t rolling over and wasn’t moving as much as other babies my age; babies younger than me were doing more it seemed. I could not bear weight on my legs. At my routine examination Mommy asked the doctor about my development, and the doctor said not to worry, that all babies are different and develop differently. Mommy agreed, but still felt in her heart that something wasn’t right. Mommy just prayed and hoped that she was wrong and that everybody else was right.

Another month went by and I still wasn’t doing anything new. What I could do at one time, I could no longer do, like hold my toys, reach for my toys while lying on my back, and it seemed that I was getting more “floppy.” Mommy had enough; she took me to the hospital to get checked out.

Once we got to the hospital, the doctors seemed to be very concerned at how little I could do for my age. They started to run all kinds of tests: X-rays, EMG (electromyography), MRI, NCS (nerve conduction studies) and I.V.’s. My mommy and daddy were so upset and could not understand what to do to help me. One of the many doctors I saw while I was in the hospital said he thought I might have SMA, but that they would have to do a blood test to confirm it, and that test would take at least three weeks to come back. On July 22, 2010 we got the news; I had SMA Type I.

As I held my daughter, my dreams for the future in my arms, and looked at her as she slept so peacefully, it was impossible to understand that we had just heard her death sentence. We had realized that she might be a little slower and maybe need extra help with meeting her developmental milestones, but the fact that we were going to lose her was beyond what we ever could have imagined.

You feel like it is impossible to live with such knowledge, but you have to go on. Life doesn’t stop just because you feel like your world has ended. I have stopped working to stay at home and be Angel’s full-time caregiver and I thank God for blessing me with the knowledge to care for Angel.

My sweet little Angel continues to be happy and smiles, she babbles, and gets so excited to see her daddy. She really loves when he dances with her; just to see her happy in her daddy’s arms is such a joy. She is such a loving baby and she really can say a lot with her eyes. She is very bright and alert and I’m sure she knows more than most kids her age.

On August 30th, Angel had a g-tube (feeding tube) and a nissen placed in her for when she loses the ability to swallow. Her surgery took two hours, and we were worried because we didn’t know if she would be strong enough to come off the ventilator or not, but God was with her. Everything went great and she was home two days later. I’m so proud of her, she is such a trooper, she goes through so much and still comes out with a smile on her face. No matter what, she is still happy. She truly is an Angel.

My daughter continues to amaze me at all the smiles she gives you even when she doesn’t feel good. Just being close to someone she trusts and loves, makes her world perfect. It is the simple things in life that make her happy. Most parents can’t wait to see how their kids grow up, what college will they go to, who they will marry, how many kids they will have and the list goes on. All I want is all so simple, just to hear my baby say “mommy” or “I love you”, or be able to give her dad and me a kiss. I would love to have the same hopes and dreams for my child just like other parents, but that changed for me and my family when we found out that our daughter was going to have a shorter life than most children. Funny how something so small can change your world in so many ways, and make you look at life in a whole new way. I never take anything for granted and I know I’m not promised tomorrow.

Everyday with Angel is truly a blessing that I never take for granted and I look forward to every new day that I have with her. I’m blessed to have been given the chance to care for a perfect being, God’s child!

The parents of Angel-
Terry and Mary Young of Louisville, KY
There are no words to describe the amount of pride, joy and awe that I am feeling today. Today, Aiden turns four; a day that seemed impossible that long ago day in Nashville when our world shattered, as a doctor told us there was no treatment or cure and that Aiden would never make it to his second birthday and probably not his first. We have come such a long way from that day. I still feel anger when I think of the cold, unfeeling way that a doctor, who had taken the Hippocratic Oath, decided that his opinion about a child’s life with SMA was more valid than the current success rate of following the proper care protocols. I will never forgive him for the amount of pain and fear that he inflicted on us by repeatedly telling us nothing could be done. Every option that we had researched, he shot down; no bipap, cough assist or feeding tubes were viable options. His opinion was that Aiden would be better if we chose to let him go simply because he wasn’t perfect, because he had a defect in his DNA.

