Seven years ago, Nancy & Mike Morris (former NFL Vikings long snapper) approached my family asking how they could help raise funds for SMA. Their daughter, McKenzie, was in preschool with my daughter Abbey, SMA II, and they saw her challenges first hand. The KFAN Superstars Events began in Nancy & Mike’s dining room with Pat Reis, of Tee-To-Green Events, and myself. We started with a handful of dedicated volunteers consisting of a few SMA families and friends. At the time KFAN was looking for a new charity so we decided to partner with them and hoped to create more awareness. Our first year goal was $15,000, and despite not selling out the golf tournament, we actually raised $70,000. The next year we raised $110,000 and from there have averaged about $250,000 each year. This year we reached another major milestone by raising $1 Million that has gone directly to FSMA National for research. It is so incredible to see where our grassroots efforts have taken us in just seven years. This is something we all have to be proud of.

Two years ago, Joe Gallagher and his company, Filo Products, helped bring us to a whole new level. They work directly with Dan Krolczyk of KFAN, Charlie’s Angels (the auction committee) and Tee-To-Green. Together they plan and promote all year to ensure we maximize our potential.

Two years ago we also met Jeff and Melissa Martineau-Andrade. Their daughter Bella has SMA. Jeff is the founder of the Home for a Cure for Families of SMA. They have built and auctioned off two homes, and a third is planned for this spring. We incorporated this event into “The

continued on page 3
Dear Friends,

Welcome to the fall edition of the newly redesigned FSMA newsletter “Directions.”

There are several modifications that we have made to Directions and our other major publication “Compass.” One of the most obvious is our new design, we have also simplified and focused the content of our publications so that information will be easier to find and read. It might seem like this change would cost us more money, but to our excitement this new standard format is actually going to cost about 20% less per issue to print and produce, allowing us to dedicate those funds to other areas in the FSMA research budget.

With Directions, we are going to focus on providing information that has a practical benefit to you today, such as useful medical and legislative updates and inspiring community stories. We also want to celebrate your fundraising accomplishments. We have removed the section of donation listings which we will now produce twice a year in a separate dedicated publication.

With Compass, we are going to provide you with updates on the progress and future plans of our research efforts to find a treatment or cure for SMA.

We would love to hear any opinions that you have on these modifications. In the near future we also plan to update our website to make that cleaner and easier for you to use.

In this edition of Directions, we have a fantastic cover story of a huge milestone that has been reached by our fundraisers in Minnesota. Their efforts are truly inspirational. We also have summaries from some of the sessions at the recent family conference that was held in San Diego.

Please try to save the date for the 2007 Research and Family Conferences, which will be held jointly in Illinois from June 20, 2007 to June 23, 2007.

This will be a very important year for FSMA as we expect to reach a critical point in our primary drug discovery program as we transition from testing in the lab to testing in humans. This has the potential to become the first novel designed treatment for SMA being tested in patients. Along with this is a goal to expand our existing clinical trials with new studies and new sites.

We hope that this and future editions of Directions will keep you informed with interesting and practical information on what is happening in the SMA community.

Kenneth Hobby
Executive Director, FSMA
Superstars” so we now host: The Aim for a Cure, Superstars Golf Classic and Gala, and The Home for a Cure.

KFAN Radio dedicates the entire day and broadcasts live from the golf course from 6:00am to 7:00pm with a radio-thon. They promote the tournament and FSMA. Families, including some of the kids with SMA, share their stories. It shows what courage, determination and strong spirits they have.

Our signature event at the golf tournament is a butterfly release. The SMA kids, siblings and parents release them. What a sight this is, and it symbolizes freedom from the disease for all the children. Butterfly sales have played a big role, where anyone can sponsor a butterfly in honor or memory of someone, raising over $50,000.

It is quite an emotional yet rewarding day. You know you are doing the right thing when you have people, including celebrities, tell you what a great event it is and ask what can they do next year and that they all want to come back.

It is also exciting when all of the local SMA families join us at our annual gala. This year a new venue helped us to host over 500 people. The kids with SMA have so much fun with their friends, in an environment where they are all equals. It is also an opportunity for our donors to see what they are supporting, since SMA remains a relatively “unknown” disease.

We always show a video of the SMA kids and angels made and produced by Bailey Neigum a young man with SMA and there is never a dry eye in the place. It really shows the effects of SMA and that no two children are alike.

We could not have accomplished what we have without the support of so many people. There are a lot of people behind the scenes who don’t ever get credit, but they know who they are and how much we appreciate their commitment, love, support, prayers and compassion. We cannot thank everyone enough; to KFAN for giving us a day to share our stories, to keep our hopes and dreams alive; To Mike & Nancy Morris for starting it all; Filo Productions for all they bring; Pat Reis for all you do, and all the volunteers, SMA families and friends, sponsors, donors and celebrities. These kids deserve so much more, they are all such gifts and have taught us all so much and we will keep going because as Audrey Lewis says, “Together we WILL find a cure”!

**CHAPTER SPOTLIGHT**

**Alabama Chapter Barbecue June 2006.**

On the left is Beverly Golightly, Treasurer and Tonya Willingham Vice President of the AL chapter.

On the right is a picture of Michael Kelley, SMA type II.
Learning to Love Political Campaign Season

By Spencer Perlman, FSMA Legislative Affairs

While those of us in Washington, D.C. have been closely following the election for some time, the traditional start of the “campaign season” for those “outside the Beltway” is Labor Day. It is during this time that most folks will begin to notice an inordinate amount of advertising by political candidates seeking your vote. You may find this to be a nuisance or downright annoying, but I implore you to look at this as an opportunity for you, your family, and the FSMA family.

Election Background

On November 7, 2006, Americans across the country will go to the polls. While there is no Presidential race this year, the election nevertheless is of great importance as voters will determine which party is in control of the United States Congress and State legislatures, and, in many States, the Governor’s mansion. Voters will be selecting an individual for every seat of the U.S. House of Representatives, one-third of the seats in the U.S. Senate, most State legislatures, and 36 Governors.

On the Federal side, the U.S. House and Senate currently are controlled by Republicans by historically narrow margins; 231-201 in the House (with one Independent and 2 vacancies) and 55-44 in the Senate (with one Independent). Most political observers anticipate the election to be tightly contested and believe that Democrats have a realistic chance to capture the House and an outside chance to capture the Senate. From the State perspective, while currently there are more Republican Governors than Democratic Governors, many of the gubernatorial races are very close and there is a realistic chance that the Democrats could make gains.

Many Republican pollsters and supporters admit that their party is in peril and they are fighting hard to maintain their advantage in the Congress and the Governor’s mansions across the country. Conversely, the Democrats are aware that the current political climate is advantageous to them as the “opposition party” and they are putting forth an intense effort to win the Congress. Since the election is so closely contested, candidates will be particularly tuned in to the needs of their constituents. This can be advantageous to the public seeking to make contact with their elected officials.

Reaching Out to the Candidates

During a campaign, candidates (whether incumbents or challengers) are more available and open to their constituents (or potential constituents) than at any other time. Take advantage of this opportunity to meet the people who will be making the decisions that affect your lives and introduce them to SMA and the challenges associated with living with this disease.

With a quick check on-line, one can find out who is running to represent you and their campaign schedule. Take the time to attend a rally or town hall meeting and make the effort to meet face-to-face with the candidate. While you are shaking their hand, explain to them that you are the parent of (or living with) SMA and that you implore her to support greater research funding for SMA. Before they move on, ask for a business card and the name of a staff person with whom you can follow up to discuss the issue in greater detail. This will help you to get your foot in the door and begin a relationship with your elected officials.

Communicating with Members of Congress (or potential Members) is among the easiest and most effective ways for the SMA community to raise awareness of policymakers to issues of interest and concern. Communication can result in garnering support for Families of SMA’s public policy priorities. Follow up with a phone call and/or a letter. The FSMA website legislative section has a Top Ten List for writing your Member of Congress. Take five minutes of time to read the suggestions at http://www.fsma.org/la_contact_congress.shtml and send a letter to your elected officials. One may use a similar format to contact one’s representatives in the State legislature.

Becoming an Advocate for the SMA Community

Establishing a relationship with your elected officials has several benefits. First, it provides you with an avenue through which to communicate your thoughts, ideas, and frustrations as well as your suggested solutions. Secondly, it raises the awareness of yet another elected official to SMA and Families of SMA. Creating a critical mass of awareness and support for SMA will help us to push for our legislative agenda, whether incorporating SMA within newborn screening panels, increasing research funding for SMA within the National Institutes of Health (NIH), securing greater resources for special education, or greater support for respite care programs.

