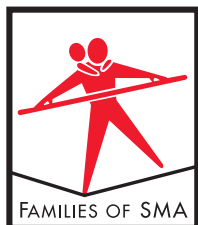




DIRECTIONS

Advancing research. Supporting families.

FAMILIES OF SPINAL MUSCULAR ATROPHY



*Special Conference
Announcement*

Conference Assistance Program

Through generous corporate sponsorships, Families of SMA is excited to announce a Room Rate Assistance Program for the upcoming 2008 FSMA Boston Conference.

Families of SMA will be reducing the hotel room rate for families as follows:

- **The room rate will be reduced from the current \$195 per night to \$149 per night.**
- This reduced rate will cover **one room per family** for three nights.
- Reduction will be applied as a credit to your hotel bill at the time of check out.

FSMA does not anticipate having to turn any families away. However, if we do have to limit the program, FSMA will extend assistance on a first registered basis, so please register early.

Please note: This assistance program applies only to The Boston Park Plaza Hotel, and to families only. No researchers or professionals or other hotels will be covered under this program.

2008 FSMA Family and Professional Conference

June 19-22, 2008 | BOSTON PARK PLAZA HOTEL— Boston, MA

Beantown – The SMA Revolution

Every year Families of SMA sponsors a conference to bring together the leading SMA researchers and clinicians, companies and our family members. This is the largest conference in the world for those affected by SMA, and also for those involved in providing support and care for SMA patients.

There is no other opportunity like this for those affected by SMA. The interactions between the researchers and families at one conference is extremely special. The advice and knowledge gained from meeting and learning from other families and also the medical and research experts in the field can have a huge impact on the quality of life for patients and their families.

The main goals of the conference are:

- 1 To allow networking between researchers involved in and families affected by SMA;
- 2 To educate professionals on the latest research advancements;
- 3 To educate patients and families on the basics of the disease;
- 4 To provide updates to patients and families on the latest research and medical results.

Boston provides us with a fantastic location to host this conference that really can revolutionize how our families cope with this disease. The regional research community of hospitals, research institutions and biotech companies is world renown. The local FSMA New England Chapter is one of the strongest we have in providing local community support and also in raising funds for research. We look forward to seeing you in Boston!



Thank you to everyone who contributed to such a fantastic end to 2007 with our fundraising campaigns. In particular, the Wall of Strength was a great success and is such a beautiful testament to the strength of all the families and individuals and chapters who support Families of SMA (see page 11). We are in the process of signing the agreements for the new clinical trial for Type I's to test Valproic acid, which should begin enrollment in the next few months.

We were also able to meet the challenge given to us from The Dhont Family Foundation to raise an additional \$100,000 for stem cell research. The Dhont Family Foundation promptly matched these funds, and the stem cell animal safety studies are scheduled to begin in March.

In the fiscal year 2007 we funded a total of \$4.1 million in research and support programs, which was split:

- \$3.4 million for SMA research (78% of total expenditures), and;
- \$700,000 for patient services (16% of total expenditures).

Families of SMA focuses all of our efforts on SMA, and we try to invest as great a proportion as possible on research. We spent \$250,000 on administration costs, which was just 6% of our total expenditures last year.

For the upcoming year we are focused on getting some key results and answers to important questions:

- 1) Is Valproic acid effective in SMA, and safe for SMA patients.
- 2) Is our leading drug discovery program, with quinazoline compounds that we have been working on for the last 7 years, safe to begin human clinical trials.
- 3) Is stem cell therapy safe to begin human clinical trials.

We are planning to fund over \$5 million for SMA research this year to answer these questions and to advance our bigger goals: Firstly, to continue to build our drug discovery pipeline with new programs; Secondly, to expand our clinical trials network to allow for easier travel for SMA patients to enter trials.

We are gearing up now for two important activities for 2008 – our annual conference and our fundraising events season. Details on both of these activities can be found throughout this edition of Directions. Please register as soon as you can for the conference on page 7.

The funds that are raised by our chapters and individual volunteers allow us to fund the research programs that are leading us closer to a treatment and cure. With your continued support we will get results!



Kenneth Hobby
Executive Director, FSMA



Mission Statement

Families of SMA is the largest international organization 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.

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

Change of address

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

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

FSMA Board Member Wins Prestigious Award From US Defense Department



Rocco Arizzi, an FSMA Board Member and electrical engineer with the Navy, is one of 16 “everyday heroes” honored in December by the Defense Department. The awards honor employees who overcome physical and mental disabilities to contribute to national security.

Rocco has SMA and uses a wheelchair. In winning the award he told the American

Forces Press Service, “I like for younger people and students with disabilities to see people accomplishing things and serving their country so that they know they can do the same.” “The more they see people not only just existing and working, but achieving great things, the more that they believe they can do it themselves.”

Congratulations Rocco. You are an amazing role model, not just to individuals with SMA, but to the entire community.



Congratulations to Alexa Dectis.

Alexa was recently featured in an episode of the CBS soap opera Guiding Light.

We hope to see more of her as she continues to represent individuals with SMA in this amazing and positive manner.

Claire Altman Heine Foundation Awards Gift to OSU For Pilot Test of Screen For SMA Carriers

The Claire Altman Heine Foundation has awarded Ohio State University Medical Center a gift to examine the feasibility of population-based screening to detect carriers of SMA and determine how best to provide education, counseling and follow-up care to people found to carry the gene. The comprehensive two-year pilot program, which is the first of its kind, is designed to obtain the necessary practical, technical, ethical and psychosocial data to form a realistic national picture of what can be expected from population-based SMA carrier screening.

A carrier test for SMA was developed in 1996 by Dr. Thomas W. Prior, director of the molecular pathology laboratory at Ohio State. While the test is highly effective, it has not been well utilized. Dr. Prior and his colleagues will address the various barriers to population-based screening using the SMA carrier test.

It is estimated that one in every 40 people carries the gene that causes SMA (about 7.5 million Americans) and there appears to be no racial or gender preferences among carriers of SMA. A child of two carriers has a one in four chance of developing the disease.

Deborah and Chris Heine established the Claire Altman Heine Foundation, Inc. in memory of their daughter, Claire, whose life was claimed by SMA in 2004 at the age of 9 months. CAHF uses its funding to identify carriers of SMA, support population-based SMA carrier screening, raise awareness of SMA and educate the public and medical communities about the disease.

June 19-22, 2008 | BOSTON PARK PLAZA HOTEL– Boston, MA

2008 FSMA Family & Professional Conference



**BEANTOWN:
THE SMA
REVOLUTION**

*Hear ye! Hear ye!
Hear ye!*

Join us for the 2008 Families and Professional FSMA Conference in Boston, Massachusetts. One if by land, two if by sea, come discover Boston's history. The Boston Park Plaza is in the heart of the city and will host the 2008 conference.

Boston is easy to get around, either on foot or by the user-friendly public transportation system, called the T. The hotel is only 3 Miles from Logan International Airport. Within walking distance of the hotel are restaurants and infamous Newbury Street with plenty of shopping.

Take in a Red Sox game or explore the Freedom Trail. No visit to Boston would be complete without a stroll through the Boston Common and Public Garden and a ride on the famous swan boats.

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

Childcare: Please note our kids' program is run on an all-volunteer basis with the majority of childcare workers being high school students. Please keep this in mind when registering your children. If you have questions please call us at 800-886-1762.

Thursday, June 19, 2008

Evening Dinner on Own
6:30pm Welcome remarks
Pre Registration
PJ Party for kids/Ice Cream Social

Friday June 20, 2008

Morning Registration &
Continental Breakfast
9:00am Opening Session
Keynote speaker
Kid Talk It Out-Part I (ages 6-9 years old)
Noon Lunch on your own
Boston Public Gardens
Afternoon Workshop Session #1
Workshop session #2
Researchers and Kids Activity
Evening Family/Research Awards Dinner & Live Auction
All Day Baby Room
All Day Childcare Room

Saturday, June 21, 2008

Morning Continental Breakfast
9:00am General Session
It's Wonderful Life Panel
Kid Talk It Out – Part II (10 years & older)
Sibling Workshop
Workshop Session #3
Noon Lunch on your own- Free Time
Afternoon Workshop Session #4
General Session –Science/Genetics
How to Make a Difference on Legislation
Evening Dinner on your own
Family Carnival/Chinese Auction
All Day Baby Room
All Day Childcare Room

Sunday, June 22, 2007

Morning Full Buffet Breakfast
General Session
Research Update (Adults only)
Q&A Session: Research, Clinical & Medical panel
Morning Childcare Open
Noon Close of Conference



The 2007 FSMA Conference
In Illinois



Registration
Form
on page 7

Hotel accommodations

Boston Park Plaza hotel reservations can be made by calling 1-800-225-2008 for a special rate of \$195 per night. Please reference FSMA or Families of Spinal Muscular Atrophy Conference. See Boston Park Plaza site for more information about the hotel and area guide: <http://www.bostonparkplaza.com/>.

- A special link is set up by hotel to make reservations online. Go to <http://www.starwoodmeeting.com/Book/FAM0614>
 - If you are traveling with a larger family and would like:
 - Two bathrooms, the hotel has put aside a limited number of Family Rooms which are described as Deluxe Doubles. They include two bathrooms. Note: some do not have tub showers.
 - To ensure a correct size room that would include a tub shower, **please have the reservationist - NOTE AND CODE the reservation as a handicap family guest. To make this reservation, call the hotel directly at 800-225-2008.**
 - If you need a refrigerator in your hotel room, you will need to call the hotel and book it in advance.
- Book early. Only a certain allotment of rooms are reserved with the conference rate for FSMA.

Travel from Airport to Hotel

1. Airport Cab Service (meter rate) Airport Cab has a fleet of wheel-chair assessable cabs –expect metered cabs to be about \$30.
2. Boston's Subway: The "T" <http://www.mbta.com/>
3. J.C. Transportation Shuttle 800-517-2281 expect service ride to be about \$13.50.

Parking at Hotel:

- Parking: Hotel offers valet parking only for \$38.00 overnight.
- Self Park: Motor Mart - conveniently located across the street from hotel. Special rate \$24.00 <http://www.motormartgarage.com>.
- The hotel will set aside limited bagged off metered spots right outside hotel at a cost \$30 a day for handicapped accessible vans. These will be on a first serve, first come basis.

June 19-22, 2008 | Boston, MA

2008 FSMA Family & PROFESSIONAL CONFERENCE

Conference registration fees:

Adult	\$145
Children	\$35*
Professional	\$240

* Children over 10 subject to additional charge for Banquet.

Additional tickets for the Friday dinner banquet or the Saturday lunch can be purchased for \$40 each.

A limited number of scholarships are available. Please apply early by e-mailing colleen@fsma.org. Scholarships will be awarded based on financial need.

"BEANTOWN: THE SMA REVOLUTION"

Workshops

The weekend is filled with numerous new and familiar workshops. The workshops are invaluable to all who attend. Workshops topics include:

GENETICS & GENERAL SCIENCE

- Basic Biology of SMA
- Therapeutic Strategies of SMA
- Understanding Genetics of SMA
- PreImplantation Genetic Diagnosis

GETTING INVOLVED & FUNDRAISING

- Walk N Roll Across America
- Building Your fundraiser into a Major Event
- Moving Forward Staying Involved
- Legislative Initiatives

RESPIRATORY ISSUES

- Respiratory Care Choices: Type I
- Keeping Lungs Healthy: Type II
- Life After Tracheostomy

PHYSICAL MANAGEMENT

- PT, OT, & Bracing
- Orthopedic Management Issues
- Care & Treatment of SMA Type III

HOUSING

- New Construction & Remodeling
- Making Housing Adaptations Affordable

RECREATION & THERAPY

- Benefits of Yoga for Kids
- Playtime for All –Adapting Toys
- Assistive Technology to Communicate Independently

SELF HELP & WELLNESS

- Mentor Thru Independence
- Life as an Adult
- Preparing for College at any age
- Healing The Grieving Heart
- Adults With SMA Roundtable

OPEN DISCUSSION

- It's a wonderful Life
- Grandparents Talk it Out
- Research Update to Families
- Knowledge is Power- Sharing Your experience - All Types
- Open Consultations –Meet your Medical professional Team

JUST FOR KIDS

- Sibshop- Having a Sibling with a Disability
- Kids Talk It out
- SMA 101- Science for Kids

FAMILY FUN ACTIVITIES

- Family Fun Carnival
- Annual Awards Banquet
- Fun time Activity with Kids & Researchers
- Multiple Children Activities



Hear ye! Hear ye! Hear ye!

June 19-22, 2008 | Boston, MA

2008 FSMA Family & PROFESSIONAL CONFERENCE

Conference registration fees:

Adult	\$145
Children	\$35*
Professional	\$240

* Children over 10 subject to additional charge for Banquet.

Additional banquet tickets can be purchased for \$40 per meal.

Limited number of scholarships are available. Please apply early. Scholarships will be awarded based on financial need.

Payment Method

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

\$

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

No. of adults attending:

No. of children attending:

List of all adults attending and their address if different from above –
(please list Type of SMA if applicable)

List of children attending –

Name	Age	Sex	Type SMA	Not Affected

Number attending banquet dinner

Adults:

Children:

Number attending banquet lunch

Adults:



www.curesma.org

Return Registration Form, no later than May 10th, 2008 to
2008 FSMA Family & Professional Conference
 PO Box 196, Libertyville, IL 60048-0196 or FAX to 847.367.7623

Newborn Screening, Federal Policy, and Spinal Muscular Atrophy

Spencer Perlman, FSMA Legislative Affairs

“Newborn screening” refers to the process of testing and screening the blood of newborns for certain hereditary disorders and genetic diseases. It is a state-based public health program; states and territories mandate newborn screening of all infants born within their jurisdiction for certain disorders that may not otherwise be detected before developmental disability or death occurs.

