



# DIRECTIONS

FAMILIES OF SPINAL MUSCULAR ATROPHY



## 2008 Family & Professionals Conference Review

Boston, MA



We had record attendance this year at our Annual Conference in Boston. The interactions with the local community were particularly impressive.

Our Annual Conference reflects the key steps that we are working through as we aim for our ultimate goal of a cure for SMA. In particular this year we focused on how everything that we have accomplished so far has

Families of SMA hosted the **12th Annual International SMA Research Group Meeting** in Boston in June. It was our biggest research conference ever with over 90 SMA research presentations given, 250 scientists in attendance, and many biotech and pharmaceutical companies represented.

During the research meeting, Project Cure SMA - the clinical trial network funded by FSMA - presented the first results from the Phase II CARNI-VAL Trial that tested the combined drug regimen of carnitine and valproic acid. A summary of these results as well as additional updates regarding SMA clinical trials can be found in the latest edition of our research newsletter "Compass".



been built from the strong base of our community. Since 1990, Families of SMA has invested over \$2 Million to bring our community together every year. Our Annual Conference allows critical networking between families and researchers. We have been able to show a tremendous amount of progress just since 2000 through significant increases in the number of SMA clinical trials, companies involved, and drug discovery programs.

### We are now working on our plans for 2009!

This will be a special year for our community as it will be the 25th anniversary of Families of SMA. We are pleased to announce that the 2009 Conference will be in Cincinnati, Ohio from June 18th to June 21st.

Our goal for this special anniversary is to reach the milestone of raising and then investing a total of \$50 Million for SMA research.



The 2008 Families of SMA Conference in Boston was a great success. We had record attendance of over 800 researchers and families. The interactions with the local community were particularly impressive, including a special day with the Boston Red Sox. Mayor Menino proclaimed an "SMA Awareness Day" for the City of Boston, and Governor Patrick did likewise for the Commonwealth of Massachusetts. Senator Kerry also addressed the conference stating his strong support for Families of SMA and the efforts of the SMA community to identify a treatment and cure.

2009 will be a special year for our community as it will be the 25th anniversary of Families of SMA. The 2009 Conference will be in Cincinnati, Ohio. Our goal for this special anniversary year is to reach the milestone of raising and then investing a total of \$50 Million for SMA research.

Please make sure to visit our new web site at [www.curesma.org](http://www.curesma.org). We hope that the new layout and features will help in providing support and updates to families and also in raising funds for SMA research.

Over just the last year Families of SMA was able to raise \$5.1 Million! Due to our thousands of volunteers, we are able to dedicate over 80% of all funds raised to SMA research. This was a record year of fundraising and we owe it all to our amazing families and chapters who devote so much time and effort to helping our community move towards a treatment and cure. Thank you all for your amazing commitment!

We are focused solely on developing a treatment and cure for SMA, and we attempt to dedicate the majority of our funding directly towards SMA research. With your support we were able to invest in the following SMA programs over the last year:

- Over 20 basic research grants were funded.
- The largest SMA research and family conference ever.
- Three translational research programs: including two leading drug discovery programs, and the most advanced motor neuron replacement safety studies.
- Three clinical trials.

Your efforts drive all of the progress we are able to make towards a treatment and cure for SMA.

Sincerely,



Kenneth Hobby  
Executive Director,  
Families of SMA



## Mission Statement

Families of SMA is dedicated solely to:

- Eradicating spinal muscular atrophy (SMA) by promoting and supporting research
- Helping families cope with SMA through informational programs and support
- Educating the public and professional community about SMA

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

## Submissions

To submit articles or make other contributions to our newsletter, please contact us at: [newsletter@fsma.org](mailto:newsletter@fsma.org).

Digital images are encouraged! Send your digital pictures to: [newsletter@fsma.org](mailto:newsletter@fsma.org)

## Change of address

Send changes, including ZIP code to:

**info@fsma.org** or call **1-800/886-1762** or mail to: **FSMA, Membership, PO Box 196, Libertyville, IL 60048-0196**

This newsletter is published 4 times per year. ©2008 Families of SMA. All rights reserved. No portions of this publication can be reprinted without written consent from FSMA.

FSMA does not support or endorse any particular treatment or therapy. Information contained in this newsletter should not be used as a substitute for consultation with a qualified healthcare professional.

June 19-22, 2008 | Boston, MA

## 2008 FSMA Family & PROFESSIONAL CONFERENCE

**RepliGen**



Booz | Allen | Hamilton



**genzyme**

**charles river**  
accelerating drug development. exactly.







**June 19-22, 2008 | Boston, MA**

## 2008 FSMA Family & PROFESSIONAL CONFERENCE





## Carnival Photos

See Website  
for Presentations  
& Photos



Kevin O'Brien, Gene Trainor and Jim Gaudreau.



June 19-22, 2008 | Boston, MA

2008 FSMA Family  
& PROFESSIONAL  
CONFERENCE



### Senator John Kerry (D-MA) Addressed the Families of SMA Annual Conference.

During his address Senator Kerry indicated his strong support for Families of SMA and the efforts of the SMA community to identify a treatment and cure.

Senator Kerry also announced that he had signed on as a cosponsor to the SMA Treatment Acceleration Act. Families of SMA thanks Senator Kerry for his strong support.

See the FSMA website to view the video from the conference.



Mike and Paula Barrett and Mary McHale at the Carnival.



Murphy Potter blowing bubbles.



## Kids talk it out 2008



June 19-22, 2008 | Boston, MA  
**2008 FSMA Family  
& PROFESSIONAL  
CONFERENCE**



Researcher relay race at the conference.



**See Website  
for Presentations  
& Photos**



## Play Ball! for SMA with the Boston Red Sox was held on Saturday June 21st in Connection with our Annual Conference.

This was a memorable event to benefit Families of SMA hosted by the World Champion Boston Red Sox at legendary Fenway Park. The event was held in conjunction with the largest conference in the world for SMA that was brought to New England for the first time, along with a state-wide SMA Awareness Day.

Red Sox pitcher Curt Schilling gave a fantastic speech in support of Families of SMA at Fenway Park. "...if there is going to be a final dollar, someone is going to donate that final dollar that will make it happen. I would love to have it be mine....."

See the FSMA website to view the video of the whole speech by Curt.

This was an incredible event to help raise awareness and funds for SMA research.



**Curt Schilling at Fenway Park event.**

Grand Slam Sponsor



Home Run Sponsor

**Booz | Allen | Hamilton**





## A VERY SPECIAL THANK YOU TO:



### **Barbara Trainor – Conference Coordinator.**

Barb has spent the past year coordinating this year's "Beantown: The SMA Revolution" Families of SMA Conference. She organizes the booking of speakers and schedules the workshops. She is the main contact for all the details of our hotel. Barb has spent many hours organizing the conference schedule, including key aspects such as the main banquet and the silent auction.

Barb is also the Families of SMA Chapter Coordinator. She spends countless hours of volunteer time guiding families to help them form new chapters, and then leading the existing 23 Chapters to ever greater heights of fundraising success and providing family support. She is always there to help the 123 chapter officers. All of this is done on top of her very busy schedule raising her two daughters, running the very successful FSMA Chesapeake Chapter, and being a member of the Families of SMA Board of Directors.

### **Adapting Toys Workshop**



# thank you

to the following Vendors for their ongoing support:

**AAA Medical**

**Davismade -Standing Dani**

**Hanger**

**Eye Tech Digital Systems**

**Permobil, Inc.**

**Promotional Solutions**

**Respironics**

### **We are now working on our plans for 2009!**

This will be a special year for our community as it will be the 25th anniversary of Families of SMA. We are pleased to announce that the 2009 Conference will be in Cincinnati, Ohio from June 18th to June 21st.

Our goal for this special anniversary is to reach the milestone of raising and then investing a total of \$50 Million for SMA research.



**Some of the FSMA staff.**





## Comments on the New Families of SMA Website

LOVE the new logo and colors!!! Such a nice change!! *-Megan Piper*

I just took a quick look at the new website...Looks good and seems easy to navigate. Congrats to all involved. *-Marge Shively*

Just to let you know again how much I love the new website!! Toooooo cool! Very informative!

**One of these days I am going to write a book on how my life changed the day a princess was born. All about Lizzy, SMA Type I, diet, experiences, care, etc....and the great people like you I have met on the way!**

You guys worked really hard on the site you can tell! Love it all! All the new info is invaluable!!! Thank you for all you do for these kids!!!!!!!!!!!!!!  
*Hugs, Jeanna Huette*

I have checked through your website which is an excellent site that has provided us with enormous help, guidance and information...thank you!!  
*-Connie Kirk*

**Pretty cool. Love it!!!! A lot of info!! Good Job!!!!!!!!!!!!!!**

Congratulations on the new web site!  
Looks much nicer than the old one! *-Andris Dindzans*

We love the new website!! It is great! *-Amy Smith*

I just noticed Sam's toy list on the new site. Thank you very much, as we like to see our daughter is helping - again thank you! *-Mary Jane Utzat*

**What a tool this is! Thank you so much and whoever selected this application made a very wise decision!** *-Doug Doebbert*

**I think it is great!!**  
*-Julie Vanderspool*



## SMA Symposium at the Annual Meeting of the American Society of Gene Therapy

### Innovations in Gene Therapy for Neurodegenerative Diseases.

The goal of this symposium was to bring together outstanding investigators with a common interest of treating neurodegenerative diseases to facilitate active discussions and collaborations. We believe this discussion will further the development of gene therapies for SMA, ALS and other neurodegenerative diseases.

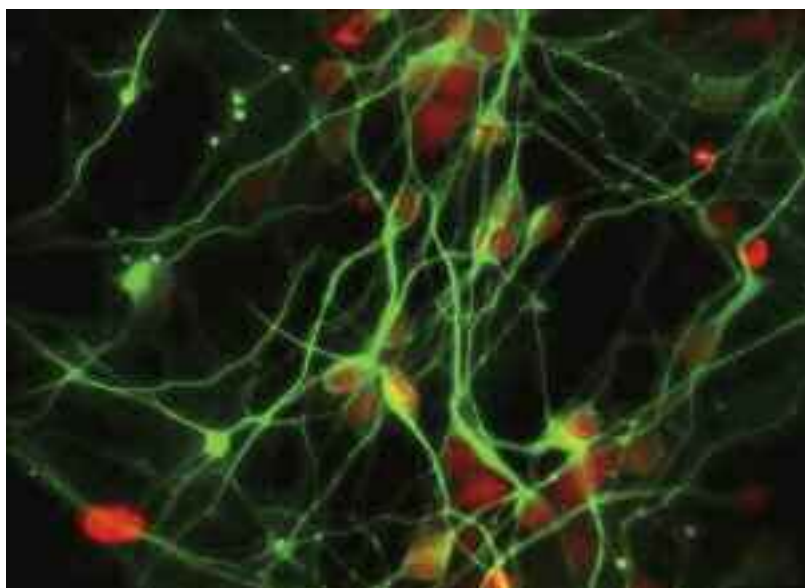
President of the American Society of Gene Therapy acknowledges Families of Spinal Muscular Atrophy and other groups for contributing to their annual conference.

An excerpt from a letter from ASGT President David M. Bodine, Ph.D.:

"A final highlight was the outstanding evening symposium presented by a team of five Patient Advocacy Groups. ASGT would like to welcome the ALS Association, Families of SMA, Fight SMA, the Muscular Dystrophy Association, and the SMA Foundation and we hope that our meeting will be the catalyst for productive collaborations between our members and the clinicians and patients your fine groups are representing."

## Stem Cell Research & FSMA Partners California Stem Cell & UCI Featured in Forbes

By Kerry A. Dolan and Robert Langreth 05.28.08



**A**n excerpt: Stem cells offer the hope of providing an unlimited supply of living human cells for use in drug discovery and cell transplant therapy. The hard part is coaxing stem cells to turn into the various types of cells that are needed for research--muscle, bone, neuron, liver cell pancreas and so on.

"The hope of stem cells is just a hope and nothing more" without an efficient method of turning them into different types of adult cells, says Hans Keirstead, a stem cell researcher at University of California, Irvine, and a member of California Stem Cell's scientific advisory board.

He says the premise behind California Stem Cell is to create an efficient process for generating large, pure batches of various types of brain cells and other cells. So far, his company has created motor neurons, heart muscle cells, neuronal progenitors and heart pacemaker cells.

California Stem Cell is working with the charity, Families of Spinal Muscular Atrophy, to use motor neuron progenitor cells made from stem cells to treat this disease. SMA is a genetic disease that strikes children and causes muscles to waste away because they cannot make a crucial protein needed for motor neurons to survive. A trial for this therapy could begin next year.

### Results Published in Annals of Neurology Entitled, "Sustained Improvement of Spinal Muscular Atrophy Mice Treated with Trichostatin A Plus Nutrition"

**T**he paper, published by the research group of Dr. Charlotte Sumner at Johns Hopkins University and partially funded by Families of SMA, shows for the first time sustained survival in SMA mice after using a specific drug regimen.

This regimen entailed early treatment with the histone deacetylase inhibitor trichostatin A (TSA), starting on day 2 post birth and nutritional support including infant formula by mouth and subcutaneous fluids, starting on day 8 post birth. Average survival time was extended by 170%, while in experiments using just TSA treatment alone survival was extended by 40% and by 19% when TSA alone began later on day 5 post birth. Nutritional support alone did not extend survival times.

TSA is not suitable for human use, but other potent second generation HDAC inhibitors are currently being explored as possible treatments for SMA.



## Groups Release Family Version of SMA Care Standard

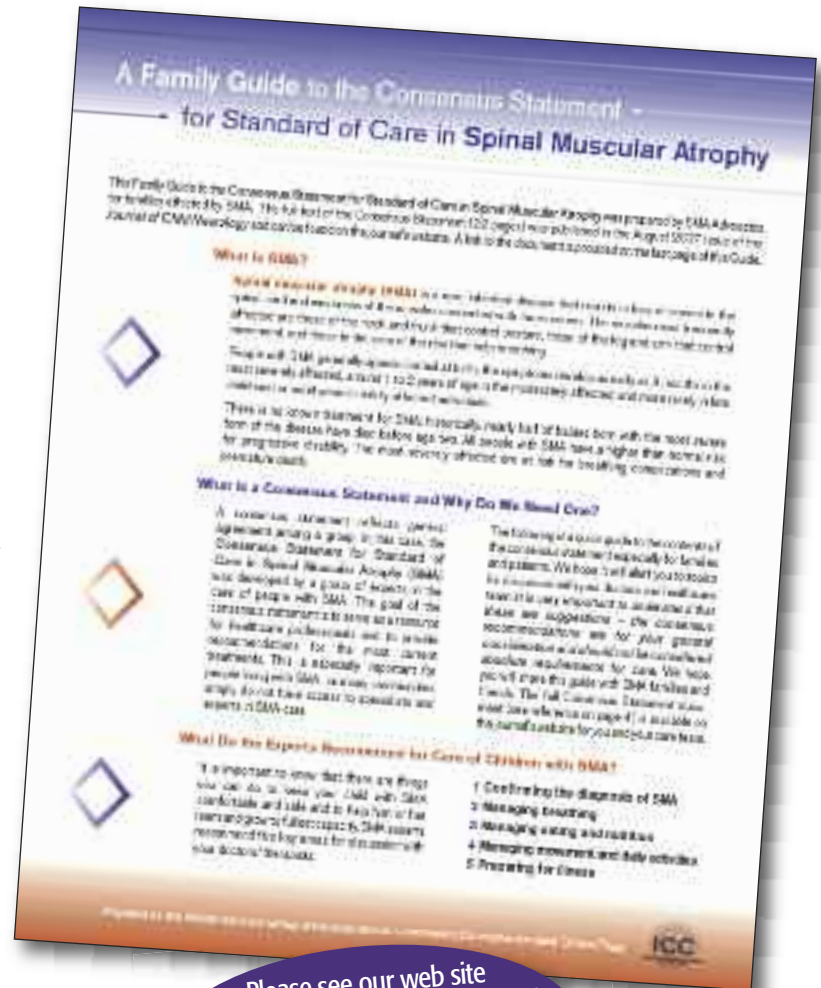
Families of SMA has worked with MDA, FightSMA, and the Spinal Muscular Atrophy Foundation to produce the "Family Guide to the Consensus Statement for Standard of Care in Spinal Muscular Atrophy," said Jill Jarecki, Families of SMA Research Director.

It is our hope that this guide in concert with the full set of guidelines published in the "Journal of Child Neurology" will allow SMA families to gain better access to a greater number of clinical care options. Doing so will be essential to the ongoing efforts at Families of SMA to enable clinical trials for SMA, where standardized clinical care is essential to success.

The new publication is designed to guide patients and families in their discussions with doctors and health-care specialists. The committee emphasizes that these guidelines are only suggestions and should not be considered absolute requirements for care.

The Family Guide covers recommendations on these topics:

- 1) Confirming the diagnosis of SMA
- 2) Managing breathing
- 3) Managing eating and nutrition
- 4) Managing movement and daily activities
- 5) Preparing for illness



Please see our web site to download a copy of the full guide, or email [info@fsma.org](mailto:info@fsma.org) or call (800) 886-1762 and we will mail a copy to you.

## Families of SMA would like to make a special announcement to recognize Sandy Wimsatt for her fantastic contributions to the SMA community.

Sandy has given many years of service to Families of SMA and our wider community. Sandy came to FSMA over 10 years ago when her son Michael was diagnosed. FSMA has benefited from her professional background as she took on the role of FSMA's Director of Fundraising and also Treasurer.

We thank Sandy for her many years of service in moving FSMA forward in a manner that brought professionalism and commitment to so many areas of our organization and programs. This was all done as a 100% volunteer with 100's of hours of volunteer service.

# FSMA's Board of Directors and Medical Advisory Board Released Position Statement on Newborn Screening

Spencer Perlman, FSMA Legislative Affairs

## What is a Position Statement?

A position statement is a summary of an organization's views on an important issue. It's an excellent communications and educational tool.

## How is a Position Statement used?

A position statement can be very useful in conversations with Senators and Congressmen, their staff people in Washington, and with other government officials at the national and state levels. The statement can be shown to the public, to other organizations, and to families, also.

## Why do we need a Position Statement on Newborn Screening?

We need a position statement on Newborn Screening because this is an important, sensitive and complicated issue. It's also, often, confused with Carrier Screening, another sensitive topic.

FSMA is very active on the issue of newborn screening and is working very hard to have SMA placed on the Uniform Federal Newborn Screening Panel. As we advocate on behalf of newborn screening, the position statement serves as an efficient "leave behind" document. It shows that we are very organized and focused when it comes to this issue. Officials in various agencies can be reminded of what is important to FSMA families by reading the statement.

## SMA Community Formally Requests SMA Screening for all Newborns

Under the leadership of Families of SMA, the SMA community submitted a Nomination Form to the Federal Advisory



Please see our web site to download a copy of the statement, or email [info@fsma.org](mailto:info@fsma.org) or call (800) 886-1762 and we will mail a copy to you.

sory Committee responsible for determining the disorders for which all newborns in the United States are screened. The Committee is presently reviewing the Nomination Form.

Newborn screening can play a vital role in SMA research, clinical trials, and drug development. Specifically, newborn screening allows for the identification of SMA patients pre-symptomatically. Early diagnosis is paramount as preliminary data in human and mice models indicates that pre-symptomatic drug intervention is more effective than post-symptomatic. Additionally, natural history data indicates only a small opportunity for intervention in the most common and severe form of SMA, Type I. Consequently, pre-symp-

tomatic enrollment into clinical trials may greatly enhance the chance of identifying an effective drug intervention for SMA, particularly for Type I SMA infants.

Additionally, diagnosis at birth would allow patients to obtain proactive treatment earlier in the disease progression with regard to nutrition, physical therapy, and respiratory care, which will lead to a better quality of life, reduce respiratory morbidity, and extend lifespan; it will eliminate the pain and cost of unnecessary testing that otherwise would take place in attempting to diagnose an affected patient; and it would provide parents with earlier genetic counseling.



## Presidential Candidate Sen. Barack Obama (D-IL) signs on as a supporter of the SMA Treatment Acceleration Act.



Sen. Barack Obama became a cosponsor of the SMA Treatment Acceleration Act on July 23rd. This follows an initial meeting with

representatives from Families of SMA to review the legislation in September 2007. Since then the organization has continued to urge the Senator's support.

The entire FSMA community is grateful to Sen. Obama and his staff for agreeing to support this critical legislation.

Senator Obama has long been a supporter of Families of SMA, whose national headquarters have been based in Illinois for the past 25 years.

This latest news on the SMA legislative adds to the increasing momentum of recent support.

## Petition from the Strong Family

Please Get the Word Out – Petition To Support The SMA Treatment Acceleration Act!!

Bill and Victoria Strong, whose 10-month-old daughter, Gwendolyn, has SMA Type I, created a simple way for the SMA community to rally support for the bipartisan SMA Treatment Acceleration Act:

They organized an online petition: [www.PetitionToCureSMA.com](http://www.PetitionToCureSMA.com), in support of this landmark legislation. In under a month, the petition has surpassed 15,000 signatures from all 50 states, and 65 countries around the world, and Families of SMA is using the petition to successfully urge key Members of Congress to support the Act.

If you have not already signed the petition, please do so today. It only takes 30 seconds. Simply go to [www.PetitionToCureSMA.com](http://www.PetitionToCureSMA.com) and show your legisla-

tors that the SMA Treatment Acceleration Act has broad national support and should be passed into law this year.

Please help to spread the word about the petition. Many SMA families have used creative initiatives such as emailing friends, family, alumnae groups and contact lists; posting the link on websites, blogs, Facebook and MySpace pages and other online forums; asking for support from church groups, moms groups, schools, caretakers and therapists; passing out promotional fliers; and good old fashioned word of mouth. This is an amazing example of the power of the SMA community and its will to end this horrible disease.

Together we can get this important legislation passed and take another important step towards ending SMA.

## Higher Education Act

Congress overwhelmingly passed the Higher Education Opportunity Act (H.R. 4137) on July 31, 2008, marking the first reauthorization of federal higher education policy in a decade. This legislation creates several new programs aimed at improving postsecondary recruitment, transition, retention, and completion rates of students with disabilities.

The National Center for Information and Technical Support for Postsecondary Students with Disabilities will provide technical assistance and information on best and promising practices to students with disabilities, the families of such students, and institutions of higher education. Demonstration Projects to Support Postsecondary Faculty, Staff, and Administrators in Educating Students with Disabilities will support model demonstration projects that provide technical assistance or professional development to faculty, staff, and administrators in order to enable the provision of a quality college education to students with disabilities.

Families of SMA will follow the implementation of the Higher Education Opportunity Act and report on any activities of interest to the SMA community.