I hope that you will take advantage of election time to meet the folks who are running to represent you. Please feel free to contact me at spencer@fsma.org if you have any questions or if you are looking for additional advice on how to make contact with political candidates.
Oct 28 Chatsworth, CA
4th Annual Zeke Lerner Bowl-A-Thon. Saturday, October 28, 2006 at AMF Rocket Lanes in Chatsworth, CA (near Los Angeles) For detailed information, please contact Andrea Rosenthal at andrearosenthal@gmail.com or go to www.bowl4fsma.org

Nov 9 Saugus, MA
Join us once again for the 3rd Annual Comedy Night at Giggles Comedy Club and Prince Pizza Restaurant (on Route 1 Southbound) for another night of laughs and fun. Tickets are $30 per person and must be purchased in advance. Your ticket includes a night of comedy with free “all you can eat” pizza from 6:30 to 8:00PM followed by an hour and a half of comedy with performances by three professional comedians. Once again the night will include a raffle table with lots of great prizes. For more information, ticket reservations and/or to help out, please contact Joanne Schamburg at joanne@yourpromosolution.com or Christine Boulter at christine.boulter@verizon.net

Nov 11 Milton, Ontario, Canada
Angel Gala for SMA - Dinner Dance and Silent Auction, starting at 5:30 pm at Glencairn Golf Club located at 9807 Regional Road 25. It will include a Silent Auction, Live Auction, Draws, Door Prizes and Raffles. There will be a limit of 250 tickets sold - 25 tables of 10 people- each at a cost of $100.00 per ticket. Tickets can be ordered from Theresa Van Fraassen vanfraassen@cogeco.ca

Nov 12 Phoenix, AZ
Walk-n-Roll to Cure SMA. Please contact Holly Cottor at azwalk-n-roll@cox.net

Nov Queens, NY
Karaoke to Cure SMA. More details to come - if you are interested in helping please email Debbie Cuevas at debra-lyn34@hotmail.com

2007
Feb 23 NJ
5th Annual Steven's Gala at Cherry Hill Hilton. More info to come - contact Jessica Moyer at jnjmoyer@comcast.net

Be a “Directions” Contributor
Photos, poems, articles based on your knowledge and experiences, summaries of great FSMA Fundraisers…we wan’t them all! This is your chance to share. Your contributions will help to make this publication even better. Please email text either in the body of an email or attached as a word document. Photos submission requirements are:

- dimensions 1600 x 1200 pixels
- jpg format
- 2 megapixel
- Approx. Print Size 4” x 6”

All materials can be sent to newsletter@fsma.org or via mail to the National Office, Newsletter, Families of SMA, PO Box 196, Libertyville, IL 60048-0196.
Families of SMA—Equipment Pool

Hidden behind the front office of National FSMA is a little known resource available to Families of SMA members. FSMA maintains an equipment pool where families can borrow medical equipment that includes:

- Power Wheelchairs
- Manual Wheelchairs
- Adapted Strollers
- Bi-Pap Machines
- Cough Assist Machines
- Nebulizers
- Feeding Systems
- Adapted Chairs & Tables
- Various Standers
- Bath Chairs & Accessories
- Walkers
- Assorted Therapy Aids
- Car Beds & E-Z-On Vests

The majority of these items have been donated by families in order to help other families in need. Other items have been purchased by FSMA to better assist with the needs of our members. Prior to issuing any equipment to members, and upon receipt of newly donated and/or returned items, every piece of equipment is tested to ensure it is in proper operating order.

There is a larger list of items available listed on the FSMA web site (www.curesma.org). However, not all items in our warehouse are posted, so a family looking for a specific piece of equipment should always double-check with the National Office by phone (800-886-1762) or via e-mail (equipment@fsma.org). If the equipment in question is not currently in stock, we maintain waiting lists so that you can be notified if the equipment you requested was returned or a new donation was received.

In addition, medical supplies are donated to FSMA on a frequent basis, and are on-hand within the equipment pool. Although brand names, styles, and sizes tend to greatly differ, please inquire about such equipment should the need arise (be sure to provide specifics).

Medical supplies typically found in the warehouse include:

- Tracheostomy Tubes (Assorted Brand Names, Styles, & Sizes)
- Suction Catheters (Assorted Brand Names, Styles, & Sizes)
- Kangaroo Feeding System Supplies
- Tubing for Nebulizers, Respirators, Suction Machines, Etc.
- Masks for Nebulizers, Respirators, Cough Assist Machines, Etc.

Equipment distributed is loaned to members at no charge and FSMA requests that any items not being utilized be returned to FSMA so they can be passed onto another member in need. We also welcome donations of equipment that your family may no longer be using; those donations may be tax deductible. Please contact the National office if you have either equipment or medical supplies to donate.

Some items in our pool will require a fully refundable, minimal deposit. Deposits are reimbursed to the member upon return of the item in good condition and working order. In order to keep the cost of maintaining this equipment pool at a minimum, FSMA will ask borrowers to split the shipping costs with us. The member pays the costs involved to personally receive the item and Families of SMA covers the shipping necessary to return the item to its warehouse.

(Unfortunately, due to customs and other shipping challenges, FSMA can only ship equipment within the continental United States).

NOW AVAILABLE

There is a new DVD that gives you an inside look at the daily respiratory care regimen of an SMA I family. This video provides a basic introduction to respiratory equipment often used to manage SMA, a step-by-step guide through a typical respiratory treatment session, many helpful hints, and a close look at how a young child with SMA can respond to such a program. Based on the concepts taught by pediatric pulmonologist Dr. Mary Schrot, this video can help newly diagnosed and also experienced families who are seeking options or a clear method of managing the respiratory complications of SMA during illness and beyond.

“This video provides a comprehensive overview of commonly used respiratory equipment and therapies for patients with SMA. This video is an invaluable tool to teach families the basics of home respiratory care and support.” Dr. Mary Schrot, MD

“A real life look at the daily respiratory care of an SMA I child. This step-by-step guide is an excellent example of a proactive approach that can positively impact quality of life for a child with SMA.” Dr. Kathryn Swoboda, MD

To receive a copy of this free video, please contact Families of SMA at (800) 886-1762.
Pfeiffer House Music is raising funds for a cure for SMA. Steve Oostdyk of Pfeiffer House Music learned about SMA when his niece Sydney Grace Potjer was diagnosed. Steve wanted to raise awareness and help raise funds to find a cure. He has set up a page about Sydney and SMA on his site and is offering a special deal for donors to FSMA. During checkout, they ask customers to donate to FSMA. If a customer makes a contribution of $10 or greater to FSMA they will receive a free Songs for Kids CD with their order. For more information see http://www.pfeifferhousemusic.com/songs.

“Angel Wings Awareness Quilt” We are collecting names of angels and dates and this quilt will continue to grow until a cure is found. As soon as a vehicle is found we will be taking this quilt cross country to fundraisers and events to display to raise awareness www.kaydence.org.

April Callahan has created a gospel CD with all profits going to FSMA. Clips from some of the songs can be heard at http://jeffrenner.net/music/sohl/sounds-ofhislove.htm. If you want to purchase online, you can do so at this site using PayPal. You may also contact Jane Whitis at janewhitis@charter.net if you prefer paying by check.

Custom Scrapbook Pages by Jenn Griffin of Middleboro, MA, in memory of her daughter Brittany Leigh Griffin. Anyone interested in having a scrapbook page made, either in memory or in honor of their child can send $5 to Jenn. Parents need to let her know if the page should be in memory, in honor, boy, girl or religious. All proceeds go to FSMA. Email JennGriffin3@aol.com.

Order Current Fun items - gifts, wraps, cards and more - 50% of sales goes to FSMA. See the catalog at http://currentfun.com/category.asp. After you select an item, choose the state of Vermont, then Families of SMA from the drop-down list. For more information, contact Sue O’Neill at caseyandcolinsmom@yahoo.com.

Moving?? Help FSMA at the same time. Use our FREE referral service to a Preferred Real Estate Broker in your area and we will donate our referral fees on your behalf to FSMA. For example, on the purchase of a $200,000 home, FSMA would receive a generous donation of approximately $1,200. Rusinak Real Estate is an independently owned real estate company in Colorado Springs. Through their affiliation with RELO, the Leading Network of Real Estate Companies of the World, they can connect you with the best Realtors at the best real estate firms. For additional information contact: Vicki Caldwell at 800-481-3485 or relocation@rusinak.com.

GoodSearch: Search with Goodsearch.com, select Families of SMA and help raise money with every internet search you make. This site is powered by Yahoo!, so you’ll get the same quality search results that you’re used to. What’s unique is that they have developed a way to direct money to FSMA with every click. The more people who use this site, the more money will go to research! So please spread the word to your families and friends. Go to www.goodsearch.com for more details.

Foundation Assistance Needed

FSMA members do so much it’s hard to ask them to do more, but there is one thing some of you may be able to do rather easily to help us. That is to put us in touch with Foundations that might be willing to help fund FSMA’s mission. Some of you may well have access to a foundation through your company, a family member, a relative, or a friend. And while it is true that many foundations have very specific missions, they are often amenable to proposals that come to them from their Director or a Trustee. If you know of a foundation that may be willing to assist us, please contact the Families of SMA office (800-886-1762 or sma@fsma.org). We can work with you on how to best approach them, and what kind of proposal would be most suitable. Your efforts in this regard could pay enormous dividends.
La Familia Mercado Fundraiser for Families of SMA
written by Paulina Mercado

The 2nd Annual Fundraiser hosted by La Familia Mercado for Families of SMA was another success! With the support from our family, friends, co-workers, and all of the generous corporations, we were able to raise about $25,000. Held again at Joe's Sports Bar, in Chicago, IL, the setting was comfortable and enjoyable.

The kids totally enjoyed it. My son, Anthony, said, “Mom, this fundraiser was way better than last year. I had a lot of space to drive around and play”. The adults were entertained with free Latin dance lessons, karaoke, and a “live” Latin Jazz Band. Jared Montz, from the Chicago Fire, attended the event and donated 4 tickets to a Chicago Fire game. Ozzie Guillen, from the Chicago White Sox, donated a signed baseball.

Although planning the 2nd Annual Fundraiser was overwhelming, we could not help but decide to do this all over again in 2007! So, again, keep your eyes and ears open for the 3rd Annual Fundraiser by La Familia Mercado for Families of SMA, to help find a cure for Spinal Muscular Atrophy.