To date, no state or territory tests newborns for SMA due to an historical bias against screening for disorders that do not have a treatment or cure. This is unfortunate because the technology exists to screen for SMA; Dr. Thomas W. Prior of Ohio State University developed a SMA newborn screen in 1997. The test is highly accurate with 95 percent sensitivity and 99 percent specificity. Dr. Prior has recently published a paper describing improvements to the screen and he is planning a large-scale pilot of the test.

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-symptomatic 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 before they are likely to have a second affected child, which frequently occurs when diagnosis is delayed.

Historically, the federal government's role in newborn screening has been advisory in nature. Congress mandated greater federal involvement in the Children's Health Act of 2000 in order to address the disparity between the numbers of disorders screened for by the states and to standardize screening activities. In May 2004, the number of disorders mandated by states ranged from three (3) in South Dakota to 40 in

Mississippi. The Children's Health Act established grants to assist states in carrying out their newborn screening responsibilities and required the Secretary of Health and Human Services (HHS) to establish an Advisory Committee on Heritable Disorders in Newborns and Children. The Advisory Committee was established by then HHS Secretary Tommy Thompson in 2004.

In 2005, the Advisory Committee and the American College of Medical Genetics (ACMG) jointly released an advisory federal screening panel containing 29 disorders for which screening should be mandated by the states; ACMG had been commissioned by the Maternal and Child Health Bureau of HHS in 2001 to outline a process of standardization for newborn screening programs. The number of disorders for which states mandate screening has dramatically increased as a result of the Advisory Committee's work, even though the federal panel has no force of law. In May 2004, only 11 states screened for as many as 30 disorders; by June 2006, 37 states screened for at least that many.

Unfortunately, SMA was not considered for inclusion in the federal panel due to the absence of a treatment. Families of SMA has worked hard to alter this bias and to advocate for the inclusion of SMA in the panel.

The Advisory Committee has been working to develop a methodology and process for expanding the panel. Recently, the Advisory Committee placed on its website (<http://mchb.hrsa.gov/programs/genetics/committee>) a Nomination Form to request formal consideration for addition of a hereditary disorder to the fed-

eral panel; Families of SMA participated in a pilot study of the form in 2006. The Advisory Committee recently finalized the criteria for reviewing nominated disorders.

Families of SMA and its partners in the SMA community are preparing a Nomination Form for presentation to the Advisory Committee. The Form is expected to be completed and submitted in the summer of 2008. The community intends for the eventual inclusion of SMA in the federal panel to lead to the adoption of newborn screening for SMA by the states.

Meanwhile, Congress is moving legislation to further strengthen the federal role in newborn screening policy and to improve the newborn screening infrastructure. The Newborn Screening Saves Lives Act of 2007 (S. 1858 / H.R. 3825) requires the Health Resources and Services Administration (HRSA) within HHS to award grants to states, local governments, and private non-profits to provide education and training in newborn screening and congenital, genetic, and metabolic disorders to health care professionals and newborn screening laboratory personnel. HRSA also is required to establish a central clearinghouse for information on newborn screening and to award grants for newborn screening educational programs and for a system to assess and coordinate treatment relating to congenital, genetic, and metabolic disorders.

The legislation requires the Centers for Disease Control and Prevention (CDC) within HHS to provide for quality assurance for screening laboratories, population-based pilot testing for evaluating new screening tools, and a national contingency plan for newborn

screening in the event of a public health emergency.

The Secretary of HHS is required to establish an Interagency Group to collect, analyze, and make available data on certain heritable disorders; operate regional centers to conduct applied epidemiological research on interventions to prevent poor health outcomes from such disorders; and research and promote the prevention of poor health outcomes.

The legislation also significantly strengthens the Advisory Committee. The bill specifically spells out in statute that the Advisory Committee is authorized to make recommendations regarding the heritable disorders for which all newborns should be screened and to develop a model decision-matrix for newborn screening program expansion. Furthermore, it requires the Secretary of HHS to act upon these recommendations within 180 days and it adds as a condition for state eligibility for federal grants for screening, counseling, or health care services to newborns and children having, or at risk for, heritable disorders assurance that the state has or is implementing the Advisory Committee's guidelines and recommendations.

In practice, this means that the uniform federal panel developed by the Advisory Committee will become the de facto law of the land with regard to newborn screening policy. At the time that SMA is accepted by the Advisory Committee for inclusion in the federal panel, the legislation nearly ensures that each of the 50 states will adopt SMA for inclusion in their state panels.

The Newborn Screening Saves Lives Act has passed the Senate and is currently moving through the House of Repre-



LEGISLATIVE UPDATE ON THE SMA TREATMENT ACCELERATION ACT

Support in Congress for the SMA Treatment Acceleration Act (H.R. 3334 / S. 2042) continues to grow thanks to your grassroots efforts.

Presently, the legislation has 31 cosponsors in the House and 11 cosponsors in the Senate. This is great progress!

If you have not already contacted your representatives in Congress, please visit the legislative area of our web site. There you will find information on identifying your representatives and their contact information, as well as draft materials that can help you prepare a communication urging support for the legislation.

Please urge your family members, friends, colleagues, etc. to reach out, too.

sentatives where it has strong support. With the legislation making important improvements to federal newborn screening policy and Families of SMA leading the way to nominate SMA for inclusion in the federal newborn screening panel developed by the Advisory Committee, it is becoming increasingly likely that all newborns in the United States will be screened for SMA at birth in the foreseeable future.

More Working Americans Need to Take Credit

by Mary Anne Ehlert, President, Protected Tomorrows, Inc.

Tens of thousands of people with disabilities are losing money each year because they are either unaware or do not know how to file for an Earned Income Tax Credit—an anti-poverty program for hard working low-income employees aimed at offsetting the burden of taxes, supplementing low wages, and providing an incentive to work. Protected Tomorrows Advocates across the nation are working to inform this population of people so they understand what they deserve. A qualified individual may receive a credit up to \$428, while a family with two or more children may receive up to \$4,716.

We suspect some people might not be filing for the tax credit because they fear they'll lose needed government benefits if they receive too much of a refund. People with disabilities receiving Supplemental Security Income (SSI) or Medicaid cannot have more than \$2,000 in assets or income above a certain level, or they will lose funding that affords them food, shelter and could impact health benefits. "But many people don't realize that the Earned Income Tax Credit does not count as income in determining eligibility for benefits like cash assistance, Medicaid, food stamps, SSI or public housing."

There are specific eligibility requirements to qualify for the EITC, one being an income limitation. These limits for 2007 taxes returns are:



- No children - income below \$12,590
- 1 child - income below \$33,241
- 2 or more children – income below \$37,783

Protected Tomorrows Advocates are specially trained to handle the nuances involved with planning for people with special needs and can refer you to a site that will prepare tax returns for individuals with disabilities free-of-charge.

An estimated 22 million Americans between the ages of 18 and 64 have a disability, according to the 2000 Census. In the National Organization on Disability/Harris "Survey of Americans with Disabilities" released in June 2004, 26 percent of people with disabilities reported an annual household income of \$15,000 or less. In addition, 83 percent of people with disabilities said they had never claimed an income tax credit or deduction related to their employment or disability.

EITC Awareness Day was Jan. 31, a day

initiated last year by the IRS to encourage more people with disabilities to file their taxes and apply for the tax credit. In partnership with the National Disability Institute (NDI), an organization promoting income preservation and asset development for persons with disabilities nationwide, more than 36,000 people with disabilities filed their taxes and received more than \$32.6 million in refunds. This filing season, NDI anticipates

low-income workers getting more than \$50 million in EITC and other refunds through its public awareness initiative, Real Economic Impact Tour. To learn more about the Tour, visit www.REI-Tour.org. To learn more about NDI, visit www.ndi-inc.org.

Our goal at Protected Tomorrows is for families with special needs to live safe and fulfilling lives. The more money they have the more independent they could be. People with disabilities are an economic force in our society, so they should maximize their earning potential by filing for the Earned Income Tax Credit.

For more information on EITCs or the find a Protected Tomorrows Advocate, visit www.ProtectedTomorrows.com or call 847/522-8086.

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Wall of Strength

Families of SMA was able to exceed our fundraising goals this holiday season thanks to the collaborative efforts of so many of you.

The idea behind the Wall of Strength was both to raise critical funds to help support clinical trials and to honor individuals, families and groups in our community during the holiday season. The response on all levels was phenomenal.

Together we raised over \$127,000!!! These funds will help keep one clinical trial site running for a full year.

Thank you.

See website for full page.



Facebook is a social utility that connects you with the people around you.

FSMA on Facebook

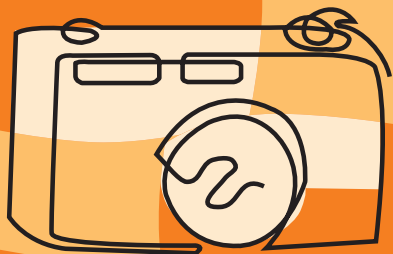
FSMA and FSMA Canada are both featured on Facebook.

Go to the website:

http://apps.facebook.com/causes/browse_causes

and search Cure SMA and you will see our logo!

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.



Arizona Chapter

November 11, 2007 marked the Arizona Chapter of FSMA's 2nd Annual Walk-n-Roll, including families and friends from throughout the state, puppies and dogs from the local chapter of Canine Companions for Independence, and a kick-off with the Phoenix Suns mascot – The Gorilla! The 2nd Annual AZ Walk-n-Roll successfully raised over \$24,000, with nearly \$58,000 raised in the first two years! The Arizona Chapter gives special thanks to all of the sponsors, families who participated, their supporters, and Honorary Spokesperson: Channel 3 Forecaster April Warnecke for making the day such fun!

Rocky Mountain Chapter

Thank you for contributing to our inaugural **Cure SMA Walk-n-Roll Across America** in the Denver/metro area at Clement Park on August 26, 2007!

Over 160 participants enjoyed a beautiful Colorado day and the Chatfield Balloon Festival as a backdrop.

It was great to have so many new faces and SMA families take part! The event was a great success and has plenty of room to grow. We could not have done it without your help and hope you can join us at one of our 2008 FSMA Rocky Mountain Chapter events...

The “**Evening of Hope**” dinner auction in March or coming this summer, the “**Scottish Stained Glass Charity Golf Tournament**” and our “**CureSMA Walk-n-Roll**” events in Colorado Springs and Denver.

Visit www.curesma.org for more information or call the chapter for more details on an upcoming event 1-877-591-4023.



Chesapeake Chapter

Our summer and fall fundraising season was quite busy. We

have all been hard at work with our Annual Crab Feast all the way through fall with the culmination of our **13th Annual Golf Tournament**. The support of our community large and small has been remarkable this year.

The Chesapeake Chapter is proud that the 13th annual CRM Golf Classic to benefit FSMA raised over \$151,000!!! Over 50 foursomes and 200 golfers participated on two adjacent courses to accommodate the demand. A logistic challenge but a wonderful testament to the many companies and individuals who continue to support the work of FSMA in Advancing Research and Supporting Families. Special thanks go out to Scott Geller, the Golf Chair and our many volunteers who make it possible to pull off an event like this.

Baltimore loves picking crabs and once again the FSMA Chesapeake Chapter held its **14th 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 raised over \$15,000.

Megan Nolan held a **Family Fun Carnival for SMA**. A student at Linganore High School in Mt. Airy, where all seniors are required to do a Graduation Project, Megan chose Families of SMA. She, along with 30 volunteers, raised over \$1,200.

Eastern Savings Bank held a ‘**Casual for a Cause**’. Employees paid for the opportunity to dress down at the office. The event raised over \$1,200! Thanks to everyone at Eastern Savings Bank for their continued support.

Caitlin and Grace Trainor along with cousins Mary Kate, Eileen, and Annie Venedam sold chocolate angel pops to the friends, family, students and faculty during the holidays. They created a flyer to spread the word and had the opportunity to get in front of their school to promote the fundraiser. They raised over \$400 for FSMA.



**Connecticut Chapter****Iowa Chapter****Variety Children's Charity of Iowa
Grant for Iowa FSMA Children**

The FSMA Iowa Chapter is pleased to share that Iowa children with SMA will benefit from a grant received through Variety The Children's Charity. The grant covers the cost of specific requested medical equipment and accessible toys. Like Families of SMA, Variety brings out the best in those who support the mission to help children in need. We are grateful to be included in this year's grant reception.

**BeaverDash Charity Run
for Families of SMA**

This year's BeaverDash was a record breaker in many ways. Over 1,000 people registered and nearly 120 volunteers along with the many dedicated sponsors and

donors helped the BeaverDash Charity Run raise nearly \$35,000 towards SMA research!!

Dale the Beaver was there to welcome the BeaverDashers, including many families from all corners of Iowa. Beaver Trotters were congratulated at the finishline by Dale as well.

Among the many teams present was "Team Stella's Warriors", with members walking and running in honor of Stella Turnbull (see team photo below).

Rudkin Annual Family Picnic

Thank you to the Rudkin family and their many friends who gathered in honor of six-year-old, Cael Rudkin and raised \$1,300 towards SMA research. Cael has also been part of the Families of SMA Project Cure by participating in the clinical trials in Madison Wisconsin. We are grateful to the Rudkin's for all they do to help Families of SMA work towards a cure!

**Stella's Prayer Warriors-Iowa Chapter****Kennedi Vondrak**

Kansas City Chapter

The Kansas City Chapter has had a busy summer and fall! This summer, Kristal Koehler, chapter vice-president and mom to Brett Wilson, organized the first, and hopefully not the last, SMA swimming pool summer camp! For six consecutive weeks, Brett Wilson, Claire and Lauren Gibbs, Lindsay Cochran and Arturo George met once a week for a one hour session of pool therapy fun! All of the kids and adults really enjoyed themselves and the kids really cheered each other on with all of their swimming accomplishments! We want to thank Kristal for organizing the event! Our annual fall event is the RoeFest Cure SMA Race-n-Roll which took

place on October 6th. We had a perfect 70 degree morning for a 5k run and one mile walk. We had nearly 600 participants and over 50 volunteers. Participants traveled from several states to take place in our yearly event and we are proud to say we raised \$50,000! Special thanks go to all of our sponsors, great volunteers and our participants and our wonderful FSMA families who attended and raised a tremendous amount of money!