But little did that doctor know, in our eyes Aiden was perfect and doing nothing was not an option. Little did he know that throughout my entire life, telling me “no” made the rebel in me want to prove otherwise. I have always had an affinity for the underdog, and my son just became my cause. Aiden is here three and half years following diagnosis because of two things: science and action. That doctor was totally correct in his assessment that Aiden would have died before his first birthday, if we chose to follow his advice. But we chose to listen to the parents and doctors that told us that Aiden beating the odds all came down to the level of care he received. There would be sacrifices, but all were minuscule when it came down to having Aiden or not. There were going to be things that would take getting used to and he was going to cry. But a few tears then would result in a healthier child later. I listened to advice from every parent I could find, thinking that those who had kids over the age of two were like rock stars. They had done it and I needed to soak up every bit of knowledge from them. Those parents were probably the biggest asset we had in learning about SMA. I learned leaps and bounds more from them than I did from Aiden’s doctors. We have been lucky that we found doctors willing to treat Aiden as an individual and not just another kid with SMA. But there is no way they can prepare you for every possible thing that will come up. They gave us the tools but some of it we had to learn on the fly, and that is where contact with other families is the key to success.

The biggest lesson I had to learn is to accept SMA. Don’t misunderstand; I hate everything that SMA has done to Aiden. It has taken his movement in all but a few fingers, his swallow and his ability to form words. I never got to hear Aiden say “momma” and we only heard “dada” for a few months before he was too weak to form consonants. But I do not hate SMA. Without SMA, Aiden would not be the child I adore. The little boy who laughs at Doofenshmirtz. The little boy that thinks that I am the Wittiest, most talented mommy alive; the little boy who, despite his overall weakness, is the strongest person I know and would not be the same child without SMA. Scotty and I have discussed it, who would Aiden be without SMA? Spoiled rotten? Definitely. Intelligent? You betcha. But beyond that we just aren’t sure. While SMA has taken so much from our son, it has also given him so much. He is a stubborn fighter, constantly defying expectations. He sees the joy in the smallest aspects of life. He smiles even when he feels like crap.

Today, I celebrate Aiden turning four and start planning for five. Because I know that he and I will give it our all to see that day.
The Whole Crew at FSMA,

Almost a year ago, just after Oscar was diagnosed, we first visited the FSMA website and read something along the lines of “Life with SMA doesn’t have to be any different.” In our state of shock and devastation after diagnosis, this infuriated us. Now, we know and understand its truth. Thank you so, so much for all your support this year, from the care package, to the conference, to the emails and the donation of bracelets and the like to our family and benefit. The conference opened our world up, gave us confidence, connections and hope. That means so much to us. It looks as though we won’t be able to make the 2011 conference, but we hope to become regulars in the future! We appreciate what you do so deeply. Oscar is doing great and he still talks about the friends he made in CA!

All the best to all of you,
Sally, David and Oscar Merulla of Rochester, NY

Elijah Robles

To Everyone at Families of SMA,

Our family would like to thank you for the care package sent to my son Elijah.

Elijah was diagnosed with SMA Type III on Tuesday, September 14, 2010. We were surprised with Elijah’s Care Package the following Friday. Elijah was so excited about all the toys. He LOVES the bubble blower and also has been carrying the blanket with him all around the house. We appreciate all of the amazing things everyone at FSMA does.

Thank You SO Much,
Heather Yost (AKA Elijah’s Mommy) &
Elijah Robles (AKA Little ROCKSTAR) of Guthrie, OK

FSMA,
I just want to send a thank you on behalf of our family.

Since September 13, 2010, our family has been forever changed. My husband and I learned that our six month old son has SMA Type I. Like most families prior to us knowing that our son was being tested for SMA, we had no knowledge of this disease. Unfortunately, things have happened so quickly that we did not even have a chance to send a thank you to FSMA for the Care Package we received before our little Diego had a crisis and stopped breathing on October 4th. My husband reacted quickly and gave him mouth to mouth. I am sending this e-mail from the hospital two and half weeks after his crisis. Diego now has a Nissen g-tube and a Trach, and will go home on a ventilator. This is all so overwhelming, but our faith in God and FSMA has made this tragedy more manageable. We have decided to take one day at a time and thank God every day for all his blessings.