Concert for a Cure fundraiser
written by Nancy Dindzans and Mary McHale

The 6th annual Concert for a Cure was held on Saturday, June 24 at the Danville Community Center, in Danville, CA. The event is held in honor of Danny, Ariana and Isabella. It was a resounding success in every way! Our guests had a fun time competing for many exciting silent and live auction items, and enjoyed the opportunity to sit down with friends and family at the dinner. Although we didn’t increase attendance from the past year, we did increase the amount of money we raised from $72,000 last year, to over $85,000 this year!! For more information visit: www.concertforacure.org

Odds on a Cure Dinner & Casino Night
written by Mindy Rush

The 4th Annual Odds on a Cure Dinner & Casino Night, in honor of Savanna Rush and others with SMA, was on August 12th, in Saginaw, TX. It was a great time and we raised approximately $40,000! To date, we have raised about $135,000 for Families of SMA and know that will make a difference in helping to find a cure or treatment for SMA. Our event includes dinner, a silent & live auction, a raffle, casino and live music. We added a 52 card pick-up this year, which turned out to be great.

We had 2 prizes, each valued about $300, and had a deck of cards for each. We sold the cards for $10 each and sold out in no time. The people that attend each year always enjoy getting to meet the other SMA children and we were so proud to have 13 SMA families represented this year. What started as a simple wish for a small fundraiser, quickly turned into a big event!

The 7th Annual Bommarito Automotive Group and Ford Motor Credit Co. Golf Event

The 7th Annual Bommarito Automotive Group and Ford Motor Credit Co. Golf Event was held on May 21st in St. Louis, MO. The event, spearheaded by Rita Schmidt and Janet Hutchinson, had many families in attendance. They raised an unbelievable $100,000 for Families of SMA.

The 3rd Annual Northern California Walk SMArt, spearheaded by Linda Fernandes, raised $46,000 for Families of SMA.

Debbie & Ron Cuevas and Mariel & Jay McDonnell, of Long Island, NY, held the 2nd “Dylan and Kiley’s Walk-N-Roll”, in honor of their children Dylan and Kiley. They raised over $45,000 at the event.

Despite the terrible downpour, over 250 dedicated participants came to the 7th Annual Hingham, Massachusetts Walk-n-Roll. This event was established by Silvia and Brian Murphy in memory of their children Cianan and Cecilia and is now attended by many of the New England Chapter families and friends. Together they raised over $35,000. It took place at Wompatuck State Park,
The 1st Annual Abbey and Garrett’s Walk and Roll in Cornelius, OR raised about $6,000.

Pictured are Stacey, Steve, Aspen, Abbey and Garrett Hassel

where those who were willing to brave the weather enjoyed the beautiful scenery. No one wanted to linger, but they did enjoy a fun raffle, getting a hug from Snoopy and nibbling some snacks. The hot coffee and hot chocolate were much preferred over the cold water this year!

Steven’s Walk took place Saturday March 20th at Knight Park in Collingswood NJ. We had around 400 walkers and raised $32,336.61. There was face painting, water ice, lots of food, prizes, live band (Steven’s grandpop’s band), special guests such as Hammer from the Camden Riversharks Baseball and Phlex from the Philadelphia Flyers!! A great time was had by all and the Potter family is planning another Steven’s Walk in 2007.

Lisa and David Hamman, along with their children Jack and Savannah, held their 3rd Luau for SMA in Naperville, IL. The Luau was held on Saturday, August 19th at the “Hamman Seaside Resort” (aka – the Hamman family home). There was a pig roast, hulas, sand, games, music and mai-ta’s. They also had a raffle and silent auction. Thanks to great friends, family and great weather, the event was a great success. They raised $26,404 in memory of their son, Henry.

Kristi and Rod Gellner, of Fargo, ND, held The Jack Attack on SMA “Round 2”, in honor of their son Jack. The event was a huge success! North Dakota rounded up over 200 walk and rollers to show their determination to help “Knock Out” SMA. The event featured a 5k walk/run followed by a hot dog picnic. Games, balloons and face painting were all a bit hit with the kids. This year there were six “Fighting Champs” with SMA in attendance. They were: Jack Gellner, Trish Kuempir, William Novak, Vincent Peterson, Cole Pulrabek and Ashley Wohl. Each “Champ” was presented a medal in their honor. All together the event raised over $23,000 for FSMA.

Steven’s Walk
Amy Drysdale, of Rochester, MN, raised $8,000 for FSMA, in memory of her daughter Lindsey Ronningen, by hosting several fundraisers for FSMA. She sold angel donation tags at different establishments around her town. She also hosted a pancake breakfast and mini-raffle.

State Senator Steve Buoniconti, of West Springfield, MA, ran the Boston Marathon on Monday April 17th. The Boston Marathon is the world’s oldest annual marathon, and ranks as one of the most prestigious road racing events. This was the third year that Steve ran the Marathon, and had an official time of 3:53:34. He ran the marathon in honor of his daughter JoAnna and raised $7,000!

Kay and Vince Wittman, of Jerseyville, IL, held the 11th Annual Amy Wittman Golf Classic for Medical Research. The event, which is the largest golf tournament in Jerseyville, was held in honor of their daughter Amy. They have many friends and family that participate, including many of Amy’s friends, who have started golfing in the tournament. Luckily, they have a large extended family, so many of the participants are Wittman relatives! The tournament offers prizes for 1st, 2nd and 3rd place, as well as for getting closest to the pin and longest drive. The tournament raised $5,600.

Mike Belcher of Kirkland, WA and Marilyn Belcher of Lebanon, OR, held the 2006 Wannabe Golf Tournament. The event, in honor of Skylar Bahrenburg, raised $5,400 for Families of SMA.

An assortment of home party vendors, such as Tupperware, Pampered Chef, Tastefully Simple and Partylight, came together in Libertyville, IL, for the annual Kullander Family fundraiser. Sherri and Dave Kullander have held this FSMA fundraiser for several years. Each year, the event becomes bigger and better than the last! This year, they raised $5,300, in honor of Leo Kullander.

There is a very special organization in Orlando, FL, called the MOMS Club of Orlando – Waterford Lakes. “MOMS” stands for Moms Offering Moms Support. This special group decided to help other Moms that they had never met – the Moms of SMA children. They chose SMA because one of the members of the group lost their 10-month-old daughter, Kylie Grace Cahill, to SMA. The MOMS published a cookbook and sold 450 copies to families in the Orlando area. The proceeds of their cookbook totaled $4,700!

Eileen Lerner and the employees at Convergys in Sunrise, Florida held their sixth book sale in Zeke Lerner’s honor. The Convergys employees in Sunrise, Florida look forward to this event where they purchase books, CDs and DVDs at bargain prices. They read their books, watch their movies and then prepare for the next sale by recycling their purchases. Everyone enjoys it as they raise money for FSMA. This sixth sale brings total donations to $4700.

Rita Schmidt and Janet Hutchinson held their annual buffet lunch and silent auction at Outback Steakhouse. Stephen Burdi, of Outback Steakhouse, again donated all of the food for the lunch. There were several families that attended the event. They raised $4,000.

Chris and Allison Aversman, of Lexington, MO, sold t-shirts to raise funds for Families of SMA. They sold the t-shirts in memory of their daughter Haley Michelle and to celebrate her birthday. They raised $2,050.

In April, a group of Mom’s from Duxbury, MA hosted the 2nd Annual All Sport Tag Sale. They raised over $2,000 in honor of Darryl Dennelle and in memory of Annika Cedarlund.
On April 30th, Christopher Kraetz participated in the Minnesota Ironman Bike Race, covering 100 miles throughout southern Minnesota. His reason for riding was to raise funds and awareness for SMA. He rode in 40 degree weather, with a 25 mph headwind. During the course of his ride, it rained 3 inches. Chris rode in memory of A.J. Lutz and in honor of Lily Lutz, and raised $1,225.

This past May, Bruce and Delores Fry, of Winchester, VA, held the 8th annual Derek M. Smith Memorial Golf Tournament and raised $1,175.

The employees of the New York City office of Reed Smith raised $1,155 for FSMA, by hosting a “Jeans day” at their office in honor of Skylar Bahrenberg.

The West Rocks Middle School, in Norwalk, CT, raised another $1,000, for Families of SMA, in honor of one of the staff member’s son, Cubby Wax. Each year the school holds a fundraiser in support of FSMA and the Wax family. To date, they have raised over $10,000!

Diana Thornburg and the Golden Gate Smart Organization, of Watsonville, CA raised $600, in honor of Daniel McHale. The organization is made up of retired military from around the San Francisco Bay area. They raised the funds by hosting a silent auction, at an organization outing in August.

Paula and David Hoffmann, of Milwaukee, WI, held a raffle for Families of SMA during their annual block party. The raffle tickets were $2 each. During the morning of the block party, Starbucks donated coffee, which they sold at $1 a cup. They raised $414 for FSMA.

Kathleen Ochoa, of Homewood, IL, sold SMA Ribbon Car Magnets to raise funds for FSMA. She took over 70 orders for the magnets and raised $400, in honor of her daughter Chloe.

The Home Laureates Extension Homemakers Club, of Muncie, IN, sold holiday candies and nuts to help raise money for Families of SMA in honor of Katie and Betsy Swetnam. They raised $300.

Andrew, Erin, Keenan & Liadan Park, of Dubois, PA, held a yard sale to raise funds for SMA. They raised $250 in memory of their son and brother Tieran James Connor Park.