This fall two kids, Lauren Gibbs and Peter Voskovitch, have been participating in the Kansas City Wheelchair Sports Program and playing in a wheelchair basketball league. We want to congratulate the two of them on their accomplishments!



Minnesota Chapter

The 7th annual FSMA walk was held September 16th at Phalen Park in St. Paul. Approximately \$16,000 was raised at the walk, and through on line donations approximately \$25,000, for a grand total of over \$40,000! This is an impressive gain over last year. A special thanks goes out to all those teams who went above and beyond in their fundraising efforts.

New England Chapter

10th Annual Christopher J. Barrett Realtors/New England Chapter Golf Tournament

On July 9th, 2007 the New England Chapter and Christopher J. Barrett Realtors of Wakefield MA hosted their 10th Annual Golf Tournament at the Andover Country Club. The day consisted of barbecue lunch, shotgun at 1:30 and dinner and live auction at night. The tournament has a "Beat the Pro Hole" with former Red Sox catcher Bob Montgomery. After dinner, Bob hosted the live auction that raised over \$12,000. Total raised at the tournament was over \$37,000 for FSMA.

South Jersey/Delaware Chapter

The South Jersey Chapter received \$10,000 from the South Jersey Charitable Foundation to assist the Wall of Strength. The money was an unrestricted grant in honor of Steven Potter to help support the efforts of Families of SMA! We thank the South Jersey Charitable Foundation and Mr Ronald Woods for this fantastic donation.

February 2007 two fundraisers were held. Steven's Gala for SMA at the Crowne Plaza in Cherry Hill, NJ raised over \$40,000 and The Young Children's Center for the Arts partnered with FSMA and donated over \$900 in memory of Camryn Kepple. May was also a busy month. Chris Cooter hosted the

Second Annual Benefit Ride to fight SMA and raised \$1,000. On May 19th The Potter family hosted Steven's Walk for SMA in Haddon Township and raised an incredible \$32,000. In July the Contento/Halabura families held Jimmy's Swim & Swing for a Cure at the Ramblewood Country Club and raised \$11,000 in honor of Jimmy Contento. In August Karina Koundahdjan hosted Nairi's Walk for a Cure in honor of her niece and raised \$3,000. She planned this walk by herself! Three golf fundraisers were held in September in three different states. Steven's Swing for A cure in Delaware hosted by Jason and Jessica Moyer and the 4th Annual SMA Golf Tournament hosted by Steve Moyer in Pennsylvania brought in over \$12,000 together. Last, but certainly not least, Jeff and Lisa Wood hosted the Drive for a Cure golf tournament in Hamburg, NJ in honor of their daughter Elizabeth and raised an incredible amount of \$25,000 with donations still coming in.

In other news, Jason and Jessica Moyer ran the Marine Corp Marathon (26.2 miles) in Washington DC to raise awareness of SMA and honor the memory of their son Steven on October 28th. A special congratulations to Laura Landre and family on the addition of baby Carson.

2008 already has some events on the calendar with the first being Friday April 11th- Steven's Gala for SMA will be held at the Crowne Plaza in Cherry

Hill, NJ. We hope you can join us for a night of dinner, dancing and huge auction. On Saturday May 17th the Potters will once again hold their annual SMA walk in NJ. Please see FSMA events calendar for additional details and more fundraisers.

Thank you to Christian Sauter who raised over \$300 through a New Year's Eve Party. Also thank you to Julie Crews for designing and selling wine charms. She raised over \$300 in memory of her brother Gavin Crews. Lastly thank you to Andrew DelRossi for holding a music jam at his college and raising close to \$100 in honor of Jimmy Contento.

We welcome any new families who would like to get involved with the chapter. Please contact Jason or Jessica Moyer at 866-774-9533 or email jnj-moyer@comcast.net for information.





Pacific Northwest Chapter

The Pacific Northwest Chapter of FSMA invites you and your family to join in the fun! We have a very good time at our quarterly meetings, and our kids have become great friends who really enjoy each other's company.

There are usually a bunch of sibs running around, including a group of teens. Everyone will find a friend to share a laugh or trade information with.

We meet quarterly-ish in Tacoma at a donated funky-but-fun VFW hall right off the freeway, 45 minutes from Seattle, about the same from Centralia. Our next meeting will be the second annual Christmas party on Dec 16th, and our Winter meeting will be in February.

Call Rick Jones at 206.284.1888 or email at pacwest@fsma.org. Join our list and plan on coming along for some fun and to meet some new friends.

Pennsylvania Chapter

Greetings from the Pennsylvania Chapter!

2007 was a busy year for us on the fundraising front! With a wonderful team of Board members and many new families, we have proudly accomplished a lot.

Our biggest fundraiser, our **Spring Walk-n-Roll to Cure SMA**, drew over 400 participants. Along with raising over \$80,000, they enjoyed games, refreshments, and a lovely stroll along the Kelly Drive bike path. Many thanks to DJ Jim Clerihan for donating his sounds. What a difference his music made! For the fourth year, our Walk has had the honor of Emcee Walter Perez of Channel 6 Action News. He spoke eloquently about the effects of SMA, our organization, and the research we are

funding. Great Awareness! Keep a lookout for information about our 5th Walk-n-Roll to Cure SMA this Spring.

Happy Birthday Matthew Freitas! Last year, this auspicious event was celebrated in a big way. Kris Gucwa, uncle to Matthew, ran the **1st Annual "Miles for Matthew Run."** It was a one man event in which Kris ran the Perkiomen Trail from the Deep Creek Trailhead to Valley Forge Park in honor of Matthew. That totaled 20.5 miles! People from across the country sponsored him leading to profits exceeding \$2200. Kris has already pledged to keep the momentum going with a repeat event this year.

Last June, Arden Rose Neff, a classmate of Connor McRory's (brother to angel Abby Negrin), worked to fight SMA! At the **"Summer Solstice" Festival** in the suburbs of Philadelphia, Arden Rose set up a stand and sold handmade bead bracelets. She raised over \$200. Apparently, Arden Rose got "the SMA bug." She decided that as part of her "Mitzvah Project," she would devote the next year and a half as preparation for her Bat Mitzvah, making SMA her charity of choice. She will be logging 13 hours of service to our organization, as well as repeating her fundraising efforts. Great job Arden Rose!

Honoring the memory of Emmy Rose Baugher, many supporters will come together on March 8th in Hanover, PA to **"Crop for a Cure."** Emmy Rose's mom, Brandy Baugher, is hosting this wonderful scrapbooking fundraiser to raise money to fight SMA. Along with this scrapbooking extravaganza, there will be a Silent Auction, Raffles, and Door Prizes. Brandy is also selling silver Angel pins, specially designed in memory of Emmy, by Carla of www.carlasangels.com. For information on "Crop for a Cure," please contact Brandy at (717) 965-5066 or emmyrose-baugher@hotmail.com.



On May 10th, 2008 in Horsham PA, Calvary Riders TEAM of Motorcyclists for Jesus, headed by Pastor Chris Cooter, will ride to fight Spinal Muscular Atrophy. This repeat event will be the **3rd Annual Ride to Fight SMA**. Last year, about 50 bikers enjoyed a sunny ride as they collectively rode for our cause. This year promises good food, a DJ, raffles, and a great ride! Please contact Chris Cooter at (215) 674-1475 or mjmcalfaryriders@verizon.net.

Along with fundraisers, we have had many generous donors including:

- Jake Saxton's preschool teachers from Kinderworks in New Hope PA, who raised \$200.00 to be matched by Johnson and Johnson
- Members of the HSBC Risk Department who raised \$570.00 in honor of Jake Saxton, which will also be matched
- Cousins of Jack Freedman, John and Rosalee Di Iulio, who donated \$2500 in honor of Jack
- Friends of Abigail Negrin - Jack and Tamara Dodds, who donated \$1000 and Nate and Allyson Andrisani who donated \$500

Looking forward to the Conference and a great year!

In Friendship,

Karen McRory-Negrin, Esq., *President*
Josephine Tripodi, *Treasurer*
Paula Saxton, *Membership Chair*
Allyson Henkel, *Corporate Sponsor Chair*
Molly Freedman, *Secretary*
Heather Kennedy, *Vice President*
Richard Negrin, Esq., *General Counsel*



NYC/Long Island Chapter

Dylan & Kiley's 4th Annual Walk N Roll to Cure SMA will be held on Saturday, September 13, 2008 on the Long Beach Boardwalk. Online registration should be available soon. For more information, please send an email to longisland@fsma.org



Tennessee Chapter

The FSMA Comedy For The Cure fundraiser was our most successful to date, raising over \$74,000! Once again, the Knoxville Museum of Art was the setting for a memorable evening. Musical entertainment in the garden by the Shoeshakerz was followed by dinner in the great hall. We were very fortunate to have comedian Leanne Morgan return to fill the hall with laughter.

Western New York Chapter

The WNY Chapter is once again busy getting things in place for the 5th Annual SMARt Walk for a Cure. It will be held at Beaver Island State Park and co-chaired, once again by Senator George Maziarz and Nickolas Pickalas from Radio station KISS 98.5.

About 350 corporate sponsorship request letters will be mailed out the first week in February.

We have added a "Presenting Sponsor-

ship" for donors of \$3,000 and over. This will entitle the donor's name to be added as a sponsor for the entire WALK. We are also redesigning the walk registration form. Hopefully, making it easier to read and understand.

Last year we raised almost \$67,000 with the help of our friends and families across Western and Central New York. This year, on August 2nd, we hope to be successful again.

We also look forward to the Wyatt Walk. This event is held on the first Saturday in May, in memory of Wyatt Sutker, the grandson of John and Sally Sherman. The money raised is used by the Wyatt Sutker Foundation to fund research and family services for infants diagnosed with type 1 SMA. Every year about 250 friends and family join Sally and John to make this a big success.

This years event will be on May 3rd in

Niawanda Park along the Niagara River in Tonawanda, New York.

Kevin Currier is a very good friend of the Blair Family and especially Alex who is 4½ years old and has SMA Type I. Kevin turned 40 on the same day of the 4th Annual SMARt Walk for a Cure.

His family wanted to have a big celebration with family and friends so they decided to have a party. On the invitations, Kevin stated "no gifts please" but requested donations to the WNY Chapter of FSMA in honor of Alex.

The day of both events, August 4th, 2007, was a beautiful day. After a successful Walk, the Blair Bunch joined the Currier Clan for some good old-fashioned party fun, which included a trio of bagpipers – who actually played "Happy Birthday".

A donation box was set up with pictures of Kevin and Alex together. After enjoying a fantastic time with good friends, family and food, Kevin raised over \$1,000 for the Chapter!

Thanks Kevin – you have a BIG Heart and are a wonderful friend to Alex.



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
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Phone: 205-979-6493
Tonya Willingham, President—
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Arizona Chapter (since 1997)

P.O. Box 641
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Karey Kaler, President—
arizona@fsma.org

Chesapeake Chapter (since 1995)

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Barb Trainor, President—
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Janet Schoenborn, President—
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Natalie Gibbs, President—
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toll-free (877) 256-9111
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David Sereni, President—
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Chapter (since 2004)

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Karen McRory-Negrin, President—
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Wisconsin Chapter (since 1999)

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Marta Meyers, President—
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**Are you interested in
starting a new chapter
for Families of SMA?**

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

Linda Shively Fernandes, Jim and Marge Shively, Dick and Pat Wolff, along with the Fiore, Galeb, Haney, and Xue families worked together to put on the **5th Annual WALK SMART** on October 6, 2007. The walk took place at Lake Elizabeth in Central Park, Fremont, CA in honor of all the local SMA families. There were over 15 SMA families represented at the walk and many helped in some way to make the event successful. This event raised over **\$48,000** and just as incredible, they had NO expenses! This group really hit the pavement and got almost the entire walk sponsored!



Once again, the **9th Annual Haley Mitchell Ski-a-thon** was a huge success!

The event is organized by Jeff and Valerie Mitchell of Elizabeth City, North Carolina, along with the River City Ski Club in honor of Haley Mitchell. This year there were a record 52 skiers that gathered at Beaver Lakes in Gates County, North Carolina. The ski-a-thon raised a record **\$47,000** for FSMA! This brings the Haley Mitchell Ski-a-thons grand total to over \$285,000 raised!



Chris and Lana Hannah hosted the **7th Annual Lanie Hannah Benefit Scramble** in honor of their 8 year old daughter Lanie. Several friends and family gathered in September at Canyon West Golf Course in Weatherford, TX to enjoy a day of golf, food, and lots of fun. The event raised a remarkable **\$41,000** for FSMA! Many thanks go out to the

Hannah family for your continued support of Families of SMA.



On October 20th, 2007 the **15th Annual Maluko Charity Golf Tournament** was held at Plantation Palms Golf Club in Land O'Lakes, Florida. The event included breakfast, 18 holes of golf, lunch, and an awards party. Chuck and Megan Hernandez, along with several others organize the tournament in honor of their son, Tyler. Along with some encouragement from the Tampa Bay Buccaneer Cheerleaders, this year's event raised over **\$35,000** for FSMA!



Christy and Kenny Greene of Riverside, CA held their first ever walk in honor of their daughter, Sara Rose. **The Inland Empire Cure SMA Walk-n-Roll** took place on November 17, 2007 in Riverside, CA. There was a great turnout by several other families. There was lots of food, entertainment, and fun had by all! The walk raised an incredible **\$45,000** for FSMA!