## Senator Hillary Rodham Clinton (D-NY) Officially Became a Cosponsor of the SMA Treatment Acceleration Act on July 17.

Families of SMA is profoundly grateful for her support and the efforts of our local families in securing her backing. The timing of this announcement coincided with the local FSMA New York Chapters securing a proclamation declaring August as SMA Awareness Month in New York State.

Governor David A. Paterson and State Senators issued a Legislative Resolution to the NYC/Long Island and Western New York FSMA Chapters! We thank State Senator Dean G. Skelos for all his efforts to make this happen.

Include pic of resolution??

In addition, a message of support was given by Senator Clinton at Spinal Muscular Atrophy Awareness Day with The New York Mets at Shea Stadium on August 24th.

See the FSMA website to view the video of the whole speech.

We also recently held successful Major League Baseball events with the Boston Red Sox and the San Francisco Giants. If you have any contacts with your local major league team and would like information and assistance with coordinating a significant event for SMA please email [fundraising@fsma.org](mailto:fundraising@fsma.org).

You can find more information on the SMA Treatment Acceleration Act online at the Families of SMA website at [www.curesma.org](http://www.curesma.org).

# SMA Treatment Acceleration Act

As of the middle of September the SMA Treatment Acceleration Act has 83 cosponsors in the U.S. House of Representatives and 21 cosponsors in the U.S. Senate. Thanks to the strong grassroots efforts of our community, lead by our state chapters, the legislation has broad bipartisan support heading into the final weeks of the 110th Congress. Families of SMA will continue to work hard to see this legislation become law.

The SMA Treatment Acceleration Act provides federal support to complement the substantial private funding that we are investing to find a treatment for SMA. Passage of this landmark legislation will enable scientific investigators to mount national clinical trials and demonstrate that potential treatments are safe and effective for SMA patients.

Shown below are the Representatives and Senators that have signed on! Keep up the good work.

## House Bill: H.R. 3334

**Sponsor: Patrick J. Kennedy [RI-1]**

### Cosponsors (76) and Date Signed-On

Rep Alexander, Rodney [LA-5] - 5/8/2008  
 Rep Allen, Thomas H. [ME-1] - 6/18/2008  
 Rep Baird, Brian [WA-3] - 9/4/2007  
 Rep Baldwin, Tammy [WI-2] - 5/1/2008  
 Rep Blumenauer, Earl [OR-3] - 6/19/2008  
 Rep Boren, Dan [OK-2] - 8/3/2007  
 Rep Boucher, Rick [VA-9] - 9/24/2007  
 Rep Butterfield, G. K. [NC-1] - 7/17/2008  
 Rep Cantor, Eric [VA-7] - 8/2/2007  
 Rep Capps, Lois [CA-23] - 6/25/2008  
 Rep Carney, Christopher P. [PA-10] - 7/31/2008  
 Rep Castor, Kathy [FL-11] - 10/17/2007  
 Rep Clarke, Yvette D. [NY-11] - 4/16/2008  
 Rep Cooper, Jim [TN-5] - 9/4/2007  
 Rep Davis, Tom [VA-11] - 10/16/2007  
 Rep Dicks, Norman D. [WA-6] - 5/8/2008  
 Rep Drake, Thelma D. [VA-2] - 9/4/2007  
 Rep Eshoo, Anna G. [CA-14] - 8/3/2007  
 Rep Ferguson, Mike [NJ-7] - 12/19/2007  
 Rep Forbes, J. Randy [VA-4] - 11/5/2007  
 Rep Goode, Virgil H., Jr. [VA-5] - 8/3/2007  
 Rep Goodlatte, Bob [VA-6] - 6/10/2008  
 Rep Gordon, Bart [TN-6] - 9/4/2007  
 Rep Green, Gene [TX-29] - 7/29/2008  
 Rep Hall, Ralph M. [TX-4] - 7/23/2008  
 Rep Hooley, Darlene [OR-5] - 4/30/2008  
 Rep Hulshof, Kenny C. [MO-9] - 4/30/2008  
 Rep Inslee, Jay [WA-1] - 7/8/2008  
 Rep Johnson, Henry C. "Hank," Jr. [GA-4] - 7/8/2008  
 Rep Kildee, Dale E. [MI-5] - 7/16/2008  
 Rep Kind, Ron [WI-3] - 7/10/2008  
 Rep Kingston, Jack [GA-1] - 10/16/2007  
 Rep Kirk, Mark Steven [IL-10] - 4/9/2008  
 Rep Kuhl, John R. "Randy," Jr. [NY-29] - 12/12/2007

Rep Langevin, James R. [RI-2] - 1/16/2008  
 Rep Lofgren, Zoe [CA-16] - 6/10/2008  
 Rep Lowey, Nita M. [NY-18] - 6/25/2008  
 Rep Maloney, Carolyn B. [NY-14] - 4/30/2008  
 Rep Markey, Edward J. [MA-7] - 6/3/2008  
 Rep Marshall, Jim [GA-8] - 8/3/2007  
 Rep McCaul, Michael T. [TX-10] - 9/9/2008  
 Rep McHugh, John M. [NY-23] - 10/15/2007  
 Rep McMorris Rodgers, Cathy [WA-5] - 6/23/2008  
 Rep McNulty, Michael R. [NY-21] - 7/23/2008  
 Rep Meeks, Gregory W. [NY-6] - 4/30/2008  
 Rep Miller, Candice S. [MI-10] - 6/18/2008  
 Rep Moran, James P. [VA-8] - 12/18/2007  
 Rep Nadler, Jerrold [NY-8] - 7/17/2008  
 Rep Napolitano, Grace F. [CA-38] - 7/24/2008  
 Rep Payne, Donald M. [NJ-10] - 9/8/2008  
 Rep Peterson, Collin C. [MN-7] - 10/2/2007  
 Rep Pickering, Charles W. "Chip" [MS-3] - 5/21/2008  
 Rep Price, Tom [GA-6] - 4/30/2008  
 Rep Pryce, Deborah [OH-15] - 11/7/2007  
 Rep Ramstad, Jim [MN-3] - 9/8/2008  
 Rep Ros-Lehtinen, Ileana [FL-18] - 9/4/2007  
 Rep Ross, Mike [AR-4] - 4/24/2008  
 Rep Roybal-Allard, Lucille [CA-34] - 7/29/2008  
 Rep Ryan, Tim [OH-17] - 7/16/2008  
 Rep Scott, Robert C. "Bobby" [VA-3] - 5/8/2008  
 Rep Sestak, Joe [PA-7] - 10/23/2007  
 Rep Shays, Christopher [CT-4] - 10/3/2007  
 Rep Stark, Fortney Pete [CA-13] - 12/18/2007  
 Rep Stearns, Cliff [FL-6] - 6/17/2008  
 Rep Tiberi, Patrick J. [OH-12] - 10/2/2007  
 Rep Towns, Edolphus [NY-10] - 4/22/2008  
 Rep Walberg, Timothy [MI-7] - 5/8/2008  
 Rep Wasserman Schultz, Debbie [FL-20] - 9/4/2007  
 Rep Westmoreland, Lynn A. [GA-3] - 10/25/2007  
 Rep Wilson, Charles A. [OH-6] - 7/8/2008  
 Rep Wilson, Heather [NM-1] - 3/4/2008



Rep Wittman, Robert J. [VA-1] - 6/3/2008  
 Rep Wolf, Frank R. [VA-10] - 9/4/2007  
 Rep Wu, David [OR-1] - 6/18/2008  
 Rep Wynn, Albert Russell [MD-4] - 8/3/2007  
 Rep Young, C.W. Bill [FL-10] - 9/10/2007

#### Senate Bill: S. 2042

**Sponsor: Debbie Stabenow [MI]**

**Cosponsors (21) by Date Signed-On**

Sen Bingaman, Jeff [NM] - 2/11/2008  
 Sen Boxer, Barbara [CA] - 4/1/2008  
 Sen Brown, Sherrod [OH] - 12/3/2007  
 Sen Cantwell, Maria [WA] - 10/22/2007  
 Sen Casey, Robert P., Jr. [PA] - 7/14/2008  
 Sen Chambliss, Saxby [GA] - 10/18/2007  
 Sen Clinton, Hillary Rodham [NY] - 7/17/2008  
 Sen Feinstein, Dianne [CA] - 4/3/2008  
 Sen Isakson, Johnny [GA] - 9/12/2007  
 Sen Kerry, John F. [MA] - 6/12/2008  
 Sen Lautenberg, Frank R. [NJ] - 12/10/2007  
 Sen Lieberman, Joseph I. [CT] - 6/24/2008  
 Sen Menendez, Robert [NJ] - 6/3/2008  
 Sen Mikulski, Barbara A. [MD] - 7/31/2008  
 Sen Murray, Patty [WA] - 12/19/2007  
 Sen Obama, Barack [IL] - 7/23/2008  
 Sen Reed, Jack [RI] - 12/14/2007  
 Sen Sanders, Bernard [VT] - 6/23/2008  
 Sen Warner, John [VA] - 9/12/2007  
 Sen Webb, Jim [VA] - 12/11/2007  
 Sen Whitehouse, Sheldon [RI] - 9/12/2007



#### Appropriations Report Language

For the fifth consecutive year, the House Appropriations Subcommittee for Labor, Health & Human Services, and Education and the Senate Appropriations Committee approved language urging the National Institutes of Health to significantly increase its investment in SMA-related research. Families of SMA is grateful to the many Members of Congress who have supported the inclusion of this report language over the years.

## Spinal Muscular Atrophy Treatment Acceleration Act Update

#### Greetings SMA families, researchers and friends:

We would like to extend our deepest thanks for your dedication and all you have done to help grow support for the SMA Treatment Acceleration Act (H.R. 3334/S. 2042). Thanks to your efforts, 83 Members of the House of Representatives and 21 Senators have signed on to the bill, a major milestone for the first-ever federal legislation authorizing SMA funding.

Our approach and goals for the rest of this year are to continue to push for consideration of the bill. Congress is likely to recess for the fall election season as early as this week, but, there is a possibility that a “lame duck” session will occur following the November elections and before the new Congress and President are sworn into office. If Congress does return for a lame duck session, it is possible that the SMA Treatment Acceleration Act could be considered. As part of an effort to create such an opportunity, our government relations team is in ongoing discussions with Congressional leadership and senior members of the House Energy and Commerce Committee on both sides of the aisle.

Regardless of the outcome of a lame duck session, we have made extraordinary progress over the past 12 months which positions us perfectly to reintroduce the bill at the start of the new Congress next January, continue to grow support, and work towards passage and enactment.

Thank you again for your continued hard work as we make progress in securing support for our Act. As we continue our discussions with Congressional leaders in the coming months, we will provide additional updates as well as calls to action to seek your help in moving key decision makers in the House and Senate.

Sincerely,

Martha Slay  
*FightSMA*

Kenneth Hobby  
*Families of SMA*

Cynthia Joyce  
*SMA Foundation*

**NOTE:** If you have any questions about the SMA Treatment Acceleration Act, please feel free to contact any one of our Government Affairs staff: Laura Breiteneicher of the SMA Foundation (laurab@wswdc.com / 202-589-0800), Spencer Perlman of Families of SMA (spencer@fsma.org / 202-333-5750), or Caroline Gibson of Fight SMA (carolinegibson@fightasma.com / 804-515-0080)

## Alabama Chapter

Baby Charles Logan Patrick came into this world on October 11, 2006 at around 6:30 in the morning. All of his family were present-including his eight year old cousin Meghan. We counted his little toes and fingers and pronounced him perfect. He was an adorable mix between his lovely mother Jennifer and his handsome father Jason.

Meghan was there later that day patiently waiting her turn to hold baby Logan. It was obvious that she adored him.

All was well with Logan for a few months. Then we realized that he was not making his benchmarks. When he began losing the motor skills he had mastered, we knew that something was wrong. Jennifer and Jason carried him to the pediatrician on March 27th, 2007 and received the grim diagnosis of Spinal Muscular Atrophy.

Meghan's parents never had a chance to tell her the devastating news that Logan was very ill. In a small town like Tuscaloosa, Alabama bad news travels very fast. One of Meghan's friends' parents had heard the news and had discussed Logan's illness with their child. Meghan heard the news from her friend.

The story below is Meghan's story that she wrote last year as a nine year old. She was and is devastated by Logan's illness and is totally devoted to him. She has never lost hope that a cure for SMA will be found. Meghan and her brother have prayed every night for Logan. She has sold bracelets and sold lemonade on the street curb in the heat of summer trying to earn money to donate for research. Meghan and her brother have even sold water from their wagon during the pre-game festivities of the University of Alabama football games. For her tenth birthday, she had a party and requested that her friends make donations to the Alabama Walk 'N Roll instead of buying her presents. \$775 was raised.

## Hope for a Cure!

*A hope story by Meghan Skinner*

I was walking out of dance class with my friends, Katie Causey and Skyler Hubbard. "Bye Sydney! Bye Mary-Katherine! Bye Jayci!" These were the words spoken by my friends as people walked by us in the hallway of The Dance Center.

"Bye girls," said my dance teacher, Mrs. Melissa.

"Bye Mrs. Melissa," we all said in unison.

Then, all of a sudden Katie stopped.

"Oh, Meg, I almost forgot to ask. How's your baby cousin, Logan? I'm so sorry about his brain tumor!"

"What?!" Skyler and I said together. I swallowed hard, I was scared and shocked. No, not my newborn baby cousin! I tried to convince myself that these words from Katie were not true! Skyler took me over to some chairs and sat me down.

"Meghan, you don't know if it's true or not. Katie might be lying," Skyler stated.

"I know... but this could be true," I thought to myself again. As I sat in silence, I felt a tear run down my face. By then Katie was in her next dance class.

"I'm just so scared, Skyler. Should I call my Gran?"

"Whatever you want to do, she'll probably be here in a second anyway." I could tell Skyler was trying to comfort me as much as she could.

"No. She said she'll be thirty minutes late." I responded as yet another tear of fright ran down my face.

"Why don't you just call her?" Skyler asked.

I felt a sort of sick feeling in my stomach as I laid my head down on my arms. Finally, after what seemed like forever, I picked my head up. I was thinking, what if Logan really did have a brain tumor, or if he didn't and Katie was lying? I was shaking as I picked up

the phone and dialed the numbers 3-4-5-3-6-5-3. Weary thoughts ran through my head as the phone began to ring.

"Hello?" I heard the familiar voice. It was my Gran's! I asked her what was wrong with Logan. She told me that he was at the doctor. I squeaked out "Bye," and she responded softly. I gently sat the phone down.

"What happened?" Skyler's mouth popped open, "Yeah, what happened?" asked another girl who had been listening in. I tried to talk but all that came out was.....

"DOCTOR!"

After 30 minutes had gone by, my dad arrived instead of my Gran. I sniffed, and then got in the car. Neither one of us said anything until we got home. "Help me with the groceries." My dad said and wiped his nose.

Later that night my mom and dad told me about Logan's diagnosis. He has a disease called S.M.A. That stands for Spinal Muscular Atrophy. This disease causes muscles in your body to grow weaker and weaker. It makes him have to use a feeding tube in his stomach because he can't suck on a bottle anymore. Logan has the worst type of S.M.A., type 1. Logan just turned one year old and he can't even sit up.

There is no cure for S.M.A. There isn't even any treatment! My aunt Jennifer and Uncle Jason, as well as the rest of my family, have great hope that one day Logan will be healed. I am thankful for people like that.

Here are two Bible verses of hope. Psalm 42:5, "I will put my hope in God!" and Psalm 119:49, "For it is my only hope."

Each day we hope and pray for a cure! Many tears have been shed for Logan. But Logan has been anointed with oil and hope is running through our family... Hope for a Cure!





### Chesapeake Chapter (Maryland/Virginia)

This year marks a special milestone for the chapter. The chapter is celebrating its 15th year of service in the Chesapeake region of Maryland/Virginia, supporting families, fundraising, and creating awareness in the community. The chapter started with the story of Erin Trainor and her battle with SMA. She lost that battle at only 5 1/2 months but her parents, Barbara and Gene Trainor started the chapter in her memory supporting other families and fundraising for much needed research. Over the years, the chapter has grown with each new diagnosis and another family's personal story. The chapter continues to move forward with the important work of supporting families and advancing research. It has been rewarding to watch how far research has come in such a short time. Providing great hope to the families and researchers. Thank you to everyone who has worked so hard to keep the chapter going. You have made a difference!

Our summer and fall fundraising season are always quite busy. Baltimore loves picking crabs and once again FSMA, Chesapeake chapter held its **15th annual Crab Feast**. The hall was again filled with over 300 people enjoying Maryland's best crabs! Participants enjoy crabs, buffet of food and a silent auction. The silent auction has been a fun and important addition to the event. Special thanks to Beverly Venedam who coordinated the silent

auction. The event rose over \$15,000.

The beginning of October will mark the 14th annual **CRM Golf Classic** to benefit FSMA at The Woodlands/Diamond Ridge Golf Club. Two courses and 43 foursomes are a wonderful testament to the many companies and individuals who continue to support the work of FSMA and its goal - Advancing Research and Supporting Families. Looking back at the 2007 Tournament, we want to Congratulate the 2007 John Sullivan 'Good Guy' awarded to CRM, our Title sponsor. Thank you, CRM, for making a difference! FSMA, Chesapeake Chapter could not achieve its goals without the support CRM gives Scott Geller, our Golf chair. The 2007 event raised over \$149,000!!! We can't wait to report what we do in 2008!

Many thanks to CIBC World Markets for their very generous gift of \$17,000 to Families of SMA. Their gift was a result of their annual **Miracle Day Project** where trading commissions earned during a day in December, 2007 go to benefit various children's' charities, including Families of SMA.

The Chesapeake Chapter ran its own **Holiday Annual giving campaign**. The chapters reached out to its entire community and were thrilled with the response. The drive raised over \$9,000!

The chapter welcomes new families to get involved. *Please contact Barbara Trainor at 800-762-0113 or email her at [fsma-chesapeake@comcast.net](mailto:fsma-chesapeake@comcast.net)*

### Connecticut Chapter



**Pedal For a Purpose** was a great day! We had a total of 110 participants over a five-hour day. The event grossed \$6,420, with more donations trickling in.

We've done a lot of fundraising over the past eight years – walkathon, Breakfast with Santa, Wine Your Valentine wine tasting, and I have to say there was really something special about this event. This seemed so much more than a fundraiser. The friendship, camaraderie, spirit, drive, energy, and motivation that filled the room was just incredible. I did three of the rides and by the last hour, it was just pure adrenalin.

*From Jennifer Tramontano*



### Minnesota Chapter



## New England Chapter

It is with great appreciation to all and immense pleasure that the N.E. Chapter of Families of Spinal Muscular Atrophy (FSMA) announces achieving a new milestone in our fundraising efforts.

The National office, along with our Executive Director Kenneth Hobby, has just informed our chapter that for the fiscal year July 1, 2007 through June 30, 2008 the New England Chapter directly submitted to the National office \$300,345 dollars from our fundraising efforts. Additionally the New England Chapter fundraising efforts generated approximately another \$30,000 in direct on line contributions to the National office for a new record breaking year of over \$330,000 dollars!!!!

This has been our largest fundraising year to date, and our fourth consistent year in surpassing our previous yearly record numbers. It is clear that these results and this achievement is directly related to everyone's perseverance here in our chapter.

To all families here in New England, please accept our sincerest and most genuine thanks for all your hard work, commitment and dedication to making this past year another record breaking year. Please feel free in forwarding to all those whom you know have donated and would be pleased to learn of this amazing achievement and extend our personal thanks to each of them.

*With sincerest thanks, Jim Gaudreau*

### Upcoming New England Chapter Events:

COMEDY NIGHT is Thursday November 13! The 4th Annual Comedy Night at Giggles Comedy and Prince Pizza Route 1 South Bound in Saugus, MA is being held Thursday November 13th, 2008. Ticket \$30 per person which includes all you can eat free cheese pizza and 1 ½ hours of three laugh riot comedians to entertain you. Doors open at 6:30PM, pizza served starting at 7PM, comedians start promptly at 8PM. Evening will include silent auction

items and raffle items.

For more information or to purchase tickets, you can email Joanne Schamberg or Christine Boulter at joanne@yourpromosolution.com or christine.boulter@verizon.net

### WALK, ROLL & RUN – November 1, 2008

FSMA N.E. Chapter 7th Annual Walk, Roll & Run. To be held in Dracut, MA in October 2008. For more information or to learn how you can help, email Jim or Sue Gaudreau at jimg@gaudreaufamily.org or sueg@gaudreaufamily.org

### Golf Tournament – Friday, October 10, 2008

FSMA N.E. Chapter along with Johnson Family announce the 2nd Annual Golf Tournament for FSMA. The event is being held on Friday October 10, 2008 at the New England Country Club in Bellingham, MA. For more information or details, interested individuals please contact Tripp and Heidi Johnson at heidikjohnson@comcast.net or call at 508-359-2803 Registration forms and details are also available on-line at www.wishesforwilliam.org

### SMA Soiree Big Fun and Big Success

*by Heidi Johnson*

Well the house is nearly put back together after the festivities this past Saturday. With pledges still coming in we have already raised over \$4100 from the night of fun. How can you go wrong there – raising huge money for SMA and having a blast doing it? It couldn't happen without the help of many. HUGE thanks to:

- Dave's Fault, our favorite local band, we so appreciate your talent making the night full of great music. If anyone cares to catch them, they play gigs at the Sherborn Inn every so often so be sure to check out the schedule there or check in with me if you want to be on

their email list for performance notification.

- all my pre-party helpers who pulled it together for me on a very busy afternoon here in Medfield.
- anyone who contributed food and fest to our event – your contributions weren't necessary, but certainly were appreciated
- all my elves during the Marathon of Beers who helped organize the course and kept things moving while I just shouted into a microphone
- everyone who came, donated and joined in the fun – we hope to see you year after year.

### Sundae Sunday

*by Kristin Pecora*

We had a wonderful time pigging-out on ice cream - I noticed there were quite a few of you who returned for seconds and even a few for thirds! The Tanglewood Marionettes put on a marvelous show called The Dragon King. All of the kids were mesmerized, I think you could have heard a pin drop. Even Murphy Potter decided to watch from the back of the room! But best of all, I was thrilled to see that both grown-ups and kids were talking and laughing and getting to know each other. I hope that everyone who attended was able to meet someone new. I think we can all agree it's nice to have someone in our life who "knows".