Rarely do you meet someone as giving of oneself as Jill Adler. Jill saw a news story by Michael Flannery on Channel 9’s, Nine on Your Kids Side news segment which had been done on Emma and Nicholas Lockwood. She was moved by the story and contacted the local chapter requesting information on SMA. For Christmas last year she had asked people to send donations to Families of SMA instead of giving her gifts, this year she ran the Flying Pig Marathon in honor of Emma and Nicholas and Families of SMA. Jill wrote letters to her family and friends telling about SMA and asking them to support her efforts. Jill ran the marathon, raised awareness of SMA and rose over an amazing $800 for FSMA. Thank you Jill!

Each year, the St. Joan of Arc Church High School Ministry program, in San Ramon, CA, puts on a musical for the parish. This year, Danny McHale was their inspiration and the teens collected donations to FSMA by selling water and cookies during intermission. They raised $700 in Danny’s honor.

Alison Dakss and Lionel Brown, of Waltham, MA, held a “Rock for a Cause”, in honor of Catherine Perkins. They raised $500.

Charles and Sharon Hutchens, of Homewood, AL, held “Zach’s Car Wash” on June 24th at Our Lady of Sorrows Church, in Birmingham. They raised $100.

Stephanie and Stewart Saxton, of East Fallowfield, PA, raised $60 in honor of their nephew Jake Saxton by collecting coins in the Families of SMA Coin Canisters.

In July, Brookdale Health, in Brooklyn Center, MN held a jeans day to raise funds for Families of SMA. They raised $85.
Abigail Leigh Lehner, of Salem, NH, turned 10 years old on May 27th. She decided that she wanted her family and friends to donate money to help find a cure for SMA instead of them buying her a birthday gift. She raised $285 for Families of SMA!

The students at Largo Senior High School, in Upper Marlboro, MD, held a penny fundraiser for one week. They collected enough pennies to raise $700 for Families of SMA, in honor of Malik Cosby, whose Mom is a teacher at the school.

For Tommy Testa’s 5th birthday party, he had a Star Wars theme. They had the Star Wars characters appear at the birthday party. The characters were from the 501st Legion Ohio Garrison. They do not take any money for their appearances, but instead ask that the fee be donated to a charity. They raised $450 for Families of SMA.

Andrew Sorrels, a seventh grader in Owensville, OH, needed a service project for boy scouts. He decided to conduct a basketball clinic for 4 hours a day, on two consecutive Saturdays and donated the fee to FSMA. Although he had a smaller turnout than he had wanted, the kids all had fun and he raised an incredible $175.

The students at PS 100 Q Glen Morris Elementary School in New York City raised $500 from their 2005 – 2006 Penny Harvest. They raised the funds, in memory of Deirdre Abraldes, for the toy box care packages that are sent out to newly diagnosed type I families.

Jackie Hoffmann and her friend Elizabeth Wachniak, of Milwaukee, WI, held a Kool-Aid stand to help raise funds for Families of SMA. They raised $36.65.

Sarah Darkow is a sophomore at Avon Lake High School, she is the older sister of Dan Darkow, SMA Type 2. Sarah wrote us this note…

For Jackie Hoffmann’s 12th birthday, in lieu of birthday gifts, she asked her friends and their parents to make donations to Families of SMA. Her birthday party, in Milwaukee, WI, was a surprise pool party. She raised $240!

Ethan Hynes, of Ridgefield, CT, decided to ask his friends to make a donation to Families of SMA, in lieu of giving him a birthday gift. His birthday party, held on June 25th, had a Red Sox theme and was held at Baseball Plus. His friends donated $510 in honor of Cubby Wax.

Dear Families of SMA,

My name is Jennifer Mannett and I am 12 years old and in the 6th grade. My friends and I decided to run a lemonade stand on June 11, 2006, and it was highly successful. Our best friend, Carly Hewitt, has type I SMA so we decided to donate all of the profits from our lemonade stand to the Families of Spinal Muscular Atrophy. Enclosed is a check for $100. We feel so great helping to make a difference. We hope to do this again and donate the profits to you.

Sincerely,
Jennifer Mannett, Erika, Monica & Jessica Donahue, and Allison & Robert Kern

Editors Note: Thank you Sarah! With your help and that of others we move closer every day. Together we will find a cure!
Dear Families of SMA,

My Name is Jessica Rosenberg. I am in the sixth grade at Bancroft School in Worcester, MA. In our English class, we did a program called Speak Out. Speak out is a program where we researched about a problem in the world and wrote a speech, made a poster, and gave a presentation about the topic. I chose spinal muscular atrophy. That was because I knew that there isn’t a lot of money donated towards it and how bad it was to have for the patient’s family. I also chose this topic because my family’s friend has SMA and I have seen how hard it is for her. She needs to use a scooter and has a hard time walking.

My activism for this problem was raising money. I raised money by doing yard work which both my friend and I together raised $20. I also participated in a bake sale at my school to raise money for our Speak Out program. In that bake sale, I raised $11.60. I also set up a fireball count where people can guess how many fireballs are in the jar. It cost $.50 to guess, and there were 24 guesses. So, I raised $12. I also recycled cans and made $3.15. In total, I raised $46.75.

I am donating this money to your organization because after doing my research, and writing my speech, it showed me how bad SMA is and why we need to cure this disease. So, I hope that the $46.75 that I am sending you contributes to your studies and helps you to find a cure as soon as possible.

Sincerely,
Jessica Rosenberg, Westborough, MA

---

Birmingham Car Wash fundraiser

Students of Racheal Luccasen at Our Lady of the Sorrows Catholic Church honor what would have been her nephew, Zach’s, first birthday with a car wash that raised over $2,500.

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Brownie Troop 103

On June 3rd, 2006 Brownie Troop 305, out of Chili, NY held a Toy and Book Sale with all proceeds going to FSMA.

The sale was held in memory of Meghan Emily Wiesner (06/03/03-06/27/03) on what should have been her third birthday.

SMA free twin sisters, Allison and Jessica Wiesner (8 years old) came up with the idea after watching Extreme Home Makeover with the Johnson family. They wanted to do something to help those living with SMA and to remember their baby sister. The Wiesner family is active members of the Western NY Chapter.

All the Brownies and parents chipped in to make the day a success and even on a gray rainy day $457.40 was raised with the sale of toys and books. The brownies also had a Brownie Special of brownies and lemonade for sale.

The leaders and parents are very proud of the girls and the Wiesner family feels very blessed to have the love and support of these special friends.
Holiday Letter Writing Campaign 2006

Did you know that Families of SMA will fund over $5 million in research this year?

Did you know that a majority of our donations come from families and friends?

Did you know that a FSMA letter campaign held in 2003 raised over $250,000?

This holiday season FSMA needs your help.
It is as easy as 1, 2, 3:

1. Fill out and mail, or fax the form below or email the information to let us know you want to participate.
2. Compile your mailing list and write a brief letter explaining to family, friends, doctors, therapists and co-workers, why FSMA matters to you.*
3. Take the packet that FSMA sends you (with the campaign letters and return envelopes) and MAIL!

FSMA will send thank you notes to anyone who donates and notify you of the donations received on your behalf.
We hope you will join us in this campaign. Together we will find a cure! Call us at 800-886-1762 or email info@fsma.org with any questions.

*If you need help with a letter, FSMA has examples available – check the website under the fundraising section or call/email the office and we can send them to you.

Families of SMA Holiday Letter Writing Campaign

Yes! I want to help, please send me

Full name(print):__________________________________________________________
Address:_________________________________________________________________
City/State/Zip:____________________________________________________________
Phone:_____________________ Email:_______________________________________

(number of letters)

Return form by FAX: 847-367-7623 or Email your information to: info@fsma.org
Mail: FSMA, PO Box 196, Libertyville, IL 60048-0196
This section has been designed to enable you pull it out. It includes membership forms, donation forms as well as a memorial section.

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**MEMBERSHIP form**

---

**Suggested Annual Donation for Membership**

<table>
<thead>
<tr>
<th>Category</th>
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<tr>
<td>Professional</td>
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<tr>
<td>International</td>
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*We ask for a donation for membership to help cover the costs associated with the printing and mailing of our newsletters. You should receive quarterly editions of both the Directions newsletter and Research Compass. We hope that these publications provide valuable information and useful support to all our members.*

**Payment Method**

- [ ] Check
- [ ] Money Order
- [ ] VISA
- [ ] Mastercard
- [ ] Discover

---

**Amount enclosed or to be charged**

---

**Return form to FSMA Membership, PO Box 196, Libertyville, IL 60048-0196 or FAX to 847.367.7623**

---
Donation Form

I want to make a donation in the amount of $ [ ]

In honor of ________________________________

In memory of ________________________________

Donor Name ________________________________

Donor Address ________________________________

Notice of donation—Name & Address ________________________________

Payment Method

☐ Check ☐ Money Order
☐ VISA ☐ Mastercard ☐ Discover

Credit Card # ________________________________

Expiration Date ________________________________

Name on card ________________________________

Signature ________________________________

Return form to FSMA Donations, PO Box 196, Libertyville, IL 60048-0196 or FAX to 847.367.7623

Gift Certificate Order Form

Retailer ________________________________

Qty ________________________________ $ Amount ________________________________ TOTAL ________________________________

Shipping Up to $499 - $8 • Over $500 - $10

Subtotal $ ____________

Shipping $ ____________

Total $ ____________

Payment Method

☐ Check ☐ Money Order
☐ VISA ☐ Mastercard ☐ Discover

Credit Card # ________________________________

Expiration Date ________________________________

Name on card ________________________________

Signature ________________________________

Return form to FSMA Gift Certificates, PO Box 196, Libertyville, IL 60048-0196 or FAX to 847.367.7623

Merchandise Order Form

Item ________________________________ Size ________________________________ Qty ________________________________ Description ________________________________ $ Amount ________________________________ TOTAL ________________________________

Shipping Up to $25 - $4 • $26 to $50 - $7 • $51 to $75 - $10 • Over $76 - $13

Subtotal $ ____________

Shipping $ ____________

Total $ ____________

Payment Method

☐ Check ☐ Money Order
☐ VISA ☐ Mastercard ☐ Discover

Credit Card # ________________________________

Expiration Date ________________________________

Name on card ________________________________

Signature ________________________________

Return form to FSMA Merchandise, PO Box 196, Libertyville, IL 60048-0196 or FAX to 847.367.7623
Connect. Be a Part.