Tim and Mindy Rush of Saginaw, TX held their **5th Annual Odds on a Cure Dinner & Casino Night** in honor of their daughter, Savannah Rush. The Rush family was joined by several other SMA families, including: Sydney Craven, Hannah Ostermeyer, Seth Gilley, Kane Urban, and Lanie Hannah. Also, Jackie Gonzales attended in memory of her daughter Isabella. The event took place at the Will Rogers Roundup Inn on November 10, 2007 and had about 350 people in attendance. For the second year the band, 3 Day Bender, provided great music for all the guests. Some of the auction items were a suite for 20 to the Texas Rangers, Dallas Maverick tickets, Dallas Stars tickets, golf packages, dinner gift certificates, and a Disney trip raffle prize. This year Odds on a Cure raised about **\$34,000** for FSMA!



The second **Rally for Reagan Golf Fore a Cure** was held on August 19, 2007 at the Oaks Golf Course in Cottage Grove, Wisconsin. Several supporters gathered for a fun filled day of golf, a dinner reception with a raffle, silent auction, and contest winners. The event is hosted by Joe and Jenny Imhoff, in honor of their daughter Reagan. This year's Golf Fore a Cure raised **\$16,500** for FSMA!

Michael and Abbie Dougherty of Charlotte, NC held the **9th Annual SMASHing Kickoff** fundraiser in honor of their son, Gray Dougherty and Gray's Gang. The event took place at the North Carolina State University vs. Virginia University football game on October 27, 2007. There was lots of food, prizes, and fun had by all! The SMASHing Kickoff raised **\$13,347** for FSMA!



The **2nd Annual Abbey and Garrett's Walk-n-Roll** was held on September 8, 2007 in Cornelius, Oregon. The walk was organized by Stacy and Steve Hassel in honor of their children, Abbey and Garrett. The weather was beautiful and more people were in attendance than last year. The event also had a special guest, Dr. Barry Russman, a SMA specialist from Schriners Hospital in Portland, Oregon. This year's walk raised over \$1,000 more than last year, bringing the grand total to over \$8,000 raised for Families of SMA!



Wannabe Cup

Since 1999, Marilyn Belcher of Lebanon, OR has chaired the charity event called the **Wannabe Cup** in Honor of Skylar Bahrenburg, along with other dedicated volunteers. The Wannabe Cup began when the founders were inspired by the Ryder Cup and wished to participate in a similar event. This annual golf tournament began with 8 players and has since grown to 36 players. The Wannabe Cup raised over \$5,000 again this year for FSMA!



For several years Janet Hutchinson, Kathy Goodyear, and Rita Schmidt have hosted the **Families of SMA Outback Steakhouse Luncheon** in St. Louis, Missouri. This event is made possible by Rick Dohack, of Outback Steakhouse, who has generously provided all the food for many years. The FSMA Outback Steakhouse luncheon raised \$4,803 on October 27, 2007 to help provide family support and fund research.

Shane and Jenifer Barber held a holiday fundraiser at their family's restaurant, Bandits' Bar & Grill in Park City, UT on December 25, 2007 in honor of their daughter, Sarah. They donated the proceeds from the sale of food as well as from some patrons making private donations to FSMA. A total of \$4,100 was raised for Families of SMA!



Thomas wins! The Miller's and their employees try each year to increase the amount raised and they are happy to say they succeeded again this year! They raised \$3,015 for FSMA!



Manny and Debbie Silveira, owners of Tony's Restaurant, Fall River, MA, hosted the **2nd Annual Tony's Shipwreck Challenge** in honor of their 3 year old grandson, Logan. The proceeds from the event were donated to Families of SMA and totaled over \$2,040!



Sheri Ricks of Milwaukee, WI, a teacher of Jackie Hoffmann, ran the Milwaukee Lakefront Marathon, on October 7, 2007 in honor of her student. In addition to running 26.2 miles, Sheri also raised \$1,900 for Families of SMA!



Joseph Bierwith, Jr. of Boston, MA along with his sister **Jamie** decided to run the Hartford Half-Marathon on October 13, 2007 to raise money for Families of SMA in honor of their nephew Cubby Wax. They raised \$3,880 for FSMA, and over \$3,000 came from their online fundraising page!

Joe and Susan Miller of Riverview, Florida held their **7th Annual Tutor Time** fundraiser for FSMA. The event takes place at Tutor Time Learning Center of Brandon, the childcare center owned by the Millers. This is a fun filled day for all, but the highlight is the "Great Wheelchair Race". For the past 5 years Mr. Joe (Type III) has raced Thomas (Type II), and every year



Bret and Julie Border of Lewis Center, OH, along with family raised \$3,000 from selling pumpkins in memory of their daughter Lainie Grace. This is truly a family affair, the Border family plants, harvests, and sells the pumpkins as a tribute in honor of Lainie's birthday with proceeds going to Families of SMA!

Doug and Heather Kennedy of East Freedman, PA hosted the **3rd Annual Lily Kennedy Memorial Golf Outing** in memory of their daughter, Lily. The event was sponsored by Saint Francis University, Dr. Mark Lynch, and the Saint Francis University Social Work Club. The day was a huge success and raised \$2,400 for FSMA!

Michael and Melissa McKeon, of Putnam, CT donated the proceeds from their **8th Annual Connor James McKee Golf Tournament for FSMA**. The golf tournament is a tribute to the memory of their son, Connor James. The event raised \$1,500!

On September 22, 2007 **Michael and Jana Gundy** held a walk for the Kyle and Friends Foundation in honor of their son Kyle Gundy. The event was held at River City Parks in Sand Springs, Oklahoma. The Kyle and Friends group donated \$1,200 to help support FSMA.



Brian and Sharon Lynch of Boothwyn, Pennsylvania raised \$1,500 through donations and flea markets in memory of their son, Colin. An additional \$1,500 was donated through Pepsi Co. matching gift program, bringing the Lynch's fundraising total donation to \$3,000 for Families of SMA!



To Our Friends at FSMA,

It is with great joy that we are sending you checks totaling \$9,000! Our 4th Annual Lukie's Fall Festival was a huge success. Each year it becomes more well known within our community. We had two bands, a karate demo, a brass trio, Caring clowns, in addition to our games, raffles, face painting, food, and lots more fun.

May God bless you all!

Together we will find a cure!

Love,

*Joe, Tara, Kadyne, and Anne
The Maida and De Crescenzo Families
Roseto, PA*



The Rollinson Family showing off their FSMA T-shirts



continued on page 30

Donation Form

SP08

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

SP08

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

Phone

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

Subtotal \$

Shipping \$

Total \$

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

Merchandise Order Form

SP08

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

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

SP08



ALEAH ROSA DURAZZO
4/5/07 - 11/26/07

Our second little girl blessed us a month early and similar to our first daughter Dolce, she did well. She needed to stay in the hospital a few extra days because she was only four pounds. There were some things that my husband and I noticed about Aleah – not lifting up her neck, her legs not kicking as much – but we assumed it could be because of the fact that she was premature. Everyone says no two children are the same so I did not want to compare her to my first daughter. It wasn't until her four month well visit that her pediatrician recommended that we see a neurologist and perhaps that Aleah might need some physical therapy.

Things moved very rapidly with getting the neurologist appointment and scheduling a MRI. However, the MRI, blood and urine test came back negative. The neurologist did not want to give too much information because he said it could be so many different things and he wanted concrete evidence. Therefore, we had an appointment at the Children's Hospital in Philadelphia on November 16, 2007.

Unfortunately, we never made the appointment because on November 7th, I rushed Aleah to the emergency room because she wasn't breathing properly. Immediately, she was transported to Jersey Shore University Medical Center, Neptune. Aleah had pneumonia. My husband and I kept asking if this was relative to what may be her condition. It was then suggested that Aleah was a SMA type I. - Like everyone else's story, the horrible news of this fatal disease. There is no treatment, no cure, no hope. Within a week Aleah needed to be put on a ventilator.

I spent almost three weeks at the hospital with her. She would have these episodes that became more frequent when her oxygen levels and heart rate would go down. My husband and I knew that this was not the quality of life for her. Monday, November 26, 2007 she was taken off the vent. It was the most difficult day of our lives and definitely has changed us. Aleah was with us a short time (7½ months).

She did bless us with her big beautiful eyes, long lashes, Mohawk hairstyle, and giddy laugh. She loved to sit in her bouncy chair and watch her big sister jump around and torment her. Everything Dolce did was amusing to her. Aleah was such a happy baby and nobody could pass her by without taking a second look and compliment how adorable she was. She will always be honored and cherished in our hearts.

As families who are devastated by this tragic disease, we need to push to find a treatment and hopefully one day a cure. Type I victims don't have a say in their wishes and as parents it's so difficult to decide what is best. They deserve a chance at life. I would curse myself with a fatal illness just to give my daughter a chance. Anyone that is reading this, if it touches your heart – reach out. Bring SMA awareness, make contributions, make a difference – a little angel will thank you one day.

Thank you. Sincerely,

Victoria and Michael Durazzo

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

LOVING memories



SAMANTHA UTZAT
9/16/06 - 9/14/07



TIERNAN CONNER-PARK
12/6/02 - 5/27/03



LUKE & MEAGAN MCWILLIAMS
2/07 - 8/5/07 2/07 - 10/22/07



RYAN NOLAN
9/15/97 - 2/24/03



BENJAMIN GUITNER
8/14/06 - 12/23/06



AVA MAE KLOIBER
5/07 - 10/26/07



SAMANTHA WOODSON
10/27/97 - 2/08

Congratulations to Matthew and Megin Blake who donated to Families of SMA in honor of their wedding day. They wrote a poem for their wedding day, in memory of their cousin's daughter, Deirdre Abraldes.

In loving memory of Deirdre Ann Abraldes

Although we can't see you,

We know you are here

Smiling, watching over us

As we say "I do".

Forever in our hearts,

Forever in our lives –

And so we say our vows

In loving memory of you

By Megin and Matthew Blake



In Loving Memory
BRITTA HALVORSON
7/8/07 - 11/9/07



SOPHIE LAINE BALDWIN
2/14/07 - 11/26/07



IN MEMORIAM
RILEY LONDON CLARK
5/9/04 - 9/04

FSMA merchandise

www.curesma.org



12 Fruit Notecards | \$6

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



License Plate Frame | \$7



Angel Wing Pins | \$10



SMA Awareness Pin | \$15

One design in sterling silver.



12 Window boxes Notecards | \$5

4 each of 3 designs (12 cards).



FSMA Lapel Pin | \$5



FSMA Car Magnet | \$5

1 design.



SMA Sticker | \$2

Created in memory of Madison Vickers



Snowman or Angels of Hope Cards | \$8

Set of 8 cards. Specially created for FSMA by Silvia Heller.

Mail your Orders to
FSMA National Office
or fax to 847-367-7623
Order form is on Page 24

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.



Canvas Tote | \$10

CureSMA design.

**Spring Note Cards | \$6**

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

**FSMA Ladies Vest | \$30**

Blue sizes: XS M L XL
Black sizes: S M

Cure SMA Bracelet | \$2

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

**12 Charlie Notecards | \$10**

Artwork by Merrle Peterson, in memory of son Charlie, SMA Type I.

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

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

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.

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

Sizes: S M L XL

**Wipe Out SMA | \$12**

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

**Cure SMA T-Shirt | \$12**

1 design on short sleeve red or white shirt.
Kid sizes: 2/4 6/8 10/12 14/16
Adult sizes: S M L XL

"Together" T-Shirt | \$15 (short sleeve) \$18 (long sleeve)

1 design on navy shirt. Kid sizes: 2/4 6/8 10/12 14/16
Adult sizes: S L XL.
Long Sleeve, Kids sizes only: 2/4 6/8 10/12 14/16



Mail your Orders to
FSMA National Office
or fax to 847-367-7623
Order form is on Page 24



Paula and David Hoffmann, of Milwaukee, WI held their **Annual Block Party SMA Raffle** in honor of their daughter, Jackie. They solicited local business to donate gift certificates and prizes to raffle off. They ended up selling \$830 worth of tickets, with the proceeds benefiting FSMA!

Kay Cahill of Vancouver, British Columbia participated in a sponsored swim event in honor of Hanna Macellaro. Through solicited sponsorships from people all over the world, Kay raised over \$800 for FSMA.

The **Marshfield High School DECA students** of Marshfield, WI once again showed their support of Families of SMA during their 2007 Homecoming Week. Through various fundraising activities they raised \$699 for FSMA in honor of Reagan Imhoff. Go Tigers!

Ky-Wai and Melissa Wong of Concord Township, OH raised an additional \$500 for FSMA through their ongoing **Amelia's Feast** fundraiser in honor of their daughter, Amelia. This brings their grand total to \$5,560 for 2007!

Tom & Rita Shutes of Lafayette, IN held their first ever garage sale benefit for FSMA in memory of their daughter, Audrey. They did an incredible job and raised \$500 for FSMA.

Once again, Chuck & Megan Hernandez of Lutz, Florida held another successful **Southern Living @ Home Party** in honor of their son, Tyler. This was

the fifth year in a row the Hernandez family hosted the event which raised \$330 for FSMA.

Pam Kuhn of Wisconsin Rapids, WI held the **3rd Annual Hot Lap for SMA** on August 18, 2007, which would have been her daughter Shania's 12th birthday. There were 49 people that braved the pouring rain, but they still had a wonderful time and raised \$314 for FSMA!

The students at Monsignor James J. Haddad Middle School in Needham, MA held a bake sale fundraiser. All of their hard work and baking paid off; they raised \$300 for FSMA.

Members of the Custar Community Harvest Festival donated the proceeds from the Pie Auction event at the festival, in honor of Kylee Gerhardstein of Custar, OH. The pie auctions raised \$162 for Families of SMA!

The staff at Grubb & Ellis Management Services, Inc. held a **Books Are Fun Fair** at Travelers Towers in Southfield, Michigan. The event raised \$120 for FSMA in honor of Sydney Grace Potjer.