One more thank you to everyone who helped with donations and helping the day run smoothly: Mark and Laurie Potter of Marshalls Miles, Butch and Sue Fransen of Kate's Place, Erica Sanborn of Children's Hospital, the NE Chapter of FSMA, and the generous anonymous donors. I would love to have feedback - positive/negative. Please let me know if this is something you would like to try again next year. I'm open to any suggestions! Email me at: jackris1@verizon.net



## New York City/Long Island Chapter



**Pictured left are the Cuevas family, The Mayer family and the Erwin family with State Senator Dean Skelos.**



The New York City/Long Island Chapter along with the Western NY Chapter had the month of August formally proclaimed SMA Awareness Month in New York State and were awarded proclamations from the New York State Senate. The NYC/Long Island Chapter had the opportunity to meet with New York State Senate Majority Leader, Dean Skelos who was the cosponsor of that piece of legislation. We also had the opportunity to attend a reception at Gracie Mansion honoring the Anniversary of the Ameri-

cans with Disabilities Act where some of the families were able to meet NYC Mayor Michael Bloomberg and his Commissioner for the Office of People with Disabilities, Matthew Sapolin. We also had several Tupperware Parties in honor of SMA Awareness Month where some of the proceeds will be donated to our chapter. Many thanks to Claudine Campanelli, aunt of Greyson Erwin for this effort.

The Erwin family also participated in the NYC Nike Half Marathon and raised a ton of funds and awareness as they ran in support of their son, Greyson. Thanks so much to the Erwins for all that they do for our chapter and for FSMA.

We also had our first ever SMA Awareness Day at Shea Stadium where we celebrated SMA Awareness with an On Field Spirit Award presented to us by the NY Mets organization and substantial donations by AIG and Sterling Stamos. This was a very successful event attended by over 200 people where we raised about \$30,000. Thank you to all who were able to participate. Senator Hillary Clinton who recently became a cosponsor of the SMA Treatment Acceleration Act sent a video message to us showing her support for SMA. Special thanks to the McDonnell, Mayer, Rubenstein, Rosenfeld, Erwin and Verdile families. Also thanks to MJ Purk, Brenda, Betsy and Tim for joining in our day at Shea. Our chapter families were so excited to meet MJ and her family. Our 4th Annual Walk N Roll is set for September 13th in Long Beach. The chapter also welcomes three new Chapter Board Members – Michele Erwin, Alisa Rosenfeld, & Michele Rubenstein.

## Northern California Chapter



## Louisiana Chapter



## Pacific Northwest Chapter

Dear Friends,

It has been an amazing summer. We had several great trips and participated in some amazing activities!

We went north and camped with a group of 9 Canadian SMA families in the little town of Kultus Lake, B.C. It is a truly beautiful spot with a big warm lake. This group has been camping together for years, watching each other's kids grow up and having a wonderful time. They 'camp' on the playfield of the community school and benefit from the large kitchen, gym and showers available inside. We stayed 4 nights and will go up a day earlier next year. We swam, hiked, biked, canoed and ran wheelchair obstacle courses. They even have a large power chair for the parents to use for the competition. This is an all are welcome event and I hope some of you will be able to join us next year.

Our girls all went to summer camp at the Seattle Children's Playgarden for two separate one-week sessions and had big, big fun. This is a project taking shape in the Central District of Seattle, a play space designed to be safe, fun and accessible for all kids, regardless of their capabilities. You can learn more about the Playgarden by going here; <http://childrensplaygarden.org>. One of the summer highlights was the chance to meet with US Senator Patty Murray and talk with her about the importance of HR3334, the SMA Treatment Acceleration Act. Senator Murray is a co-sponsor of the bill and, as a former special ed teacher, really gets it.

OK, 2 items of business; we have not met as a group since last Valentine's Day. I would like to go back to that crazy little VFW in Tacoma for a Halloween party, and to get our families caught up.

Secondly, I am seeking a permit for an October Walk-n-Roll at Greenlake Park in Seattle in October. This will be a fledgling fundraiser. It is a roughly 3 mile loop with kazillions of people

walking, running, biking etc and I think we can blend right in. The New England chapter raised \$300,000 for research this year vs the NW where the vast majority of our fundraising was done by Steve and Rozie McClay with a golf tournament and a wreath-making and sales effort. It would be a very good thing for us to grow our presence in fundraising and it creates wonderful opportunities for our kids to be together.

Please take a moment and send me a very quick update on your family. Let me know your interest level in a Halloween party and an earlier walk-n-roll around Greenlake. And, oh boy! If you can help with either activity that would be a great thing as well!

*All the best!*

*Rick Jones, Pacific Northwest Chapter*

## Pennsylvania Chapter

2008 has been both a year to celebrate our success, but also a year stricken with loss. It was with much sadness that we learned of the sudden passing of Skylar Elizabeth Saranchuk this Spring. She lost her battle with SMA only a short time before her 8th birthday. Our sympathy and support extends to the entire family, a founding family to this Chapter, as well as to all our families and friends who have suffered the loss of a loved one to this horrendous disease.

As part of our continued and committed effort to cure Spinal Muscular Atrophy, the PA Chapter hosted the 5th Annual Walk-n-Roll to Cure SMA on May 18th in Philadelphia, PA. Over 500 people attended this tremendous event, many of which were family and friends of new Chapter members. Reporter Walter Perez of ABC Action News emceed the event, which included childrens' games, a successful Raffle, and a leisurely stroll along the Kelly Drive Bike Path. Many thanks to "DJ Gary in the Morning" and

photographer, Susan Pardys, who both donated their talents to enhance our event. Thanks to the generosity of all involved, our total funds raised exceeded \$100,000!

Over the past couple months, our PA families and friends have been working hard to fund research and raise awareness:

### • Crop for a Cure

On March 8, 2008, The Star Fund for Disabled Children sponsored the 2nd Annual Crop for a Cure at the Parkville Fire Company in Hanover, PA. One hundred women scrapbooked from 9AM to 9PM, while enjoying time with friends and family. Along with the scrapbooking, there were also free make and take classes, best page contests, raffles and a silent auction. Proceeds exceeding \$8200 were donated to FSMA in memory of Emmy Rose Baugher, a beautiful little baby girl who earned her wings at six months of age. Unending gratitude goes out to Brandy Baugher, Emmy Rose's mom, and Sandra Cromer. We look forward to the 3rd Annual Crop!

### • Shoot for a Cure

On June 28th, 2008, the Conner-Park family of Dubois, PA held its 1st Shoot for a Cure to honor the memory of Tiernan J. Conner-Park and raise funds for FSMA. Through the combined effort of participants, sponsors, and donors, the Conner-Parks not only raised \$1256.43, but personally matched this amount with an additional \$1200, for a total raised of \$2456.43! Many thanks go out to the fantastic people at the Firebird Wing Shooting Club in Brookville, PA. Tom, J.R., and all of the other wonderful members gave of their time, resources, and more in order to make the shoot a true success. With the spread of hot dogs, sloppy joes, baked beans, and a variety of delicious desserts, nobody went home hungry!

Andrew, Erin, Liadan, and Keenan Conner-Park wish to extend a heartfelt thanks and a written hug to all who had a hand in helping with the 1st Shoot for





a Cure. Because of your thoughtful gestures, donations and time, we can honor Tiernan's name by helping FSMA shoot for a cure. Thank you!

• **The Agnes Irwin School, Rosemont, PA - "Community Service Day"**

This past Spring, The Agnes Irwin School sponsored a Dance-run-jump-a-thon. This was one of many events held as part of a campus-wide Community Service Day. The children had a terrific time, not only getting a good dose of "fun" exercise, but helping others at the same time. The school chose Families of SMA as its charity of choice that day, donating \$2070 to research for a cure. Peter Henkel's mom, Allyson, teaches Spanish to the students at Agnes Irwin. Muchas gracias Senora Henkel and the entire Agnes Irwin community!

• **3rd Annual Ride to Fight SMA**

On May 10, 2008, the Calvary Riders sponsored this Motorcycle Ride to help raise funds for FSMA. Both the Pennsylvania and South Jersey Chapters worked to support Chris Cooter organize this wonderful event. What a beautiful day for 34 bikers to "Ride for SMA." With the help of registrations, raffles and donations, this year turned out to be his most successful yet... \$1230 raised! Many thanks to Chris and all those who participated in this fun day!

• **Happy Birthday Arden Rose Neff!**

As reported in earlier editions, Arden Rose is a seventh grader at William

Penn Charter School who has chosen Families of SMA as the recipient charity of all the fundraising (and "good deeding") she is doing as part of her Mitzvah project. In lieu of birthday presents this year, Arden Rose chose instead to ask all those attending her Philadelphia Phillies game birthday party to donate to FSMA! We are proud to announce that she raised a whopping \$800 in one night! We so appreciate her generous deed and hope that she had the best time ever! Go Phillies! Go FSMA! Go Arden Rose!

• **The New Hope Solebury Brownie Troop**

This past Spring, Sydney Garvin, decided to tell the other girls in her Troop about a friend of hers named Jake Saxton. She also told them about SMA and how important it is to help find a cure. The Brownie Troop decided to have a bake sale to help support a charity. They all voted and decided to support Sydney's choice and donated a portion of the proceeds to the PA Chapter of FSMA. The girls must have been pretty busy baking because they donated \$200 from selling their delicious cookies. Jake and his mom, Paula, had a fun time visiting and talking to the Troop.

Wishing everyone a safe and healthy year! Thanks for all that you do!



## Rocky Mountain Chapter

The Rocky Mountain Chapter of Families of SMA had a successful summer of fun and fundraising in Colorado. The Colorado Springs Annual Walk n Roll kicked it off in the shadow of Pikes Peak. A beautiful day and really cool new t-shirts greeted the 150 plus walkers who gathered to support Families and Friends of SMA. Vicki Caldwell and Team Kennedy put on a successful walk and everyone received a medal to prove that they did it! Thank you to Chic-A-Filet, 3 men and a truck, and the Caldwell's and all volunteers who made it possible.

Next up was the 5th Annual Scottish Stained Glass Golf Tournament to Benefit FSMA. The greens were fast, the cash was green, and a fun time was had by all. A special thank you to Martin and Gillian Faith who put this great event on each year!

At the same time as the Golf Tournament, the Weisman's were representing the Rocky Mountain Chapter along with Khristy Preston, membership chair, at the Annual Conference in Boston! The conference was amazing, so much was learned, and the kids had such a great time. The National Office of FSMA and the New England Chapter outdid themselves with fun activities, informative sessions, surprise addresses, and a wonderful team of Volunteers. Thank You!

Wrapping up the summer was our 2nd Annual Walk -n- Roll in Denver. The day was perfect but the mood was somber as we dedicated our walk to our newest angel, Jay Randall Marlow, January 25 - August 25, 2008. His



parents Lee and Marla were there to walk with us supported by their many family and friends. We walked for Jay, we walked for all of the angels that have preceded him and all of those living with SMA. We walked with hope, to raise money and awareness for SMA. We walked, like all of you, for a CURE! Over 300 turned out for the walk, our best showing ever including some of our wonderful friends from Children's Hospital! Thank you to Julie Lino, her family and friends, for bringing the Walk-n-Roll to Denver.

## South Jersey/Delaware Chapter



**Above: Troy and Jamie Lino at the CO Chapter Walk N Roll.**

As we usher in the change of leaves and the cooler air, we reflect on the spring and summer months and wonder where time has gone. On Good Friday we lost an integral part of our chapter, my Dad, Dr. Michael Smith so I ask you to keep him in your prayers. We are ever grateful to our chapter families who continue to support the fundraising efforts in turn supporting research for a cure. First, thank you to the Potter family for hosting the 3rd Annual Steven's walk to Drum out SMA in May. They had a wonderful event, a huge turnout and raised over \$25,000. Also this spring Francine Eisenmann hosted a home party and all proceeds benefited our chapter. In August Steve Moyer hosted his annual SMA Golf event in Tunkhannock, PA and raised over \$2,000. Thanks Dad in memory of baby Steven!

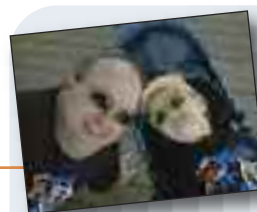
We are in our final preparations for Steven's Gala for SMA which takes place September 19th. Thank you to so many who have donated many items, precious time and talents to make this event hopefully the most successful yet. The same weekend our chapter will once again be highlighted at Indian Acres Tree Farm Fall Fest. We will have kids

games, crafts, bake sale and basket raffle along with bringing awareness for SMA. This event is chaired by The Halabura and Contento Families in honor of Jimmy Contento. On November 23rd Jason and Jessica Moyer will be running the Philadelphia Marathon to raise awareness of SMA. If anyone is interested in joining our "Cure SMA" Team please contact us at [southjersey@fsma.org](mailto:southjersey@fsma.org).

We are always looking for new families to join our chapter family and get involved.

On a final note, I ask you to keep in mind all of those who have passed from SMA and all of those who live with this disease every day. We are all in the same boat paddling towards the shore where a cure is waiting to be found.

**OKI Chapter Kentucky Walk N' Roll**





## Southern California Chapter

### FSMA Southern California Chapter Third Annual Walk-n-Roll

**Sunday, November 16, 2008 - Johnny  
Carson Park, Burbank**

*Dear Friends,*

The FSMA So. Calif. Chapter invites you to attend our third Annual Walk-N-Roll Event. This is a great event for the entire family.

It will be held Sunday, November 16th at Johnny Carson Park across from NBC Studios in Burbank. Registration begins at 8:30am the walk begins at 10:00am. The course will wind its way around NBC Studios. You can go around once if you choose (1.5 miles) or twice to complete the 5K. This course is wheelchair accessible on side-walks. Before and after the walk games will be set up for the kids, and you will have a chance meet/greet other FSMA families.

The entrance fee is \$15.adults, and \$10 children - all those registered receive tee-shirts.

**FORM A TEAM OF WALKERS** (Ask friends, family & co-workers to join you)  
**AND SET UP YOUR OWN  
FUNDRAISING PAGE FOR SPONSORS.**

If registering on-line, go to [www.fsma.org/burbankwalknroll](http://www.fsma.org/burbankwalknroll) - as you register, you are provided the option to create your own fundraising page. This is secure and easy to do. Then, email your friends, family & co-workers asking them to join your team of walkers on November 16th and provide them the link to register. If they cannot participate in the walk, ask them to sponsor you and provide the link to your fundraising page. It is that easy!

Also...we will be posting team signs along the park path. These signs are FREE and yours to keep following the walk. They usually have a photo of the loved one you are walking for, along with a message for your team of walkers (example..... "Go Smith Team - Walkin & rollin for Joey!"). If you are gathering a team together, and wish to have a sign, please email me the photo and text to be used on the sign no later than October 18th. I will be ordering all signs on October 19th. Email to Rosie at [scalif@fsma.org](mailto:scalif@fsma.org).

We hope you will join us. If you have questions regarding registration, forming a team of walkers, submitting artwork for your team sign, or building

your fundraising page, please contact Rosie Roope at [scalif@fsma.org](mailto:scalif@fsma.org) or 818-846-6589. Donations are tax deductible.

### FOR FAMILIES IN THE RIVERSIDE AREA:

Don't miss the Cure SMA Walk in Riverside on Sat., November 15th

Please go to [www.fsma.org](http://www.fsma.org) to for more information and to register.

## Texas Chapter

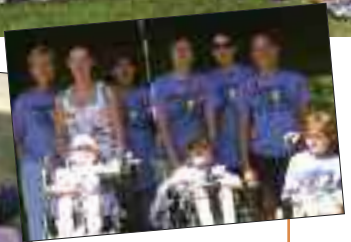
On March 29th, Becky Long and Amy Horak, hosted the FSMA Texas Chapter BBQ Round-Up in Houston, TX. This event included a BBQ plate dinner, kids entertainment, raffles and silent auctions. All the children enjoyed the music, face painting, cake walk n' roll and clown. The adults had an equally great time with the silent auctions. It was exciting to see everyone try to up their bids as the auction was coming to a close. Through the wonderful support and generosity of everyone, we raised \$17,463 for Families of SMA! They were happy to receive many donations which kept their expenses down. The event had about 10 SMA families in attendance...The Coggin, Campbell, Horak, Lackland, Furnish, Russell, Scurria (from Louisiana), Wigglesworth and Garza families.

## Western NY Chapter

The Western NY Chapter of FSMA, along with the Long Island Chapter, received a Legislative Proclamation signed by all the Senators from the state of New York. The proclamation named the month of August as SMA Awareness month for the entire state. The WNY Chapter was presented with the certificate at the 5th annual SMARt Walk on August 2nd by Senator George Maziarz, who also acted as Co-chairman for the event.

The Chapters 5th annual Walk started out on a rainy note but by the time the walkers were ready to take off, the sun was out. After participating in the one or three mile walk, everyone was treated to hot dogs and a beverage. The basket raffle and 50/50 split was a great success and added \$\$\$ to our grand total. Almost 350 people, many traveling from far, participated in this effort to raise money and awareness. Over \$35,000 was raised to help fight SMA.

Diane Blair, the chapter VP, organized a display in the local newspaper's front window for 3 weeks in July. FSMA merchandise, newsletters, banner and SMARt Walk t-shirts were arranged in the window, along with walk registration forms to raise awareness.



THE INTERNATIONAL  
**SPINAL MUSCULAR ATROPHY  
PATIENT REGISTRY**



...uniting families  
with SMA...



...with the researchers  
& doctors studying SMA...



...giving tomorrow a  
fighting chance.

<http://smaregistry.iu.edu>

**Participants**

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

**Researchers**

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

The International SMA Patient Registry is maintained through the  
Department of Medical and Molecular Genetics at Indiana University School of Medicine.



**Alabama Chapter** (since 2005)

P.O. Box 43918  
Birmingham, AL 35243  
Phone: 205-979-6493  
Jennifer Patrick, President—  
alabama@fsma.org

**Arizona Chapter** (since 1997)

85 W. Combs, Ste #101, PMB 410  
Queen Creek, AZ 85240  
(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—  
chesapeake@fsma.org

**Connecticut Chapter** (since 2003)

PO Box 185744  
Hamden, CT 06518  
Tel: (203) 288-1488  
Jonathan Goldsberry, President—  
conn@fsma.org

**Illinois Chapter** (since 2006)

P.O. Box 684  
Grayslake, IL 60030  
Tel: (847) 373-3762  
Janet Schoenborn, President—  
illinois@fsma.org

**Iowa Chapter** (since 2000)

P.O. Box 326  
Johnston, IA 50131  
Fax/Phone 515-986-2181  
Staci Bailey, President—  
iowa@fsma.org

**Kansas City Area Chapter** (since 2004)

P.O. Box 1214  
Mission, KS, 66222  
Tel: (913) 262-6468  
Natalie Gibbs, President—  
kansas@fsma.org

**Long Island New York City Chapter**  
(since 2006)

PO 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—  
michigan@fsma.org

**Minnesota Chapter** (since 1992)

P.O. Box 1961  
Maple Grove, MN 55311  
Tel: (763) 370-6460  
Jeff Cowan, President—  
minnesota@fsma.org

**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, OH 45254  
513-753-8222  
Beth Lockwood, President—  
oki@fsma.org

**Pacific Northwest** (since 2006)

P.O. Box 173  
Galvin, WA 98544-0173  
(206) 284-1888  
Rick Jones, President  
pacwest@fsma.org

**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 1913  
Arvada, CO 80001  
Tel: (970) 349-0418 or  
(877) 591-4023 (toll free)  
Loree Weisman, President—  
rockymt@fsma.org

**South Jersey/Delaware Chapter**  
(since 2002)

PO Box 538, Medford, NJ 08055  
Tel: (866) 774-9533  
Jessica Moyer, President—  
southjersey@fsma.org

**Southern California Chapter**  
(since 1999)

1070 E. Orange Grove  
Burbank, CA 91501  
Tel: (818) 846-6589  
Rosemary Roope, 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)

PO Box 627  
Hutto, TX 78634  
512-846-2239  
Eric Ostermeyer, 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)

Franklin, WI  
Tel: (414) 324-0499  
wisconsin@fsma.org  
Contact: Kate Vogedes, Laurie King,  
Jenny Imhoff

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

Please contact our Chapter  
Coordinator, Barb Trainor at  
chapters@fsma.org



## Families of SMA Gift Registry Success Story

Douglas and Michele are the proud parents of Greyson Erwin (SMA Type II), of Massapequa, NY. In May, Douglas phoned the FSMA National Office with his desire to help fund the necessary research to find a cure for SMA and had decided to form a team to run in the Nike Half Marathon in New York City.

This was a perfect opportunity to utilize the new online fundraising tools available on the FSMA website. The Erwins set up their page, including their personal story, a photo of Greyson, choosing their goal amount. Once their page was created, the Erwins sent out their direct link to their page to friends and family. Those who visited the page were able to "click" the red donate button and donate directly through their page. This allowed the Erwins to track their goal and see the list of names grow rapidly on their page!

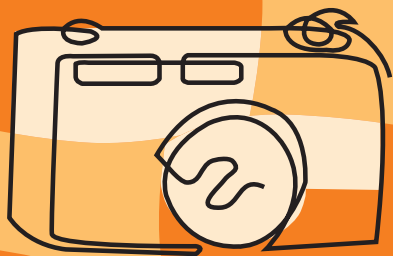
Through "Greyson's Team" the Erwin's managed to raise over \$60,000 through their online Gift Registry and smaller events leading up to the marathon. This was the Erwin's first major fundraising endeavor and through the use of the internet they were able to reach out to hundreds of people.

Families of SMA is sincerely grateful to Douglas and Michele for their hard work and dedication to finding a treatment and cure for SMA. Their efforts put us one step closer to our goal. We also thank Phillips -Van Heusen Foundation and friends and family who helped the Erwin's exceed their fundraising goal!

If you need assistance in setting up your online Gift Registry or have any questions please call or email: fundraising@fsma.org or (800) 886-1762.



## Be a "Directions" Contributor



Photos, poems, articles based on your knowledge and experiences, summaries of great FSMA fundraisers...we want 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.

*Dear Friends*

We are proud to announce that Jacob's Run, Walk & Roll to Cure Spinal Muscular Atrophy has raised \$109,500! The event was a huge success - it was attended by more than 600 people and the day was a celebration of life and love. We had two beautiful little girls affected by SMA join us and 10 other families who joined us to walk in memory of their children who have lost their battle to this horrible disease. We were also fortunate to welcome Amy Marquez and her family to our event. At 36 years old, Amy is the oldest, known living survivor of Type I SMA.

We would like to thank all of our donors, volunteers and participants. We would like to especially thank our top three fundraisers: Rachel & Josh Altchek (who raised over \$10,000);

Tanya Bowser (who raised over \$7,700); and The Painter Family (who raised nearly \$5,200). We would also like to thank our Shooting Star Sponsors: Rooms To Go and The Kaplan & Diamond Families. Since our inception, Rooms To Go has contributed more than \$30,000 to fight against SMA.

Although we miss our son each and every day, we are so grateful to know how many lives he has touched and what a difference his short, yet meaningful life continues to make.

Last year, our Foundation contributed \$116,000 to Families of SMA with \$50,000 being allocated to further drug discovery; \$50,000 to begin a trial for Type I patients in the Southeast; and \$16,000 to fund stem cell research. The \$16,000 was matched by a generous grant from another organization. As a result of the enormous success of Jacob's Run, Walk & Roll, we are looking forward to presenting Families of SMA with another large donation this summer, when our family attends the annual conference in Boston.