Blessings to FSMA,
The Mojarro Family of Alhambra, CA

Wyatt Arnold

Families of SMA,
We got the car bed over the weekend and all I can say is WOW. We haven’t installed it yet but it’s quite an impressive device. We can’t thank you enough.

Wyatt has also been enjoying all of the items in the gift box. Chris and I were just overwhelmed with all the great stuff in there. Its funny how Wyatt seems to enjoy the little things the most (like the cat toys, pinwheel and feather); these were such a great idea since Wyatt’s nanny and I were trying to figure out ways to play with Wyatt considering his limited mobility.

Thank you very, very much again.
Paula Lavigne & Chris Arnold of Omaha, NE

Sally, David and Oscar Merulla
**FAMILY letters**

**Eloise Pillarellas**  
Dear FSMA,  

Happy Holidays! Eloise is now a sophomore in the International Baccalaureate (IB) and Arts Programs at our high school. She is taking the city bus with her friends and looking for a college.  

**The Pillarellas** of Staten Island, NY

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**Ella Peters**  
Families of SMA,  

Thank you so much for the care package. It brought some happiness to a week that was so devastating. Ella and her brother Kaleb had so much fun looking through the box and playing with each new thing. Ella’s favorite was her new phone! :) We are so lucky that an organization like this is here for us.  

Thank you,  
**Jen, Brandon, Kaleb and Ella Peters** of Omaha, NE

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**The Tomkos Family**  
FSMA,  

Thank you for all that you do for families! Enclosed is a picture from the Spring of 2010 when our daughter Heather (now 22, SMA Type II) graduated from Carnegie Mellon University in Pittsburgh (Mechanical and Biomedical Engineering degree). Our other daughter Jessi (age 20, also SMA Type II) is a junior at Duquesne University in Pittsburgh, majoring in Music Therapy.  

Merry Christmas and Happy New Year!  
**The Tomkos – Tom, Carol, Heather, and Jessi** of Pittsburgh, PA

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**Dear Families of SMA,**  
Our family would like to extend a very special thank you for all your support during our recent fundraising events! You all have been tremendously helpful in reaching out to me with fundraising ideas, supplies and banners. Without your help, these events would not have been possible. We thank you for your quick responses and your timely information. Our goody bags for Annie’s 1st Birthday celebration were a huge hit! The golf tees, bracelets, magnets, flyers and angel cards were perfect and went home with over 300 people who attended! We especially thank you for the balloons that were sent for our release ceremony. This was a very touching experience and Annie received 300 SMA balloons on her birthday! We cannot thank you enough for your support! Together, I know we will continue to do great things for SMA awareness!  

Sincerely,  
**Nicole Grimes** of Bowling Green, KY  
Mother of SMA Angel Annie

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**Garrett Grimes**
Everyone at FSMA,
Keep on Researching!
Our Aly May is 14 now and is doing so well; she even has her own “helper dog” Stuart. She is our Inspiration!
God Bless your researching!

Sincerely,
Joanne and Larry May
of Birchwood, WI
Grandparents to Alyson May of Mahtomedi, MN

Dear FSMA,
Thank you for your tireless efforts to research, heighten awareness and find a cure for SMA.

In honor of our Sawyer’s 9th Birthday, we made a donation to the “Wall of Strength.” Please accept this additional donation in his memory.

We are forever grateful for the love and care FSMA showed us during our son’s life and for the support you all continued to give, even after his passing. Because of FSMA, we know we are not alone, have made friendships to last a lifetime and are given a hope for a cure through all the good you do.