The staff of **Greater Clark County Schools** of Jeffersonville, IN collected \$103 as a result of their 2007 Casual Fridays, wherein they drew a name from a list of employees at their Administration Building. The person whose name was drawn offered his/her "charity of choice" and the money collected was donated to Families of SMA in honor of Colby Russ!

Amy Kieffer of New Berlin, WI organized a dinner fundraiser at Noodles & Co., with 25% of all sales being donated to Families of SMA in honor of Reagan Imhoff. Everyone had a great time getting together and dining for a great cause. The event raised \$100 for FSMA.



Thank you to Marie and Taylor Smelser, and the Hailey Mae Foundation, for their donation of 5 AmTrykes tricycles to the Families of SMA Equipment Pool.

Mikayla Jean of Highland, CA and her cousins held their **4th Annual Lemonade Stand** to raise funds for FSMA in memory of her brother, Joseph Jean. Mikayla and her family wanted to help raise awareness about SMA and raise money for research. The children raised \$600 through their lemonade sales!

Charlie Vogel of Knoxville, TN celebrated his birthday with family and friends and requested in lieu of gifts, donations could be made to FSMA. Through Charlie's generosity \$455 was donated to FSMA in honor of his birthday

The Byron West Middle School Student Council of Byron Center, MI held a fundraising event for the second year in a row for FSMA in honor of Sydney Potjer. The students created a Haunted House and donated \$200, the proceeds raised to FSMA.

Lydia Wallis and The Stars Team of Longview, TX donated an additional \$195.32 to FSMA in honor of her cousin Matthew Wallis. This brings The Stars Team's total raised for FSMA to almost \$700! **Way to Go!**

Nine Year Old Raises \$495 for Spinal Muscular Atrophy in Memory of BFF Courtney

Sarah experienced losing her BFF, “Best Friend Forever” in text language, Courtney at much too young an age; nine years, three months, and 20 days. Courtney was diagnosed with Spinal Muscular Atrophy Type II at thirteen months old and lived her life in a wheelchair, but “She is completely normal,” Sarah always said. Sarah wants everyone to know that a wheelchair does not make someone an odd person.

Sarah and Courtney met when they were four on the playground at the Lincoln School and were instant friends. They both loved clothes, Polly Pockets, riding around the playground and at their brother’s baseball games, watching movies and Hilary Duff. Their birthdays were only six days apart and they had a private celebration every year in addition to their parties with family and friends. The biggest memory they shared was in February of 2005 when they had a one-on-one “Meet and Greet” with Hilary Duff at the Verizon Center in Manchester, NH. The girls were star-struck and left speechless. They did get some wonderful photos that were proudly displayed in their rooms.

In January, 2006 Sarah moved an hour away from Courtney, but that did not stop their friendship. They continued to visit each other and their interest remained the same. Sarah visited Courtney last on June 28, 2007. They squeezed in the visit before their families’ crazy summer schedules began. It could have been months before things calmed down again after school started in September.

That Thursday in June was a blessing, because Courtney passed away on the night of July 2, 2007, just four days later. No one should experience the loss of a



friend at the age of nine. It happens all the time all around the world, but you never want it to happen in your child’s world.

Sarah cried...and cried...and cried until there were no tears left to cry. She attended the funeral, released butterflies and balloons with Courtney’s classmates, friends and relatives. Courtney loved butterflies and the color purple. Whenever butterflies fly by Sarah always says hello to Courtney.

Is it coincidence or fate that so many butterflies have fluttered by Sarah this summer? That is why Sarah named her handmade earring business Flutter-By Butterfly. Sarah wanted to do something in memory of her BFF Courtney. First it was to knit scarves, but that would take too long. Then it was to knit small doll blankets. That would still take too long and not really a summer activity. Then it came to her like a butterfly fluttering by...handmade earrings by Sarah for Courtney to benefit the New England Chapter of Families of SMA, one of the charities chosen by Courtney’s family to benefit from gifts in her memory.

The business was born overnight, supplies purchased and work began. Each pair would sell for \$5. She hoped to raise \$100. Within days 25 pair of earrings were made. Each one was an original design. The plan was to set-up a card table at her summer vacation spot on Cape Cod. The sale was set for Friday morning from 11-Noon. But, it was only Tuesday and she had sold almost everything she had made. More work, more supplies and 50 more pairs were designed.

On the day she opened her card table shop at 11AM the people were coming and coming and coming. Children were buying some with their own allowance money, for themselves, teachers and friends. Parents were lined up buying them for themselves, sisters, mothers and friends. Many had tears in their eyes, while smiling and complimenting Sarah for what a wonderful thing she was doing for a friend. A friend she knew for far too short a time, but one that will stay with her for a lifetime.

As of September 24, 2007 checks have been sent to Families of SMA of New England for \$495. That’s 99 pair of earrings. That is the total for three sales to date and Sarah just announced at breakfast that she wants to make it \$1000! Courtney will be with her forever – in her heart, in photographs, dangling from her ears and whenever butterflies flutter- by.

For more information contact Sarah’s Mom at jill.sykes@comcast.net

Sarah Sykes, currently lives in Holliston, MA and is in the 4th grade at Miller School.

“Courtney Rosas - the Grand Marshall of the Parade”

By Linda Rosas

My older daughter Shirley, middle daughter Candace, my youngest daughter Sarah and her boyfriend Taylor, my granddaughter Courtney and I were getting excited about the parade. I didn't know what to expect, I couldn't recall ever being to a parade before, I have always watched them on television. Courtney was the Grand Marshall meaning that her float was the leading float, the first, even before the Mayor of the city.

The float we were on was simply decorated, no special theme. This was a very special float not like the others in the parade at all. This float would not win any awards for its beautiful lights or outstanding decorations. There was a banner on the front of the truck that pulled the float and another on the back of the trailer that proclaimed “Cure SMA”. This float represented one thing only, love. Love from a bunch of volunteer fire fighters for a little red headed girl with a terminal illness.

As I looked up at the star on Courtney's float that fire fighter Joel Ferguson had put up the night before I recalled his comment to me as he was testing the lights on it while Sarah and I were there helping decorate the float. He said “Courtney has to have a star because she is our little star”. Courtney had her very own star, on her very own float leading the parade, Courtney's parade, that the City of South Houston's Volunteer Fire Department had made possible for her to be in.

The parade theme was Super Hero's this year. Although we didn't see too many super heroes in costume's or floats decorated in the super hero theme there were plenty of super hero's all around. We saw our super hero Fire Dept. Captain Daniel Olivo racing back and forth



in his little golf cart taking time to stop and check in on us each time he passed by. There was another of our super hero's Joel Ferguson and his lovely wife Karen, each of them also rushing around but still taking time to check up on us. I could not even imagine what all they had to do to insure that everything in the parade would go smoothly. Another of our super hero's Fire Chief Garcia, he stopped by several times as well to keep us updated on the parade's progress and to see if we needed anything. There were Fire Fighters from near by Pasadena, Police Officers, even Vietnam Vets. all surrounding us.

For Courtney's safety we all agreed that there should not be any candy thrown from her float because of the crowd rushing too close to her. The streets were lined with people looking at Courtney's float, the children holding out their bags anticipating candy to be thrown. We all were waving at the crowd and I called out to them wishing them a “Merry Christmas”. One man shouted “Cure SMA” as he thrust his arm high in the air with his hand held in a tight fist. Many applauded as we passed. Our little princess, our “Star” of the night, watched all the people as we

passed them. We pointed out the people that were holding their pet dogs for her to look at. She loved seeing all the children waving at her and clapping their little hands to the tune of the Christmas carols that were blaring from our float. Candace and I would take turns holding Courtney's little hand up to wave at the crowd. After we got to the parking lot at the end of the parade route we got Courtney down off the float then went to stand in front of the stage to hear who the winners of the parade would be but Candace mostly just wanted for Courtney to see Santa coming to town. He arrived in a extra long limousine at the end of the parade. Right afterward Courtney fell fast asleep, she had such a busy evening.

All the Fire Fighters were on the stage with Capt. Daniel Olivo as he started to announce the parade winners then give the winners their trophies but first he introduced the Grand Marshall, Princess Courtney Rosas and our family to the crowd. I could not believe this great blessing taking place for Courtney. After Daniel had given all the awards he stopped speaking for a moment, cleared his throat and began talking again saying “and now we have a special award



Courtney Rosas Lost Her First Tooth!

I cried with joy! All along I was thinking about that one doctor who told us that Courtney would never live past the age of two and to just take her home, love her and just let her go! Thank you Lord for our many blessings!



for our Grand Marshall, Courtney Rosas!" I started crying as Candace approached the stage to receive the plaque for Courtney. She hugged Daniel and returned to where our family was standing with a huge smile on her face. All I could think of was how precious Courtney is to me and how these wonderful people have gone out of their way to include her in their lives.

Our small town is not a wealthy city at all. We don't have a beautiful golf course, country club or blocks and blocks of new homes in large subdivisions. We are proud of our little city, just as it is. This parade brings the whole community together. The Fire Department consists of all volunteers, not the big city calendar model types at all. All the time and effort it takes to have this parade is done with volunteer hours. These people have regular jobs and families but take time to do this out of the goodness of their hearts. As I look back to last August when we first met these men, our super hero's, I am trying to imagine what must have been in their thoughts as they met us for the first time. What made these guys say "we will be there for you, always, just say it, whatever you need and we will take care of it"? These are real men with big hearts doing what they do best, caring for others. This is the stuff that real super hero's are made of.

This is dedicated to all who worked so hard to make the parade a wonderful success, families, friends, city employees, schools, volunteers, all working together, all one community.



As first grade Brownie Girl Scouts, Cookie Sales were a much anticipated event. The girls from **Troop 483 at Walt Disney Elementary School** in San Ramon, California, worked hard to sell as many boxes of cookies as they possibly could. Part of the reason for their hard work was knowing that a portion of their cookie sale income was going to be donated to FSMA, in honor of their sister Girl Scout, Ariana Dindzans. Although Ariana has SMA, she is a dedicated member of our Brownie troop. She doesn't let anything slow her down! From collecting goods for the troops in Iraq, to tying red ribbons throughout the neighborhood for Drug Awareness week, Ariana has not skipped a beat. Troop 483 is proud to donate \$100 to FSMA in honor of Ariana!



Happy New Year to Everyone! I wanted to let you know about a speech that Mallory (age 12, SMA II) gave to help raise money for Families of SMA. On December 11 she spoke to approx 85 adults at a luncheon in Lansing, Michigan. The attendees were all members of the Mid-Michigan Chapter of CPCU (an insurance organization) that Ken belongs to. The Chapter chose Families of SMA as their charity for the year. Mallory's speech raised approximately \$4,500 for FSMA. Please see the attached picture and the speech that Mallory prepared with only a little assistance. We are very proud of Mallory and wanted to share this with you.

Ken & Cindy Armbrustmacher

Congratulations to Hannah Soyer who recently received an award at the University of Iowa for outstanding scholastic achievement. She scored in the top 1% out of 7,000 kids who took the PSAT test.



Dear Families of SMA,

The Jack Rabbit was unlike any in years past- it rained! The rain did change the events of the morning, but did not dampen our supporters spirits. Around 9:00 AM, hundreds of runners took off running in the rain while the walkers came prepared for their trek with umbrellas and ponchos. It was truly astounding to see how many people turned out to support Families of SMA despite the undesirable conditions.

Many families were involved and helped raise money in honor of Vinny Rini, Tylar Michalski, Bryce Wilson, Halima Truesdail, Jack Kotheimer, Alivia Kopal, Tommy Testa, Michael Brodsky, Brandon Johnson, Kylie Gerhardtstein, Dan Darkow, Jack Soroka, and Cage Nolen: and in memory of William Blumensadt, John Turner, Ethan and Ellianna Alford, Jack Karpanty, and Madison Vickers.



Even though the Inlet Dance Theatre could not perform due to the rain there was lots of food, music, clowns, a large raffle, kids fun run, awards, and a Starbucks booth. Even on a stormy morning the event raised over \$60,000!!!

**Barry and Mary Beth Kotheimer
Chesterland, OH**

To our friends at Families of SMA:

On Friday, September 14th, the third annual Grant Sheppard Memorial Scramble for SMA was held at Hickory Hills Country Club in Chilton, Wisconsin. Grant (Type I) was our third child and he taught us a great deal in his short time with us. One of his lessons was that life with SMA is difficult and help is always needed for equipment and ongoing research. We are pleased to be sending you the proceeds of the golf outing held in his memory. Enclosed with this letter is \$10,300, which was the proceeds, raised from the scramble.

Thank you for all that you do. Please know the Sheppard family is available to return the help that has been graciously sent in our direction.

**Sincerely,
Scott and Lisa Sheppard
Sherwood, WI**

Dear Families of SMA,

Enclosed you will find several checks collected during a recent fundraiser we had in memory of Jackson Hedgepeth. I wanted to take a quick minute of your time to let you know how we went about raising the money. We purchased bracelets with the following written on them: In Memory of Jackson Help Find a Cure for SMA. As a kindergarten teacher I decided to sell the bracelets to students at school for \$1.00 and to share with the school my experience (though they already knew) and ask for donations in memory of Jackson. That small effort rose close to \$700 alone in money for Families of SMA. I also contacted my local skating rink and organized a skate night for the school...called "Skate to Cure SMA" and raised about \$250. Enclosed you will find a total of \$1,022.50...all in memory of Jackson Cole Hedgepeth.

**Sincerely,
Nichole and Joseph Hedgepeth
Charlotte, NC**

Dear Families of SMA,

My name is Joseph Paul and I am a teacher and soccer coach at Arrowhead High School in Hartland, Wisconsin. Every year our soccer program does a citizenship project to help develop positive character attributes in our student athletes. This year we raised money for a member of our soccer family in need of a bone marrow transplant and for FSMA.

