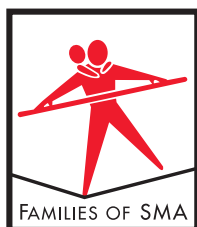




DIRECTIONS

Advancing research. Supporting families.

FAMILIES OF SPINAL MUSCULAR ATROPHY



One of the main missions of the Families of SMA Medical Advisory Board is to provide information and guidance to our membership on the best and most up-to-date clinical care for SMA. They do this in a number of different ways: answering ask the expert questions submitted by families, writing articles for our newsletters, conducting on-line chats about pressing issues on living with SMA, and giving seminars at our annual conference.

In order to accomplish this goal, the Medical Advisory Board consists of SMA professionals with a number of different areas of expertise, including child neurology, adult neurology, physical therapy, and genetics—just to name a few. We are excited to announce that our Medical Advisory Board has recently initiated a new project. They will write a series of short educational pamphlets on different topics related to SMA.

These will include the following topics among others: genetic diagnosis, respiratory care, nutritional guidance, and physical therapy. Our current plan is to release one pamphlet per quarter starting in early 2007 with the first one focusing on Genetic Diagnosis. These will be available both on-line and by mail. This first pamphlet is being funded by the Shish Family's Angel Baby Foundation, and we are very grateful for their help. Please let us know if there are any topics of particular interest to you and your family.

Respiratory Issues in SMA

A chat with Dr. Mary Schroth, Pediatric Pulmonologist at the University of Wisconsin in Madison

Dr. Mary Schroth has been involved with FSMA for the past 8 years. This chat discusses respiratory issues related to SMA. It has been edited for space and flow, a complete transcript is available on the web site.

Q: My daughter (3 years old) received the flu shot. She hasn't had any side effects (for example high temperature etc.). Does this mean that her immune system is not prepared for the virus attack?

Dr Schroth: The flu shot is a killed virus so it does not cause infection. The flu shot stimulates the immune system to make its own antibodies to fight infection when the body "sees it" during flu season. The most common reaction is soreness at the sight of the shot. So, it is normal and good that she did not have any side effects and it should help protect her from the flu this winter.

Q: What is your opinion of RSV shots for children over 2 (my son is 3 and a Type I)?

Dr Schroth: Synagis is a humanized monoclonal mouse antibody given by a shot once per month to prevent RSV infection (Respiratory Syncytial Virus). So it is different than the flu shot where you give a flu protein that stimulates the immune system to make antibodies. Synagis is the actual antibody and it breaks down over a month and has to be redosed. It is given for 6 months out of the year during RSV season.

Q: Do you recommend Synagis for a 3 month old not big enough to receive flu shot? Do the full 6 doses need to be done to be effective? Are there any risks with Synagis shots?

Dr Schroth: Synagis is given during RSV season. In Wisconsin, we give Synagis from Nov to April, every 4 weeks. Children must be 6 months old to get the flu shot. For children less than 6 months old, their family members should all get the flu shot.

For children over 2 years old with SMA I, my advice is to ask your insurance company whether they will pay for Synagis. The current guidelines and research suggest that children over 2 may not benefit from it. The other thing to realize is that Synagis does not provide perfect protection and children can still get RSV even with Synagis. The best prevention is to avoid others who are sick and to practice good handwashing.

Dear Friends,

With this winter edition of Directions we are continuing with our efforts to bring you the best practical articles about living and coping with SMA. As always, we welcome your comments and ideas regarding this publication.

Our lead article is from Mary Schroth, a key leader in our Project Cure SMA clinical network. We spoke with Mary on SMA respiratory care. Her article focuses on a variety of respiratory issues, including cold and flu season, particularly relevant at this time of the year. In the future our Medical Advisory Board will be contributing practical articles like this one on a regular basis to Directions.

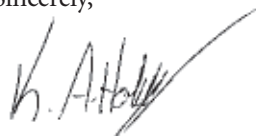
In this edition we also have several very interesting articles on current legislative issues that are relevant to our community. One article is on changes to Medicare reimbursement for durable medical equipment like wheelchairs. We are looking forward to the political year ahead of us. The new democratic Congress along with the upcoming 2008 presidential elections have the potential to affect our community in many critical ways, from insurance coverage to research funding.

We are also gearing up for our annual conference in June, and we will once again be bringing families and researchers together for research updates, informational seminars and social activities. It is a great way to connect with other SMA families and professionals. Details are included on the back page.

The cycle of planning for the 2007 Walk and Roll's to Cure SMA is getting into full swing. Last year was fantastic for these events, which are so important to our fundraising results and our ability to move research forward. We know 2007 will be even more impressive thanks to all of your hard work.

We look forward to seeing many of you in the Chicago area at the conference this summer, and continuing to make progress with our critical research efforts to find a treatment and cure for SMA. Thank you all for your continued support.