Again, thank you all from the bottom of our hearts. Please save the date for next year's Run, Walk & Roll- March 22nd, 2009! We look forward to your continued support.

**Sincerely, Shaina & Adi Rappoport and the Jacob Isaac Rappoport Foundation**

**This fantastic donation from the Jacob Isaac Rappoport Foundation is made in memory of Jacob Rappoport, Taylor Bowser, Shelley Cahlon, Payton Freeman, Maxwell Merritt, Caitlyn Munson, Ryan Nolan, Shreeya Patel, Drew Selogy, Alexander Tozzoli, Tyler Yunes, and Margaret Zayas; and in honor of Zeke Lerner, Amy Marquez, Chloe Painter, Natalie Quintana, and Madison Smith.**

# Faith's Lodge

By Justin Kuester

There is nothing better than having the opportunity to get together with other families who are going through the same life challenges as you are. This is exactly what was recently afforded to a group of SMA families primarily based in the Midwest.

At the end of July, eight SMA families traveled to a place called Faith's Lodge. Faith's Lodge is located in Danbury, WI. Faith's Lodge is truly an amazing place. The tag line for Faith's Lodge reads, "a place where hope grows". This is a very appropriate tag line for the experience our group of families had.

Faith's Lodge is nestled in the woods of northwest Wisconsin. It is off the beaten track and most of us got lost since GPS did not even know all the roads. We arrived on a Thursday and stayed through Sunday. Every family had their own "suite". The rooms are very large and very accommodating to all the equipment most of us travel with. The rooms are equipped with sleep number bed(s), bathroom, fireplace, flatscreen TV and a deck/patio.

Faith's Lodge came to life because of the Lacek family. The daughter of Susan and Mark Lacek, Faith Ann Lacek, was stillborn due to an unexplained umbilical cord accident. As the Laceks journeyed through the grieving and healing process, they decided to create Faith's Lodge as a way to help other families who have experienced a similar loss or whose children are facing a serious medical crisis. It is their hope that Faith's Lodge will offer these families a place of sanctuary as they travel through their own healing journeys.



The Doeberbert family was instrumental in the planning of the event. They arranged for a group of volunteers to provide and serve all the food for the weekend. This was wonderful since it allowed the families to concentrate on visiting with one another. As you looked into each room it was very familiar: cough assist

machines, suction machines, BiPAPs and humidification units. As you roamed the lodge you also had the familiar sounds of power wheelchairs, alarms and suction machines.

Faith's Lodge has 3 levels and everywhere in the lodge is powerchair and stroller accessible. There is a screen porch, great room, play room, dining room, library, outdoor deck and Eagles Nest (lookout on 3rd floor). Outside on the property there are trails, paved basketball court and the very popular bonfire pit.

We had several activities through the whole extended weekend. A popular activity was going to the Circle JC Faith ranch. This was a small farm where the kids were able to see ponies, chickens, bunnies and sheep. We also had each of the kids leave a hand print on some t-shirts. The t-shirts were presented to Dr. Mary Schroth and Lisa Pharo when Addison Kuester had an appointment shortly after the trip. A huge care package of "goodies" that was put together by all the families of "goodies" was also presented to them.

**For more information about Faith's Lodge please go to**

**[www.fsma.org](http://www.fsma.org).**





We introduced our new Families of SMA logo at the annual conference. Our goal with the redesign was to communicate the hope that has been created in our community.

We are no longer just about balancing tough times, coping with SMA and just getting by. We have made dramatic progress in research and are in a vastly different place from 25 years ago. We have a bright future ahead of us.

We thank the team of **Shaina Rappoport, Dana Craven, Sherryl Langland, and Paula Barrett** for all their efforts and amazing creativity in developing the new logo for us.

The new look that they have developed represents the progress we have made and shows the unique partnership we have between researchers and families all working together to find a treatment and cure for SMA.



Families of SMA would like to say "thank you" to Macy's for including us in this year's Shop for a Cause. Thank you to so many of you who purchased tickets and helped spread the word within your community.

*Have you ever thought about starting a chapter?*  
**We want to hear from you.**

CHAPTERS ARE REACHING OUT TO COMMUNITIES ALL ACROSS THE COUNTRY.  
 Families of SMA currently has over 23 chapters in the United States.

*Do you live in one of the following states?*

Montana	Utah	South
Idaho	Nebraska	Carolina
Nevada	Oklahoma	North
New Mexico	Arkansas	Carolina
Wyoming	Missouri	Florida
North Dakota	Mississippi	West Virginia
South Dakota	Georgia	

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



Contact Barbara Trainor at [chapters@fsma.org](mailto:chapters@fsma.org) to receive more information on how to start a chapter in your state

# CONGRATULATIONS

www.curesma.org

Dear FSMA,

We would like to proudly introduce Abigail Perez to our family. Born on 2-12-08, Christian is now a BIG brother, and he couldn't be better at it. I would really like to thank everyone at FSMA. If it wasn't for your organization, I do not know if I would have had the courage to take the risk again. But now I am so happy. My life is truly complete. Thank you so much. All of you are truly angels.

Mandi Lee  
Mayfield, KY.

- Congratulations to Tonia, Shawn and big sister Hailey Paite on the birth of their son and brother Brandon Lee. Brandon was born on July 23rd, 2008.



- Congratulations to Mindy, Tim and big sister Savanna Rush on the birth of their son and brother Boston.

- Congratulations to Amy Wittman! Amy, from Jerseyville Illinois, graduated from Southern Illinois University in Edwardsville on May 10th with her teaching degree. She is getting married to Danny Green, a Jerseyville Police Officer, on October 18th, 2008.

- Congratulations to Amanda Lapka, age 23, who just graduated with honors from Roosevelt University with a degree in Psychology. Amanda is now going for her masters.



- Congratulations to Vicky, Michael and Dolce Durazzo on the birth of their children and siblings Maximus Mario and Layla Giovanni.



- Congratulations to Jake, Kathleen and Chloe Ochoa on the birth of their son and brother Tysen.



**Congratulations** to Kathy LeMieux, Morgan Joyce Kelly and Katrina Gossett! Kathy LeMieux, who is currently Ms. Wheelchair Michigan, recently competed in the Ms. Wheelchair America pageant.

10 year old Morgan Joyce Kelly has won the senior division of the Pre-Teen Florida scholarship competition.

23 year old Katrina Gossett represented Indiana in the Ms. Wheelchair America Pageant. Katrina is now in her final year of classes at the University of Chicago Law School.



Kathy LeMieux

Morgan Kelly



# MEMBERSHIP form



## Suggested Annual Donation for Membership

Family	\$30
Professional	\$35
International	\$40

\* 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

Credit Card #

Expiration Date

Name on card

Signature

Family Name

Email

Address

City, State, Zip

Home Phone

Work Phone

Mobile Phone

Mother/Wife/Guardian

Father/Husband/Guardian

Relationship to affected person

Affected person name

M / F      Date of Birth

SMA Type

Current Status

Date of diagnosis

Date of death  
(if applicable)

Other persons NOT affected by SMA (siblings, children, parents)

Name      M / F      Date of birth

Name      M / F      Date of birth

Can we add your name/address to our family contact list?    ☐ YES    ☐ NO

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

FA08

This section has been designed to enable you pull it out. It includes membership forms, donation forms, as well as a memorial section.



**Skylar William Bahrenburg passed away peacefully on Saturday, June 21, 2008 at the tender age of 7.**

Skylar was born at Queen of the Valley Hospital in Napa. At 10 months of age, he was diagnosed with a terminal disease called Spinal Muscular Atrophy (SMA). This is a motor neuron disease that affects the voluntary muscles. Involvement of respiratory muscles (muscles involved in breathing and coughing) causes increased tendency for pneumonia and other lung problems. Sensation and the ability to feel are not affected. Intellectual activity is normal and patients with SMA are extremely bright and sociable.

Skylar lived 7 full and beautiful years beating the odds of his 2 year life expectancy. Skylar was an active playgroup member in the Sonoma Valley Mother's Club starting at three months old. He attended preschool at Crescent Montessori in the Community Center and Headstart at Flowery. He continued on to the Presentation School where he spent two wonderful years in Kindergarten and First Grade. Skylar loved school. He had many friends and enjoyed the challenge of going up to Second Grade for Language Arts and Math. Skylar had a zest for life and a strong spirit which compensated for his weak body. He was an avid sports fan and dreamed of being a professional basketball player. He knew every sports statistic about every player and team in the NBA, NCAA, NFL, and MLB. What he couldn't do on a sports court, he made up for on the X-Box 360 beating everyone at all sports games although his brother Spencer gave him a run for his money. He could be seen all over Sonoma zooming around in his bright yellow powerchair.

Skylar was a loving brother and son. His humor, wisdom beyond his years, love of life, courage, soft touch, thoughtful ways, bright blue eyes, and sunny smile will be missed by everyone. He was a gift that was given to our family, friends and community for too short a time. We will treasure him and our cherished memories forever in our hearts.

Skylar is survived by his brothers, Spencer James and Sawyer Thomas of Sonoma, his parents James and Elizabeth of Sonoma, his maternal grandparents, Susan and Thomas Amlicke of Larchmont, NY and his paternal grandmother, Susan Bahrenburg Matthews of Honolulu, HI.

## ALL WE REALLY NEED TO KNOW WE LEARNED FROM SKYLAR

Have a positive attitude at all times.

Laugh from your toes up.

Sing loudly.

Smile often.

Love your family.

Be protective of your friends, and let them be protective of you.

Zoom around and if you run over someone's toes say you're sorry.

Be silly.

Don't let anyone name your baby brother Slug.

Even if you can't play, jump in and try.

Read as much as you can – and if you can get away with it,

Read Captain Underpants or Pokemon during silent reading.

Hold hands in class.

Touch each other.

Cherish your siblings.

Take risks.

Insist on fairness.

Be good to everyone.

Push the rules.

Challenge yourself.

Don't let anyone tell you you can't do something.

Squawk when you want to be heard.

Always bring something for sharing.

Live life to the fullest.



## Dear FSMA,

I learned about SMA in 1986 after years of doctors being perplexed with my personal muscle weakness. I was officially diagnosed with Type III in 2002 through genetic testing. Before my wife and I had children, my wife was tested for carrier status of SMA. We were told that being a recessive disease, both parents have to be carriers of the gene that causes SMA. We were relieved that my wife tested as not being a carrier.

Yet, on August 11th, 2006 our son Camden was born with SMA Type I. My wife and I were disheartened like many parents everyday who are told their child has SMA. Camden was a very bright boy with a contagious smile, piercing blue eyes, and a loving personality. He smiled despite his face being covered with his Bipap mask to aid his breathing. He was pleasant regardless of the awful respiratory treatments. He loved reading books with anyone willing to read to him, but especially mom and dad. We read books many times in a day. His loving behavior and attitude was a testimony to all those who touched him. His example was powerful humility and contentment in a society which too often looks for unfound reasons not to smile. As a visiting friend said to me in a letter about Camden...

## Dear Camden,

Today you are in the best place of all. How happy I am for you. Your life was short, too short for us, but just perfect in God's timing. Now that you are with Him, you understand that He does things differently than we do, and we aren't capable of figuring Him out. It's really better that way, even though we are to just trust—a very hard thing. I will never forget the day I met you last spring. My husband and I were in California for my husbands work. Your dad and I have been friends since we were in tenth grade. I knew that you were sick, and I wanted to see you and him while I had the chance. Never will I forget your beautiful face and enchanting blue eyes. Those eyes are seared into my soul, and that day in the intensive care of the hospital will always be an important day in my life. I have children of my own, and seeing you there with your parents gave me a perspective that I will try by God's grace never to forget.

Sometimes, when things aren't going my way, and I desire things to be different, I remember you. The Lord puts your beautiful face lying on your hospital bed right in my mind. I have to say the Lord Jesus, "I am sorry. I have what I need. I have more than I deserve. Forgive me."

So Camden, Sweet baby, you changed my life forever. I'm glad I was able to see you and to touch you and to see how beautiful you are and how much your parents loved you. I am sure you are enjoying heaven. You can run and play. I hope you've met my son. Tell him I love him and will see him soon.

Thanks, Camden, for impacting my life forever.

Enjoy the mansions, the gold streets, the famous godly people, and most of all God Himself. He took you home and ended your pain—just like He always does.

I look forward to seeing YOU again too.

Joanna Carter

CAMDEN BURCH DIED NOVEMBER 23RD, THE DAY AFTER THANKSGIVING.



*Oh, God Almighty, I miss my little man.*

*I miss his incessant smile and chubby thighs.*

*I miss his big blue eyes saying "read to me dad".*

*I miss his little giggles when I tickled his little legs.*

*I miss the Joy you brought to everyone who came into your room.*

*I miss his unremitting smile despite continual pain.*

*I miss your steady example of why I should not complain.*

*I miss him and still love him so much and will see him again someday!!*

**-Written by his Dad, Mark R. Burch, from his Mom, Dad and his brother Aeden.**

*Dear Our Friends at FSMA,*

It has taken me over a year to be able to sit down to write this letter. You know already that my daughter Maria Gloria Verdile passed away on February 18th, 2007. Less than 30 days earlier she had celebrated her 12th birthday with some friends and family. It was a great birthday party with the theme "Mystery Party" where the kids solved a mystery of a 'pet kidnapping'. We had lots of food and Maria and her friends played freeze dance and other games.

Who would ever know what was to be still us in less than 30 short days.

We had been on a 17 day vacation to Disney World just in November 06 into December...what a great trip that was.....

So many plans to accomplish...just maybe 2 weeks before Maria passed away she gave a speech at a large MDA Fundraiser on her experiences at MDA Camp and how it was so wonderful. That fundraiser was attended by many businesses and Maria spoke eloquently, clearly and with pizzazz in front of 100's of people with a microphone. Maria and I walked around the banquet room that night after her speech and as people stopped to speak to Maria and to me, I looked at Maria speak to the others and my heart just swelled as to what I saw possible in Maria's future...my daughter was 12 and becoming a young lady, handling herself and her conversations so maturely, growing up and I was able to be witnessing that and reaping the benefits of it as I stood proudly by Maria's side as she spoke to people about her experiences. I will never forget that night. Who would ever know what would happen in less than 25 short days.

Maria loved her life...all day and everyday she made the most out of what was put before her. Maria was of course a straight A student, honor roll, and Maria had been set to begin an EXCEL program (gifted program) for her grade the very week she passed away. Maria was in girl scouts for over 5

years and went to Girl Scout sleep away camp. Maria loved her friends and had many sleepovers' and also slept over at her good friends' house for a slumber party, bi-pap and all. Maria played adaptive sports when they were available and absolutely loved the adaptive playground we had went to. It was kind of far so we did not go that often, though there should have been more in our area, but we did find 2 different playgrounds and went to them a few times. Maria loved everything and everyone. Maria loved life. Maria was a cheerleader for our local football team with her peers. She would drive around in the moves on the field, she just made everything work. I can't even count the number of parades Maria has been in between Girl Scouts and cheerleading. One year Maria's Girl Scout troop all dressed as presents for the xmas parade, another year they were snow men. On homecoming Maria marched in the parade with her cheerleading team, with colored hair and painted faces for homecoming. As you read this you begin to see that life for us was working. Yes Maria had SMA II and we fought from day one for a cure, however as we fought, we continued to live, to the best of our abilities.

Maria had so many dreams. Maria wanted to grow up to be a number of things as a career...on her list were a veterinarian, a famous writer, or maybe an illustrator for veterinary medical books. Maria had dreams...

Maria dreamed of finding a cure for SMA and often wrote about it in school papers. Maria also wrote about "Living with SMA". The key word is 'living'. In Maria's paper she wrote how having SMA was normal for her and many of her friends, she wrote about how they love to do the same things everyone loves to do. She wrote about her dream to find a cure for SMA and how we need to fundraise because to find a cure will cost a lot of money. She made an excellent illustration when she wrote of the mice used in research for SMA having SMA. She illustrated that page



with a mouse driving a power wheelchair, her thoughts were so incredible.

Maria played orchestra bells for 3 years. She took lessons at home for 2 years then was in band in school for 1 year. Maria was set to be in NYSSMA this year. It is where you perform a music solo and you are judged for your technique. Her instructor from school contacted the proper management and there were adaptations made to the music so Maria did not have to play so fast. However, the piece would have been challenging for Maria and that was the point of the program, to challenge yourself and see how well you could perform beyond what could be expected of you with more practice. Maria has always been her own judge, and has been a true believer in equality for all, Maria loved life.

We never expected what fell before us on February 18th, 2007.

Maria has always loved the FSMA conferences. Her 1st conference took place when she was one over Easter time in Las Vegas. It was the beginning of what becomes a life filled with many issues. However we never lost sight of the purpose for our life, to live it to its fullest capacity, the best we could with what we could.

Maria's life however was not without its very difficult times. Maria had been hospitalized many times for pneumonia and atelectasis, however she had become more healthy as she grew up and also after her spinal fusion which she had at age 10. Maria spent holidays and birthdays in the hospital, she has been hospitalized on vacations and has had to cancel outings due to an illness, so life



was not all that easy. However Maria's attitude and her ability to take what life had to offer and run with it is a lesson to me and to all. I have been so proud and impressed by how Maria has handled herself every day in all situations she finds herself in. Maria would be so sick in the hospital, doing cpt, over and over and over, and rarely was there ever a complaint. She would just want to enjoy anything the hospital could offer or we could play, make up games, turn the lights down, draw the curtains and have a movie night in the hospital, all the pleasure that can be found in the simple things in life, each other. I miss Maria so incredibly much as do her family.

Maria's brother Steven also has SMA II. He is as fine as Maria was also. We all live in shock and more disbelief of what transpired that night that led to the end of Maria's life on earth so before her time. The events of that night will be with me forever and I will fight for justice. For Maria did not die from SMA Type II. In the middle of the night I woke to hear a faint sound coming from Maria's room over the monitor I had in my room. I went into Maria's room and Maria was unconscious, as I yelled the nurse that was working that night came into Maria's room. Maria was later stabilized, then by another bad twist of fate ended up being transferred from hospital A to hospital B with a student, a maternity resident who was supposed to be supervised by the attending physician. We were told that the attending physician was supposed to be on that ambulance for the transfer, and yet they had left without her. She later made the fateful decision to just let them bring Maria to her. Well, Maria proceeded to

spend 30 minutes in the parking lot of the first hospital, as I was there too, with the student and something went wrong, however due to inexperience no one knew if it was the equipment, the monitors, Maria or what. I physically jumped off that ambulance several times to run back into the hospital where we left to get the doctor from the ER back out to us. He came out, the nurses came back out, the respiratory therapist came back out. They could not believe they were still there as Maria was declining in the ambulance. The ER doctor said you need to either leave or come back in as we had been in the parking lot about 30 minutes...30 golden minutes as they tried to figure out what to do. Why the attending did not make us wait there for her to come to us...I will never know.. To make matters worse as these people did not know the hospital well we were going to, they parked about as far as you could possibly park from the PICU and we had to walk about 12-15 minutes once we entered the hospital, quite a confusing walk that since the resident was new and the ambulance personnel didn't know, I mostly navigated the way, as I watched them am-bu bag with Maria. They had disconnected the respirator in the parking lot of the other hospital as they weren't sure it was working properly. Now can you believe this insanity? The time Maria needed these people...all went horribly wrong. Maria was not that sick at all, she had been in school on Friday, she had a cold but was home playing pinball on Saturday night and passed away Sunday morning. There will be consequences however, you cannot simply just tell me as I was told this is a teaching hospital and we are human and we make mistakes, to that I say, you made mistakes that cost Maria her life.

Where has this left all of us here. Maria's family, brothers, relatives, friends, Maria herself and me as Maria's mom. Mostly lost and confused, each day we struggle to make any kind of sense of something that just never will make sense. We continue to live this life on earth as we always have and as I know Maria wants

us to...It is a constant daily struggle but we do what we can for Maria, for her brother, for all the other kids, those with and without SMA. We started a foundation called "Maria Gloria Foundation" to help serve all children with any disability. We had our first fundraiser close to one year after Maria had passed away. We raised close to \$15,000 and have earmarked one half of the proceeds directly for Families of SMA. So as you accept this check please say a prayer and reflect for a moment on Maria. A beautiful child given a life so incredibly worth living, so very incredibly enjoyed, appreciated, and loved by Maria and by those around her. I speak as Maria's mom, there are just no words for me to convey the true thoughts. As best as I can say, Maria's life on this earth ended way too early, tragically and by a series of errors and bad choices that ultimately led to Maria's death. It is not her death but her LIFE that has been a tremendous example for us all, differently abled, sick, healthy, whatever.. There is a time in someone's life where if they are lucky enough they learn to live, to enjoy each moment for what it is, not to be living only for a future, but the skill to build for the future but live and enjoy each moment or each day in the present. To not worry so much at all what others have or are doing but to expend that energy on the here and now. Stop, watch, enjoy, feel, live. Relish in who you are and what is going on around you. Enjoy things. Of course Maria wished she didn't have SMA. Most will wish they didn't have hard times, different times, things are not fair, that is the truth, but somehow in the midst of our life here we had discovered how to really enjoy the moment. Be present in what we did, big and simple. That is very much something that matters.

Each day is a challenge, but I do know that for the short time Maria lived on this earth she gave me gifts to last eternity.

Sincerely,

**Holly Verdile, Always Maria's Mom**



## Dear Friends,

I thought you might like to know that Alex fought a good fight but finally lost to SMA. His fellow students and Mastersingers said he was an inspiration and role model for them. Over 400 people had been touched by him and attended his funeral. We have been members of FSMA since he was diagnosed 13 and a half years ago. His parents Eric and Alisa Taylor have been members and have supported FSMA since his diagnosis also.

Thanks for your support throughout the years!

*Rita Lyda*

*Alex's Grandmother*

*P.S. He actually flew a Cessna for a short time!*

## ALEX KRESTENSEN TAYLOR

Alex K. Taylor, 15, of Charlotte, died peacefully on March 5, 2008, after a brief battle with pneumonia. Alex was born in Charlotte, NC on October 30, 1992, the only child of Eric T. and Alisa Lyda Taylor. He was the greatest inspiration and biggest blessing in their lives.

Alex was an A/B honor roll student at Tuckaseegee Elementary and Wilson Middle School. He was in the 9th grade at Phillip O. Berry High School. In 1997, he was appointed State Goodwill Ambassador for the Muscular Dystrophy Association.