Thank You!
Sincerest wishes and gratitude,
Amy, Jason, Mimi, Devon Smith of Crofton, MD

Hi FSMA!
We received the care package today and I must say, WOW. I was not expecting all that! Gavin loved all the toys and so did his big brother, Caden. It feels really good to have so many great resources and know there is so much support out there.

Enjoy the pics!
Thanks Again,
Cassie Stech of Chaska, MN

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Dear Families of SMA,
We would like to thank our dear friend Lauren Lundy O’Connor for running a race in Central Park on a very cold and icy morning in December in honor of our son, Dylan. Lauren, thank you for all that you do to help raise awareness for SMA. You are one amazing woman. We also appreciate Lauren coming to cheer Dylan on in his first ever Wheelchair Basketball Tournament. Thanks for all that you do for Dylan and our family, Lauren.

With love,
The Cuevas Family of Rockville Centre, NY

———

Masie Bognatz
Hello FSMA,
Our two year old was recently diagnosed with SMA and we had never heard of SMA. Needless to say, we were stunned and terrified.

FSMA has helped us tremendously already. The doctor’s read from a book and really didn’t tell us much at all. We greatly appreciate all you’ve done so far and our daughter loved her care package. Please let us know if there is anything we can do to show our thanks.

Thank you so very much.
Sincerely,
Joe, Heather and Masie (The Bognatz Family) of Carbondale, PA

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Dylan Cuevas with Laura Lundy O’Connor

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Gavin Stech
FSMA,

As anyone in the SMA family knows, the diagnosis is the first step in a journey typically unparalleled in virtually all ways up to that point. Like the vast majority of you, Randy and I were stunned to learn that we harbored genes capable of producing anything more challenging than a few inconvenient allergies, and devastated to learn that the havoc of Type I included death at an unfathomably early age. Our third baby, Jeffrey, certainly brought a surprise to our family in more ways than one. Choosing not to give in to the pessimism displayed by the rather arrogant neurologist, Randy and I set out to prove Dr. Doom wrong via an alternative route; ‘alternative’ to simply biding our time until SMA had made its complete rounds. Because there was next to nothing in the way of information in 1997, we tried herbs, vitamins, chiropractic treatment, therapeutic electrical stimulation and were investigating BiPAP and gabapentin when we hit a snag (to put it mildly), courtesy of an overzealous pulmonologist. At that time, our steady prayers shifted to requests that Jeffrey earn his wings peacefully at home, with just our family present. He did just that at 5½ months.

It’s no surprise that our lives were changed because SMA changes everyone unwittingly hurled into this family. While we have never stopped rooting for our other two children in their endeavors, it is SMA that has pushed me personally into obsession mode. Randy and I won’t be having any more children (we’re grandparent age now!), but Matthew and Katie will have families one day, and I’d prefer not to do battle with SMA again. Consequently, I have spent the years since Jeffrey’s brief earthly stay trying to think of ways I could best contribute to the collective quest to end SMA’s wrath. I decided to write a book.

The Jeffrey Journey is based on notes I kept during our Jeffrey assignment, and while the ‘end’ isn’t a shocker, perhaps the fact that it includes humor and optimism is. One of my favorite parts of the book is the Special Dedication, with one section honoring those living with SMA, and another serving as a memorial. There were a few hundred names in the first edition (2003); a few revisions later, there are over 1,000. And that brings me to one purpose for writing now. If you’re interested in becoming a part of this project, please contact me! If you’d like to submit a name, all I need is the name as it should be listed, including a nickname if desired, and whether it belongs in the ‘honor’ or ‘memorial’ section. There are no restrictions regarding age, date, location, type of SMA, or number of names submitted. If you have SMA yourself, please don’t hesitate to submit your own name! One look at the list of names in the dedication is proof that they - we - are by no means alone. If you previously submitted a name that needs to be moved to the ‘memorial,’ please let me know. I’ve tried to keep up with new angels, but I’ve surely missed more than a few. The dedication as it is in the most current edition of the book, available at Amazon.com. At some point I will update with the changes for the next revision, but I don’t know when I’ll be able to get to that.