Sincerely,



Kenneth Hobby
Executive Director, FSMA

Respite Bill Passes the Senate

On December 8, Congress approved H.R. 3248, the Lifespan Respite Care Act of 2006. This legislation authorizes \$290 million in Federal funding from fiscal year (FY) 2007 - 2011 for grants to states to allow them to develop or enhance lifespan respite care at the State and local levels. It also provides respite care services for family caregivers caring for children or adults, trains and recruits respite care workers and volunteers, provides information to caregivers about available respite and support services, and assists caregivers in gaining access to respite care services. The bill creates training programs to assist family caregivers in making informed decisions about respite care services, creates training and education programs for new caregivers, and establishes a National Resource Center on Lifespan Respite Care that will maintain a national database on lifespan respite care.

At press time the legislation was on its way to the President. It is expected that the bill will be signed into law. Enactment of this legislation is an important victory for family caregivers as it will lead to greater resources and support. Families of SMA will continue to track this issue as the new law is implemented by the Department of Health and Human Services.



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 Lenna Scott at: newsletter@fsma.org.

Deadline for the next newsletter is:
February 20, 2007.

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.

Changes to CMS Wheelchair Payment Rates



The Centers for Medicare and Medicaid Services (CMS) announced in early November a new Medicare payment rate schedule for power mobility equipment.

The new schedule has been modified from the original proposed rule published in October due to pressure from industry and patient advocacy groups, which argued that a drastically reduced Medicare reimbursement rate could lead to reduced patient access to the equipment they need and layoffs for employees of manufacturers and suppliers.

Disability advocacy groups identified additional challenges with the proposed rule, including that it would:

- Significantly “downcode” the Medicare wheelchair benefit, placing many individuals into inadequate and often unsafe power wheelchairs;
- Require that a beneficiary must be unable to “stand and pivot” in order to qualify for the highest functioning chair (Group 3) - a standard that fails to take into account the functional needs of many individuals, especially those who may be able to stand and pivot but need a Group 3 device to participate in their daily activities.
- Create a more limiting definition of the “in the home” restriction by denying patients access to wheelchairs that have capabilities which are deemed unnecessary for indoor use.

CMS reported that the changes were necessary to prevent fraud and improve the accuracy of Medicare payments. The cost of the Medicare program has increased significantly and the agency has been seeking to ensure that the right beneficiaries receive the right mobility technology to meet their needs. A 2004

CMS study had shown that Medicare expenditures for Power Mobility Devices, including wheelchairs, had increased from \$43 million to \$1.2 billion between 1996 and 2004. According to CMS, key elements in its decision making process with regard to the proposed rule includes:

- A National Coverage Decision for mobility assistive equipment that more closely ties the Medicare coverage for a Personal Mobility Device (PMD) to a beneficiary’s medical condition and ability to function in the home.
- Final Regulations that establish the requirement that the treating practitioner conduct a face-to-face examination of the beneficiary and provide a written prescription.
- Quality standards for durable medical equipment suppliers that will be applied by independent accreditation organizations.
- Local Coverage determinations issued by CMS’ contractors that ensure that beneficiaries will receive the right technology to meet the mobility needs.

CMS officials said that they ultimately decided to revise the proposed reductions based on newer data “that reflects the full and complete manufacturer applications, test results and attestation.”

Under the final rule, Medicare reimbursements for “Group 3” power mobility devices for the severely disabled will be between \$1,000 and \$1,700 higher than the rates listed in the proposed rule.

Reimbursement rates for “Group 2” devices, which include the most commonly provided standard geriatric mobility wheelchairs, will increase to about \$301 more than the rate proposed in October, according to CQ HealthBeat (CQ HealthBeat, 11/9).

However, “in the home” policy remains in place and is even more prominent in coverage standards than ever before! As long as this harmful restriction remains in place, Medicare will continue to deny individuals with mobility impairments the devices necessary to meet their functional needs both inside and outside of their homes.

ACTION REQUESTED by Ability Magazine and other advocacy groups:

Although the recent changes are important improvements, we must continue to advocate for a reasonable Medicare wheelchair policy. This policy must reflect the true functional needs of individuals with mobility impairments and recognize the important role of wheelchairs and other assistive devices in the goal of independent living for people with disabilities.

Please call or write your Members of Congress and ask them to:

1. Support legislation to eliminate Medicare’s “in the home” restriction on mobility devices (S. 3677/H.R. 5983). Without enactment of this important legislation, Medicare may continue to utilize this discriminatory coverage restriction which prevents access to appropriate mobility devices for people with disabilities.
2. Contact Health and Human Services (HHS) Secretary Leavitt and ask him to take action on the “in the home” restriction. The agency has the authority to determine how Medicare interprets this language and we need to continue asking the HHS Secretary to change this policy.
3. Press Medicare to seriously examine the impact of the new reimbursement cuts on individuals requiring high-functioning wheelchairs.

Election Analysis

By Spencer Perlman, FSMA Legislative Affairs

Election Overview and Implications

During the November mid-term elections, one-third of the Senate was up for reelection (33 members) with two open seats where no incumbent was running. The entire House of Representatives was up for reelection (435 members) with 32 open seats where no incumbent was running. Exit polling data show the top three issues for voters were the economy, the war in Iraq, and corruption in Congress.