Although Alex was affected by Spinal Muscular Atrophy (SMA), he lived a full life in his 15 years. He was a member of the Mastersingers at St. Peters Choir School. Alex had many adventures such as climbing to the top of Jockys Ridge at the Outer Banks with his 4x4 wheelchair, hiking in the mountains, fishing, and flying in a Cessna plane and a helicopter. He took trips to Denmark and England and looked forward to his summer tours with the choir, traveling throughout the northeast and southeast United States sharing music and making new friends. Among his other hobbies and adventures, Alex loved the beach, the snow, watching movies, his PS3, the Atlanta Braves, the Panthers and Tennessee football. But most of all he loved being in the comfort of his home with his family.

We find comfort in knowing that Alex is now free and taking his first steps in Heaven and singing in God's choir. Alex knew that he was loved by everyone and he will be missed terribly.

He was preceded in death by his paternal grandparents, Frank W. and Frances Sanford Taylor, and his cousin, Jacob Emmanuel Lyda. He is survived by his parents; his maternal grandparents, Roger and Rita Lyda of Asheville, NC; uncles and aunts, Steven Lyda and Diane Roberts of Winston-Salem, NC, John and Amy Lyda of Swannanoa, NC, Mike and Kim Lyda of Concord, NC, Chris and Jennifer Taylor of Asheville, NC; cousins, Cameron Taylor, Chloe, Sam and Keegan Lyda, Abbey and Emory Lyda and his best pal, Sparkey.

The family would like to express their sincerest appreciation to the Levine Children's Hospital, 8th floor nurses and doctors, and PICU nurses, especially Lisa, Maria and Sara, and Doctors Bailey, Timmons and Young and all of the friends, family and co-workers who have provided support, love and prayers throughout Alex's illness.



## ISABELLA CHRISTINA IRISH ANGERAMI

was born on July 18, 2007, diagnosed on October 10, 2007 and passed away on May 7, 2008. She was always smiling and was my girl. I am her MiMa and she was my best friend. My daughter and Isabella (Bella) lived with me and my husband (Gampi) and our Son her Uncle Nick who she just adored. He is a police officer and God knows how we all wanted to and did to our fullest to protect her. But with the devastating (SMA) no baby can ever be protected enough. Thank you for responding. She was and always will be the LOVE OF MY LIFE.

*Sincerely,*

*Julie Angerami*



### ZACHARY BRIAN DEUTSCHLE

was born on April 22, 2008 at 11:35 A.M at Rush Copley Medical Center in Aurora, IL. He was born 7 weeks early. My wife had HELLP syndrome and had to have an emergency C Section. So when we heard Zachary cry for the first time we were so happy. We couldn't believe the love we felt, automatically, for this little boy. He was only 4 lbs when he was born. For the first week he was doing so well. He was off the CPAP and oxygen support after only 24 hours. He had even started taking some breast milk from a bottle. The doctors and nurses were very happy with his progress. On about the 8th day he started to have some problems. He had Tachypnea, which means he was breathing too fast. The doctors said this was a common problem in premature babies and there was nothing to worry about. They said he had low tone but that was not uncommon for preemies. Over the next few weeks he got progressively worse. He had to have a nasal cannula. He would have bradycardias and have trouble keeping his oxygen saturation at the proper levels. The doctors and nurses solution was to just keep increasing the oxygen level through the nasal cannula. They ran all kinds of tests and everything came back normal. They kept saying it was just because he was premature.

On May 17th we had enough and

wanted an answer. I confronted the doctors and they finally admitted they did not know what it was and why he was not getting better. At this point the decision was made to transfer him to Lutheran General Children's Hospital in Park Ridge, IL. All the tests that had been run on Zachary at Rush Copley went to the specialists at Lutheran General. It was decided it would be better if he had the specialist close by. Park Ridge is about an hour and fifteen minutes from our home. We decided to stay in a hotel close to the hospital. As soon as we got to Lutheran General they did a lot of tests and put him on a ventilator. His body was exhausted from breathing fast for so long and the doctors wanted to give him a break.

All the tests still came back negative. After 3 days he was taken off of the ventilator and put on CPAP. He seemed to be getting better and we got our hopes up he would be coming home with us. A few days later they tried to take him off CPAP and put him on a nasal cannula. He was only on the nasal cannula for 24 hours and had to go back on the CPAP. The doctors were not concerned because this sometimes happens and they were going to try again in a few days.

Meanwhile they are continually running more and more tests and everything was still coming back negative. There were a few times they were sure it was

something and then the test would come back negative. We would get our hopes up because the things they thought they were could be fixed. He started to go downhill again and had to go back on the ventilator. One of the neurological tests came back that it could be SMA. They decided to do a muscle biopsy because they said it would come back faster than the genetics test to confirm he had SMA. They were wrong, we had to wait for the genetics tests. We had two weeks of waiting around knowing our son was going to die. During those last few weeks with Zachary we tried to do normal baby stuff. We bathed him, had him baptized, and watched as he began to smile at us and his toy fishes. When they came back the test confirmed what we already believed; he had SMA Type I. His body had already begun to shut down.

He could not move his arms and legs or breathe on his own and he sometimes made faces that looked like he was in pain. The doctors said we could keep him alive on machines a little while longer and he probably would suffer, or we could allow him to die comfortably in our arms. We decided he had suffered enough and allowed him to pass away in our arms. This was the hardest decision we have ever made, but we know we made the right choice for Zachary.

**From Brian and Sherri Deutschle**





*IN MEMORIAM*  
**CRUCIANO FANARO**  
4/9/08 - 9/7/08



*IN MEMORIAM*  
**BENJAMIN JERREL WHITE**  
11/19/03 - 3/15/06



*IN MEMORIAM*  
**DAHRIAN PIMENTEL**  
11/18/06 - 1/9/08



*IN MEMORIAM*  
**GAVIN HARVEY**  
9/26/07 - 03/08



*IN MEMORIAM*  
**GIANA GAVILANES**  
1/13/07 - 11/20/07



*IN MEMORIAM*  
**RONALD L. LOVE II**  
3/9/07 - 4/27/08



IN MEMORIAM  
**LILY EILEEN KENNEDY**  
7/28/00 - 2/2/01



IN MEMORIAM  
**TIERNAN CONNER-PARK**  
12/6/02 - 5/27/03



IN MEMORIAM  
**MADELYN GRACE SHANNON**  
2/26/07 - 3/18/07



IN MEMORIAM  
**MADISON VICKERS**  
8/1/03 - 8/26/04



IN MEMORIAM  
**EDEN KATHLEEN FOLEY**  
6/5/07-1/18/08



IN MEMORIAM  
**JAY RANDALL MARLOW**  
01/25/08 – 8/25/08

It's hard to believe that it's 3 years. The hole left has healed somewhat, but will never be totally healed. While I was in St Augustine, FL, I came across this wonderful playground. On leaving it, I had an afterthought to get a picture of the sign to ID it in the future. The SMA connection wasn't noted until after returning home and looking at the pictures (The park was dedicated to Kourtney Nicole Schmidt who passed away in 1999 from SMA). It's amazing how we are drawn and led to be in certain places at certain times. I know that MJ would very much have enjoyed just tooling around in the park, even though she never could/would join in such fun, just watching the children having fun would have made her little toes dance in her chair. I really miss sharing those little things with her. It's amazing how you feel all the tears have been shed and there are always a few more waiting to be set free.

**Hank Ausse**

# FSMA merchandise

www.curesma.org



## 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.



Mail your Orders to  
FSMA National Office  
or fax to 847-367-7623  
Order form is on Page 42



## Angel Wing Pins | \$10



## SMA Awareness Pin | \$15

One design in sterling silver.



## FSMA Car Magnet | \$5

1 design.  
NEW ITEM!



## License Plate Frame | \$7



## 12 Fruit Notecards | \$6

4 each of 3 designs (12 cards). Artwork by Holly Campbell, in memory of nephew Charlie, SMA Type I.



## Cure SMA Bracelet | \$2

Available in small or large.  
Created in honor of Steven Potter.

Check the FSMA  
website for new merchandise  
**curesma.org**

## TOTES



## Canvas Tote | \$15ea.

Choose either Flower or Seascape design. Artwork by Katie Gardner 11/89-4/03.



## Cotton Tote bag with Zipper | \$17

Together design.



## Bag | \$10

New FSMA logo.  
NEW ITEM!



**Spring Note Cards | \$6**

Alyssa Silva's "Working on Walking" note cards. 6 different cards.

**"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 L XL.

Long Sleeve, Kids sizes only: 2/4 6/8 10/12 14/16

**FSMA "Moving Forward" T-Shirt | \$12**

Sizes: S M L XL

Check the FSMA website for new merchandise  
**curesma.org**

**Families of SMA T-Shirt | \$12**

1 design on short sleeve white shirt.

Kid sizes: 2/4 6/8 10/12 14/16

Adult sizes: S M L XL **NEW ITEM!**

**American Cards | \$6**

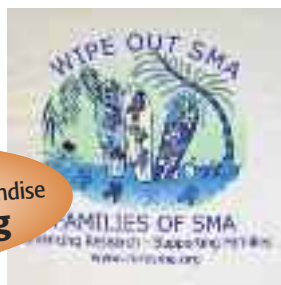
Alyssa Silva's "American" note cards. 6 different cards.

**Thank You Cards | \$6**

Alyssa Silva's "Thank You" note cards. 6 different cards.

**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.

**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

**Cookbook for a Cure | \$14**

The FSMA cookbook contains almost 400 recipes from SMA families all over the world!

Mail your Orders to  
FSMA National Office  
or fax to 847-367-7623  
Order form is on Page 42

## Donation Form

FA08

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

In honor 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

FA08

Gift Certificate vendor list available online or by calling 800-886-1762.

Retailer

Qty

\$ Amount

TOTAL

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

### Payment Method

☐ Check ☐ Money Order  
☐ VISA ☐ Mastercard ☐ Discover

Credit Card #

Expiration Date

Name on card

Signature

Ship order to

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

Subtotal \$

Shipping \$

**Total \$**

Phone

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

## Merchandise Order Form

FA08

Item

Size

Qty

Description

\$ Amount

TOTAL

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

### Payment Method

☐ Check ☐ Money Order  
☐ VISA ☐ Mastercard ☐ Discover

Credit Card #

Expiration Date

Name on card

Signature

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

Subtotal \$

Shipping \$

**Total \$**

Ship order to

Phone

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



*Dear FSMA,*

In honor of Grace DeGraffenreid, the elementary students (pre-school through 6th grade) at ColeR-V School in Eugene, MO completed their 1st annual Change for a Cure and Wear Your T-shirt to Work Day the week of May 20th. Gracie's grandmother Sherry Degraffenreid, who is a bus driver for Eugene School challenged each class to raise the most money. For the class that raised the most money, Sherry provided a Pizza Party. Second and Third place winners had an Ice Cream Sundae Party.

1st place winners were Mr. Barger's 5th grade class who raised over \$180.

2nd place winners were Mrs. Ousleys 5th grade class who raised over \$90.

3rd place winners were Mrs. Carrender's 2nd grade class who raised over \$80.

Staff and students at Eugene School purchased \$710 in FSMA T-shirts.

It is my pleasure to present FSMA with a check for over \$1,700!!

Also, the DeGraffenreid family has "adopted a highway" which will be known for SMA. The sign will be placed on the major highway that goes to the Lake of the Ozarks, HWY 54. We are having a sign made that will display "spinal muscular atrophy" in hopes of

bringing more awareness to this horrific disease.

Thank you for all that you do for the patients and Families of SMA.

**Sherry Degraffenreid**

*Dear Families of SMA,*

On behalf of the West Rocks Community Service Club, enclosed please find a check in the amount of \$1,000. This is a result of a Penny Drive that was recently held at West Rocks Middle School to support the wonderful work that you do in funding research and education for Spinal Muscular Atrophy.

We have supported your efforts for the past eight years in honor of Cubby Wax (Cubby has SMA Type I). His mother, Laura Wax, is a well loved and respected sixth grade teacher here at West Rocks Middle School.

We will continue what we can to support your efforts and we hope that this contribution can be put to good use.

**Sincerely, Jacqueline Roberson  
The West Rocks Middle School in  
Norwalk, CT**

The Student Council, called "CONCLAVE", of **Marquette University High School, in Milwaukee, WI**, raised funds in honor of Jackie Hoffmann. For their prom they donated the money that they would have spent on renting tuxes or flowers for their dates. They called the fundraiser "Suits for SMA". They raised an incredible \$2,400 for Families of SMA!!

*Dear FSMA,*

Students in the seventh grade Home and Career Skills classes, at Weldon E. Howitt Middle School in Farmingdale, NY, participated in service learning activities this year. They became entrepreneurs and ran their own restaurant businesses. They learned that it is important to give back to others, so they were encouraged to take the profits they made from the businesses and donate to a charity of their choice. After engaging in heart wrenching debate over where the money should be

donated, they chose to donate to your organization! We are hoping this money (\$50) will help others in need.

**Sincerely yours,**

**Sonia Chodhury the Home and Career Skills Teacher**

*Dear FSMA,*

On behalf of the Hutcheson Junior High Student Council, we are donating to Families of SMA money totaling \$1,555, in honor of Kennedy Robinson. We hope that this can and will help in some type of way.

**Sincerely, LaShall Jones  
Student Council Sponsor  
Hutcheson Junior High  
Arlington, TX**

*Dear FSMA,*

Each payday, our staff at Tolland Middle School in Tolland, CT, has a Dress Down Day, in which the staff members make a donation in exchange for dressing comfortably for the day. During the month of May money was collected for Spinal Muscular Atrophy. On behalf of the staff at Tolland Middle School, we would like to donate \$214. We know that you can always use the extra money and hope these checks will help!

**Sincerely, Duska Hepner  
On behalf of the staff at  
Tolland Middle School**

**In Memory of Alexander Tozzoli**

**Stacy Fox's third grade class, in Alvord, TX**, filled canisters of coins to raise funds for FSMA in honor of a fellow student. They raised \$202.

The **George G. White Middle School in Hillsdale, NJ** held its annual walkathon in late April. The Children and the Teachers were able to raise funds for Families of SMA as well as heightening awareness of SMA in their area. They raised over \$600 for FSMA.

The Teachers at **Cumberland High School, in Cumberland, RI**, raised \$65 for FSMA from a Dress Down Day at their school in honor of Alyssa Silva.





**The 8th Annual Concert for a Cure** was held Friday, May 16th, 2008 at the Blackhawk Country Club in Danville, CA. Concert for a Cure is in honor of Danny McHale, Ariana Dindzans, and Isabella Andrade. The evening included silent and live auctions, dinner, and dancing with Jamie Lynn Morgan & The Hired Gunz. This year, once again, Concert for a Cure raised over **\$115,000** for Families of SMA! This brings their grand total throughout the years to over \$550,000!

Paul Kapellas, of Chicago, IL, has raised **\$32,000** for Families of SMA, in memory of Cru Fanaro.

“The **2008 Chicago Marathon** will be my 7th marathon. In years past, my goal has simply been to better my time. This year, I have decided to try to use my running to help others. I am raising money and awareness for Families of Spinal Muscular Atrophy. My original goal this year was to raise \$3,000 to help find a cure for SMA. After an amazing first day, we raised the goal to \$7,500. We smashed through that goal on Day 3. We then decided to raise the goal to \$20,000. We broke that mark in mid-July. We reset the goal to \$25,000 and surpassed that in late July. We have reset the goal to \$30,000.

The reason I chose to run for SMA is this:

In June of this year, my co-worker and friend Ken’s baby boy Cruciano was diagnosed with SMA Type 1. Cru and his family have an extremely tough battle ahead of them. Please help me support FSMA as I run for Cru to help find a cure through research.”

David and Lisa Hamman of Naperville, IL hosted the **Hamman Family Luau** in memory of their son Henry. The Luau drew a record crowd this year, over 600 people in attendance! The entire Hamman block was filled with friends and family. This year they added some additional attractions such as a moon-walk for the kids! The Luau had a silent

auction and raffle that raised nearly \$6,000. In total the Luau raised **\$30,650** for Families of SMA!

T-shirts for the TV Show “**House**” were sold on www.Seenon.com and a portion was given to Families of SMA in honor of Zeke Lerner, of Oak Park, CA. They raised an amazing **\$25,000** for FSMA!

Stan and Terri Severance of Brewer, ME together with Ben Potenziano, Strength & Conditioning Coach for the San Francisco Giants, hosted **Logan’s Freedom Ride Rolls On** at Apartment 24 in San Francisco, CA on August 6th, in honor of Logan Severance. Also joining in support were San Francisco Giants Players, Matt Cain, Tim Lincecum, Rich Aurilia, Omar Vizquel, Noah Lowry, Kevin Frandsen, and Vinnie Chulk. The evening kicked off with a VIP reception, with guests being treated to a baseball and Sharpie pen to have signed by the Giants players. As the party opened to the general public, the Giants took over as guest bartenders. The event raised nearly **\$20,000!**

Jack and Kim Nadeau, and the Nadeau family, of Springboro, OH, held the **7th Annual Nicole Nadeau Golf Tournament**. Their extremely successful golf outing raised an amazing **\$18,000** for Families of SMA in honor of their daughter Nicole.

Ryan and Kate Nelson of Charlottesville, VA held their first ever fundraising event for Families of SMA and did an amazing job! They organized a bike race titled “**Miracle for Mary**” in honor of their daughter, Mary Nelson. The day started out cloudy but the sun eventually came out in time for the festivities. A big thank you to the Nelson family and their volunteers who helped raise nearly **\$15,000** for FSMA.



Laurie and Todd King of Boscobel, WI held their first ever **Walk-n-Roll** on August 9th in honor of their son, Easton King. The event was a huge success and raised over **\$11,500** for FSMA.



**Kyra Scadden and friends held a garage sale for Jungin Angin Lee.**



Inspired by the Philadelphia Freedom Skate – **The Great ESkate** was born in 2001 in Miami, FL and immediately took on a South Beach flavor. The concept is simple: this is a chance to escape the frigid winters elsewhere and attend a non-stop weekend of skating activities, private parties, entertainment, prizes, and fun. Every year Families of SMA has received a donation from this amazing event, in memory of Ryan Nolan. This year, they donated **\$10,000** to FSMA! Thank you for all of the hard work of the volunteers, especially Bernadette West and Larry Kaplan, and for the generosity of many sponsors and the skate enthusiasts who have supported this event year after year.

**Christopher and Melissa House** of Ann Arbor, MI raised \$9,195 in honor of their daughter, Abigail for the 2008 Michigan Chapter Walk.

8-year-old **Kyra Scadden** and her family successfully managed a wonderful garage sale in Naperville, IL, with the help of the May Watts Elementary Community. Kyra is Jungin Angin Lee's best friend, who has SMA Type II. The garage sale raised an amazing \$9,260 for Families of SMA! They have already planned another garage sale fundraiser!

**Michele and Douglas Erwin** of Massapequa, NY in cooperation with their employer, Phillips-Van Heusen Company, held a Calvin Klein Sample Sale fundraiser to benefit Families of SMA and SMA research. The sale was in honor of their son, Greyson. The event raised \$9,100 for FSMA.

The Wester Family of Louisburg, NC held a **Cruiz In and Pig Cook Off** in April to benefit Families of SMA. The idea was introduced by their daughter Katy, who was preparing for a senior school project and wanted to do some-

thing in honor of her brother, Tyler. From car to BBQ enthusiasts, the event was a hit and raised nearly \$9,048 for FSMA!

**Bommarito Nissan** of St. Louis, MO, headed by Janet Hutchinson, hosted the annual Gateway Z Club Car Show to benefit FSMA. The car show was a great success! Volunteers sold food and refreshments, there was a raffle and numerous donations were made. The event raised \$6,505 for Families of SMA.

Holly Verdile and the Maria Gloria Foundation, of Bay Shore, NY, held a **"Live and Love Life – Maria's Night"** in memory of her daughter Maria Verdile. They raised a fantastic \$6,000 for Families of SMA.

Marge Shively, of Los Altos, CA, with the help of many of her friends and family members, sent out her **"Spotlight on SMA"** annual news letter writing campaign, where she requested that donations be sent to Families of SMA. Marge started the campaign in memory of her granddaughter Jessica Fernandes. They have raised over \$4,500 so far!

Helayne Jobson, of Jamaica Plain, MA, held a Walk-N-Roll called **"Dahrian's Walk"** for Families of SMA in memory of her son Dahrian. She raised \$4,300 for Families of SMA.

Sheri and Dave Kullander of Libertyville, IL held their **10th Annual Kullander Family Fundraiser** in honor of their son, Leo. On March 9th, family and friends braved the rain in support of the Kullander's event that featured Pampered Chef, Southern Living, Tupperware, Tastefully Simple, and many more! The event raised nearly \$3,500 for Families of SMA. Thank you to the Kullander Family for their drive and dedication to FSMA.

Vince and Kay Wittman of Jerseyville, IL held their annual **Amy Wittman Golf Classic for Medical Research** and raised over \$3,427 for SMA research. The event drew over 100 golfers and while they had everyone in one location they asked participants to help with their legislative efforts. Thank you to the Wittman family for your constant support.

**Kent and Eileen Lerner** of Delray Beach, FL held their annual book sales event in honor of their grandson, Zeke Lerner. The book sale event raised nearly \$2,100 this year!

**Brad and Jenny Campbell**, of New Braunfels, TX, raised \$1,800 in memory of their son Braden and in honor of what would be his 5th birthday.

Bruce and Delores Fry held the **10th Annual Derek W. Smith Memorial Golf Tournament** for Families of SMA on May 18th. The golf tournament raised \$1,800 for FSMA in memory of Derek Smith.

The **CA Montessori Children's Center in Oslandia**, NY offered a dance class to their families and donated all of the proceeds to Families of SMA. The event raised over \$1,400 in honor of Greyson Erwin.

Family and friends of **Sophia Doebeert**, of Edina, MN, raised almost \$1,400 for FSMA in honor of Sophia for Christmas gifts.

The Jojo Baudin's Team in honor of Joseph Baudin of Bordelenville, LA, participated in the **Louisiana Chapter Race-n-Roll** on May 3, 2008. Their team raised \$1,375 in support of Families of SMA.

The MJM Calvary Riders, of Warminster, PA held the **3rd Annual Ride to Fight SMA** on May 10, 2008 at the Seafood Factory in Horsham, PA. The generosity of these individuals helped raise awareness for SMA and over \$1,230 for SMA research.

**Samantha Moucha**, of Chesterfield, MI, aunt to five year old Jacob Slaymaker, raised over \$1,200 for Families of SMA in her local "Run, Walk and Roll".

**Jessica and Ken Adams**, of Washington, NC, raised \$600 for Families of SMA by selling Cure SMA bracelets, in honor of their daughter Jamie.

Debby and Robert St. Onge, of Bigfork, MT, held a garage sale called "**Veronica's Closet**" to raise funds for Families of SMA in honor of their daughter Veronica. They raised an incredible \$600!

**Justin and Danielle Barry, and their family**, held a "cook out" with the Kroger Company in Lawrenceburg, IN, in honor of Karah Elyse Barry. They raised \$560 for Families of SMA.