I was first made aware of your organization at a golf outing this summer (Golf Fore a Cure) which was in honor of Reagan Imhoff. Reagan is a wonderful two year old girl who suffers from Spinal Muscular Atrophy, 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 Joe and Jenny Imhoff, 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 as a result I am proud to say that enclosed you will find

checks totaling over \$2,500 for Families of SMA, donated in the name of Reagan Imhoff. All of us in 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, Boys JV Soccer Coach
Hartland, WI**

To Families of SMA

My son's preschool had a walk-a-thon to raise funds and awareness to help find a cure for SMA. The walk was held September 25, 2007. It raised \$399.65 for Families of SMA. The name of the school is, The Kathy Herwood Child-care Center, in Andover, MA.

One little boy named Bryan broke open his piggy bank and made a donation of \$19.65. We would like to thank Bryan and all of the other walkers, parents, and the school, for putting on and participating in this event, to help our son and all of the other people afflicted with SMA.

Yours Sincerely, Eric and Dena Miller
Parents of Joseph Miller, Type II
Haverhill, MA

Dear FSMA Staff,

I am a member of the Moms Club of Suwanee, Georgia. Recently, we had a consignment sale with our members and were able to collect \$325 through sales and donations. We would like to donate this amount to help the Bruner family. My dear friend Jenny and her daughter Ashley are such lovely and giving people.

Enclosed is a check for \$325 to your association to help in finding a cure for SMA. Bless all of you, for all that you have done and making a positive difference to the Bruner family.

Sincerely,
Rachel Meyer
Member of Moms Club
Suwanee East, GA

Dear Families of SMA,

The month of December is bittersweet for me. My twins were born December 28, 2004 and they passed away March and April 2005. Last year I just had to do something for them in remembrance. It's not much, but if this small amount aids in saving another mother from the grief that I carry, it will all be worth it. Again this year, I held a Pampered Chef fundraiser in their memory

and raised over \$300.

My aunt and I also have made an agreement, instead of purchasing gifts the money we would have spent is sent to you. So here is my donation in honor of Owen Michael and Grant William Burns.

Many blessings to all your staff during the holidays and best for the New Year.

Vanessa Burns
Marietta, OH

Dear Families of SMA,

Enclosed please find a check for \$300 that was raised from the Basket Auction held on November 15th, for an event we called SMA Day 2007. We sold pizza, baked goods and held a basket auction with a total of 32 baskets. The sisters of Gamma Sigma Sigma, the service sorority of Duquesne University and the sisters of Kappa Epsilon, a pharmacy sorority on campus graciously created these amazing baskets and baked goods.

I have also included some pictures from the event to show our enthusiasm to find a cure! We would like to make this donation to FSMA in memory of my sister Allison Magoffin and in honor of my cousin Lily LoTempio.

Having been personally touched by this devastating disease I am grateful for the opportunity to spread awareness and raise funds to help find a cure.

Sincerely,
Kelly Magoffin
Duquesne University Sister of Gamma
Sigma Sigma and Kappa Epsilon

Dear FSMA,

My name is Heather Tomko, and I am a sophomore at Carnegie Mellon Univer-



Kelly Magoffin & Gamma Sigma Sigma & Kappa Epsilon sisters

sity, where I am a brother in the co-ed service fraternity, Alpha Phi Omega. I also have SMA.

Every year, APhiO has National Service Week, where each chapter is required to host a service project open to the outside community. This year, the theme for National Service Week was "Helping Children with Disabilities" and thus my chapter decided to hold a service event to raise money for FSMA. We ended up with an event called "Wheels of Glory," a team manual wheelchair relay race. Enclosed is the money we raised from the event, \$245.

Everyone who participated had a blast, and we look forward to making "Wheels of Glory" an annual event and watching it grow.

Sincerely,
Heather Tomko
Pittsburgh, PA



Heather Tomko and friends

Wipe Out SMA Day

By Tonya Willingham

Wipe out SMA Day is a wonderful opportunity for businesses and employees to support Families of SMA without leaving the workplace. On the designated date participants will wear their Wipe out SMA t-shirts to work in a show of support for children with SMA.

Sign up today to be a team leader for your office!

How it Works:

Get Approval: Wipe out SMA Day is an event that encourages employees to wear jeans or khakis with their Wipe Out SMA t-shirt to work on the day of the event. Speak to your supervisor or your HR Department about coordinating this in your work place. Many offices are happy to sponsor a casual Friday for charity.

Set a Goal: How many employees do you think you can get to participate? Or what percentage of your group or organization? Aim high!

Get the Word Out: Only you know the best form of communication for your team. Send an email; contact them individually; do what works for you.

Start Taking T-shirt Orders: Email fundraising@fsma.org to ask for a team order form. This will help you take orders, collect payment and keep track of T-shirt distribution. Each t-shirt is a \$10 donation to Families of SMA. For this event we will only be accepting cash or check (made payable to: Families of SMA). Send your money and completed form to **Families of SMA, PO Box 196 Libertyville, IL 60048-0196** at least 2 weeks prior to the event. We will send you your t-shirts.

Celebrate! \$10 a head can add up quickly. Celebrate Wipe Out SMA Day and the difference your office had made! Have a Wipe Out SMA breakfast or special treat around lunchtime. Make sure your co-workers know that their efforts make a difference.



Just a few ideas to make the event more fun and meaningful for your team

Issue a challenge to your company's competitor's or business associates. Which business can persuade the highest percentage of employees to participate? Families of SMA will include the results in our next newsletter. Or, if your company is large, the same idea can work between departments. Come up with a reward or incentive plan for the department that wins.

Recruit Additional Team Members: Open your team to neighbors, family, friends and associates. Come up with a reward or incentive plan for the person who sells the most t-shirts.

Create an Honor Board: Display pictures and stories of families who have been affected by SMA. You can't help but be inspired.

Tokens of Appreciation: Give small tokens of appreciation to each person who participates. It could be as simple as a piece of candy, but everyone likes to feel his/her contribution has been noticed.

Coins For a Cure

By Tonya Willingham



Coins for a Cure is a wonderful opportunity for children to show their support for children with SMA. This event can be done in one classroom or the entire school can participate.

How it works:

- **Get Approval:** Coins for a Cure is an event that encourages children to fill a 35mm film canister with change and bring it back to school to show their support for children with SMA. Speak to your child's teacher or school principal about making this work in your child's school.
- **Designate a week:** With the help of the principal or teacher select a week that will work best for the event. "Coins for a Cure Week"
- **Collect 35mm film canisters:** Ask local film developing stores to save 35mm film canisters for you. Arrange to pick the canisters up weekly; most businesses usually collect the most after a weekend. Place a label on each canister with the name of the event.
- **Get the Word Out:** Along with the film canister send a letter home with each child that explains the event, SMA and how the money will be used.
- **Roll the coins:** At the conclusion of the event roll all of the change received. You may suggest to your child's teacher (who would make a good coordinator for the event) that the children in the classroom separate the coins and possibly help roll them as a math lesson. Once you have them all rolled take them to your local bank and cash the money in; mail a check to **Families of SMA to PO Box 196 Libertyville, IL 60048-0196**. Make the check payable to *Families of SMA*. Be sure to include what school raised the money and any specific information about the event you would like included in the next newsletter following your event.



Sample letter to go with canisters:

Dear Parents,

This week at (name of school) is Coins for a Cure week in support of children with Spinal Muscular Atrophy. SMA is an often fatal genetic disease. 1 in 6,000 babies is born with SMA. SMA can strike any race or gender. 1 in 40 people carry the gene that causes SMA. SMA is the #1 genetic killer of infants.

SMA occurs when a vital gene (SMN 1) is missing, this missing gene prevents the creation of a protein needed for nerve survival. This in turn causes the muscle cells to atrophy, leading to dramatic muscle weakness. The mind of a child affected with SMA is not affected, while their muscles waste away. In the worst cases, it causes loss of the ability to swallow and breathe, and eventually death. There is no cure or treatment for SMA. Research for SMA is desperately under funded.

Include a story about a child you know that is/was affected by SMA.

We are sending home a 35mm film canister with your child. We are asking each child to bring back the canister by Friday (date) filled with change. The money collected during this coin drive will be donated to Families of SMA to support funding of research for a cure. Each child that participates will be given a (cure SMA bracelet; piece of candy; sticker; etc) to show our appreciation for their support. Every penny makes a difference!

Thank you for your support!

UPCOMING events

www.curesma.org



March 2008

Mar 29 –
Houston, TX

FSMA Texas Chapter BBQ Round-Up. BBQ dinner, kids' entertainment, raffles & silent auction Contact: Becky Long at stebeclong@att.net

Mar 30 – Walk-n-Roll To Cure SMA
Boca Raton, FL

5th Annual Jacob's Run, Walk & Roll to Cure SMA. The event will be held at South County Regional Park. Registration will begin at 9:30 am. It is a paved fun run/walk, barbeque lunch and family day (interactive bounce houses, games, music, live performances and more)! We have a fabulous raffle and an amazing silent auction. Some of the items that we will be auctioning include: a weekend at The Boca Raton Resort & Club; a weekend at The Ritz Carlton, Palm Beach; Round Trip tickets on jetBlue Airways, an authentic University of Florida Football Helmet, Signed by Coach Urban Meyer, and more! For more information, see <http://www.ourshootingstar.com/>

Mar 30 –
Cheshire, CT

Pedal for a Purpose - An indoor cycling event to benefit SMA. Cheshire Fitness Zone 132 Elm Street. For more information email Farrah at ffiedlerofcheshirefitness@yahoo.com or visit www.cheshirefitnesszone.com

April 2008

Apr 4 –
Birmingham, AL

2nd Annual Swing Fore a Cure Golf Tournament at the Highland Golf

Course. Registration/Lunch 11 AM Shot Gun Start 1 PM For more info. contact the Alabama Chapter at alabama@fsma.org See flyer for details.

Apr 11 –
Cherry Hill, NJ

Steven's Gala for SMA at the Crowne Plaza. Email Jessica Moyer at jjmoyer@comcast.net for details.

Apr 26 – Walk-n-Roll To Cure SMA
Norwood, OH

5K "Walk-n-Roll Across America to Cure SMA" 10:00 a.m. (registration begins at 9:00 a.m.) at Cintas Center at Xavier University. (Indoor walking route in case of rain). \$10 registration fee includes tee shirt, refreshments, lots of carnival games, face painting, clowns, magicians, balloon sculpture, music, raffle, family fun. Email Rosemary Hilston for more info: rosemary@waronsma.com

Apr 27 – Walk-n-Roll To Cure SMA
Hamden, CT

7th Annual Walk-n-Roll

May 2008

May 3 – Walk-n-Roll To Cure SMA
Baton Rouge, LA

Louisiana Chapter 2008 5K Race-n-Roll and 1 Mile Fun Run/Walk. Contact Krista Scurria or Emily Green at louisiana@fsma.org

May 3 – Walk-n-Roll To Cure SMA
Lansing, MI

Michigan Chapter Walk-n-Roll at Hawk Island Park. Registration begins at 8:30 am and the race starts at 9:30am Contact: Holly Schafer at hollyschafer@comcast.net

May 4 – Walk-n-Roll To Cure SMA
Millburn, NJ

Walk-n-Roll for a Cure at Slayton Field. Contact: Randi Mazzella at rmazzella4@comcast.net More details to follow.

May 10
Horsham, PA

3rd Annual Ride to Fight SMA. Registration 9:30-10:30AM. Location: the Seafood Factory. For more information email mjmcalfaryriders@verizon.net

May 10
Clarksville, TN

Miracle Ride for Mary. Registration begins 7:00 am Race begins at 8:30 am. Beachaven Winery: 1100 Dunlop Lane. Contact: fundraising@fsma.org for more information. Donation/Registration: <http://www.active.com/donate/miracleformary>

May 16
Danville, CA

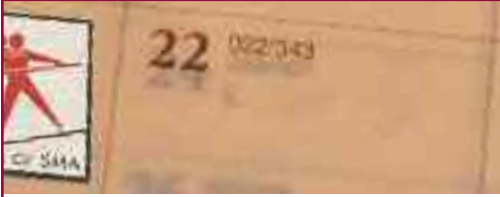
Concert for a Cure - 6:30 PM at Blackhawk Country Club. Contact: Nancy Dindzans or Mary McHale at info@concertforacure.org

May 17 – Walk-n-Roll To Cure SMA
Hingham, MA

8th Annual Cure SMA Walk-n-Roll. 10 am Wompatuck State Park. Contact: Silvia Murphy at brianandsilvia@verizon.net

May 17 – Walk-n-Roll To Cure SMA
Haddon Township, NJ

Steven's Walk to Drum Out SMA. Location: Newton Lake Park Lees Lane-Pavilion. For more information contact: Terri Potter at m.potter9@verizon.net



May 18 Walk-n-Roll To Cure SMA
Philadelphia, PA

PA Chapter Walk-n-Roll at Lloyd Hall, Art Museum. 10 AM. Registration and 11 AM Walk Begins. Contact: Karen McRory-Negrin at kmcnegrin@comcast.net

May 31 Walk-n-Roll To Cure SMA
Colorado Springs, CO

Rocky Mountain Chapter Walk-n-Roll at Cottonwood Creek Park. Registration 9 am and walk begins at 10 am with a balloon release. Online Registration only: Registration ends May 20, 2008 Contact Vicki Caldwell: vicki@chetwooddr.com



Join the FSMA E-List!

With each research breakthrough or other important event on the road to a cure, Families of SMA sends an e-mail to everyone on its e-mail list. If you would like to join our e-list please e-mail Bettylou Ross, our webmaster, at bettylou@fsma.org with the following information: (Use "subscribe FSMA" in the subject line.) Name, E-mail address, City and state or country of residence.