The new Members will be seated for the first session of the 110th Congress on January 3, 2007.

House of Representatives

For the first time in 12 years the House of Representatives has converted to Democratic control. There will be 232 Democrats and 203 Republicans.

Senate

The Senate will shift to Democratic control. The Democrats will control the Senate 51-49 because the two Independent members, Senator Joe Lieberman (CT) and Senator-elect Bernie Sanders (VT), have said they will caucus with the Democrats. There were five women elected to the Senate, bringing the number of women Senators to 16, a record high.

House and Senate Leadership

House Republicans and Democrats met in November to select their party leaders for the 110th Congress. The Democrats chose Nancy Pelosi (D-CA) to be Speaker of the House, Steny Hoyer (D-MD) to be Majority Leader, and James Clyburn (D-SC) to be majority whip. The House Republicans also deter-

mined their leadership. Speaker Dennis Hastert (R-IL) relinquished his leadership position as a result of his party's loss of the House. Thus, John Boehner (R-OH) was chosen as Minority Leader and Roy Blunt (R-MO) won the race for Minority Whip.

Senate

Senators met in November to formalize their leadership. Senator Harry Reid (D-NV) has been chosen by the Democrats to be Majority Leader and Senator Dick Durbin (D-IL) will be the Majority Whip. Senator Mitch McConnell (R-KY) was chosen by the Republicans to be Minority Leader, replacing retired Senator Bill Frist's (R-TN) as the Senate Republican Leader. Former Senate Majority Leader Trent Lott (R-MS) won a race to become the Minority Whip.

Outlook for Health Issues - 110th Congress

Health care, always a popular issue for Congress, likely will return to the top of the national agenda in the 110th Congress. Democrats will try to focus on their priorities such as: modifications to the Medicare prescription drug program, funding for stem cell research, Food and Drug Administration (FDA) reforms, and legislation to address health care disparities. In addition, expect tough oversight hearings on a number of issues, particularly those related to Medicare and the FDA. Below is a brief description of popular health issues and their outlook in the 110th Congress.

Medicare and Medicaid

Rapidly rising costs and Democrats' concerns over the "Medicare Prescription Drug, Improvement, and Modernization Act of 2003" ensure that

Medicare and Medicaid issues will top concerns in the 110th Congress. With Democratic control in the House, support for cuts will diminish. Representative Pete Stark (D-CA) has pledged to use his role as chairman of the Ways and Means Health Subcommittee to conduct extensive oversight hearings on the Medicare and Medicaid programs, including the prescription drug benefit and Medicare payments to managed care plans. In the Senate, Finance Committee Members Max Baucus (D-MT) and Charles Grassley (R-IA) are expected to continue to exercise oversight concerning payments to Medicare managed care plans.

Physician Payment Fix

Medicare payments for physicians will decrease by 5.1 percent starting January 1, 2007 unless legislative action is taken. Although several Members of Congress, including current Senate Finance Committee Chairman Grassley, are committed to passing legislation blocking the physician payment cuts before adjournment of the 109th Congress, this has proved difficult. It is likely that the issue will be left for the next Congress.

Congress has discussed several "fixes" to the cut, with a temporary one-year fix, either through a payment freeze or a small increase, the most probable. Tying Pay-for-Performance (P4P) or Value-Based Purchasing measures to a short-term fix is opposed by the American Medical Association. Many lawmakers support a temporary fix, which will allow them to wait for a report by the Medicare Payment Advisory Commission that is due in March 2007. If Congress considers a longer-term fix to the physician payment formula, then P4P measures could be back on the table.

National Institutes of Health Launches “Health Information Rx Program” on Newborn Screening and Related Genetic Disorders

Physicians Can Direct Patients to Consumer-Friendly Online Information with the NIH Seal of Approval

After a doctor sees a patient, he or she often prescribes medications. But what if such a doctor also wants to direct a patient to up-to-date, reliable, consumer-friendly information about a genetic condition, or an explanation of the basics of genetic science? Under a new program launched today, practitioners are being encouraged to refer their patients to Genetics Home Reference, a free, patient-friendly Web site of the National Institutes of Health (NIH), at <http://ghr.nlm.nih.gov>.

Under this program, doctors can request free “Information Rx” pads, which will enable them to write “prescriptions,” pointing patients to the Genetics Home Reference site and to the wealth of information it contains. Obstetricians can direct their patients to the site’s explanation of newborn screening, so expectant mothers will better understand why this testing will be important for their baby.

All states screen newborns for certain genetic disorders. These conditions are usually not apparent in the newborn, but can cause physical problems, mental retardation and, in some cases, death.

Fortunately, most babies receive a clean bill of health when tested. When test results show that a baby has a health defect, however, early diagnosis and treatment can make the difference between lifelong disabilities and optimal development.

Four of the nation’s most respected medical associations, with a combined membership of over 200,000, have teamed with two NIH institutes on this ground-

breaking initiative. The National Library of Medicine (NLM), the world’s largest medical library, and the National Institute of Child Health and Human Development (NICHD), the research arm of NIH dedicated to ensuring that every child in the U.S. is born healthy and grows up free from disease and disability, have entered into partnerships with the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), the American College of Obstetricians and Gynecologists (ACOG) and the American College of Medical Genetics (ACMG) to encourage physicians to point patients to first-rate online health information in NLM’s Genetics Home Reference database.