**Melanie Bennzenuto and family**, of Valdez, AK, sold Cure SMA bracelets to raise money for Families of SMA. They have raised over \$500 so far in memory of her son Alberto.

**Paddy Long's Irish Pub**, in Chicago, IL, held a fundraiser for Families of SMA in memory of James Patrick Giroir and raised \$440.

**Tonya and David Willingham**, of Columbia, AL, held a breakfast fundraiser to "Wipe Out SMA", in memory of Piper Olivia Willingham. They raised nearly \$400 for Families of SMA!

**Sarah Hinke, of Merrill**, WI, raised \$360 by selling "Wipe Out SMA" T-shirts to friends and family.

**The Church of St. Jude of the Lake**, of Mahtomedi, MN, held a Greek Fair Fundraiser and donated the funds to Families of SMA. They raised \$331.

**Victoria and Michael Durazzo**, of Toms River, NJ, sold Cure SMA Bracelets to friends and family to raise money for FSMA. They raised \$330 in memory of their daughter Aleah.

**Kari Ann Cisco**, of Holbrook, NY, held a Pampered Chef Party in memory of her daughter Eleanor Rose, for the 2nd anniversary of her death. She raised \$250 for FSMA.

**Lana Weisenberger**, of Mosinee, WI, raised \$215 for Families of SMA by making and selling Christmas Ornaments called "Tessa's Angels", in honor of her daughter Tessa.

**Cargill, Inc.** in Shippensburg, PA, has a program called CHIPS (Community Help Involving People). The hours that employees donate to community organizations can be cashed in towards donations to a non-profit of their choice. Employee Jody Harker choose FSMA to receive the gift of \$200.

**Rick and Kelly Turner** of Hudson, OH held a Southern Living at Home Fundraiser in memory of their son, John Michael Turner. The Hudson's generously donated \$200 of the sales proceeds to Families of SMA.

**Brian, Bob and Lois Schraut, Uncle and Grandparents** of Eric and Stephanie Manda, raised \$163 for Families of SMA during their Annual SMA Drive in St. Louis, MO. They raised these funds in memory Eric and Stephanie.

**The Home Laurentes Homemaker Club**, of Muncie, IN, sold holiday candy and nuts for FSMA, in honor of Katie and Betsy Swetnam, and raised \$100.

**Peggy Foor**, of Naples FL, sells Premier Designs Jewelry and donates the proceeds to Families of SMA. She raised \$100 for FSMA in memory of her daughters Crystal Rose, Cori Lynn and Sunshine Rose.

**The Foothills Congregational Church**, in Los Altos, CA, donated \$74, which was their Sunday offerings, to Families of SMA in memory of Jessica Fernandes.



The band **Deepfield** is used to playing shows for hard core rockers who mosh and bang their heads along to their music. They spend time after their sets talking about SMA. They are selling CureSMA bracelets at all of their shows. Not only are they spreading awareness but they are rocking their way towards a cure in honor of Zoe Grisez, a six year old with SMA Type II who is a huge music fan.



The four piece rock band from South Carolina heard Zoe's story on the popular social site myspace.com. The lead singer, Baxter Teal III, immediately wanted to raise awareness for SMA. And as soon as they came out to Colorado where the Grisez family lives, all four members

of the band wanted to do something more than just talk about SMA. They have toured with bands like Drowning Pool, Saliva, Shinedown, and Puddle of Mudd, and fans of rock music are indeed good hearted people as the bracelets sell at every show. Most fans are happy to buy a simple bracelet to help a great cause but many will throw down extra money to just be added towards the fundraising. You can learn more about Deepfield by visiting them at [www.myspace.com/deepfield](http://www.myspace.com/deepfield) and if you have an account, take the time to thank them for doing what they do.

**Lomas Financial Services**, in Hillsboro, OR, raised \$45 from their 7th Annual Holiday Celebration and Giving Tree in honor of the Hassel Family.



**Gina Bish** of Andover, KS has started a company (Larkie Lu Bows) in honor of her daughter, Larkin Bish. Larkie Lu Bows creates beautiful bows in a variety of colors and styles. Gina has offered to donate part of the proceeds from sales of the bows to FSMA, and her first donation was for \$35 in honor of Larkin.

See our website for interesting ways to support the cause.





Hi FSMA ,

It's Allie Mazzella. Just wanted to tell you how the Walk-n-Roll went. In total, we had over 120 participants and raised nearly \$5,000! The Santiagos' and I were overwhelmed with support!

Most people actually did walk the full mile – even the first graders! Of course, some did stop and get a snack in the middle. A lot of places in town donated drinks and snacks.

We had two people with SMA participate in the Walk-n-Roll. One girl named Eloise, a family friend of the Santiagos. She is in seventh grade and came all the way from Long Island to participate. A lot of her teachers also came to the walk to support her (she goes to Shongum School). I think both girls enjoyed themselves at the walk and Darcy said a few words before we began. Katherine's sister, Julia Santiago also spoke and she was pretty funny. I used to think she was shy! The walk was a huge success and I know everyone had a good time, even the Santiagos. I know everyone felt Katherine's spirit as



we were walking, maybe that's why it didn't rain! If you have any questions, please feel free to contact me.

**Thanks, Allie Mazzella – age:12  
Milburn, NJ**

*Dear Families of SMA,*

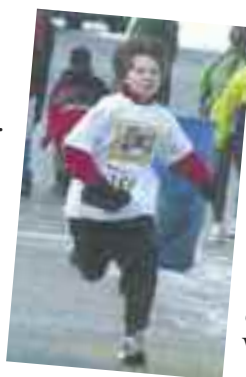
My name is Kennedy Montoya and I have Spinal Muscular Atrophy Type II. My Grandparents belong to the orange County Mustang Club. The club has two car shows a year and their 50/50 raffle goes toward SMA. I got to pick the winning ticket and presented \$335 to the lucky winner. The other \$335, I am sending to you so that you can put it to good use. Thanks for all this organization does to help with research to find a cure for this disease.

**Kennedy Montoya - 5 years old  
Garden Grove, CA**

*To Families of SMA,*

My name is Ian and for my birthday this year, I collected money for SMA research. Please send this \$66 directly to buying whatever is needed to help find a cure. It's not too much, but I'd like to help.

**Yours truly, Ian Stillmunks  
From Des Moines, Iowa**



**Philip Meneghini**  
of Haverhill, MA ran in the Bradford Valentine Road Race in memory of his sister, Victoria Meneghini. Philip is an amazing 9 year old and raised \$300. Way to go Philip!

*Dear Families of SMA,*

I am so pleased to be able to present you with \$260.65. From our previous letters, I know that it will be put to good use.

Being a child, I hardly ever get mail. Therefore, you might know that I jump for joy and announce to my parents and two older brothers that I got mail from you every time.

I put up a box in my daddy's office. It shows a picture of my cousin, Matthew Wallis, and asks for loose change to go to FSMA. The money I raised here came entirely from the donations box.

Please reply to my letter and put this money to good use. I would also like some pictures of the scientists and something telling me what the money was used for. I am happy to be able to participate in this.

**Lydia Wallis  
Longview, TX**

*Dear Families of SMA,*

Enclosed please find a check made out to your organization for \$285. These are funds that were raised in a car wash by the 2nd grade Wolf Cub Scout Den of Pack 632, in Arlington, VA. The boys paid for the car wash supplies themselves, and are contributing 100% of the proceeds they received!



There are 18 boys in this Den. One of the boys has an Uncle with SMA. Accordingly, we are making this contribution on behalf of Warren Een, of Warrenton, VA. "Uncle Warren" as the boys call him, is 48 years old and – in addition to being a tremendous character role model for the boys – does a great deal of work helping with phone calls to set up scouting activities. We



love him and thank God for all that he does for us.

These boys have strong character, wonderful, supportive parents and are also building a great sense of patriotism. Thank you for all you do for the Families of SMA.

**Warm Regards, Eric Gerner  
Wolf Den Leader  
Arlington, VA**

*Dear FSMA,*

On August 16th, we had a lemonade stand to raise money for FSMA. We had it in memory of our brother and sisters. We sold lemonade and cookies. We made a big sign to explain about it. And we had my 3 year old brother with SMA Type I sitting beside the sign. We raised \$320, but I made it an even \$350 with my personal money. I hope this will aid you in your research to find a cure for SMA.

**Sincerely, Delmar Martin and my cousin Glen Martin  
From Bainbridge, OH**

*PS – I am the brother of Lewis my 3 year old brother with Type I.*

*Dear FSMA,*

Enclosed you will find donations made in honor of Colby Russ (SMA Type I, Louisville, KY).

Colby Russ turned 6 on July 22nd. His birthday party was held on July 20th at a local pizza pub with 60 of his family and friends attending. They were all asked to donate to Families of SMA in lieu of birthday gifts.

We are very proud of Colby and all of the accomplishments he has made over the years. We're also thankful for all those who care about Colby and finding a cure for SMA. They raised \$656 for FSMA.

**Sincerely, Amy Russ**

**The McGuire children and Jillian & Jack Devine, of Braintree, MA,** held lemonade stands for Families of SMA in honor of Own Norton and raised a combined \$51!

For **Molly Piper's 3rd birthday**, in lieu of birthday gifts her family and friends gave donations to Families of SMA in memory of her brother Benjamin. Molly, who is from Pittsburgh, PA, raised \$215!

**Ethan Schoenborn, of Grayslake, IL,** sent his \$2 weekly allowance to Families of SMA in honor of his brother Sam!

For **Reagan Imhoff's 3rd birthday**, in lieu of birthday gifts, donations were sent to Families of SMA. They raised \$658 in their town of New Berlin, WI.



On **Catarina Kropsch Magnago's 2nd birthday**, in lieu of birthday gifts her parents, Fernando and Izabel Magnago, of Rio de Janeiro, Brazil, asked friends and family to send donations to Families of SMA. They raised over \$2,000 for Families of SMA!

**12 year old Talia Cohen, of East Northport, NY,** handmade braided bracelets and sold them at various craft shows, jewelry shows and flea markets. She also passed out literature on FSMA. Talia raised \$37 in honor of her friend of Michael Brodsky.

Friends **Jackie Hoffmann and Annie Barrett** held their 14th birthday party together on June 18th in Milwaukee, WI. In lieu of presents, people could make donations to Families of SMA. They raised \$505 for FSMA!

**Helen from Edmonton, Alberta, Canada,** had a fundraising birthday party for her 8th birthday. Instead of presents, her friends made donations to Families of SMA. Helen has SMA Type II. She thinks her friends donations are

a very precious present for her and the other children like her. She hopes that there will soon be a cure for SMA. Helen and her friends had a wonderful bowling party and raised \$202.25.

**Sincerely, Helen's parents**

*Dear Families of SMA,*

Talia Cohen, a 12 year old close friend of our own son Michael Brodsky, raised both money and awareness for SMA.

Talia did this by hand making unaided bracelets and placing literature about SMA at various craft shows, jewelry shows and flea markets.

This was entirely her idea. Please except this check for \$37 from Talia in Michael Brodsky's honor.

**Thank you, Alyssa Brodsky**



**School children making Cure SMA bracelets to sell for Families of SMA.**



Hi FSMA,

I hope you all had a wonderful summer. We held the 3rd Rally for Reagan Golf FORE a Cure again on August 1, 2008. It was an outstanding day for golf and getting together with family, old friends and new friends. We are really excited because this year we were so fortunate to have four other SMA families join us...Scott and Lisa Sheppard and angel son Grant (SMA I), Kate Vogedes and daughter Leah (SMA II), Eric and Angie Nelson and son Ben (SMA II), and Angie and James Damon and daughter McKenzie (SMA II). I made them all guests of honor.

This year we raised over **\$25,000** for FSMA!

**Thanks so much, Jenny Imhoff**



Dear Families of SMA,

On March 8th of this year, the Hailey Mae Foundation held their 5th annual "Ski Away SMA" event at Magic Mountain in Londonderry, Vermont. The support we had during Hailey's time with us and after her passing in December of 2002 has been unbelievable. We are so grateful to our family and the many friends who make this event such a success every year.

It is with great pleasure and gratitude for all you do that the Hailey Mae foundation will be donating **\$22,000** raised from our "Ski Away SMA" event to FSMA to help in your fight to find a cure for SMA.

We continue to pray for strides toward a cure each and every day. Taylor and I hope in some small way our donation gets us there a little faster.

Fondly,

**Marie & Taylor Smesler**



usual. This year we had a record of about 275 walkers!! We had 4

Dear Families of SMA,

Round 4 of the Jack Attack on SMA was held June 14th in Lindenwood Park in Fargo, ND. Our day was filled with tattoos, balloons, great weather, and an even better turn out than

"Returning Champs" with SMA in attendance: Jack Gellner, Trish Kuemper, Cole Pulkrabek and Ashley Wohl.

This year we were excited to have 2 new "Fighting Champs" join us as well: Chloe Bartholome and Payton Krebsbach. Payton even made an incredible 7 hour drive just to be with us! We were so pleased and honored that they came to walk and roll! As always, each "Champ" received a medal of honor and special recognition to kick off the event. The walk was followed by a great lunch and plenty of time for networking with family and friends. This year the park boasted a brand new all accessible "universal" playground structure. It was fun to see all those wheels flying around on all the equipment! Thanks to everyone who came out and supported Families of SMA – we raised close to **\$20,000!**

Together we WILL "Knockout" SMA!

**Kristi Gellner**  
Fargo, ND

To Families of SMA:

Please accept the enclosed donation of \$7,150 on behalf of my daughter, JoAnna. As you are aware, JoAnna suffers from SMA, and on Monday, April 21, 2008 I ran the Boston marathon in her honor.

The Boston marathon is the world's

oldest annual marathon and ranks as one of the world's most prestigious road events. This is the fourth year that I have participated in the race. My official time was 3:47:42; this is my personal best, and I am so proud to have done this as a tribute to JoAnna.

I am grateful for the support of my friends and family, and I am hopeful that their kindness and generosity will help find a much needed cure for SMA.

**Very truly yours,**  
**Stephen J. Buoniconti**



## Bowling for SMA Fundraiser

**In memory of Evan Peter Deddeh**  
(April 28, 2007 – November 28, 2007)

On June 8th, the 1st Annual Bowling for SMA fundraiser was held at Wonderland Lanes in Commerce Twp.

MI. Family, friends and supporters enjoyed three fun-filled hours of bowling. Mike Scott, the mid-day radio host from 99.5 WYCD, joined the festivities and helped promote raffle and silent auction items throughout the afternoon.

Over \$7,000 was raised in memory of Evan Peter Deddeh who died this past year from SMA Type I at seven months of age. The proceeds from this event were donated to Families of SMA to support other families affected by this disease and for the research needed to find a cure. Evan's family would like to thank everyone who came out to support them and Families of SMA. They feel truly blessed to have had such an amazing turnout for this event.

*Dear FSMA,*

The 2nd annual Ayden's Swim for a Cure was held in Phillipsburg, KS on July 16th in honor of Ayden Trammell. Ayden is the two year old son of Cortney Studley and Matt Trammell of Lincoln, NE. Kids in the area collected donations and then a swim party and balloon launch were held with many prizes given away. The kids did a great job and collected over \$3,900 for SMA research. Ayden and his parents were there and after some convincing, let Ayden try out the pool – which he loved!

**Thank you,  
Donna Studley**



*Dear Families of SMA,*

My name is Jon Boller, I am the cousin of Luke and Meagan McWilliams. Unfortunately Luke and Meagan were diagnosed with Type I SMA and both passed away far too early. While they were here, Luke and Meagan gave and received nothing but love; those two really knew how to light up a room. I am sad to say I never got to hold Luke before he passed, as we arrived on our trip to California the week following Luke's death, but I cherish that week with the family and the time getting to know Meagan. During Luke and Meagan's time with us we heard many great things from Aunt Colleen and Uncle Glenn about how FSMA had supported, provided and made the process a bit easier. I know that they have been big supporters of FSMA and I wanted to do my part to help.

If two children suffering from such a horrible disease can be that strong and always wear a smile, then I can challenge myself to not just complete a run of 13.1 miles but to push myself to a higher level and achieve a timed goal. So in late November I made the decision and set my goal, I would run the Frederick half-Marathon and aim for a time of 1:30:00 or better. I have always been in good shape from playing soccer but have never run a competitive race before or really enjoyed running anymore than I had to. Since Luke and Meagan would be my inspiration for this run it only seemed fitting that I would run this race in support of Families of SMA.

I set up a website explaining why I was running and what donations would be used for. I used your donation form and included plenty of pictures of Luke and Meagan. After passing the address along to friends, family, co-workers and teammates I wasn't sure how much money we could raise and started with a goal of \$1,000. I feel very blessed by the support that I received from everyone and I am glad to be able to include \$1,595 worth of donations.

As Sunday, May 4th approached I felt ready to go and anxious for the race to finally get here. Of course, as everything seemed too smooth, I came down with a cold on Saturday less than 24 hours before the start. Race day was perfect; Frederick couldn't have scripted better weather. After training for so long by myself, running with all of those people around me seemed so easy. I went out strong and ran a great race but my cold caught up to me after 8 miles and I had to slow a bit for the last 5. I'm happy with my finish time for my first ever half-marathon and although I missed my goal slightly, I finished in 1:32:47, it was a great experience and tons of fun.

I want to send my sincere thanks for all of the support and guidance you have provided my family during our time of need. I know that you will put this donation, in honor of Luke Charles and Meagan Marie McWilliams, to good use.

**Sincerely,  
Jon Boller**

*To Whom it May Concern:*

Enclosed you will find 2 checks totaling \$1,500 to Families of SMA. The Delta Phi Chapter of the Ladies of Phi Tau Omega Sorority held their annual trivia night and are donating this sum to help the children. I had two boys that passed away with this disease a long time ago, before you were finding medicines to help. God be with you.

**Sincerely,  
Kathy Goodyear**





*Dear FSMA,*

On June 28th, 2008 the Conner-Park family of DuBois, PA held its 1st Shoot for a Cure in order to raise money for Families of SMA. The sporting clay event turned out to be a real blast for all involved. Through event participants, various sponsors, and monetary donations, \$1,257 was raised for the fight against SMA. The shoot, which was held in memory of Tiernan Conner-Park, would not have been possible had it not been for the fantastic people at the Firebird Wing Shooting Club in Brookville, PA. Tom, J.R. and all of the other great individuals at the club gave of their time, resources, and more in order to make the shoot a true success. The event also gave an opportunity to friends and family members to show off their culinary skills. With a spread of hot dogs, sloppy joes, baked beans and a wide variety of delicious desserts, nobody went home hungry. We also want to extend our appreciation to all of the fine competitors who participated. We truly hope they had as much fun as we did!

Andrew, Erin, Liadan and Keenan Conner-Park want to extend a heartfelt thanks and a written hug to all who had a hand in helping with the 1st Shoot for a Cure. Because of your thoughtful gestures, donation, and time, we can honor Tiernan's name by helping Families of SMA shoot for a cure.

**Thank you,  
The Conner-Park family**

*Dear Families of SMA,*

Enclosed you will find donations totaling \$1,000 that were raised in honor of our son, Cole (SMA Type I). My husband Rick ran the half marathon in honor of our son and to raise money for FSMA. In addition to this, we ordered 70 Wipe Out SMA T-Shirts that our supporters wore for the marathon.

**Sincerely,  
Dori Fiedler  
Rothsay, MN**

*Dear Families of SMA:*

I have been touched by the outreach of FSMA has had in creating awareness of this difficult disease. My husband and I have dear friends, Jenny and Joe Imhoff, whose precious daughter, Reagan, is fighting SMA. She is a strong 3 year old and everyone who meets her is truly inspired. My husband recently turned 30 and we used his party as a venue for awareness and fundraising for SMA. We received \$400 worth of gracious donations! It was a wonderful event and we hope to be a part of many more in the future!

**Sincerely,  
Amie Farley**

*Dear FSMA,*

This year for our daughter Madison's 4th birthday we decided to try something different and had a joint birthday party for her and her best friend, Daniel Chavez. Daniel is the son of our very dear and supportive long-time friends, Steve and Julie Chavez. It was Julie's idea to ask our friends and families to consider making a donation to FSMA in lieu of bringing gifts to the party. Our guests were very generous – not only did we raise \$400 but the kids also received quite a lot of presents. I was shocked at the amounts that were so generously donated and my only regret is that we have not done this for the past birthdays since her diagnosis almost 3 years ago. This is definitely a tradition that we will continue to do, not only for Madison's future birthdays but for her siblings as well. Please accept the attached checks as donations made in honor of both Madison Herreria and Daniel Chavez.

**Best,  
Brandy Herreria**

*Dear FSMA,*

My husband and I have close friends who have suffered the tragic loss of their daughter, Aleah, from SMA. Aleah's parents are now determined to raise awareness and money to help find a cure. They are launching an Angels of

Hope Campaign. As soon as I mentioned this to my staff, they wanted to reach out and help.

In an effort to spread awareness and raise money towards SMA, the staff of Osage School had a dress down day on April 25th and raised \$143. We are proud to donate this money in honor and in memory of Aleah Rosa Durazzo.

**Thank you,  
Natalie Medolla**

*Dear FSMA,*

Every year at our family reunion, we have a silent auction to raise money for a charity. This year it was unanimous – FSMA and Rebeckah Courtt! Usually we collect about \$100. On behalf of the Nelson family, I am proud to forward \$207 to FSMA in honor of Rebeckah.

**Sincerely,  
Julie Courtt  
Peoria, IL**

*Dear Families of Spinal  
Muscular Atrophy,*

My two second grade religion classes at Immaculate Heart of Mary Catholic School recently took part in a Lenten Service Project. I asked that each child earn \$2.00 by doing a chore and to please donate their earnings to SMA. My family has a close friend whose baby girl Chloe Painter has SMA and I wanted to find a way to help her and other children with this devastating disease. Some of the parents were extremely generous in donating more than the requested amount. I am including their donations in the form of checks with this correspondence. I will send the cash donations of the children to the SMA fundraiser, "Jacob's Run, Walk and Roll" to be held in Florida next weekend. The Painter family will be participating in this fundraiser.

My family has donated to Jacob's Run, Walk and Roll, and it is my plan to continue to ask my students and parents to help SMA through this annual Lenten Service Project. May God bless you for your efforts on behalf of SMA. My students and I will continue



to pray for these precious children who have been stricken with this terrible illness as well as for their parents that they will be blessed with strength and courage as they care for and help their little ones. We will continue to pray for a cure for SMA.

**Sincerely,  
Ruth Patch**



*Dear FSMA,*

On April 5th, Tori Wissman came to our home to help us with a garage sale with proceeds going to Families of SMA. We, unfortunately, did not have

very good weather. The temperature was in the 30's and rain made it very difficult for Tori. She had just been in the hospital over Easter and we didn't want to take any chances so we did close early. We did however make \$77.10 that day! I have enclosed a check in that amount along with some photos.