Help find a CURE for Spinal Muscular Atrophy.

The International Spinal Muscular Atrophy Patient Registry is a resource by which individuals and families affected by SMA and researchers working on approved SMA research projects can be connected.

Patients have the opportunity to learn and receive information about the latest clinical trials and research studies for which they may qualify.

Researchers gain important statistical data that can benefit the entire SMA Community.

By registering information with the SMA Patient Registry you are in no way committing yourself to participate in any research project. Your name will not be released to researchers without your specific permission.

The SMA Patient Registry is coordinated by the Department of Medical and Molecular Genetics at Indiana University.

If you wish to participate in the International Spinal Muscular Atrophy Patient Registry, please contact Connie Garland at Indiana University by phone at (317) 274-5745 or by email at cjarlan@iupui.edu and she will mail you a registry packet. (Or see the Registry Information web site http://www.iupui.edu/~medgen/hereditary/sma.html and simply download the forms, fill them in and mail them.)
Creating a Memory…

In 2004 we decided to have a professional family picture taken because the last one we took was when Kathryn was one (she was 8 in this photo). We booked a photographer and an outdoor location so our family dog Jack could also be involved. But the family picture wouldn’t be complete without including our daughter Emily who died of SMA type 1 in 1999. Emily had a soft sunflower that played the song “You are my sunshine”. She loved that sunflower and everywhere Emily went so did her sunflower! Because Emily liked her sunflower so much we have added them to certain parts of our house. It was hard to think of a way to recognize Emily, I suppose most people would think why bother, but she was a part of our family if only for 4½ months and we believe that we are the family we are today because of her...So we decided to hold a sunflower, the picture was taken in black & white and the photographer highlighted the sunflowers yellow.

Even though we can’t hold Emily or see her everyday she is still part of our lives and always will be...

Caren Green

AYDAN EMMANUEL MABE
12/28/05–03/11/06
…and are about to step off into the darkness of the unknown, of this we can be sure either God will provide something solid to stand on, or We will be taught to fly.
We are but tenants and shortly the great landlord will give us notice that our lease has expired.

MEGHAN WIESNER
6/3/03–12/27/03

ANDREW “DREW” SEDOLOGY
10/14/97–5/18/06

SHAUN CAMPBELL
6/26/05–4/23/06

AMANDA MARIA CANARTE
1/11/93–5/13/94

TAYLOR LEE REAGAN
2/13/03–10/9/03

WOODROW HARDING
10/4/05–12/15/05
FSMA merchandise

Snowman or Angels of Hope Cards | $8
Set of 8 cards. Specially created for FSMA by Silvia Heller.

Holiday Note Cards | $5
Alyssa Silva's “Working on Walking” note cards for the holidays. 5 different cards.

Spring Note Cards | $6
Alyssa Silva's “Working on Walking” note cards. 6 different cards.

FSMA Holiday Ornament | $4

FSMA Ladies Vest | $30
Blue sizes: XS M L XL
Black sizes: S M

FSMA Golf Polo Shirt | $24
Sizes: S M L XL XXL

Cure SMA Bracelet | $2
Available in small or large. Created in honor of Steven Potter.

Wipe Out SMA | $12
1 design on short sleeve shirt.
Kid sizes: 2/4 6/8 10/12 14/16
Adult sizes: S M L XL

Cure SMA T-Shirt | $12
1 design on short sleeve red or white shirt.
Kid sizes: 2/4 6/8 10/12 14/16
Adult sizes: S M L XL

“Together” T-Shirt | $15 (short sleeve) $18 (long sleeve)
1 design on navy shirt. Kid sizes: 2/4 6/8 10/12 14/16
Adult sizes: S M L XL.
Long Sleeve, Kids sizes: 2/4 6/8 10/12 14/16

FSMA Famlies of SMA
www.CURESMA.org

Directions | Fall 2006
**FSMA merchandise**

**12 Fruit Notecards | $6**
4 each of 3 designs (12 cards). Artwork by Holly Campbell, in memory of nephew Charlie, SMA Type I.

**FSMA Lapel Pin | $5**

**SMA Awareness Pin | $15**
One design in sterling silver.

**Angel Wing Pins | $10**

**License Plate Frame | $7**

**12 Window boxes Notecards | $5**
4 each of 3 designs (12 cards).

**12 Charlie Notecards | $10**
Artwork by Merrle Peterson, in memory of son Charlie, SMA Type I.

**FSMA Travel Mug | $12**
Keep your coffee hot!

**FSMA Car Magnet | $5**
1 design.

**Canvas Tote | $15ea.**
Choose either Flower or Seascape design. Artwork by Katie Gardner 11/89–4/03.

**Canvas Tote | $10**
CureSMA design.

**Cotton Tote bag with Zipper | $17**
Together design.

**FSMA Tote Bag | $10**
2-sided design.

**FSMA Tote Bag | $15**

**SMA Sticker | $2**
Created in memory of Madison Vickers

**Donation Gift Card | $10ea. or 5 for $40**
Have you ever needed a gift for a teacher or a birthday gift for a “hard to buy for” person? These elegant cards are a perfect gift for when you want to thank someone for their kindness, honor someone who makes a difference in your life, or mark a celebration. Instead of buying teachers, doctors and anyone else another scarf or trinket, consider giving a FSMA gift card.
This is only a partial listing of gift certificate vendors.

For a complete list, please call the FSMA National Office at 800-886-1762 or e-mail colleen@fsma.org.

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<th>Gift Certificate Amount</th>
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<td>Amazon.com</td>
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<tr>
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<td>LL Bean</td>
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<td>Loew's Cineplex</td>
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<tr>
<td>Lord &amp; Taylor</td>
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<tr>
<td>Lou Malnati's</td>
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<td>Lowe's Home</td>
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<td>Improvement</td>
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<td>Old Navy (Gap)</td>
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<td>Olive Garden</td>
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<td>Winn Dixie</td>
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“Cookbook for a Cure”

The new Families of SMA “Cookbook for a Cure” cookbook contains over 350 recipes from SMA families all over the world!

- Available in December 2006, while supplies last.
- They make a perfect holiday gift!

Call the FSMA National Office at 800-886-1762 for more information.

Cookbook Order Form

Please send me _____ cookbooks at $14 each.

Subtotal: $_______
Shipping: $_______
Total: $_______

Payment Method

☐ Check ☐ VISA ☐ Mastercard ☐ Discover

Credit Card # ____________________________ Expiration Date ____________________________
Name on card ____________________________
Signature ________________________________

Ship order to:

__________________________
__________________________
__________________________
Phone ________________________________

Return this form to:
FSMA Cookbooks, PO Box 196, Libertyville, IL 60048-0196

Help us Create an FSMA License Plate.

FSMA member Michelle Vickers is working to create a FSMA license plate in Ohio. If she can obtain 1,000 signatures, of Ohio residents who will purchase the license plate, it will be made. The annual cost for this plate is $25, in addition to the annual registration fee. $15 from each plate sold will be donated to FSMA. Michelle started this project in memory of her daughter Madison Claire and all her little friends.

Contact Michelle with any questions or to sign the petition. vickersteam@aol.com

Join the FSMA E-List!