“Part of a physician’s job is to explain illnesses, diagnoses and treatments to their patients,” says Donald A.B. Lindberg, MD, Director of the National Library of Medicine. “NLM’s Genetics Home Reference provides authoritative, user-friendly, and commercial-free information that doctors can use to supplement information provided in the office or clinic. We think it saves time and improves doctors’ communications with patients, in addition to its obvious value in helping keep babies healthy.”

“Physicians have always known that an informed patient who takes an active role is a ‘better’ patient,” notes Duane Alexander, MD, Director of the National Institute of Child Health and Human Development. “We believe that both patients and their doctors will welcome this additional tool — good medical information — in their continuing efforts to provide good health care, for newborns and for people of all ages.”

Genetics Home Reference includes over 500 topics on genetic conditions and

related genes. The site is regularly updated by scientific staff and reviewed by external experts.

A similar Information Rx Project, pointing patients to NLM’s MedlinePlus database (medlineplus.gov), was launched in 2003.

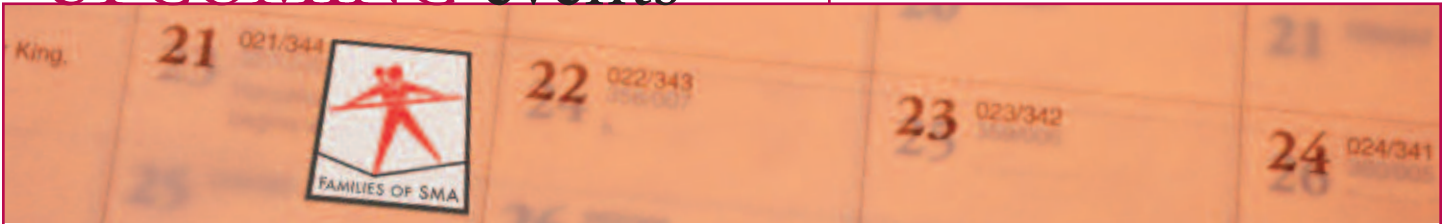
The National Library of Medicine, the world’s largest medical library, is a component of the National Institutes of Health, an agency of the U.S. Department of Health and Human Services.

The National Institutes of Health (NIH) — The Nation’s Medical Research Agency — includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

Note: Families of SMA is included on the web site as a resource for information about SMA and advocacy issues.

UPCOMING events

www.curesma.org



2007

Feb 23 NJ

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

March 4, FL

Jacob's Run, Walk & Roll to Cure Spinal Muscular through the Jacob Isaac Rapoport Foundation.

S. County Regional Park,
Boca Raton Florida.

Contact: shaina@ourshootingstar.com

March 24, AL

Race, Walk & Roll to Find a CURE!!!

Target Date & Time

Saturday - 8 AM

Location: "Boundless Playground"

Joe Tucker Park

230 Tucker Rd, Helena, AL

Contact: Amy Smith

sawyersmom@prodigy.net

March 10, CO

6th Annual Evening of Hope Gala Event at the PPA Event Center in Denver, Colorado.

Contact: rockymt@fsma.org

May 5, MI

3rd Annual Run, Walk and Roll at Hawk Island Park in Lansing, MI

Contact: Michigan @fsma.org for details.

August 27, MI

3rd Annual Malorie Fox Golf Outing

Contact: Michigan@fsma.org for details.



Families of SMA has partnered with GoodSearch.com to raise money for FSMA.

GoodSearch.com is a search engine, like Google. The site is powered by Yahoo!, so you'll get the same quality search results that you're used to. What's unique is that they have developed a way to direct money to FSMA with every click.

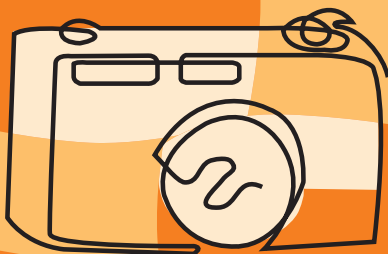
The more people who use this site, the more money will go to research. If 1,500 people search only twice a day that will equal over \$10,000 a year for FSMA. Just from searching the Internet. There is no limit. the more searches, the larger the donation.

So please spread the word to your friends and family.

<http://www.goodsearch.com>

put FSMA in the "Who Do You Good-Search For?" box and get clicking!!!

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.