Thank you for everything that you do for our little angels.

**Dorothy Tessaro  
St. James, MO**

*Dear Families of SMA,*

My name is Joseph Paul and I am a teacher and soccer coach at Arrowhead High School in Hartland, WI. Every year our soccer program does a citizenship project to help develop positive character attributes in our student athletes. This spring we raised money in the name of Reahan Imhoff for Families of SMA.

I was first made aware of your organization at a golf outing last summer (Golf Fore a Cure) which benefited Reagan

Imhoff. Reagan is a wonderful two year old girl who suffers from SMA and she very quickly melted my heart. Since several members of the soccer coaching staff have children the same age as Reagan, her cause was a perfect fit for our program. Using some of the literature provided by Reagan's parents Joy and Jenny, we educated the players about SMA and then sent them into the community to inform the public and seek donations. The players took this responsibility very seriously, and we are proud to provide the enclosed funds to FSMA, donated in honor of Reagan Imhoff. All of us at the Arrowhead Soccer Program and the larger Arrowhead community wish your organization, and Reagan in particular, the best of luck in the future.

**Sincerely,  
Joseph Paul  
Arrowhead High School, Hartland, WI  
Raised \$1,504.**

As part of our summer activities this year, my family and I kicked off the month of August with our first ever fundraising adventure for Families of SMA; our youngest son Ian has SMA Type II.

For our event we were fortunate enough to be able to partner with Carvel Ice Cream and Cottage Inn Pizza, and it was quite an experience!

As the month of August drew closer, my husband Eric strapped on his roller blades and became my main flier delivery person - of some 1,200 fliers! Between that and postings on community event boards, distribution in our oldest son Cole's preschool, coverage in local newspapers, mention of the event on radio stations, and listings in our church bulletins, we had done everything we could except sky write it across eastern Michigan.

And yes, they did come. We had a great time meeting people from our neighborhood and others that came specifically to show their support for our family, and other families that had been affected by SMA. Cole and Ian were ecstatic to be having pizza and ice cream on a weekly basis, but hey, it was for a great cause!! Never having thrown a fundraiser before, I was not really sure what to expect. It was a lot of fun and worth all of the work that had come beforehand - we'll definitely have to give fundraising another shot.

**Liz Zurawski, Macomb, MI**



**Ian Zurawski with the  
Michigan Proclamation**





## A beautiful story about a 9 year old girl named Gracie.

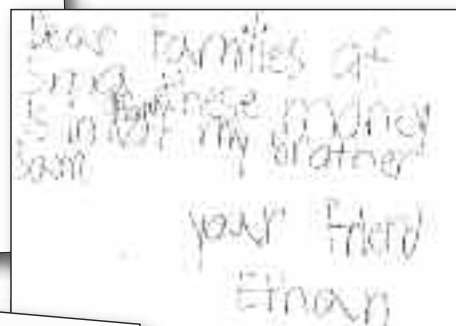
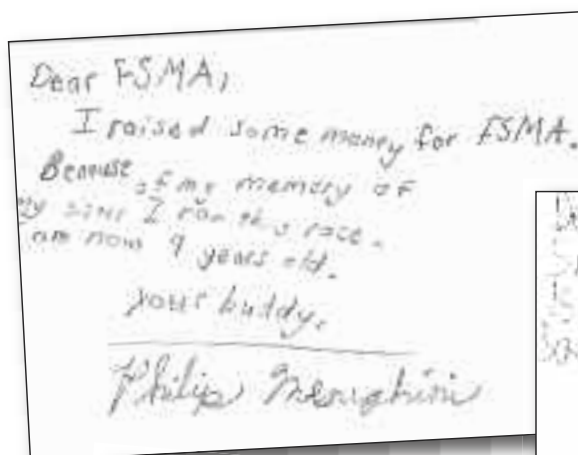
Gracie saw Sophia's picture and website on a shirt I was wearing. She asked me about her. I told her Sophia has Spinal Muscular Atrophy, to feel free to go to her website and read her story.

A few weeks later Gracie came and said she had something to give Sophia. She had collected money in her neighborhood because she wanted to help Sophia get well, so that some day she can walk.

She got to meet Sophia and gave her the \$54.50 that she had collected. I was touched to the depths of my soul by this beautiful little girl's great big heart. The enclosed check is from Gracie, a 9 year old angel walking among us.

Thank you for reading this beautiful story and for all the work you do.

Sincerely,  
Patricia M. Ross (Sophia's GaGa)



On June 21st our daughter, Paige, with the assistance of her younger brother Ethan, set up a lemonade stand at a local grocery store to benefit FSMA. They were part of Crayon Beverages Nationwide Pink Lemonade Brigade. Paige and Ethan were 1 of 1000 stands across the nation on June 21st working for their designated charity. Paige and Ethan have a younger brother, Brett, with Spinal Muscular Atrophy Type I. Brett turned 2 in March and they all love each other very much. The brigade was a great opportunity for Paige and Ethan to help Brett and his friends. They were able to raise \$840 for FSMA and they look forward to helping again.

Scott, Allison, Paige, Ethan and Brett Kingsley  
Columbus, Ohio

*Hello Families of SMA,*

April 5th would have marked our daughter Aleah's first birthday. During the time that we were losing Aleah I found out that I was pregnant with twins. My husband Mike and I wanted to do some type of fundraiser in Aleah's honor, but I was on bed rest and our options were limited. Therefore, we decided to do an Angels of Hope Campaign. Several of our family and friends own restaurants and pizzeria's. So I made up a poster with her picture and SMA facts. The angels would cost a \$1 and I also, put literature for people to take with them. It was a such a success - so many people contributed and the angels hung proudly in the establishments till the end of August. We made about \$1,000.

When I was told Aleah would not survive and found out about the twins within three days of one another I was on a roller coaster of severe mixed emotions. Many doctors, family, & friends suggested that I be tested immediately to see if the twins would have SMA. Some even suggested I terminate the pregnancy because I was going through too much. I had a lot of confusion. But I also knew I was not about to leave her side for nothing. When she did pass I didn't even want to be tested. I had to put my trust into something, so I put it in God's hands. May 13th the twins arrived. Layla Giovanni (named after her last sister & late uncle) and Maximus Mario (named after "Gladiator" and his grandfather). Being at the same hospital was a bit difficult at first but made me feel good as well. Some of the staff at the PICU came down to visit us. Even the neurologist remembered us and came down to my room to say he looked at the twins. Waiting the four weeks for the results seemed never ending. But the news came and the babies are ok. Maximus is a carrier. I'll never understand why we lost Aleah but her short life has brought SMA Awareness to us and in a sense can save generations of new family members to come. She is my little angel and I only hope that we can help contribute to treat and

hopefully cure this disease someday. Thank you FSMA for all your support and to Jessica Moyer who after her terrible loss still found time to call me and check in with the twins. We truly appreciate it. Our next SMA fundraiser will be the twins baptism. The theme will be SMA Awareness with in lieu of favors (donations) along with the bracelets and other small items to be handed out. Once again - thank you Sincerely,

**Vicky Durazzo**

---

*Dear Families of Spinal Muscular Atrophy,*

My name is Renee King and I am the Secretary of the Orange County Mustang Club. My grandson, Kennedy Griffin Montoya, has SMA Type II. He will be 5 years old in June. Here is a picture of him standing with two of his Papa's mustangs. He loves to sit in them and pretend he is driving. His Papa has already started a tool box for him so Kennedy can help him in restoring his future mustangs. This year, the Orange County Mustang Club made SMA their Christmas project. Their check for \$500 was a wonderful surprise. I am very proud of my club. Kennedy participates in many of the club events and is a great ambassador for SMA. He is a happy boy and enjoys meeting new people.

Thank you, FSMA, for being there with all the information and insights to this new (for us) disease and being able to ease our minds with our endless questions. Thank goodness we can find the answers on [www.FSMA.org](http://www.FSMA.org).

Bless you all,

**Renee King**

---

*Dear FSMA,*

This check is the total sum of my families 2008 Economic Stimulus Payment from the U.S. Government. Put to good use, Government funds at work! I would like to donate the total amount to stem cell research for SMA.

Sincerely,

**Tony, Charisse, Cole & Maya Pulkrabek**

*Dear Families of SMA,*

Thank you so much for the use of the wheelchair. It fits great and has allowed so many outings already. Our daughter's power chair is so heavy and not user friendly while she is sick. The use of the manual one has been a life saver, thank you!

**Cynthia Smith**

---

*Dear FSMA,*

We want to introduce you to our son, Seth. He was diagnosed with SMA Type II in March 2007. Seth is such a happy and loving child. He recently has started driving his wheelchair and is enjoying his new found independence. He has a 7-year old sister, Caroline, who he loves to play with.

Although having known a year and a half, we continue to find comfort, strength, knowledge, and great support in your organization. The website is such a wonderful resource. Thank you for your commitment and dedication to our SMA children and families. We recently attended our first FSMA conference in Boston and found it to be a wonderful experience in many ways. A special thank you goes out to the families iwhich we have come to know and love. The Hannah family and Campbell family have been such a blessing to us.

Thank you for everything!

**Chad and Lacy Gilley  
Stephenville, Texas**

---

*Families of SMA,*

My name is Angelica Formica. My cousin Giuliano Nitto grew up in the town of Palazzolo Acreide, in Sicily. Giuliano suffered with Spinal Muscular Atrophy his entire life and passed away in September of 2006 at eight years old. Giuliano was one of the most well spirited, loving, caring people in the entire world. He was very mature for his age understanding more about his sickness than a lot of us in the family did. Losing him was the hardest journey our family has ever had to face and slowly overcome. On Friday, July 25th, 2008, I am having a sweet sixteen party. Instead



of giving favors at the party, this donation is being made in loving memory of Giuliano. Our love and prayers are with Families of SMA in the hopes of one day finding a cure for these children. Our family would like to take the opportunity to thank everyone working with this foundation; it truly is dear to our hearts.

Thank you.

Sincerely,

**Angelica Formica**



I never had a chance to thank you for putting Jacob's picture on the website! It was just by chance that his picture was up when I went to your site one day (now I know how to refresh until he comes up). What an incredibly neat feeling we had when we saw it and continue to have each time. Upon Jacob's diagnosis, and first learning of FSMA and your website, we never would have imagined that 5 YEARS later, Jacob would be part of it. WOW. It means that much. We also use it to get many others to your site.

So Thank YOU so much!

**Laura-Lee Slaymaker**

*Dear Everyone at Families of SMA,*

Just wanted to send a thanks for the conference. What a great job you and others did in organizing such a major accomplishment. The subjects covered were wide and helpful, the speakers all good, the "little" touches terrific, etc. I

wandered around almost in shock noticing the people around me, the dear parents tending to their kids, the healthier ones having a wonderful time, and all the bubbling chatter. Cynthia already knew a lot (I didn't) but she said she learned a lot too.

Life has been busy here or I would have written you much sooner. Do you know that we appreciated your help in getting us to the conference.

**Karin Bleakney**

*Dear Friends,*

I want to thank you all for all you have done and continue to do for FSMA. I don't know what connected you to this organization but you have a golden heart in doing so. You are very appreciated. Especially for dealing with all my phone calls. Thanks a million! Hope to see you soon! XOXO

Best Regards,

**Helayne Jobson**

*Dear Families of SMA,*

Ok, well I'm not real sure where to start but I know I definitely would like to share my story with others. Well first let me start by introducing myself. My name is Amanda Hockensmith. I'm 24 years old and I'm living with SMA type II. However this is not the whole reason for me writing to you. See living with this disease really didn't make me any different than every one else growing up around me. My mother never lead me to believe that there was any difference between me and all the other "bad ass" kids running around. Believe me, I too was a handful. I always went to regular schools, I graduated from high school always staying on honor role, and I'm a senior in college now with just one semester to go. But my one greatest accomplishment of them all is none of this, not me beating the odds so many times, not me doing so good in school, not me keeping my head up and going through life as any one else my age would. None of these could even begin to reach my biggest accomplishment.

Without a doubt my greatest accomplishment of them all is my beautiful, beautiful ten month old son who we call JC. He's perfect! And he is everything I could ever have dreamed of or even began to want out of life. Honestly, I could die tomorrow and not have any disappointments. Every part of him is perfect. He's handsome, smart, giggles all the time, and loves to love you!

See at the time I first found out I was pregnant I was going through a lot in my life, and even though me and his father had been together for almost four years, we were not in a relationship for about a year before I found out that I was pregnant. So everything began with a great surprise for the fact that we never got pregnant during the four years of our relationship but I did get pregnant when we were just seeing each other occasionally. Although I was frightened the day I found out that I was pregnant, something inside of me could not help but to feel joy. And with the next couple of weeks I heard so many negative things. I had doctors ask me, "You are terminating the pregnancy, correct?". - Four different doctors to be exact, same question, just different words. But each of them reacted the same once I told them that I was not terminating this baby and that I was willing to die trying to have my child. Of course their job was to tell me it wasn't worth all that but to me it was. I knew that there was something so special about this little baby growing inside me.

So days turned into weeks and I found myself always looking forward to the appointments. I will never forget the day I first saw him on the screen. You could barely tell that it was a human. But I knew. I knew that was my boy and Yeah I was right. At about four months along he had his man hood all out letting the world know that he was going to be his mommy's baby boy. When it came time for his father to get tested for the SMA gene, he bailed. But it was ok... I had already decided that I was going to keep this little boy to



### Hockensmith Family

matter what. No matter if he carried the same disease as me. No matter if I died trying to have him. He was meant for me! And believe me, the only way that you could really understand the feeling that I'm talking about is if you are a parent yourself.

So while everyone around prepared for this baby, things started to change. My son's father decided to not be a part of our lives and actually married someone else. And I prepared for the day that I was going to have to start being on bed rest. And to be honest the doctors that I saw at the beginning of my pregnancy were not very optimistic at all. Once I started being seen at a high risk clinic, I was a little more comfortable simply because they were more positive about my pregnancy.

As time went on the more anxious I got to meet my baby boy. But along with that I was getting more and more uncomfortable. However to the Doctors surprise I actually was very healthy during my pregnancy and was never even on bed rest. I was up and going until the day I had him. I was only almost 4 weeks early when I went to the hospital because of my blood pressure being high. And that's when they told me they were going to deliver him there.

I was originally supposed to have a scheduled cesarean October 10, 2007, but he was ready October 5, 2007. I was already prepared for being put to sleep during the cesarean because I have a metal rod down my spine and I could not have a basic epidural to just be numb from the waste down. I have to admit I was very emotional going into the operating room though. And I wasn't fond of the fact that I was in there by myself. But it all seemed so quick. When I woke up they were still wrapping him up. When I opened my eyes and she was holding my perfect baby boy and I gave him that first kiss before they had to take him to the NICU to be fully checked out. I couldn't hold back the tears. I mean he was PERFECT. 5 lbs 10 oz, 17 inches long, head full of black hair and the most gorgeous complexion.

All I could think about was how happy I was to have believed in myself and in my baby, and carried out with my pregnancy despite what anyone thought or said. I couldn't believe God had given me such a perfect boy who was so handsome and grew to be so smart. He is very advanced and he is doing so much for only being 10 months old. And I will admit that it has been extremely hard. Nothing is easy. It

wasn't so easy to take care of myself alone so of course if I needed help with taking care of me, then I definitely needed help taking care of this perfect little gift of mine. And with me being in my last year of college and only getting disability, and absolutely no help from his father, financially it hasn't been easy either. Thank God I have my mother and father and step mother. I do everything that I possibly can for him but I do need help with certain things like lifting him and getting him out of his crib and handing him to me and all the basic's. But my son loves his mommy and he lets me know that everyday. And honest to God I could not imagine my life with out my son. He is the best thing that has ever come from me. And I thank God for giving such a perfect baby to me. I hope that any one reading this just keeps in mind that miracles really do happen. I gave birth to one of God's miracles and I want every one to know that people do beat the odds each and every day - I did! So for whatever its worth I wanted to share my story. I don't know if it means anything at all but I know my son means the world to me and I want to share that with anyone possible.

Sincerely,

**Amanda and JC Hockensmith**

## Thank you Mary Jane Utzat!!

Mary Jane Utzat has so generously created toy packages to be sent to type I families the day that they contact Families of SMA. These packages include a few items that her daughter Samantha loved to use, which were not already in the care packages created by Donna and Alex Abrales.

# Type I Infant Toy Ideas

By Mary Jane Utzat

**Wind chimes** – These are very easy for her to move and make music. Obviously be careful, as children like to put things in their mouths.

**Balloons** – These are very light and easy for SMA kids. We would let her bounce our heads with the balloon and make a big deal. We also used to lie her on the changing table part of her pack and play, and hang things from the mobile of the pack and play. She would then hit the wind chimes hanging down somewhat next to her with a balloon on a stick. Hanging things for her to tug at was a big theme.

When she grew out of the changing table of her pack and play, we used a regular changing table, and put a mirror right next to her. Mirrors that played music, or had something to pull on, or something like that were more interesting for her.

When she got a little bigger, a little floppier, it became a little more difficult to carry her around. We would then place her on a jumbo sized pillow, and sometimes use that to carry her, or rock her on my lap. This also helped us keep her flat yet comfortable when secretion control really became an issue.

**Fisher Price Swing** – I will say, she LOVED swinging. I had bought all of the swings at Toys R Us, and the Fisher Price one worked best for her. This swing reclined a bit, and when she got a bit weaker, we just adjusted the ties with zip ties to recline it a bit more. I used an infant head rest to stabilize her head on the swing. As for the frame, we bought an adult swing seat at Lowes, and just put her swing on that frame instead.



**Trevor Broton in his swing from the FSMA Care Package.**

Then I hung things next to the swing so she could watch them blow around in the breeze.

**Links** – These were great to link things low enough for her to tug on. I put a picture of Sam in the stroller in the lying down position. I always had things hanging from it for her to play with while strolling. She also used to just put the links in her mouth, like teethers as the standard teethers were too heavy for her to hold.

Her play mat was used everyday. I just replaced the hanging things with my own toys (rows of links, windchimes, plastic slinky, pull toys). The star above her played music when I brought her feet up to kick it. I had it so she could watch cartoons from here as well, so I could empty the dishwasher or do a load of laundry while she entertained herself for a few minutes.

**Symphony in Motion Mobile** – This mobile would swoop down. I would elevate her head a bit on a blanket, and elevate her arms on rolled up receiving blankets, and she would be able to grab the animals as they swooped by her. This



**Samantha Utzat**

can be found online with Toys R Us. I would often help her grab the animals.

**Cat toys** – Cat Toys worked well. Be careful of the ball inside as it can be a choking hazard.

**Feathers** – We would let her tickle our faces with the feather and make a big deal.

She loved her **binkies**, and I found the ones with the wide rim were easier for Sam to hold.

**A flag** was light enough for her to swing around. Watch the infant as this is a poking hazard.



**Samantha Utzat**

**Spoons** were light enough for her to bring to her mouth.

My mother in law makes a blanket for each toy package. We only used these blankets, as they were soft and lightweight. My mother and father in law also make a rattle.

**Rainforest Bouncy** - This was the only one I found sensitive enough for Sam to manipulate. When she pulled the animals that hung down, the bouncy would make music and the animals would move around. I did have to add links in order for her to reach the animals to pull.

**Crib Toys.** We used the Fisher Price Rainforest Soother. It hooked to the side of her crib and would play soft music and nature sounds. It lights up and a monkey would swing. This seemed to catch her interest for a few minutes, with the crib mirror hooked onto the other side, and some light toys in hand, she would entertain herself again for a short time.

**Empty Lotion Bottles.** We would put them next to her on her changing table in her room, and when we would turn away, she would push them over. She would giggle at this game.

**Tim, Mary Jane and Samantha Utzat**

## An Example of a Letter Written to the Parents and Classmates of a Child with SMA

*To the Parents and Classmates of Elizabeth Hallam:*

My name is Jeanna and I am grandma and caregiver to Elizabeth. Elizabeth is a bright, fun loving, and happy almost 4 year old who happens to have a physical disability called SMA. You have just heard about SMA and are now wondering what that is. SMA is a short way of saying Spinal Muscular Atrophy, which is why everyone just says SMA. SMA is an "illness" that you can't catch. People are born with SMA. Kids with SMA are just like everyone else, they just do things differently. Kids with SMA use wheelchairs or specialized strollers to get around. Kids with SMA don't have a lot of muscles. In kids with SMA their muscles don't grow. They have little muscles because their muscles didn't get the message from the brain to grow. Thankfully, the brain isn't a muscle so kids with SMA are smart and love to talk and laugh and sometimes even tell jokes. Everything you do involves muscles like how you eat, how you move, and even how you talk. Any movement is hard when you have no muscles, so doctors are trying to find a way to make the muscles grow bigger.

Because of Elizabeth's weak muscles she can catch colds easily. For Elizabeth, a cold can, and has several times, turn into something more serious. To be extremely blunt, a "simple" cold for your child, is life threatening for Elizabeth. Elizabeth's body doesn't have the strength to fight the "average" cold.

That is why I am writing to you today. I am writing to ask for your help in maintaining not only Elizabeth's health but the health of all the children in the school. If you think your child is sick please keep your child home from school. Encourage your child to wash their hands frequently, especially when ill or around someone who has been sick. I realize your child's health is extremely important to you, so please help us keep Elizabeth healthy and able to attend school.

Sincerely,

Jeanna Huette and Christen Huette (Elizabeth's Mom)

## New Multi-Center Trial of Valproic Acid and Carnitine in Infants with Type I Spinal Muscular Atrophy is Currently Recruiting at Six Centers Across North America.

In April Families of SMA announced a new clinical trial designed to evaluate the combination of Valproic Acid (VPA) and L-Carnitine for the treatment of SMA in infants with Type I SMA, called Carni-Val Type I. Specifically this trial, which is fully funded by Families of SMA, will assess the safety of VPA and L-Carnitine in infants and develop improved methods to assess the strength and motor abilities of severely affected infants.

The following six North American sites are currently enrolling infants. A German site will begin enrollment in several months.

- Salt Lake City, Utah
- Detroit, Michigan
- Baltimore, Maryland
- Montreal, Canada
- Columbus, Ohio
- Madison, Wisconsin

Thirty-six infants with SMA Type I, ages 2 weeks to 9 months at the time of enrollment, who have clinical features of SMA confirmed by genetic testing, will be enrolled in the trial. Because travel for infants with severe SMA is often difficult, study site investigators will be looking to enroll subjects who live close to the individual centers.

If you are interested in participating in this study, please contact the clinical coordinator at a particular site closest to you. More details regarding eligibility criteria and potential enrollment can be found at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and [www.projectcuresma.org](http://www.projectcuresma.org). In addition, we recommend that families who are interested in being contacted for this trial or future clinical trials should register with the International SMA Patient Registry at Indiana University.