With each research breakthrough or other important event on the road to a cure, Families of SMA sends an e-mail to everyone on its e-mail list. If you would like to join our e-list please e-mail Bettylou Ross, our webmaster, at bettylou@fsma.org with the following information: (Use “subscribe FSMA” in the subject line.) Name, E-mail address, City and state or country of residence.
### Alabama Chapter (since 2005)
P.O. Box 680  
Trussville, Alabama 35173  
Phone: 205-661-6423  
Ann Peterman, President—alabama@fsma.org

### Arizona Chapter (since 1997)
P.O. Box 641  
Queen Creek, AZ 85242-0641  
(480) 752-8093  
Karey Kaler, President—arizona@fsma.org

### Chesapeake Chapter (since 1995)
P.O. Box 354  
Cockeysville, MD 21030-0354  
Tel: (800) 762-0113 or (410) 561-9355  
Barb Trainor, President—fsma-chesapeake@comcast.net

### Chicagoland Chapter (since 2000)
Call National for Details  
chicago@fsma.org

### Connecticut Chapter (since 2003)
P.O. Box 185744  
Hamden, CT 06518  
Tel: (203) 288-1488  
Jonathan Goldsberry, President—conn@fsma.org

### Iowa Chapter (since 2000)
P.O. Box 326  
Johnston, Iowa 50131  
Fax/Phone 515-986-2181  
Michelle Soyer, President—iowa@fsma.org

### Kansas City Area Chapter (since 2004)
P.O. Box 1214  
Mission, Kansas, 66222  
Tel: (913) 262-6468  
Natalie Gibbs, President—kansas@fsma.org

### Long Island New York Chapter  
(since 2006)  
P.O Box 322  
Rockville Centre, NY 11571  
Tel: (516) 214-0348  
Debbie Cuevas, President—longisland@fsma.org

### Louisiana Chapter (since 2005)
P.O. Box 1189  
Prairieville, LA 70769-1189  
Tel: (225) 744-3812  
Krista Scurria, President—louisiana@fsma.org

### Michigan Chapter (since 2004)
P.O. Box 500, Ada, MI 49301  
Tel: (517) 669-1665  
Ken Armbrustmacher, President—ka14@comcast.net or hollyschafer@comcast.net

### Minnesota Chapter (since 1992)
P.O. Box 1961  
Maple Grove, MN 55311  
Tel: (763) 370-6460  
Jeff Cowan, President—cowan.jeff@comcast.net

### New England Chapter (since 1987)
P.O. Box 2902  
Woburn, MA 01888  
Tel: (978) 256-9007  
toll-free (877) 256-9111  
Jim Gaudreau, President—newengland@fsma.org

### Northern California Chapter (since 1998)
P.O. Box 9014  
Santa Rosa, CA 95405  
Tel: (707) 571-8990  
David Sereni, President—ncalif@fsma.org

### OKI (Ohio, Kentucky & Indiana) Chapter (since 2004)
P.O. Box 541012  
Cincinnati, Ohio 45254  
513-753-8222  
Beth Lockwood, President—oki@fsma.org

### Pacific Northwest (since 2006)

#### New Chapter

P.O. Box 173  
Galvin, WA 98544-0173  
Rick Jones, President

### Pennsylvania Chapter (since 2003)
Box 4307  
Philadelphia, PA 19118  
(866) 647-8113  
Karen McRory-Negrin, President—pennsylvania@fsma.org

### Rocky Mountain Chapter (since 1998)
P.O. Box 102705  
Denver, CO 80250  
Tel: (303) 934-3094 or (877) 591-4023 (toll free)  
Julie Lino, President—rockymt@fsma.org

### South Jersey Chapter (since 2002)
P.O. Box 538  
Medford, NJ 08055  
Tel: (866) 774-9533  
Jessica Moyer, President—njmoyer@comcast.net

### Southern California Chapter (since 1999)
1070 E. Orange Grove  
Burbank, CA  
Tel: (818) 846-6589  
Rosemary Rooper, President—scalif@fsma.org

### Tennessee Chapter (since 2001)
P.O. Box 7025  
Knoxville, TN 37921  
Tel: (865) 945-7636  
Lise Murphy, President—tennessee@fsma.org

### Texas Chapter (since 2005)
P.O Box 627  
Hutto, TX 78634  
512-846-2239  
Rhea Canfield, President—texas@fsma.org

### Western New York (since 2003)
P.O. Box 444  
North Tonawanda, NY 14120  
Tel: (716) 622-0804  
Bonnie Shiesley, President—wny@fsma.org

### Wisconsin Chapter (since 1999)
P.O. Box 7402  
Madison, WI 53707-7402  
Tel: (608) 223-9408  
Marta Meyers, President—wisc@fsma.org

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**Are you interested in starting a new chapter for Families of SMA?**

Please contact our Chapter Coordinator, Barb Trainor at fsma-chesapeake@comcast.net
CHAPTER updates

Arizona
The Arizona Chapter joins up with many other Chapters across the country and will host the first ever “Walk N Roll” event on November 12, 2006. Please visit our website for more information. We hope to see you there!

Chesapeake
Many thanks to CIBC World Markets for their very generous gift of $25,000. Their gift was a result of their annual Miracle Day project where trading commissions earned during a day in December 2005 benefit various children’s charities, including FSMA. Special thanks to Cramer Rosenthal McGlynn, LLC and many other financial institutions who sponsored FSMA in this cause.

Rave reviews were received at the 13th annual Crab Feast. All enjoyed tasty and plentiful crabs. The silent auction has been a fun and important addition to the event. In all, the crab feast raised over $12,000.

The chapter is gearing up for its 12th annual CRM Golf Classic to benefit FSMA. To accommodate the demand of participating golfers they are moving up to 36 holes. Lastly, thank you to Caitlin Trainor, Sarah Koch, and several other students at Maryvale Preparatory School who made fleece blankets for babies. These blankets will be included in newly diagnosed care packages.

Long Island
The newly formed Long Island Chapter held the 2nd Annual Dylan & Kiley’s Walk N’ Roll to cure SMA on Saturday, June 3, 2006. The event was a huge success raising almost $50,000. All donations were in honor of: Kiley McDonnell, Max Rubenstein, Ross Rosenfeld, Alexa Rodriguez, Julia Lincoln, Connor Rummel, Ava, and Dylan Cuevas. The Rubenstein and Rosenfeld families raised over $20,000 between them. Congratulations!

New England
On Saturday, June 10th, 2006, FSMA New England chapter held its first annual 5k road race. And while it poured buckets, the race itself was extremely successful. The FSMA Dracut 5K Road Race, attracted 75 runners of all ages, and raised $10,000 for the cause. The chapter would like to thank our race committee members, Eileen Dufour and Laurie Cahill and their families, for their unending dedication in organizing the race and making it so successful. Additionally, another thank you to all our race committee members and all our FSMA Race Staff Volunteers, over 30 in total. Finally another thank you to Dracut’s finest, our police officers and fire fighters/ EMT’s, for lending their help with leading the road race, handling the traffic detail and making sure all our runners were safe and well taken care of.

OKI
The FSMA Annual Garage Sale took place June 16th and 17th at the home of Rick and Shelly Uhlenbrock in Newtown, Ohio. This is the 3rd year for this Garage sale in honor of Emma and Nicholas Lockwood, the Uhlenbrock’s niece and nephew, who have SMA Type I. Several families and their friends donated items for the sale helping to raise over $3500 for research. Thanks to Shelly,Rick, and their family and friends for all their hard work.
Rocky Mountain
It has been a busy few months for the Rocky Mountain Chapter. We hosted our 5th Annual Evening of Hope Gala Event on March 10, 2006. It was another fantastic FSMA event raising over $32,500 for SMA! Over two hundred and sixty guests attended this years Gala. They listened to the sounds of Bobby Marchetti…renowned adventure/climber, Jeff Evans kept the evening flowing as our EMCEE…and the evening concluded with SMA medical expert and Associate Professor of Neurology at the University of Utah, Dr. Kathryn Swoboda, MD who shared the latest in SMA research.
That amazing event was followed up by another very successful Scottish Stained Glass 3rd FSMA Charity Golf Tournament. The Vigil family continued a wonderful tradition that they began in 2004. During the month of August, they place a tea-light candle and note card in a small Ziplock ® bag and deliver it to friends and neighbors. They include a card that reads: “We would like you to light your candle wherever you are on Saturday, the 19th of August and think of Evan and all the other children who struggle with SMA and for the many who have lost the battle to SMA. Please, light your candle!”

Texas
The Texas Chapter had it’s first fundraiser on June 17th in Austin, Texas. We had our first annual Hill County Smoke Out for FSMA and we raised a little over $5000.00. Families from all over the state were able to attend and enjoy wonderful BBQ, live bands and a silent auction. Thanks to all of those that made our first fundraiser as a chapter very successful!!!

Western New York
The WNYFSMA Chapter SMArt Walk for a Cure was held on August 5th. The day was perfect for the 3 mile and 1.5 mile walks. A record number of 400 people raised over $52,000 to help find cure. Our biggest and best WALK yet!!! We had over 100 baskets, gift certificates and bikes that were raffled and raised about $3000. A 50/50 split was also held and Andrea Grieg graciously donated her winnings of $234 back to FSMA. We sold FSMA shirts, pins, car magnets and cards. A photo album was available for viewing photos from previous walks. A vintage racing truck with the FSMA logo, along with other sponsorship logos was available for the kids to enjoy. Pictures were taken with the kids inside and the families outside of the car.
Appreciation plaques were presented to our Gold and Silver sponsors and a special one was presented to the Matthew Reilly Team which raised over $15,000!
Plans have already been started for next years walk which will include a car raffle. The car is being donated at cost by KIPO Motors and tickets will sell for $20.
The chapter has also benefited from a variety of fund raisers. A pig roast was held by Kale Shiesley’s Aunt and Uncle and over $500 was raised to find a cure.
The chapter was also the recipient of proceeds from a Teddy Geiger concert. Teddy, who is the cousin of Alex Blair, preformed for a packed house at Club Infinity. A portion of the tickets sales and merchandise sales were donated to WNYFSMA. Teddy can be seen wearing the black and red FSMA bracelet in some of his posters. Also, there is a link on his web site to his charity of choice, FSMA.
The 3rd Annual Kale Shiesley Volleyball Tournament was held and once again was a success. The tournament, which is the brainchild of Kale’s uncle Rob Litten, raised over $2,800.
Our Children “Talk it Out” in San Diego

By Dr. Al Freedman and Angela Wrigglesworth

It was again my privilege to facilitate the second annual “Talk it Out” session for SMA-affected children at this year’s FSMA conference. Twenty children representing Kansas, Arizona, Oregon, Washington State, Georgia, Minnesota, Colorado, California, and Canada participated in this year’s session. The children and I were fortunate to be accompanied by Ms. Angela Wrigglesworth, a third-grade teacher from Houston, Texas who is affected by SMA. Angela shared important insights based on her experiences and contributed a great deal to our discussion. Together, Angela and I would like to give you a small glimpse of the time we shared with a wonderful group of young people.