**Ann Hamman,
Kathy Hamman,
Julie Hamman,
Nancy Hamman,
Coleen Hamman,
Kaitlin Carlson**



FSMA Luau

Aloha! On August 19, 2006 a little bit of Hawaii came to Naperville, Illinois, and all in support of Families of Spinal Muscular Atrophy. **The Third Bi-Annual Hawaiian Luau in Memory of Henry Hamman** was held on a beautiful August night. Guests were greeted at a Tiki Hut, draped in leis, and sent to the islands where they found a street lined with 14ft. palm trees, tiki torches, a 10 foot waterfall coming out of a tree, and a smoldering volcano in the middle of it all. While guests enjoy the tropical feel they are treated to Mai Tai's and other island delights. Early in the evening the carving of the Pig is always a highlight. Young and old gather around as the pig is removed from the roaster and carved to perfection for the evenings feast. Throughout the evening, children enjoy games and contests to receive fun prizes.



Amy Marquez



Hula Lessons for the guests

The DJ's keep the evening flowing with incredible music, the limbo and hula hoop contests. Again this year, professional Hawaiian Hula Dancers were featured during the evening to tell stories through dance and teach guests how to really hula! Some hula on over and try their luck at winning raffles and silent auction items that include sports tickets, hotel stays, gift certificates and more. This family event was attended by over 400 and supported by over 100 more friends and family from all over the country. Before the last tiki torch was out, over **\$22,000** was raised for FSMA. The evening was lots of fun and a great success. So we say, Mahalo – **THANK YOU** to everyone who made this event possible and came to celebrate Hawaiian style!



Savannah Hamman

The Great ESkate

Inspired by the Philadelphia Freedom Skate - The Great ESkate was born in 2001 but immediately took on a South Beach flavor. The concept is simple: this is a chance to escape the frigid winters elsewhere and attend a non-stop weekend of skating activities, private parties, entertainment, prizes, and fun, fun, fun. Proceeds go to Families of SMA!



"We pour our heart, soul, and energies into it - driven to make people aware of this horrible disease and raise funds for researching a cure. EVERY cent went to FSMA. The city of Miami Beach declared it Great ESkate Day". Every year Families of SMA has received a donation from this amazing event... this year over **\$7,000!** Thank you to all of the skaters who have supported this event. More information on the 2007 event is at www.skatemiami.com.



Tyler Hernandez Maluko Golf Tournament raised \$28,000 for FSMA in Florida!

large raffle, clowns, music, and face painters. Starbucks and Wild Oats were wonderful sponsors that set up beautiful booths and distributed their products throughout the morning. In addition The Inlet Dance Theatre performed a piece called "Ascension" which concluded with a symbolic release of butterflies carrying prayers and wishes for a cure. The Jack Rabbit Run/Walk in Ohio raised over **\$60,000** in their annual event.



The **Harges Family (Wade, Keri, Macy and Hallie)** held a series of fundraisers for FSMA raising \$5,425. Their Aunt Seresa, a cosmetologist, offered customers special \$5 haircuts with the money benefiting FSMA

and they also held a Home Interiors Fundraiser- selling candles and accessories. Their efforts were strengthened with the support of family, friends and their community.



Simon Geelon (of Dublin, Ireland) and Jonathan O'Grady (of Tipperary, Ireland). Simon ran the Dublin marathon in honor of his friend Jonathan and raised \$10,000.

Once again, Jeff and Valerie Mitchell of Elizabeth City, NC, held the **Haley Mitchell Ski-A-Thon** and hit the slopes for SMA. Hundreds of skiers made donations in Haley's honor totaling over **\$47,000**. This annual event helps further SMA research, thanks for hitting the slopes for FSMA!

Each year **Jack & Kim Nadeau** of Springboro, OH, members of the OKI Chapter, host a golf tournament to raise money for FSMA and help find a cure for SMA. This year the **4th Annual Nicole Nadeau Golf Tournament** raised **\$13,600** in Nicole's honor. Each year the tournament fills up with more than 150 people and more than 40 businesses and individuals sponsoring portions of the tournament. An amazing team effort for FSMA!



Katie Scaccia

The **Windcrest E. "Walk-A-Mile"** fundraiser on behalf of Katie Scaccia raised \$5,371. The residents at Windcrest East in Long Island, NY, recognized the importance of research towards a cure for SMA! Thank you!

The **5th Annual Jack Rabbit Run/Walk for FSMA** took place in Kirtland, Ohio on September 10th. The run was dedicated to the memory of William Blumensadt who passed away 6/11/05 at about 9 months old. His mom, Jennifer, summoned the courage to speak of his life and the affect he had on all who knew him. Many families were involved in the run and helped to raise funds in honor of all individuals with SMA but especially Vinny Rini, Tylar Michalski, Bryce & Alexis Wilson, Halima Truesdale, Alivia Kobal, Jack Kotheimer, Michael Brodsky, Brandon Johnson, Kylie Gerhardtstein, Tommy Testa, Dan Darkow; and in memory of William Blumensadt, John Turner, Madison Vickers, and Jack Karpanty. The day was full of food and fun which included a

The friends and family of Reagan Imhoff hit the links for the annual **Golf for a Cure/Rally for Reagan** fundraiser in New Berlin, Wisconsin. They raised over **\$11,350** for FSMA.

The **2nd Annual Grant Sheppard Memorial Scramble for SMA** in Sherwood, WI raised **\$11,000** on what would have been Grant's second birthday. Grant was the third child of Scott and Lisa Sheppard. They wrote "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, medical costs and ongoing research." Thank you for honoring Grant's life with continued support to FSMA.