Once again it is time for Double H Ranch to think about our Camp Inspiration session. From June 11-15, 2008 they will again welcome campers who are vent dependent and their families to a wonderful 5 days at Double H!

Double H Ranch (www.doublehbranch.org) is a Hole in the Wall Camp for children with serious illnesses. All campers and their families attend for free. During the summer, they welcome children to a regular camp session without their parents. For Camp Inspiration, however, parents and siblings are welcome as well. Campers will participate in Arts and Crafts, fishing in the lake, swimming in an indoor pool, making "slime" in the Discovery Shack, and maybe swinging on the Giant Swing in a Ropes Course! There will be a dance and a talent show. Parents will get a little pampering, with special meals, massages, and a break from being the only care taker. Everyone will get a chance to meet and share thoughts with families who are facing similar issues.

Camp Inspiration has been serving children on ventilators and Bipap, full or part time. Campers have had diagnoses

such as high cord lesions, spinal muscular atrophy, central hypoventilation, muscular dystrophy, etc. Campers should be 6-21 years old. They have respiratory therapists, PICU nurses and 2 physicians on site for the session. There is no cost for the camp, but families are responsible for transportation to and from the facility, which is in Lake Luzerne New York, in the Adirondack Park. For more information on the Camp Inspiration session, or for an application, contact the Admissions Coordinator, Tara Bogucki at theranch@doublehbranch.org.



CONGRATULATIONS

www.curesma.org

- Congratulations to Ron and Rita Alexander on the birth of their son Sean Henry Alexander.

- Congratulations to Jim, Liz, Spencer and Skylar Bahrenburg on the birth of their son and brother Sawyer Thomas Bahrenburg.



- Congratulations to Tonya and David Willingham on the birth of their son Grant David Willingham.



- Congratulations to Mark, Laurie and Murphy Potter on the birth of their son and brother Anders Matthew Charles Potter.



- Congratulations to Laura, Anna and Will Landre on the birth of their son and brother Carson.



- Congratulations to Kim, John, Lily and Charlie Sykora on the birth of their daughter and sister Emma Sykora.

- Congratulations to Steve, Julie, Noah and Quinn Sutker on the birth of their son and brother Dylan Sutker.



- Congratulations to Janet, Brian, Ethan and Samuel Schoenborn on the birth of their daughters and sisters Sydney and Taylor Schoenborn.

Hi my name is Teresa Johnson and my daughter Briahnn Johnson is 18 months old and was recently diagnosed with SMA Type 2. She currently is unable to walk, stand, crawl, sit up on her own, or raise her hands over her head. When we found out in July 2007 we felt as if we were hit by a ton of bricks, but with all the support of family, friends, other SMA families and your web site we have found hope. My daughter is the most important thing in this world to me and it means so much to me to know that there are organizations out there like this one to help us out in our tough times. Thank you!!! I am sending you a couple pictures of Bri.

Thank you again for everything you do for the families of SMA.

Teresa Johnson
From Edmond, OK



To the Families of SMA Team:

I hope that you all had a wonderful holiday and are looking forward to a healthy and happy new year! Every year at this time we make a donation in memory of our niece Deirdre Abraldes who had SMA type I. She was a fighter and during her one year and 8 days with us she taught our family more about life than most people learn in a lifetime. We miss her terribly, but her memory lives on and she is always with us.

We will never forget the support and hope that Families of SMA provided to us. We hope that you continue providing support and guidance to families and that you never give up your fight to find a cure!

Sincerely,
Chris and Kim Foy
Holtsville, NY

Dear Families of SMA,

My youngest daughter was diagnosed with Werdnig-Hoffman, SMA Type I when she was about 9 months old. It was suspected at 3 months but courses had to be taken, tests, exams, mis-diagnoses, etc, etc. You know the drill.

The neurologists gave us literature (a pamphlet), a gruesome 30 minute speech of how she would die. I was told by this "doctor" that "If I had a dog with

your daughter's disease, I'd have it put to sleep!" And sent us home with the gloom & doom prognosis. In fact, they point blank told me she would be dead by the time she was a year or so.

She will soon be 18! Praise God!! He walked in when they all walked out!!

I wanted to thank you for your support and fine work. I only wish an entity like yours existed 18 years ago! Back then, our support group consisted of half a dozen families meeting in the hospital cafeteria every so often. It took one of those to turn my husband and I into a self-sufficient support group. We chose not to attend.

You have such an informative and compassionate delivery of what we families need to know!

Plus your networking is so appropriate for anyone seeking knowledge or contact.

Thank you again.

Best Regards,
Vickey Green, Mother of Shaylin Green

Dear Families of SMA,

With our membership renewal we are enclosing a donation in honor of our



Dear SMA,

Thank you so much for the kid kart and vest! I cannot tell you what this means to my family. I will take pictures of her in her new "Lazy-Boy" on wheels and send them to you. Thanks again and God bless you!

*Jennifer Brock, Joe Bush,
 Chloe and big sister Abby
 From Huntsville, AL*

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Dear Families of SMA,

In March of this year our son Luke was diagnosed with SMA type II. Then in August, I was diagnosed with breast cancer. Even as I go through chemo, my main focus has always been on Luke and finding a cure for SMA. I am writing you today to share with you our incredible fundraising and awareness experiences. Enclosed you will find a copy of our firstgiving site as well as the checks from offline donations.

We are still shocked at how much money was raised in such a short time for the Minnesota Chapter Walk and Roll this past September. As I mentioned, In August I was diagnosed with breast cancer and had to undergo surgery. We had not started on Luke's fundraising efforts yet and it was put off until after my surgery and essentially until I was starting to recuperate. Two weeks before the September walk, I stumbled upon the firstgiving site and set up a page for Luke setting a goal of \$3,000. I didn't think that this was a realistic goal given the amount of time that I had to fundraise, but I thought I would give it a shot anyways. Much



to my surprise by the time the walk came about on September 16th, we had raised over \$6,000. Luke's site was listed as the most popular site on firstgiving for over a week. We had 21 people on Team Hennessey walking for SMA. It was such a wonderful experience and we are looking forward to participating in it next year.

Then in October we received an email from you announcing the "House" episode and Tom and I decided to call our local Fox affiliate to see if they were interested in doing a story on a local boy with SMA. They contacted me and said that they were interested and came out to our house and did a 3 minute story on Luke!

Tom and I would like to take this opportunity to thank you for all of the services provided by Families of SMA. Your organization has helped

guide us through some tough times. Thanks for all you have given us.

**Sincerely,
Tracy, Tom, Seth and Luke Hennessey
From Plymouth, MN**

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son Nathan. Just last month, Nathan celebrated his 19th birthday and we couldn't be more delighted! When he was diagnosed with SMA in September 1989, we were devastated and confused. A dear friend located FSMA for us and I had the opportunity to call Audrey Lewis, who, if I remember correctly, was living in California at the time. Audrey gave us wonderful support and information at a time when we needed it most. Nathan's doctors had given us limited guidance and little hope, but Audrey changed all of that. It was especially helpful to talk with someone who truly understood what we were feeling. My husband and I were able to attend the very first conference that was held at Pheasant Run just outside of Chicago. It was there that we met Audrey and her family for the first time (she was even more impressive in person!). Since that first conference, we have attended two

others and many wonderful families.

Our son is now taking college courses toward his Bachelor's degree in Finance/Economics. He is a wonderful young man who is intelligent, focused, witty and personable. I don't know what his father and I would do without him. We truly feel blessed to have him as our son, and we truly feel blessed by all those at FSMA! Please accept our sincere gratitude for working so hard on behalf of everyone impacted by SMA. We have great faith and hope for the future because of your dedication!

At this time of thanksgiving and holiday spirit, we just wanted to send you all a special thank you. May you have a joyous holiday season! We wish that 2008 will bring many exciting discoveries for us all!

**Sincerely,
Jeff and Susan Yates
From Clintwood, VA**



Dear FSMA,

My 9 month old granddaughter Stella has Type I SMA. You have been so supportive to my daughter Sarah and her husband Travis throughout this ordeal. I have enclosed a check to show you how much grandmothers of SMA kids appreciate all you do and I know that you will keep promoting the research that will cure this devastating disease.

Thank you and God bless all of you,

**Maureen McLaughlin
From Sperry, IA**



Dearest family and beloved friends,

I just put Sydney to bed tonight and said, "Do you know that I love you more than anything?"

She asked, "Why?"

I answered, "Because you're sweet and smart and if I could have any little girl in the whole wide world to be mine, I'd pick you."

After a pause of thought, "Okay... My ear itches. My left one. On the inside."

If someone had told me five years ago that we'd be celebrating Sydney's fifth birthday, I never would have believed them. We spent the day at Fossil Rim, a gorgeous outdoor wildlife preserve where animals come right up to your car window and pop their heads in to be fed. Sydney came face-to-face with ostrich, emu, antelope - and she wasn't the least bit worried by the giraffe whose head came right in through the van sunroof to nibble from her hand. Sydney underwent spinal surgery in October where rods were installed on either side of her spine to correct the curve imminent from SMA. Such a significant surgery, but Sydney amazed us with her strength and will to heal and go home. She now sits more comfortably, breathes easier, and knows nothing of the scar that stripes her from neck to tailbone.

Sydney compares herself regularly to

"Ramona," whose Kindergarten perils we read about nightly in the Cleary series. I'm not sure, however, that Ramona could read at a third grade level at age five, which Sydney does. Our local library (and home-schooling mom's best friend) has been a resource on subjects from shadows to Native Americans, maps and globes, weather and seasons, and offers plenty of reading material to keep up with Sydney's demand. Pivotal to her learning this year was her new computer! With a monitor that hangs over her head, she can lie down comfortably and control her environment in many ways. She plays games (even Sudoku puzzles), watches movies, takes spelling tests, and sends e-mail, all while on BiPap support, if she wants. Some days I struggle to get her out of her room because she loves it so much. Second to her computer, she loves her little brother - "Mr. Mischief," as she calls him. Sydney finds him very entertaining, and gets a big kick out of this one year old boy who already tries to suction her and hold her mask on during respiratory treatments.

How we wound up with two such opposite children, I'll never know. Dressing and diapering Scott looks like some sort of strange hog-tying event, and I've learned to do it while he's backwards, upside down, climbing, rolling and crawling away. Morgan and I get an unusual joy out of watching him do all the simple things that Sydney never did, like eating and crawling, but my biggest joys are just two. First, I love being hugged! He wraps his arms and legs around me and squeezes - a healthy child's way of saying "I love you Mom!" And second, I love his big cheeky smile and constant look of glee, like the world is his oyster and nothing can hold him back! He explores every inch of everything, and despite the heap of toys in the living room, he'd much rather dismantle the house drawer by drawer, room by room. Having a "normal" child still comes with our own brand of chaos... Scott trying to eat the cork ball off Sydney's joystick; Scott trying to pull out Sydney's feeding tube; Scott tossing Cheerios all over the kitchen floor so

that Sydney can crush them into little piles of dust with her front tires. My days with the two kids are tiring, frustrating, humorous, wonderful, and irreplaceable. Some days I go to bed wondering how I'll ever go on, and some days I go to bed feeling like I'm privy to some little-known secret about how marvelous it is to be a full-time mom.

I'm frequently reminded that tomorrow is promised to no one. I lost two more people in my life this year, both to unforeseen tragedies. And despite our wonderfully "healthy" period with the kids, we still came closer to losing Sydney this year than ever before. For five years, I've spent every moment trying to help her live, and this unexpected afternoon was the first and only time since her birth that I'd ever paused to consider whether I ought to let her go. It changed me, and what can I say? Living with SMA and all of its terrors has left me with little else to fear in life. So I've thrown caution to the wind and pursued a couple of my own dreams lately. I've taken up western-style horseback riding, my new love which gives me a delightful escape for a few hours every Sunday. Sydney enjoys coming to the stables to watch the class and feed the horses carrots. She usually spends the next day "cantering" around the house in her powerchair. I've also started my own medical supply company centered around the needs of children with SMA. This industry is vastly complicated, riddled with billing fraud and widespread mistreatment of patients - a couple of injustices that I hope to rectify in the lives of a few families like mine. I suppose I'm announcing my new venture because I'm hoping I'll then be too embarrassed to fail. But after the experiences of the last five years, even failure - something I've always feared - doesn't seem so frightening anymore.

May your New Year also be filled with exciting adventures and unknown possibilities!

Love, Dana, Morgan, Sydney and Scott Craven
From Dallas, TX



The Luccasen family



Jennifer & Jerika Bolen



Michael Pezzuto on halloween and his family



Allison, Mark & Kaley Leiter



The Anton-Jensen family



The Bahrenburg family



The Potter family



The Dindzans family



Natalie & Tim Gibbs



The Murray family



The Henry family



Courtney Rosas and her Mom, Candace



The Campbell family



The Eide family



The Rosbrugh family



The Armbrustmacher family



The Trainor Family



Cubbie Wax



The Kennedy family



The McHale family



The Hamman family



The Hoffmann family



Odds On A Cure fundraiser



The Craven family at Odds On A Cure



Quinn Anton Jensen



Abbey Hassel



Adam Woodson



Addie & Molly Piper



Addison Kuester



Addie and Molly Piper



Alex Dzimitowicz



Allyson, Kristyn & Melissa Krajewski



Anthony, Jamie & Troy Lino



Ariana Dindzans



Brianna Johnson



Caitlin & Grace Trainor



Bernie Ross



Carolyn Barrett



Casey & Colin O'Neill



Chelsey & Sarah Grace Baker



Chloe Bush



Chloe Bush



Delaney, Jack & Ava Long



Cole & Celeste Heine



Yuliya Matyushenko



Zeke and Lily Lerner



Chase Langland



Eleanor & Jack Bolton



Elias Wydooghe



Elizabeth Hallam



Elizabeth Hallam



Elizabeth Hallam and cousin Rachael



Ellie and Olivia Zayas



Eloise, Samantha & Jamie Pillarella



Emma & Nick Lockwood



Emma, Charlie and Lily Sykora



Garrett Hassel



Gray & Riley Dougherty



Haley Mitchell's 10th birthday



Haley Mitchell



Ian, Megan & Ellie Socha



Isobel, Blaise & Jake Moyer



Jack and Rose Gellner



Jack Gellner



Wyatt & Jack Tranby



Jacob Slaymaker



Jacob Slaymaker enjoying his winter!