When the children arrived for our session, we discovered the room was not large enough to accommodate all of us. The children impressed us immediately with their patience and positive attitudes as we located a larger space. Once properly situated, we introduced ourselves by sharing our names, hometowns, and any questions, concerns, or ideas we hoped to discuss during our time together. We also discussed the concept of confidentiality so everyone would feel safe sharing his or her thoughts and feelings. The children clarified that while they may choose to talk with their parents about our discussion, we agreed to not identify other children by name in order to respect everyone’s privacy.

A number of themes emerged during our session. First, for many in our group, this was their first experience being in the presence of so many other children affected by SMA. For most children, the opportunity to attend the session was a relief, while a few initially felt a bit overwhelmed. By the end of our session, we sensed that all of the children adapted to the experience quite well.

Secondly, our children have many questions: “Will I be able to drive a car?” “…How will kids treat me when I get to Middle School?” “…How should I react when adults stare at me?” “…Will my wheelchair make it hard for me to get a job when I get older?” “…Can I become a veterinarian?” “…Can I become a scientist?” “…Can I become a SMA researcher?”

Third, our children are extraordinarily perceptive and articulate. They are aware of the “advantages” of being affected by SMA: “…I get to be first in line at Disney Land” “…People give me free stuff all the time.” “…When the lift got stuck at the restaurant, we didn’t have to pay for our meal.” “…Everyone at school knows who I am.” “…Most people are really nice to me…” Our children are just as willing to speak their minds about the challenges they face every day: inaccessible buildings; insensitive adults; the stares of strangers; and the frustrations associated with the inability to walk or run.

Fourth, our children have aspirations: They want to go to college, get jobs, and make significant contributions: “I want to be…” “a veterinarian” “…a teacher” “…a SMA researcher…” Our children are determined. They believe that most things are possible for them. They are seeking our reassurance and support that their disabilities will not stop them from achieving.

As we listened to the children share their thoughts, feelings, experiences, ideas, and observations, we learned a great deal from them, and we believe they learned much from each other. All children need opportunities to speak and be heard—children affected by SMA have an additional need to speak and be heard as a result of the unique challenges they face every day. We highlighted the value of learning from the experiences of others, recognizing that there may be more than one way to approach a problem.

As the end of our session approached, we asked the children to think for a moment about a wish they have. Here are some of the wishes our children shared with the group:

“I wish we all could walk and run.”

“I wish that all buildings and houses had elevators or ramps so we could go everywhere everyone else can go.”
“I wish that all grown ups would talk with me instead of talking only to my mom and dad. Some grown ups don’t understand that I can think and talk for myself.”

“I wish people who think my wheelchair is cool would understand that it’s really hard to have to use a wheelchair.”

“I wish scientists could get rid of all diseases…not just SMA, but all diseases everywhere in the world.”

It was truly a privilege for us to be in the presence of such a remarkable group of young people. We are thankful for the opportunity to facilitate the children’s Talk It Out session.

I got to go to the “talk it out” session at the SMA conference. It was so fun. All of the kids in the session were able to talk about life in general. We enjoyed it because there weren’t any adults and we could talk about anything. It was nice being around so many kids that have the same disease as me. It was great having an adult that’s a teacher even in the session. An example was we talked about not being able to go upstairs. I hope all the conferences will now have the “Talk It Out” session!

Courtney Faye Smith, Type II, 9 years old, 4th grade, San Clemente, California

“Big Truths” Poem
By Courtney Faye Smith, Type II, 9 years old

I wish I were not so athletic.
I wish I were not so athletic.

My fantastic arms are very strong willed and determined to finish what they have started.

My fantastic arms are very strong willed and determined to finish what they have started.

I’ve won every U.S. Marathon and broken all their records.

If someone were to touch my head, my super powers would rub off on them and they too would become as incredible an athlete as me.

Dr. Al Freedman is a child and family psychologist in independent practice near Philadelphia, PA. His son, Jack, is 11 years old and affected by SMA Type I. You are welcome to contact Dr. Al via email at freedman@fsma.org.

Angela Wrigglesworth is a third grade teacher and graduate student in Houston, TX. She was diagnosed at sixteen months with SMA Type II. Angela can be reached through email at awrigglesworth@kleinisd.net.
Clogging for Awareness

A clogging group from around the Cincinnati area that used to be called Spectrum Dance Co. decided to change their name last year to SMA Cloggers. The group, of about 10 individuals, are either related to or good friends with Emma and Nicholas Lockwood. The SMA Cloggers felt this would be a good way to help spread awareness of the disease. They perform a couple times a month at Stonelick Lake State Park campground and some area festivals. At the beginning of each demo, a brief explanation of SMA is given and a little bit about Emma and Nick. Sometimes if weather permits, and Emma and Nick are doing well, they attend the performances and love participating in the Chicken Dance and Hokey-Pokey. This year the group has had shirts designed with Emma and Nick’s pictures on the back along with the words SMA Save More Angels. They don’t solicit for donations but spectators have given donations to help find a cure.

Thank you to the SMA Cloggers!

Spencer Cook, 19, has been working with Richter Architects during summer breaks while he pursues an architecture degree from the University of Texas. Spencer is pictured with the team at Richter. They have been a wonderful source of inspiration, motivation and experience for Spencer, but he has also impacted them as well. At the conclusion of Spencer’s work this summer, David and Elizabeth Richter made a donation to FSMA in Spencer’s honor!

Dear friends,

We are from the Czech Republic and we have 3½-year-old son Simon with SMA I. Simon is a very nice and clever boy, and we love him very much. Since he was six months old he has been on a ventilator. Although Simon has to overcome really big obstacles, he struggles hard and he is a very brave boy. SMA totally changed the life of our family, at the beginning we were helpless and depressed - but now we take it as a challenge. Many good friends are around who are coming and helping to take care of Simon and his enthusiasm for life is bringing a great encouragement to them. When we see how happy is he with his books, toys, movies, father, mother, grandma… we understand that the physical circumstances of our lives are not the most important things.

You can live an absolutely valuable life without your legs, arms… you need only a heart full of love and faith!

With love
Simon, Bohdana, Tomas Sedlacek

www.curesma.org

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“Being defeated is often only a temporary condition. Giving up is what makes it permanent.”

Above is Kale Shiesley in a drag truck. Notice the SMA logo on the side.

Below is Kale Shiesley and his sister Kyler doing a little belly time!

Joshua & Daniel Tramantano

Joshua & Anna Rose Scurria

Kennedy Caldwell (Type III) is doing her part to get the word out about SMA awareness month. Kennedy threw out the first pitch August 5th at a Sky Sox baseball game in Colorado Springs (the Colorado Rockies farm team). One picture is with Colorado Springs’ Mayor, Lionel Rivera and a photo of Kennedy, Wes Caldwell (father) and grandfather, Vince Rusinak.

Luke William Snyder

Morgan Kelly had a great time at the Preteen America Florida Finals! Way to Go Morgan.
taken for granted. Be flexible whenever possible; be straightforward and to the point. Always use more than one attendant, and have a backup plan available should it be necessary.

Insurance Ins and Outs–
• If you can afford it, purchase an individual insurance policy (in addition to your group plan). This would help if you need to initiate a lawsuit for any reason. You can’t sue for punitive damages under group coverage, unless your employer is a state employer.
• PRE AUTHORIZE, PRE AUTHORIZ E, PRE AUTHORIZE!!!
• Persistence is everything. If denied coverage, keep appealing. Use every outlet possible before giving up. Check out your state’s Department of Insurance website.
• Part of a doctors’ job is to advocate for you- enlist your doctors help.
• Keep all records- phone logs, mail, who you spoke with, etc.
• Meet your Senators/ Congressmen/ State Legislators- connections with these people are very valuable.
• Clinical visits are billable- research visits are not. Know what will be paid for (and how) if you are involved in a drug trial.
• Get a case manager assigned to your case if possible through your insurance company. They are required to document everything with you.
• Be sure to disclose to HR that you have a child with SMA.
• Estate planning- Set up a Special Needs Trust to leave assets for long-term needs, should your kids outlive you.

PT/OT/Orthotics
Physical therapy is for gross motor development, range of motion, flexibility, minimizing contractures and strengthening. Working on positioning and respiratory play are also important benefits. Occupational therapy focuses more on the upper extremities - hand function, arms, trunk support and again focuses on range of motion, flexibility and functionality. The best care is coordinated care - with the PT and OT working together - or at least communicating. Positioning and adaptive equipment are very useful and your PT/OT should be able to help you with this. Walkers were mentioned and the natural tendency is to go towards a light, small walker. SMA patients need a heavier, wider based walker. They tend to shift more and if fatigued need to be able to be supported by it. Reverse walkers also seem to work the best.

Orthotics should be used to help weakened muscles, for stability, and should not hinder function. The main brace that was discussed was the TLSO. It must be remembered that the TLSO does not prevent scoliosis. It is used to help maintain flexibility of the curve and hopefully delay scoliosis and the need for surgery. In many cases it also allows more arm control/movement by conserving energy that is generally needed for holding up the body. Important things to remember with a TLSO are that it should have an opening in the front to allow movement of the diaphragm and there should be ventilation. You also want to make sure it is lightweight and has total body contact. The longer you can postpone surgery the better - because the child will have more growth time. The thing to remember with scoliosis is not so much the degree of the curve as the flexibility of the curve. A few websites and companies were mentioned - WetVest, Danmar Products (neck float), www.keepingpace.com (for shoes to fit over orthotics).