The **Turner Family (Kelly, Rick, Andy, Haley, Mary Beth, Simon and Grace)** held a Splash Party, complete with a DJ & raffle, in memory of John Michael Turner. The event in Hudson, Ohio, brought people together for the common cause of honoring John's memory and raising funds to support FSMA and Project Cure SMA! They raised **\$3,254!**

The **5th Annual Cut-A-Thon** held at Shine Salon in Ridgefield, CT, in honor of Cubby Wax, raised \$2,841 for FSMA. Every year this salon generously donates their services to raise awareness and funds for SMA. We thank them for their continued support!

Jamie & Jason Feagans held a **Pumpkin Dash Race** in Bloomington, Indiana that raised \$1,728 for FSMA. The 4 mile run/walk was held partially on primitive and converted rail trails and finished on the Freeman Family Farm. There was a pumpkin patch, hayride, corn maze and petting zoo following the race.

The 2nd Annual SMA Benefit: Spaghetti Dinner and Talent Show in Comanche, TX, organized by Nolan Sturdevant, raised over \$1,300 for the Tumbleweed Wagon Fund of Families of SMA in memory of Braden Campbell. The Tumbleweed Wagon fund provides Radio Flyer Wagons to newly diagnosed Type I families as part of Families of SMA's Type I care packages.

Thank you to the McNelly family of Jackson, Ohio, who hosted the **Drive for MDA & SMA** and donated \$895 to Families of SMA in honor of David McNelly.



The **Hunkpapa Nation of Native Sons and Daughters** held a Car Wash in Mundelein, Illinois. Moms, Dads, sons and other family members helped wash over 50 cars in 3 hours and raised \$400! Thanks to these young men and their parents.

An **SMA Awareness Barbecue** hosted by Holly Verdile and Linda Tirado fired up \$375 in donations and also generated increased awareness about SMA at Maria and Steven Virdile's school, Sherwood Elementary in Bay Shore, NY.

The **Hernandez Family** of Lutz, FL, hosts an **Annual Southern Living @ Home Party** each August in honor of Tyler Hernandez and as a way to improve awareness during SMA awareness month. They raised \$300!

The **Cheltenham Township Police Association of Pennsylvania** hit a home run with three great events that raised \$310 in memory of Gavin Patrick Crews. They organized two trips to see the Philadelphia Phillies along with the "Walk Away SMA." Thank you!

The first birthday of **Jessica and Sydney Greenberg** became an amazing fundraiser in honor of their first cousin, Nathan Yates. A donation was made in their honor for \$200!

The youth at **St. Peter's Evangelical Lutheran Church** in Pen Argyl, Pennsylvania held a breakfast fundraiser, raising \$195 for FSMA.

Anita Waghorn and Andrew Holmes raised \$172 with their cookbook "Recipes for a Cure."

The teachers at **Cumberland High School** in Rhode Island held a "dress down day" for Families of SMA in honor of Alyssa Silva. They raised \$149!

The **Gateway Z Club** continues its generous support of FSMA through a donation of \$650, raised by their annual car shows. The Gateway Z Club is inspired by Brittany Carpenter and the staff at Bommarito Nissan in Hazelwood, Missouri!

The **I Do Foundation** helps couples bring a charitable focus to their weddings. **Christina Costa and Robert Felt** selected Families of SMA as their charity in honor of their wedding and helped us to raise \$477!



The Crews Family Fundraiser

Dear Friends,

It is with the deepest, heart felt thanks that I write to you all today. Just now, I am able to put the whole experience in perspective. The whole thing is still much a blur, but this much is certain: raising money/awareness for Spinal Muscular Atrophy made my Ironman World Championship experience so much more meaningful and fulfilling.

I've just been notified that because of our efforts, Janus investments are contributing an additional \$750 for SMA research. All said and done, we have raised over \$3,300!

After the 2.4. mile ocean swim, I found myself 30 miles into the bike, alone and hurting very badly in the middle of a desolate lava field. My system was shutting down and I couldn't imagine going another inch forward. All I saw in front of me was 82 miles of road...and that was before I would start a 26.2 mile run.

I got off my bike and looked around...I contemplated just lying down and waiting for the medics to find me and cart me away. But then, instead of looking around, or at the miles ahead, I looked within. I got back on my bike and worked one pedal stroke at a time, overcoming each moment as best I could. I thought of my situation as a struggle I had to push through with fortitude and deal with as best I could. I thought of Chaz and his strength as he copes with SMA. I thought of all of you who took part in this amazing journey with me. I thought about how this is just a tough spot in life, no different than the ones we all face. And inch by inch, foot by foot, and then, mile by mile I finished the bike course. I was half an hour back...but I had done it.

The feeling of accomplishment was so strong, and I was so moved...I set my fastest Ironman run ever. This doesn't matter to me. What matters is the lesson that we can overcome anything if we persist. This includes beating SMA.