### About Project Cure SMA:

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

Funding for all support staff and for all sites in the United States is being provided by Families of SMA. Funding for the site in Cologne, Germany is being provided by the "Initiative Forschung und Therapie für SMA". Funding for the site in Montreal, Canada is being provided by Families of SMA Canada.

## Proactive Medical Care in Type I SMA Can Make a Difference

By Dr. Petra Kaufmann, Assistant Professor of Neurology at Columbia University, and approved by the FSMA Medical Advisory Board. Dr. Kaufmann summarizes her published article in "Neurology" entitled "The changing natural history of spinal muscular atrophy type 1" by Oskoui M, Levy G, Garland CJ, Gray JM, O'Hagen J, De Vivo DC, Kaufmann P.

In the past, survival of children with Spinal Muscular Atrophy Type 1 was universally very short, averaging just 8 to 9 months and rarely beyond the second birthday. In our experience, however, advances in supportive care may extend survival well beyond this age. To prove this hypothesis, we collected information through the International Spinal Muscular Atrophy Patient Registry with a mail-in questionnaire. One hundred forty-three families who had a child with SMA Type 1 responded to this questionnaire, and were included in our analysis. We found that children born in 1995 through 2006 had significantly longer survival compared with those born between 1980 and 1994. What accounted for this longer life span was ventilation for more than 16 hours a day, use of mechanical insufflation-exsufflation device ("cough assist"), and gastrostomy tube feeding.

Our results confirmed the hypothesis that use of these and potentially other supportive therapies for children with SMA 1 can extend survival. The magnitude of the response seen in our survey should be interpreted with caution, however, as the nature of a voluntary questionnaire may favor responses from those families whose children lived longer. Also critical to interpretation of these findings, and not assessed in this study, was parents' (and when possible, patient's) satisfaction with the choices they had made in favor of these complex and often burdensome therapies. Not all families have the resources to enable a choice. A prospective study of the quality of life of the patients and their families who elect to use these new technologies, and those who are aware of their choices but decline their use, is needed. In addition, it is important for parents to understand that SMA 1 itself is a spectrum disorder with a range of severity.

Major advances have been made in the last ten years in our understanding of the Biology of SMA. This research demonstrates that there have also been advances in clinical care of children with SMA. While we are all hoping for a new and effective drug treatment, our study shows that it is now possible to extend survival of the most severely affected group of infants. Parents with newly diagnosed children with SMA type 1 should be made aware of the range of potential therapies that can extend survival. In our respondent group, approximately 30% survived to early school age; they will need appropriate support, adaptive equipment, and often a change in social attitudes to participate successfully in school and community. The authors thank all patients and families for the gift of their time and effort when they participated in the registry.

## Call for Patients with Spinal Muscular Atrophy for the Pilot Study of Biomarkers for Spinal Muscular Atrophy

A "biomarker" is something that can be measured in a lab test. The purpose of this study is to discover new biomarkers to measure how SMA affects a child and whether they are getting better, worse or staying the same. If a new biomarker is discovered in this study, it may help us understand whether and how future drug treatments work.

### Important things to know:

- This study will NOT involve any drug treatment.
- It will only take one visit to complete and it will involve a single routine blood draw.
- We are looking for 100 children between the ages of 2 and 12 years with SMA Type I, II or III and 20 children between the ages of 2 and 12 without SMA to participate in this study.
- To get the best data from the lab tests, children should be otherwise healthy and not taking medications for other illnesses for at least 14 days. If you have, any questions about this study, please contact your doctor.



If you and your child would like to participate in this new study to help future clinical trials with SMA, please contact your physician for more information about the study – or visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and search for the term spinal muscular atrophy.

This study is sponsored by the SMA Foundation.



# What It Means to Care

By Albert Freedman

## Dear Home Health Care Professional,

Six years ago, in an open letter published in CARING magazine, I welcomed you to our home (Freedman, 2001). I told you about our six-year-old son, Jack, who at six months of age, was diagnosed with an incurable neuromuscular disease called Spinal Muscular Atrophy (SMA), and given one year to live. I told you about the many nights we spent in the intensive care unit at our local children's hospital, and the medical equipment our son needs on a daily basis: the pulse oximeter, feeding tube, cough-assist machine, standing frame, wheelchair, and Bipap ventilator. In my letter, I asked you to approach your work with our son with confidence and compassion. I asked you to share your knowledge by teaching us what you know. I asked for your patience and understanding because we worry about Jack all the time. Most importantly, I asked you to help us have hope for our son and our family. When I wrote "Welcome to Our Home" late one night, I didn't think anyone would actually read my letter. I was surprised when my words were published in CARING magazine, and I was even more surprised to receive email messages from across the country in response to my story. Nurses, physicians, ministers, home care administrators, social workers, policy-makers, and parents and relatives of other pediatric patients provided words of encouragement and appreciation. I'm pleased to know "Welcome to Our Home" has been used to orient, train, teach, and recognize home health care professionals in so many places. Six years later, the editors of CARING magazine asked me to write to you again, so I suppose I should say ...

**Welcome back to our home.**

Our son, Jack, is not a little boy any longer. He's twelve years old, and on the cusp of becoming a young man. Jack attended school almost every day of fifth grade, and he is excited about beginning middle school in the fall. He's able to operate his power wheelchair and his computer independently. He loves swimming, going to the movies, and traveling to the beach and to a special camp in the summer. Most importantly, Jack is happy. He feels good about himself, and approaches every day with confidence and a positive attitude.

The past six years have not been easy. Our son continues to face many medical challenges. Five years ago, Jack underwent spinal fusion surgery to correct severe scoliosis. Four years ago, he was fitted for a new motorized wheelchair with sensitive fiber optic switches because he has almost no movement in his arms and fingers. The wheelchair is larger because Jack has grown, so we needed to purchase a conversion van with a wheelchair lift.

Three years ago, we moved to a new home and made major modifications to accommodate Jack's wheelchair and other medical equipment. Our son's bedroom now includes a specialized hospital bed, a gurney, a ceiling track lift, a potty chair, and an emergency oxygen supply. A large generator outside our home provides electricity when power outages occur. Over the years, I've lost track of the number of nights Jack has spent in the pediatric intensive care unit. We spent a week in the hospital last December as our son fought through a severe respiratory illness.

Every day seems to present a new trial as we work to keep up with Jack's special needs. But despite the many

challenges we face as a family, we feel fortunate to have every single day with our son. Twelve years after being given only one year to live, Jack is very much alive. Against all odds, he has somehow overcome one obstacle after another with determination, dignity, and a very positive spirit. We are very proud of our son.

How have my wife, Anne, and I coped over these twelve years? How have we faced the complicated and unique challenge of caring for a severely disabled, medically fragile child? Being Jack's parents is not easy, and there are times when we feel overwhelmed, discouraged, and alone. Families like ours can not bear the burden of our parenting responsibilities entirely on our own. When other people support us, we're stronger as a family, and our lives feel more manageable. Our family and friends do the best they can to help us, and personal support is critically important. But given Jack's medical fragility and the demands of his day-to-day care, we need the help of professionals who have the knowledge, experience, and skills to help us take care of our son.

As I reflect back on our twelve years with Jack, I've concluded that there is one simple but critical ingredient that sets some professionals apart from others. There is one characteristic that determines whether we feel a professional can truly help us. It's hard to measure, and impossible to teach. It's expected of all health care professionals, but isn't always evident to patients and families. With it, relationships are immediately strengthened. Without it, building trust is next to impossible.

*What, exactly, is this necessary ingredient?*

It's written across the cover of this very



**Jack and Cara Freedman**

publication you're holding in your hands. CARING. Families like mine need the help of professionals who demonstrate what it means to care.

Over the years, dozens of professionals have worked with Jack and our family: physicians; speech pathologists; physical and occupational therapists; special educators; pharmacists; respiratory therapists; social workers; medical supply vendors; wheelchair, van conversion, and assistive technology specialists; and contractors for our home. Each of these professionals has played an important role in helping us with our son, and many have demonstrated what it means to care. We are indeed grateful for their help.

But every step of the way, one professional accompanies Jack wherever he goes. That's you, Jack's home care nurse. Because you spend so much time with our son, you have a unique relationship with Jack and our family. You're with Jack at school, and help him interact with peers and his teachers. You're with Jack and our family in our home, so you observe our good days and our bad, our strengths and our stressors. Of all the professionals we work with, you have the ability to make the greatest impact on our son and family on a daily basis, every month of the year. As pediatric home care nurses, each of you has shown Jack what it means to care in your own unique way. Although all of you follow the same

treatment plan, each of you brings something distinctive and special when you join us in our home.

You demonstrate what it means to care every time you talk with Jack as you transfer him to and from his wheelchair, feed him, dress him, give him his medications through his feeding tube, and help him with his breathing treatments. You demonstrate what it means to care every time you help Jack communicate with his classmates at school, every time you adjust the switches on Jack's wheelchair so he can drive independently, and every time you read him a story. Jack relies on you, respects you, and cares about you. Jack cares about you because he knows you care about him.

I believe most people choose to work in health care because they care about other people and want to help. Why, then, does there appear to be a shortage of truly caring health care professionals?

Over the years, I've come to realize that professionals are best able to demonstrate what it means to care when they feel supported and cared for in their work. As a home care nurse, you play a unique role working in the homes of patients and their families.

You, too, need support to do your work with care. You need and deserve adequate orientation, training, and supervision. You need ongoing communication with your agency's support staff, and you need to feel part of a

team. You need to know your agency will help you when you need help with a child. You need to be fairly compensated for your time and work. You will be better able to care for your patients when your home health care agency demonstrates that it cares about you.

In our society's current health care environment, your agency may be hard pressed to provide you what you need and deserve. When Medicaid funding and programs for disabled citizens are reduced or eliminated, nurses like you can not be adequately supported and compensated. When insurance companies freeze reimbursement rates for years at a time, health care organizations find themselves unable to attract and retain professionals to care for our family members. Our society as a whole needs to demonstrate what it means to care if we would like our health care professionals to follow suit.

As the population ages and as more children like Jack beat the odds, home care services will become increasingly important. Will our federal and state leaders demonstrate what it means to care by supporting organizations and professionals that support families like ours? Will health care policymakers demonstrate what it means to care by offering our most vulnerable citizens access to high quality home care services?

Certainly, our country's health care system leaves much to be desired, and the wheels of change move very slowly. Meanwhile, families like ours live our lives one day at a time, grateful for the support of nurses and aides who, working against the odds, find it in their hearts to care. To you, home care professionals everywhere, please know how much your work is appreciated. We did not choose to have a medically fragile, disabled child. But you did choose to become home health care professionals. Families like ours are very fortunate and grateful that you made that choice.

*Reprinted from September 2007 issue of "Caring".*



**Jim and Jennifer Gaudreau**



**Chloe Bush**



**Loren Picinich**



**Lyza Weisman and Shannon O'Brien at the Red Sox Game**



**Brett Kingsley**



**Larkin Bish**



**Bella Andrade in her new powerchair**



**Braelyn & Tambryn Campbell**



**Brett Wilson**



**Aiden Bundy**



**Ava McLin**



**Alyssa Silva**



**Dolce and Aleah Durazzo**



**Courtney Brooke Rosas**





**Brianna Carlino**



**Abby, Emma and Nate Ferrell**



**Brynlee Liston**



**The Zurawski Boys– John, Ian and Cole.**



**Caroline Freire Dos Santos**



**Amy Horak & Syndey**



**Caroline and Seth Gilley**



**Charlie & Lily Sykora**



**Angel, Madison, Ella & Ryan Wolff**



**Briahna Johnson with Grandpa & Grandma**



**Briahna Johnson**



**Courtney Brooke  
Rosas**



**Devika Moholkar**



**Greyson Erwin**



**Charlie Sykora and Dad**



**Jacob Jackson**



**Chloe Ochoa**



**Jamie and Kelly Adams**



**Gwendolyn Strong**



**Grace Elizabeth  
Degraffenreid**



**Henrique Cortinhas  
Rogge Dibbern**



**Colby Russ**



**Elizabeth Hallam**



**Doug, Sophia & Lila Doebbert**



**Karah Barry**



**Quinn Anton Jensen,  
Katlyn, Traci and  
Shannon O'Brien**





**Dr Schroth & Lisa  
Pharo with the Faith's  
Lodge T-shirts**



**Nathan Cooper's 2nd Birthday**



**Kuester family - off to conference**



**Olivia Ann Ralston**



**Lizzy Hallam and Dr.  
Mary Schroth**



**Lizzy Hallam with  
IL state senator  
Rutherford**



**Nuria Ensenat**



**Larkin Bish**



**Lisa, Elizabeth and Jeff  
Wood at conference**



**Morgan Kelley  
Scuba Diving**



**Kennedi & Jaycie  
Vondrak**



**Lindsay Cochran**







**Shay Factor &  
Sierra Journey Factor**



**Sofia Bastos**



**Sohia Salus**



**Sydney & Taylor  
Schoenborn**



**Sue and Jen  
Gaudreau**



**Sophia Doebbert**



**Trevor Broton is his wagon**



**Videl Hinke**



**Trevor Broton in his  
Snug Seat Stroller**



**The Cusack Family**



**Sophia Doebbert**



**Hannah Jean Campbell in her  
Radio Flyer Wagon**



**SMA Families Get Together in Kansas City**



  
**Families of SMA**  
*Research. Support. Hope.*



**Paige, Ethan & Brett Kingsley**



**Jerika Bolen and Mom Jennifer**



**Jacob Cole Slaymaker on 4th of July**



**Pierina Naori Miyadi Diaz**



**Kale and Kyler Shiesley**



**Jacob Slaymaker's  
5th birthday**



**Jaycie Vondrak**



**Hannah Jean  
Campbell**



**Ragnar  
Gudmundsson**



**Danny McHale**





**Larkin Bish**



**Elizabeth Hallam**



**Kennedy Griffen Montoya**



**The Gehman Family**



**Samuel Schoenborn**



**Sean and Brendan White at the conference**



**Seth Gilley**



**Kash Golobic**



**Ava McLin**



**Briahnna Johnson**



**Henrique Cortinhas Rogge Dibbern**



**Grace Elizabeth Degraffenreid**



## 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](mailto: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.



**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](mailto:colleen@fsma.org).**

1-800-Flowers	\$25	10%	Dillard's	\$25/\$100	9%	Old Navy (Gap)	\$25	9%
A & P Food Stores	\$25	4%	Disney	\$25/\$100/\$1000	2%	Olive Garden	\$25	9%
Albertsons	\$25/\$100	4%	Dominicks	\$25/\$100	4%	On the Border	\$20	11%
Amazon.com	\$25	4%	Dominos Pizza	\$5	5%	Outback Steakhouse	\$25	4%
AMC Theatres	\$25	7%	Dunkin Donuts	\$10	4%	Panera Bread	\$10	9%
American Eagle Outfitters	\$25	8%	Expo Design Center	\$25/\$100/\$500	3%	Pathmark	\$25	4%
Applebees	\$20	8%	Express	\$25	13%	Peapod Online Grocery	\$25/\$100	4%
Babies R Us	\$20	2%	Exxon	\$50/\$250	2%	Payless Shoes	\$20	13%
Bahama Breeze	\$25	9%	Footlocker Stores	\$25	9%	Peets Coffee and Tea	\$20	8%
Baja Fresh	\$25	7%	Game Stop	\$25	3%	Pier 1 Imports	\$25	9%
Banana Republic (Gap)	\$25	9%	Gander Mountain	\$25	8%	Piggly Wiggly	\$25/\$50/\$100	3%
Bass Pro Shops	\$25	9%	Gap	\$25	9%	Pizza Hut	\$10	9%
Barnes & Nobles	\$10/\$25	9%	Giant Eagle / Giant Foods	\$25/\$100	4%	Pottery Barn	\$25/\$100	8%
Baskin Robbins	\$2	9%	GNC	\$25	8%	Pottery Barn Kids	\$25/\$100	8%
Bath and Body Works	\$10/\$25	13%	Gymboree	\$25	14%	Qdoba Mexican Grill	\$25	7%
BD's Mongolian Barbeque	\$20	8%	Harry and David	\$25	10%	Rainforest Café	\$25	9%
Bed Bath & Beyond	\$25	7%	Home Depot	\$25/\$100/\$500	3%	Red Lobster	\$25	9%
Bergners	\$25/\$100	8%	HomeGoods	\$10/\$25	7%	Red Robin	\$10	9%
Best Buy	\$25/\$100	2%	Honey Baked Ham	\$10	12%	Ross Dress for Less	\$25	8%
Best Western	\$25/\$100	12%	Houlihans	\$10	9%	Ruby Tuesday	\$25	8%
Blockbuster	\$10	7%	Hyatt Hotels	\$25/\$100	9%	Safeway	\$25/\$100	4%
Bloomingdales	\$25/\$100	12%	Jamba Juice	\$10	7%	Sam Goody	\$25	30%
Bob Evans	\$10	10%	J Crew	\$25	13%	Save Mart Supermarkets	\$25/\$100	2%
Bonefish Grill	\$25	4%	JCPenney	\$25/\$100	6%	Sears	\$25/\$100/\$250	4%
Borders	\$10/\$25	8%	Jewel / Osco	\$25/\$100	4%	Sephora	\$20	4%
Boston Market	\$10	12%	Jo Ann Fabrics	\$20	6%	Service Master	\$50	10%
BP Gas	\$50	2%	Joe's Crab Shack	\$25	9%	Sharper Image	\$50	16%
Brookstone	\$25	12%	KB Toys	\$20	9%	Shell	\$25/\$50/\$100	2%
Brooks Brothers	\$25	16%	KFC	\$5	9%	Shoe Carnival	\$25	5%
Build-A-Bear Workshop	\$25	8%	Kohl's	\$25/\$100	4%	Shutterfly	\$25	9%
Burger King	\$10	4%	Kmart	\$25/\$50	4%	Spa Finder	\$25	8%
Cabela's	\$25	11%	Kwik Star (Kwik Trip)	\$20/\$100	4%	Speedway	\$25/\$100	4%
California Pizza Kitchen	\$10	4%	Landry's Restaurants	\$25	9%	Sportmart	\$25	8%
Carlos O'Kelly's	\$10	9%	Lands End	\$25/\$100	9%	Sports Authority	\$25	8%
Carson Pirie Scott	\$25	8%	Lettuce Entertain You Restaurants	\$25	12%	Staples	\$25/\$100	5%
Carrabba's Italian Grill	\$25	4%	Limited	\$25	9%	Starbucks	\$10/\$25	7%
Chevy's Fresh Mex	\$10	8%	Linens & Things	\$25	8%	Steve & Barry's	\$25	6%
Cheesecake Factory	\$25	5%	Little Caesars Pizza	\$20	9%	Stop & Shop	\$25/\$100	4%
Chili's	\$25	11%	LL Bean	\$25/\$100	15%	Structure (Express)	\$25	13%
Chipotle Mexican Grill	\$10	6%	Loews Cineplex	\$25	7%	Subway	\$10/\$50	3%
Chuck E Cheese	\$10	8%	Longhorn Steakhouse	\$25	9%	Sunglass Hut	\$25	12%
Cineplex Odeon	\$25	7%	Longs Drug Store	\$25/\$100	5%	Sunoco	\$50	2%
Circuit City	\$25/\$100	3%	Lord & Taylor	\$25/\$100	4%	Sweet Tomatoes	\$10	8%
Claim Jumper	\$25	8%	Lou Malnati's	\$10	8%	Talbots	\$25	11%
Claire's	\$10	9%	Lowes Cineplex Entertainment	\$25	7%	TGI Friday's	\$25	9%
Comfort Inn	\$25	4%	Lowe's Home Improvement	\$25/\$100/\$500	4%	The Children's Place	\$25	12%
Cooking.com	\$25	12%	Macaroni Grill	\$20	11%	TJ Maxx	\$25/\$100	7%
Country Buffet	\$25	5%	Macy's	\$25/\$100	10%	Toys R Us	\$20	2%
Cracker Barrel	\$10	9%	Marathon Gas	\$25/\$100	3%	Ulta Salon	\$25	4%
Crate and Barrel	\$25/\$100	8%	Marriott Hotels	\$50/\$100	12%	Unos Chicago Grill	\$25	12%
CVS Pharmacy	\$25/\$100	2%	Marshalls	\$25/\$100	7%	Walmart	\$25/\$100/\$250	2%
Damons	\$25	9%	Max & Emma's	\$10	13%	Waldenbooks	\$10/\$25	8%
Denny's	\$5	9%	Menards	\$25/\$100	3%	Walgreens	\$25/\$100	6%
Dicks Sporting Goods	\$25	8%	Mens Warehouse	\$25	8%	Wawa	\$25/\$100	2%
			Michaels	\$25	4%	Wendy's	\$10	4%
			Mobil	\$50/\$250	2%	Williams Sonoma	\$25/\$100	8%
			Mrs. Fields Cookies	\$5	50%	Winn Dixie	\$25/\$100	4%
			Noodles & Company	\$10	8%	Wolf Camera	\$25	6%
			O'Charley's	\$25	13%			
			Office Depot	\$25	4%			
			Office Max	\$25	5%			
			Old Country Buffet	\$25	5%			

Mail your  
Gift Certificate Orders to  
FSMA National Office  
or fax to 847-367-7623  
Order form is on Page 42

## EVENT update

[www.curesma.org](http://www.curesma.org)



### Another SMA family was selected to receive an Extreme Makeover from the ABC Show!

The Akers Family from Ohio received an Extreme Makeover earlier this summer. The family has three children - Christian, Brooke and Faith. Brooke was diagnosed with SMA Type II at 15 months. Faith was also diagnosed with SMA. In 2005, their first child Christian was diagnosed with Crohn's Disease.

See our web site to view Michael Moloney from the show with a quick message supporting Spinal Muscular Atrophy.

In 2005 The Johnson Family of Massachusetts was selected for this amazing benefit – their whole story can be found on our web site. We are so lucky to once again have one of our own chosen by the fabulous team at ABC!

The local OKI chapter had members staffing a fundraising and informational booth on set during the build. They handed out FSMA t-shirts and bracelets to the thousands visiting the shoot. Several children from the local chapter also had Ty join them for aqua therapy.

A very special thank you goes out to the amazing local SMA children who braved

blazing hot sun and 90 degree plus temperatures to help raise SMA awareness while the build was going on! Emma and Nick Lockwood, Leah Miller, Chase Langland, Alex Marshall, Haley Wooding, William Johnson, and Roman Anderson all went above and beyond (while many others in the crowd were being taken away for heat stroke). They will all be at the conference in Ohio next year. We also thank all those who turned out in memory of our Ohio SMA Angels, such as in memory of Madison Vickers to help support the effort.



Featuring  
 the Akers family  
 from Ohio

1984-2009  
**25 years**  
 FAMILIES OF SMA  
 \$50 million raised for SMA research