Hospitalization
Most SMA families will endure a hospitalization sometime in their lives. Many will endure multiple hospital stays and if you’ve already been through one, you know just how frustrating and down right scary they can be.
This session provided helpful tips and guidelines to prepare us all for what might happen. It was a compilation of SMA families and their experiences covering the acceptance that you may have to teach the medical team about SMA, suggested SMA practices, hospital staff hierarchy, respiratory apparatuses and how a written protocol may help in these situations.

See the FSMA web-site under Medical Issues for the PowerPoint and example protocol for more information.

Using The Web
The “Using the Web” session was an opportunity to meet with BettyLou Ross regarding the new First Giving website that can be used for fund-raising. This is primarily for Walk n Roll events but has the potential to be used to collect money for other events. Using the web has great potential for simplicity for donors as well as mass communication for participants.

I created a demo site, located at http://www.firstgiving.com/kevencogginDEMO.

The Healing Process
During this workshop, Dr. Trotman helped us talk about the feelings that we seem to keep bottled up inside of us instead of talking about them. We also realized that everyone does not grieve the same as their partners or family, which sometimes can cause an uncomfortable relationship. The worse thing to ever happen to a person is to lose a child. It seems that you will never heal from this disaster, but learn to cherish the time that you did have with your precious one.

We received a hand out on the second day of the session. It explains the “Tasks of Mourning. They are 1. Accept the Reality of the Loss. 2. Experience the Pain of the Grief. 3. Adjust to an Environment Where the Deceased is Missing. 4. Withdraw Emotional Energy and Reinvest in Other Activities and Relationships.
Grief is what we feel on the inside. Mourning is emotions we let other people see on the outside.
Those of us who have suffered the loss of a child with SMA experience a great loss. We not only lose them in the present, but also their future (graduations, marriage, children, etc.) and our future (their live experiences, grandchildren, etc.). A loss means an unexpected change for the rest of our lives. Losing a child disrupts the natural flow of things. Parents do not normally outlive their children. Although mourning doesn’t last forever, this is not something you can just “Get Over”. None of us, who have experienced that loss, will have that expectation. If you want to mourn, go ahead and cry. We know that the pain is great inside. Don’t keep it bottled up. Talk with someone, it will help. We have had the same feelings since we lost our child to SMA.

**PGD (Pre-Implantation Genetic Diagnosis)**

Dr. Stern’s presentation first reviewed the recent history of progress in SMA research.

Because there is no cure for SMA at this time, families who have been affected by a diagnosis of SMA face difficult decisions regarding future pregnancies. Options relating to family planning include: 1) a decision not to have more children, 2) “play the odds” by conceiving again naturally, 3) natural conception with pre-natal testing via CVS or amniocentesis with the option to terminate the pregnancy, 4) adoption, 5) in vitro fertilization (IVF) with donor sperm or egg, or 6) IVF with PGD

A PGD cycle involves the creation or embryos by IVF from the parents’ sperm and eggs, followed by the testing of the embryos for the presence of absence of SMA (or other genetic disorders), and finally the transfer of non-affected embryos to the uterus such that, if pregnancy is successful, the child will very likely be unaffected by SMA. The advantage of PGD is that it allows genetic analysis to be performed prior to implantation and initiation of pregnancy.

The PGD technology was first developed in 1985, and it was first used clinically in humans in 1990. Currently, over 1,500 PGD cycles have been performed for genetic disease testing, and 6,000 for chromosome testing of embryos.

The PGD process is initiated when the fertilized egg is approximately 72 hours old. By this stage, the embryo (blastocyst) has divided several times to form a cluster of 6-8 individual cells. Under a microscope, a single cell (blastomere) is removed (biopsied) from the cluster using a fine glass needle (pipette). The nucleus of this cell houses the DNA. DNA in the cell is then analyzed for the presence or absence of exons 7 and/or 8 on the SMN gene. The absence of one or both of these exons would result in a diagnosis of SMA. Data from animal experiments and more than 2,500 human live births after embryo biopsy does not indicate that the biopsy process leads to an increased incidence of malformation or other birth defects.

Upon completion of PGD testing, any remaining viable and SMA-free embryos are considered for implantation into the uterus on day five after retrieval. The number of embryos implanted is determined based upon the woman’s age and fertility clinic’s policy. Affected embryos may be discarded or donated for research purposes. A pregnancy test is performed 14 days after retrieval. In cases of a positive pregnancy test, many patients elect to undergo CVS or amniocentesis to verify the results of PGD testing.

When considering IVF with PGD, there are numerous issues to discuss in order to make a sound and informed decision. First, there are possible complications with the IVF cycle including poor egg production, fertilization problems, multiple gestations, ectopic pregnancy, infection and bleeding (rare), and ovarian hyper-stimulation syndrome (OHSS). With PGD, there is the concern that all embryos might be affected by SMA or that SMA-free embryos will not be of high enough quality for implantation. All these factors elevate stress levels, create worry that the process may not work, and therefore result in a high emotional investment. Financial costs are very high and can run as much as $18,000 - $20,000 for one combined IVF cycle with PGD.

Insurance coverage is extremely variable. Some may cover PGD, but not IVF. Statistically, PGD testing has proven to be close to 99% accurate, particularly when testing is done using two blastomeres from each embryo and when done in conjunction with the appropriate link markers derived by taking DNA samples from parents and determining their carrier status. While there are several reputable labs performing PGD, it is important to note that there is no established regulating authority or standardized regulations governing the application of this technology. It is imperative that those considering PDG fully understand the testing procedures and protocol, weigh the emotional and financial cost against the possible outcomes, talk with several labs about their successes and failures, and talk with families about their experiences with PGD at various facilities.

**New FSMA Celebrity Spokesperson Announced**

Attendees to the keynote address at the FSMA Family Conference were suprised by Constance Ramos, a designer on ABC’s Extreme Makeover: Home Edition, who worked on the home of a FSMA member, the Johnson Family, last year. Ramos announced to the group that she was going to donate her time and serve as a celebrity spokesperson for FSMA! More details on this exciting announcement, and pictures from her participation in an FSMA Walk ‘n Roll, will be in the next issue of Directions.

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**Spokesperson Announced**

**CONFERENCE summaries**

Spokesperson Announced

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**Special Thanks to Staci Bailey, Beverly Biesemeier, Vicki Caldwell, Bradley Campbell, Kevin Coggins, Amy Marquez, Eric Ostermeyer and Ann Peterman for conference summaries.**
Advocating For Your Child: Knowledge is Power-
The most important thing to remember with advocating is that you are your child’s best advocate! If something doesn’t make sense to you, don’t agree to it. Advocacy is an attitude. Don’t be rude, be real. Your goal is to get a result. Be sure you are educated on the language and terms used by doctors, insurance, hospitals, etc...If you do not know what a code is or a word means - look it up or find it out.

When you go into a conversation with someone be sure you have the right attitude. But go in with a goal in mind and keep working towards it. People truly do want to help-let them.

• Know your insurance policy and know what your coverage is. If you are denied, appeal, keep appealing and don’t give up. Be sure to look up the Department of Insurance in your state.
• Get clarity. The time you spend understanding the language will be time well spent. An IEP can be changed, but make sure it says what you want it to say. Children with other neuromuscular diseases. Respiratory therapy is different, too. A pulmonologist needs to know SMA needs and differences.
• Bracing doesn’t correct a spine curvature, but can slow progression and get a child to an older age where growing will be less of an issue. Age 10+ is optimal.

Physical/ Occupational Therapy and Bracing-
• Make stretching a part of your child’s daily routine, but not on too tired days where it will be counterproductive.
• SMA is rare and since doctors don’t see it very often, different doctors will have different treatment options. SMA kids develop very different than kids with other neuromuscular diseases.

College & Independent Living Lecture
In an effort to pick a college, start by choosing an end goal (career of choice), and narrow future goals down to a major; from there, find the college best suited for the major and personal needs. Choose a career best based on your personal tastes and interests, as well as physical realities and capabilities. Visit and spend time with someone working in your career or profession of choice; this will allow hands on exposure to field and duties involved ensuring it is what you want for the duration of your life.

Going to college is an investment. A college education brings about higher wages, more options along career lines, opens many more doors of opportunity, and enhances independence.

Check out the local hospitals and medical staff; introduce yourself to medical professionals in the area, and provide a medical history of your condition before health becomes an issue. Research available means of transportation in the area.

Going to college while living with a disability requires one to research any accessibility related issues and available attendants. Be sure to conduct dry runs of the campus grounds and your schedule; make sure you have enough time in between your classes to arrive on time. Take the time to personally visit and introduce yourself to your professors; explain what your needs will be as a student in their classroom.

College life requires that you, as a disabled student, balance your goals with your health and physical needs. Pace yourself; take time for yourself when needed. Be persistent; set goals for yourself and stick with them, despite setbacks. Do not be afraid to ask for help, both from other students and academic staff. Do not restrict yourself to the disabled community; able bodied students need to interact with you as much as you need them.

College life offers a huge step in independence and with that comes the concept of working with attendants. It will be up to you to recruit, interview, hire, and train attendants. Be certain to thoroughly go through the job routine prior to hiring any attendants; run background checks on potential candidates. Working with attendants is often a give and take, but do not allow yourself to be