Regards,
Jason Jaksetic

Custom Paintings by MAC Studios— Portion of Sales Donated to FSMA

Melissa A. Cuthbertson, proprietor and artist of MAC Studios, creates customized paintings of loved ones from cherished photos, and has graciously offered to donate one-third of each sale to the Families of SMA Illinois Chapter when FSMA is mentioned upon placing an order. The completed portraits are large scale paintings, ranging from 24" x 36" to 36" x 36" to 30" x 40" (depending on customer's preference), and offer a variety of color schemes (also in accordance to customer's tastes).

The cost of each painting, regardless of size, is \$300.00, of which \$100.00 will go to support the Illinois Chapter of FSMA. For additional information and to order such a unique customized treasure, please contact Melissa via e-mail at mac.studiomelissa@hotmail.com.



Who would you give a Volvo to?

How about Alyssa Silva of Cumberland who, despite living with Spinal Muscular Atrophy (SMA), designs and sells note cards to raise funds to help find a cure for her disease.

Alyssa is one of the five extraordinary Rhode Island heroes named as semi-finalists in the 5th Anniversary Volvo for life Awards—Volvo's annual search for hometown heroes across America. This year, in honor of the Awards' 5th anniversary, Volvo selected the top five heroes from every state in America and is asking the American public to visit www.volvoforlifeawards.com to vote for their favorites now through February 4, 2007.

- Alyssa Silva of Cumberland was not expected to survive past her second birthday, yet now, at age 15, she is not only surviving with Spinal Muscular Atrophy (SMA) in a full body cast and a wheelchair, but is a highly motivated honors student and a determined fundraiser. Silva works through her disability to design and sell note cards and has raised tens of thousands of dollars for SMA research through Families of SMA!!!

Once the public vote concludes, the top three vote getters in the categories of safety, quality of life and environment will be named finalists. Then, a panel of distinguished judges—including Hank Aaron, Sen. Bill Bradley, Caroline Kennedy, Maya Lin, Paul Newman, Dr. Sally Ride, Val Kilmer, Eunice Kennedy Shriver and previous Volvo for life Awards top winners -- will select winners in each category. Winners receive a \$50,000 charitable contribution from Volvo; remaining finalists receive a \$25,000 contribution.

On April 4, 2007, Volvo will fly the winning heroes to New York, where Volvo and members of the celebrity-judging panel will honor them at the 5th Annual Volvo for life Awards Ceremony. At the climax of the ceremony, Volvo will reveal which of the three top heroes is also the Grand Award winner of a Volvo vehicle every three years for the rest of his or her life.

“Over the past five years the Volvo for life Awards initiative has received more than 15,000 hero nominations,” said Anne Bélec, president and chief executive officer of Volvo Cars of North America. “All of these heroes demonstrate incredible conscience, care and character. Having the public help us select the winning heroes is a truly exciting—and democratic—addition to this year's program.”

To learn more, or to vote for Alyssa, visit www.volvoforlifeawards.com. A Spanish version of the site can also be accessed at this address.



Littlest Volunteers Contest

Have you found a way to teach your young child the joys of volunteering? Please share your story with us — and tell us what you and your little one have learned from the experience. You could win up to \$5,000 to donate to your favorite charity. Wondertime magazine and The Walt Disney Company, with judging help from the Points of Light Foundation, will award 3 Grand Prize \$5,000 awards and 10 First Prize \$1,000 awards to the charities of the winners choice. The entry deadline is March 1, 2007.

Note: To participate in this contest, an adult (parent, caregiver, or early childhood educator) must volunteer with a child aged 7 and younger.

As part of the entry process, you'll be asked to answer the following questions:

Short Questions

- When you volunteered with a young child, who participated? Please give names, ages, and relationships.
- What was the volunteering project and organization? Please be specific when naming organizations helped.
- How often and when did you volunteer?
- Approximately how many hours per person were spent on this project? Please list each person and their total volunteer hours.

Essay Questions

- What was special about the experience of volunteering with a young child?
- How did your work benefit others or improve the community or world you live in?
- What did your volunteer work teach both you and your young child?

NOTE: You'll probably want to take a moment to get your answers ready before entering (a good idea is to use a word processor, then paste your entries into the form), since all entry fields must be completed in one session.

So enter the Littlest Volunteers Contest! All you need to do is submit an entry by signing in (you must be a registered visitor). www.wondertime.com

Families of SMA Receives the 2006 Advocacy Award of Merit from the Child Neurology Foundation



The week of October 13th was an exciting one for the SMA community.

Several events focusing on SMA were held at national conferences, which greatly enhanced SMA visibility in both the child neurology community and the neuroscience research community.

On October 18th, the 5th “Neurobiology in Disease of Children” Symposium focused entirely on Spinal Muscular Atrophy. Over 300 child neurologists were exposed to the latest research and clinical findings on SMA during this day-long event. Overall the symposium was a very exciting and important opportunity to educate child neurologists, who are on the front lines of caring for children living with SMA, about the most up-to-date practices in clinical care for the disease.