My other purpose for writing is that my good friend/fellow SMA mom, Cindy Schaefer, and I write a blog - The Suite Life of Lucy and Ethel. Cindy’s son, Kevin, is 17 and fast approaching his senior year in high school. Her experience with the challenges and frustrations of Type II presents a different perspective of SMA. And while it’s an eclectic blog, we love focusing on SMA families and projects, so if you would like to be featured, please let us know!

For questions regarding either the book’s dedication or blog, please contact me at

Thanks so much for helping!

All the best,
Helen Baldwin of Jefferson, NC
Mother to Angel Jeffrey Baldwin

FSMA,

I dedicate this assignment in memory of my daughter, Mia Noelani Garza, (September 15, 2003 – April 14, 2006). As part of my college class assignment, I was required to find an organization and design a poster and a tri-fold brochure about the organization. I chose Families of SMA because I had a child with SMA and was interested in educating the public about the effects of the disease and some of the misconceptions I experienced while having a daughter with SMA. Research about the organization was easy since I already had much of the information I needed. I just needed to contact FSMA for the logo they were currently using. I had photos of friends I met because of SMA, and also the new friends I met at a fundraiser, of which I had a part, for the SMA organization. I got permission from Steve and Becky Long, in order to use the photo of Steve and their son Jackson.

All in all, I was one of the last ones to present my poster and tri-fold brochure. My goal was to educate and inform, and along the way, many classmates’ hearts were touched by my story of strength, hope, encouragement and eventually loss. My greatest desire is for the discovery/invention of a cure so that no one else has to suffer loss. I hope that the poster and brochure is something that can be passed along to others, such as families in need or friends. Each of you can touch so many people, so much more than one can do alone. I hope you use the brochure and may it affect and touch one person at a time. Who knows? Your “one” may be the one to make a difference for us all. May the Lord bless, strengthen, and encourage each and every one of you.

With hugs of hope,
Irma Garza RDH, B.F.A. of Taft, TX

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FAMILY photos

The Navarro Family

The Hernandez Family

The Kettler Family

The Campbell Family

The Armbrustmacher Family

The McHale Family

The Lino Family

The Rush Family

The Turnbull Family

The Saxton Family

The Patrick Family
Congratulations to the Stack Family of Seattle, WA, on the birth of their new baby girl, Juliette Grace Stack!

Congratulations to the Meigs Family on the birth of their beautiful twin girls, Isabella and Calla!

Congratulations to Jim, Alesha and angel Josiah Weiberg on the birth of their new baby girl, Journee Marie, born January 13, 2011!

Congratulations to Charles and Sapna Pringle, and big sister, Maya, on the birth of their new baby boy, Kayden Neal!

Congratulations to the Johnson’s on the birth of their new baby girl, Samantha, born February 11, 2011!
Families of SMA invites you to join SMA Community Connections

Everyone at Families of SMA is extremely excited to offer an enhanced FSMA Community site to replace the forum section on our website. This community site allows families from all over the world to connect with each other to chat, organize, and share stories, photos, news and information. Just log in and start sharing. 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 you and your family. In just 9 months, we have over 1,800 members including SMA families, doctors and researchers. There are a significant number of newly diagnosed SMA families who have joined the site and are looking to connect with experienced SMA families for advice and support.

If you have not already joined SMA Community Connections, sign up today at www.smacommunity.org to check out our newest features!

Some of the new features include:

• A 2011 Family Conference group which allows conference attendees to connect with one another before and after conference as well as receive any updated information on the conference.

• The 2011 Conference Agenda is now available on the community for all members to see.

• Go Facebook - This Facebook service allows you to sign into SMA Community using your Facebook account and it allows members to “like” our Community which will then be automatically posted to your personal Facebook page for all your friends to see!