Jacob Slaymaker



Jane Coggins



Jenna Boguhn



Jennifer Gaudreau



John Bottone



Jordan & Abbey Partridge



Josh & Jacob Garrison



**Joshua & Daniel
Tramontano**



**Kale and Kyler
Shiesley**



Kale Shiesley



Karah Barry



**Karlie Henry &
Sara Greene**



**Kate & Caroline
Pecora**



Katelyn Stare



**Keenan & Liadan
Conner - Park**



Katie Scaccia



**Kevin & Ryan
Rollinson**



Kyle & Lanie Hannah



Kylie Niedermier



**Lanie Hannah & friend
Mattye at Hannah
Montana concert**



Lexus Stipanovich



Valentino Zegarelli



**Will, Anna Landre &
baby brother Carson**



Lyza Weisman



**Maeve, Bridget,
Shannon Abraides**



Malorie Fox



Marian Sereni



Mason Baker



**Megan & Carly
Hewitt**



**Melisa, Peyton, Jack
and Danielle Tansey**



Michael Pezzuto



Michael Pezzuto



**Michael, Hope &
Noelle Hazel**



**Michelle and Jenny
Gaudreau**



**Mitchell, Jack, Leah
& Will Kotheimer**



Natalie Quintana



**Nick & Hanna
Macellaro**



Reagan Imhoff



Rodrigo Orozco



Ryan Viano



Sahil Darekar



Sahil Darekar



**Skylar, Spencer and
Sawyer Bahrenburg**



**Santa visits Charlie
and Lily Sykora**



**Skylar and Sawyer
Bahrenburg**



Sophia Salus



**Tambryn and Braelan
Campbell making
cookies**



**Tyler and Haley
Hernandez**



**Stella and Treyton
Turnbull**



Tambryn and Braelyn Campbell

**Sami and Cole
Abraham**



continued from back page

Early Childhood Educator, or services coordinator, they should be able to point you in the right direction of who to contact. Our Birth to 3 program has access to a lending closet, but the waiting list to try out the IST switch was too long. So I contacted the company that makes the switch and they were happy to send it to me for free for a one month trial. At the end of the month trial I could either send it back or purchase it, we purchased it. So if you do find that your service coordinators can not help you, don't be afraid to look online and make some phone calls yourself. We had a very positive experience doing it this way.

It is much cheaper to permanently adapt a toy yourself then to purchase one already done. A lot companies that sell adapted toys raise the price to cover their labor. (Don't throw that over priced catalog away though, it's a great place to get ideas from and decide what toys you want to adapt yourself!) I have found that most toys are really not that hard to adapt once you get inside them. Depending on the toy, you can use a screw driver, a seam ripper, or scissors to get inside. Once inside You will need to locate the wires leading to the button that turns the toy on and off. These are the wires you will cut, strip, twist back together and twist the wires to your 1/8" plug to as well. You will then have to solder them together so they don't come untwisted. Don't be afraid of the Soldering Iron, it's like a hot glue gun with metal instead of glue. I also like to coat the soldered wires in a little hot glue so that they don't accidentally touch and make the toy dance or sing when no one is using it. Then you screw the toy back together (some toys will need to be sewn or hot glued) and you have an adapted toy! I usually assemble the 1/8" plug before I start working on the toy, I typically will put a few together and keep them on hand so that when I want to adapt a toy I have the plugs ready in advance. Don't be afraid to give it a try. I did ruin and break a couple of toys in my learning process, so I wouldn't rec-

ommend starting with your child's favorite toy. I purchased a couple toys from a local second hand shop and practiced on them.

Some toys can be adapted by using another device. A battery interrupter can simply be placed in the battery compartment of a toy. This is a little metal plate that slides between the battery and the spring. It has wires hanging off it and a plug on the end of them that you can plug a switch into. They come in a couple of different sizes and you purchase the size based on the battery size the toy requires, like AAA or D. These are relatively cheap and can be purchased from a variety of vendors online. There are also devices that can allow your child to use a computer. There are a variety of Switch Interfaces available that allow you to do all the functions of a computer mouse with an adaptive switch. A Powerlink box allows you to plug a wall outlet plug, like on a lamp, into the box and also plug your adaptive switch into the box making the lamp work with the switch. A Switch Latch timer will allow you to plug a toy in that normally will only stay on while your switch is being pressed/ activated and set a time so that the toy stays on until the switch is activated or pressed again. This works well for things like a bubble blower and makes it so your child does not get tired holding down the button for a long time. Most of these devices can be pricy. Many times you can get them on loan through local programs or organizations, lending closets, and sometimes on loan from the company that makes them on a trial basis before you decide to spend the money.

Adapting toys your self can be inexpensive and easy. It opens a whole new world of experiences, learning and fun to children with SMA. Come see me at the Families of SMA conference in Boston this spring for a step by step class on adapting toys. If you have questions, please feel free to contact me at info@addysadaptations.com.

For step by step instructions on adapting toys please see the fsma website.

KIDS corner



Hello

My name is Stacie Edwards and I have 2 sons who have SMA Type 2. For our Halloween costume we used our 2 seater stroller and made it into a firetruck. The boys dressed up as firemen and they won 1st place at our local mall! I have attached some pictures and we would love to see them in the newsletter or on the website if you have room to share them! Hunter is riding in the back of the firetruck and he just turned 4 years old. Cody is riding in the front of the firetruck and he is 15 months old.

Thanks
Stacie Edwards

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.

99 Restaurant & Pub	\$25	8%	Dicks Sporting Goods	\$25	8%	Olive Garden	\$25	9%
Amazon.com	\$25	4%	Dillard's	\$25	9%	On the Border	\$20	11%
AMC Theatres	\$25	7%	Dominicks	\$25/\$100	3%	Outback Steakhouse	\$25	4%
American Eagle Outfitters	\$25	8%	Dominos Pizza	\$5	5%	Panera Bread	\$10	9%
Amoco	\$50	2%	Expo Design Center	\$25/\$100	3%	Pathmark	\$25	4%
Applebees	\$20	8%	Express	\$25	13%	Payless Shoes	\$20	13%
Babies R Us	\$20	2%	Exxon	\$50	2%	Peets Coffee and Tea	\$20	8%
Bahama Breeze	\$25	9%	Footlocker Stores	\$25	9%	Pier 1 Imports	\$25	9%
Baja Fresh	\$25	7%	Gander Mountain	\$25	8%	Pizza Hut	\$10	9%
Banana Republic (Gap)	\$25	9%	Gap	\$25	9%	Pottery Barn	\$25/\$50	8%
Barnes & Nobles	\$10/\$25	9%	Home Depot	\$25/\$100/\$500	3%	Pottery Barn Kids	\$25/\$50	8%
Baskin Robbins	\$2	9%	HomeGoods	\$10/\$25	7%	Rainforest Café	\$25	9%
Bath and Body Works	\$10/\$25	13%	Honey Baked Ham	\$10	12%	Red Lobster	\$25	9%
BD's Mongolian Barbeque	\$20	8%	Houlihans	\$10	9%	Ross Dress for Less	\$25	8%
Bed Bath & Beyond	\$25	7%	Hyatt Hotels	\$25/\$100	9%	Safeway	\$25/\$100	3%
Bennigans	\$25	13%	JCPenney	\$25/\$100	5%	Sam Goody	\$25	30%
Best Western	\$25/\$100	12%	Jewel / Osco	\$10/\$25	4%	Save Mart		
Blockbuster	\$10	7%	Jo Ann Fabrics	\$20	6%	Supermarkets	\$25/\$100	2%
Bloomingdales	\$25/\$100	12%	Joe's Crab Shack	\$25	9%	Sears	\$25/\$100/\$250	4%
Bob Evans	\$10	10%	KB Toys	\$10	9%	Sephora	\$20	4%
Bonefish Grill	\$25	4%	KFC	\$5	9%	Service Master	\$50	10%
Borders	\$10/\$25	8%	Kohl's	\$25/\$100	4%	Sharper Image	\$50	16%
Boston Market	\$10	12%	Kwik Star (Kwik Trip)	\$20/\$100	4%	Shell	\$25/\$100	2%
BP Gas	\$50	2%	Landry's Restaurants	\$25	9%	Shoe Carnival	\$25	5%
Brookstone	\$25	12%	Lands End	\$25/\$100	9%	Shop N Save	\$25	4%
Build-A-Bear Workshop	\$25	8%	Lettuce Entertain			Speedway	\$25/\$100	4%
Burger King	\$10	4%	You Restaurants	\$25	12%	Sportmart	\$25	8%
Cabela's	\$25	11%	Lilian Vernon	\$20	21%	Sports Authority	\$25	8%
California Pizza Kitchen	\$10	4%	Limited	\$25	9%	Staples	\$25/\$100	5%
Carlos O'Kelly's	\$10	9%	Linens & Things	\$25	8%	Starbucks	\$10/\$25	7%
Carrabba's Italian Grill	\$25	4%	LL Bean	\$25	15%	Steve & Barry's	\$25	6%
Chevy's Fresh Mex	\$10	8%	Loews Cineplex	\$25	7%	Stop & Shop	\$25/\$100	4%
Chili's	\$20	11%	Longhorn Steakhouse	\$25	11%	Structure (Express)	\$25	13%
Chipotle Mexican Grill	\$10	6%	Longs Drug Store	\$25/\$100	5%	Sunglass Hut	\$25	12%
Chuck E Cheese	\$10	8%	Lord & Taylor	\$25/\$100	4%	Sunoco	\$50	2%
Cineplex Odeon	\$25	7%	Lou Malnati's	\$10	8%	Talbots	\$25	8%
Claim Jumper	\$25	8%	Lowe's Home			TGI Friday's	\$20	8%
Comfort Inn	\$25	4%	Improvement	\$25/\$100/\$500	4%	The Children's Place	\$25	12%
Cracker Barrell	\$10	9%	Macaroni Grill	\$20	11%	TJ Maxx	\$10/\$25	7%
Crate and Barrel	\$25/\$100	8%	Macy's	\$25/\$100	9%	Toys R Us	\$20	2%
CVS Pharmacy	\$25	2%	Marathon Gas	\$25/\$100	3%	Ulta Salon	\$25	4%
Damons	\$25	9%	Marriott Hotels	\$50/\$100	12%	Waldenbooks	\$10/\$25	8%
Denny's	\$5	9%	Marshalls	\$10/\$25	7%	Walgreens	\$20	2%
			Max & Emma's	\$10	13%	Wawa	\$25/\$100	2%
			Menards	\$25/\$100	3%	Wendy's	\$10	9%
			Mens Warehouse	\$25	8%	Williams Sonoma	\$25/\$50	8%
			Mobil	\$50	2%	Winn Dixie	\$25/\$50	4%
			O'Charley's	\$25	13%			
			Office Depot	\$25	4%			
			Office Max	\$25	5%			
			Old Country Buffet	\$25	5%			
			Old Navy (Gap)	\$25	9%			

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Adapting Toys for Your Child

By Shannon Kuester

As the mother of a type 1 child, I was immediately concerned with how I could make her life as “normal” as possible. How could I give her the experiences that my older daughter had? How would she play with toys? Most of what I found online in reference to SMA and type 1 children recommended light weight objects such as feathers and balloons. So I ran out to the local dollar store and began my hunt for light weight objects. I was disappointed in what I found. Was this really all there was for my daughter? Then my daughter was generously given an adaptive switch and one switch adapted toy. She loved it! At 5 months of age she knew exactly what that tiny sensitive button in her hand did. But one toy wasn’t enough. She needed more. She needed to experience new things, make choices, learn cause and effect... So I once again began my search for things my daughter could play with. After many dead ends I ended up on E-bay. I purchased 2 switch adapted toys for an outrageous amount of money. I couldn’t help but think there had to be a better way, a cheaper way. The toys I purchased were simple, they were just like other toys I already had in my house, a singing and dancing Blue from Blue’s Clues and a cheap pretend radio that played music when you pressed its button. Curious, I took the toys apart. I found that the simple plug



**Adapted
Doodle
Doug Toys**



that was hanging out of the adapted toy for me to plug my daughters switch into was simply connected to 2 wires inside the toy. I was inspired and motivated. I ran to Radio Shack and I purchased a Soldering Iron, some Soldering wire, wire cutters, wire strippers, a spool of wire, and a package of 2 In-Line 1/8" Phone Jacks. I practiced on a couple of old toys that my kids were not as interested in and in no time I had figured out how to adapt a toy on my own. I tell you all this because I think it is important for you to know that I have no

background in adapting toys, electronics, etc. I am simply a mom. So if I can adapt a toy, so can you.

Before you begin adapting toys you need to locate a switch that your child can use. Based on ability and movement each child will need a different switch to meet their needs and have success.

There are many different switches available with a wide variety of different ways to operate them. My daughter started out using a Tash Microlight switch. As she lost some of her movement though, it became too difficult for her to squeeze or press it. She now uses an IST Switch by Words Plus (Infrared, Sound, Touch), she uses the infrared feature and simply has to move her finger to interrupt the infrared beam. Depending on where you live and what services your child receives, there are different people that can help you acquire these switches. Sometimes they will buy the switch for your child or submit it through your insurance. Other times they can get you one as a trial only and then you would have to purchase it on your own if you were interested in keeping it long term. Some of the companies that sell the switches are even willing to work with your insurance or accept flexible spending accounts. Talk to your child’s Occupational Therapist, Physical Therapist,

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