There is also a Comprehensive SMA Resources Section with information, links & articles on the following important topics: genetics, respiratory care, nutrition, physical and occupational therapy, orthopedics, palliative care, education for SMA affected individuals, parenting issues, adapting toys for SMA children, Standard of Care documents, equipment, home renovations & accessible designs, insurance, travel and books on medical information and life with SMA. A total of 33 Presentations which were given at the 2010 SMA Annual Conference are now available for download and viewing. Recorded Care Workshops from the 2010 conference can be viewed online at SMA Community. These videos include: Respiratory Care Choices, 911: Ambulance Services & Emergency Medical Care, Q & A Session with Researchers, and Primary Care: Staying Connected With Your Primary Care Provider. The community also has Commonly Asked SMA Questions, with searchable answers from our Medical Advisory Council.

Care Package Recipients

Josef Stoop

Jessika Parry
Maya Pringle

Madison Wolff ice skating with friends

Makalya and Mariah Adamas

Gray and Riley Dougherty

Jenna Boguhn playing vet

Jaelie Williams

Dylan Cuevas and Owen Cain

John Rossmiller

Gavin and Big Brother Caden Stech

Jeremiah Hinkle with the feather from the care package

Morgan Steward

Lizzy Hallam

Greer Ramsay

Evan Odenwalder

Nicole and Alli Juntunen

Sophie Frederick
Julian Lewis with Sister Siena

Phillip Mayer

Kai Kai

Madi Wolff and Bella Andrade

Kennedy Swann

The Weisman Sisters

Nicole Barrett

Malorie Fox

Audra and Lucy Butler

Greyson and Vivian Erwin

Jack, Rose and Howard Gellner

Lily, Charlie and Emma Sykora

Maci Fournier

Lyza Weisman
SHARING page

Beatriz Sampaio Bastiao
Brett Kingsley
Addison Tarrence
Addison & Carlee on Horse

Bri Johnson
Casey O’Neil
Carolyn Barrett
Anita Balisteri
Alli Juntunen

Aubri Navarro and her mom Shelley Lopes
Ava Johnson with Mom

Braelyn Campbell
Brooklynn Santos in dancing school

Angel Young’s 1st Birthday
Angel & Madison Wolff with Kurt Warner
Avery Schmid
Aiden Bundy and Alexa

Families of SMA
uniting families with researchers to find a treatment and cure for SMA

Researchers
Visit the site to learn how the registry can help connect you to the people and data your research needs.

Participants
Visit the site for more information or to learn how you can join the registry.

This project is supported by the Patient Advisory Group of the International Coordinating Committee for SMA Clinical Trials, which includes Families of SMA, FightSMA, the Muscular Dystrophy Association, the Spinal Muscular Atrophy Foundation, and other SMA advocacy groups.

For more information call 1-866-482-0248
e-mail smareg@iupui.edu  https://smaregistry.iu.edu
437 Quilts and Counting…

As of March 1st, Montana Grandma has made over 437 hand sewn quilts for the Families of SMA Newly Diagnosed Care Packages. Cindy Bobolz, aka Montana Grandma, is grandmother to Nora Madison Gooden, who has SMA Type I. She started the quilt project shortly after Nora was diagnosed over a year and a half ago. “I felt the pain of my son, TJ and daughter-in-law, Jaime, as they faced this incredible ordeal of living with SMA. And through them I realized many other families were going through the same pain. So I decided the way to help was to make a quilt for each child. I’ve made over 437 quilts so far with many more in the works.”

These beautiful quilts arrive weekly at the FSMA National Office, full of bright colors, unique patterns and lots of love and determination. Each quilt arrives at a Newly Diagnosed families’ house in their care package, once they contact Families of SMA.

Montana Grandma is currently retired and living in a small town in the mountains of Montana. She has been sewing for over 50 years and quilting for over 35 years.

If you have received a quilt from Montana Grandma and would like to share your comments with her, please check out this website dedicated to her and her amazing quilting abilities, www.smaquilts.com. This website was created by Nora’s parents, TJ and Jaime, to allow everyone in the SMA Community an opportunity to connect with Montana Grandma.