The symposium was held in conjunction with the 35th Child Neurology Society Meeting in Pittsburgh, PA and sponsored by the National Institutes of Health, Families of SMA, the Claire Altman Heine Foundation, and the Child Neurology Society. Families of SMA and the Claire Altman Heine foundation also organized a lunchtime presentation for the neurologists, which focused on the human side of SMA. This presentation allowed families to share their experiences and perspective on living with SMA with the neurologists and hopefully assist the neurologists in providing better care for other families living with this disease.

During the 35th Annual Meeting of the Child Neurology Society in Pittsburgh, Families of SMA was very proud to receive the 2006 Advocacy Award of Merit from the Child Neurology Foundation. This award recognizes patient support organizations for outstanding achievements on behalf of patients and families with neurological and develop-

mental disorders. We believe this award recognizes the many individuals and families who have devoted their time and energy to advance the FSMA mission of supporting families and advancing research. The award was presented simultaneously to Families of SMA and the SMA Foundation for their contributions.

Earlier in that week, Families SMA and the SMA Foundation co-sponsored a satellite symposium at the Society of Neuroscience Meeting in Atlanta. This symposium provided an opportunity for the SMA community to showcase the latest SMA research developments to a new audience of researchers. The theme of the symposium focused on disease models for SMA, and speakers included Dr. Arthur Burghes of Ohio State University, Dr. Christine Beattie of Ohio State University, Dr. Beth Westlund of Cambria Biosciences, Dr. David Van Vactor of Harvard University, Dr. Jon Tinsley of Vastox, and Dr. Kathryn Swoboda of University of Utah. This event was a terrific forum for raising awareness about SMA among the 25,000 researchers attending the main sessions of the Society of Neuroscience meeting this year.

Planning A Walk

It's the New Year...time for a new resolution; THIS YEAR I AM GOING TO HOST A WALK 'N ROLL!

It may sound like a lot of work, but as hundreds of families can attest hosting a Walk 'N Roll to Cure SMA is a wonderful opportunity to spread awareness about spinal muscular atrophy and raise funds for Families of SMA.

Your walk can be a large event or simply asking a group of friends to join together and walk in a local park. Large or small, your contributions make a difference in helping Families of SMA with the work we do and we couldn't accomplish our goals without your efforts.

With your help Families of SMA is closer to a cure.

For more information call the FSMA office at 800-886-1762 or email walk@fsma.org



KEY STEPS:

- 1. One of the keys to your success will be finding other people who are willing to help.** Start looking for your volunteers within your immediate family. Share your enthusiasm and encourage your family members to join in as committee leaders or members. Then spread outward; let other family members and friends know about your desire to raise funds.
- 2. Choose a walk location, check with your Parks and Recreation Department.** They might be able to direct you to some local resources. If you have Internet access, get online! A quick search can provide you with all the information you need to begin. Don't be afraid to look into other fundraising walks. Other Walk 'N Rolls are listed on the FSMA web site www.curesma.org. You may be able to have your walk at the same location on a different date. If a walk is already being held somewhere, chances are it's an ideal location.
- 3. REMEMBER FSMA IS HERE TO HELP.** Once you have the basics- a time, place and committee we can help with the rest. Again, it can be as simple or large as you would like. We can help you order t-shirts and design posters, and set-up a web site.

Dear Friends,

My Name is Eric Bonin and I am the northern program coordinator for Vermont Adaptive Ski & Sports. I have been asked to explain to you what Vermont Adaptive has available to offer individuals with spinal muscular atrophy.

The program offers everybody — regardless of their degree of disability — the opportunity and ability to enjoy the sights and sounds, smells and adventure of the great outdoors in a safe and nurturing environment.

With programs and specialized equipment for those individuals with spinal muscular atrophy, Vermont Adaptive promotes independence and furthers equality through access and instruction to sports and recreational opportunities. Through this access the organization is committed to empowering individuals with disabilities —bringing them a new level of independence, skill and enjoyment.

For nearly 20 years this state-wide non-profit organization has grown to where it now serves upwards of 2,500 clients each year, thanks to 400 dedicated and trained volunteers. Vermont Adaptive also offers year 'round special programming for groups which may wish to have specialized training or have a Vermont outing on their own.

In winter, Vermont Adaptive's lessons usually run 2½ hours

and each person is accompanied

by both a lead and secondary instructor. Often a “shadow” — for safety's sake a person who clears the trail of other skiers —accompanies them. As coordinator, I consult with each client and the instructor to determine the level and ability and best equipment that will enable to client to achieve the results he or she wishes.

Often our lessons are inclusive—bringing in family or friends to learn and help so that, ultimately, wherever possible, the client will be able to participate without the help of Vermont Adaptive.

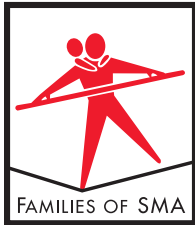
Without question, access to recreation is a critical part in our lives. Participating offers people a social, mental and physical benefit that is immeasurable. Vermont Adaptive provides all these benefits in a safe, fun and educational environment.

For more information you can give me a call at 802-583-4283 or go to our web site www.vermontadaptive.org. We truly believe that sports is for every body!



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

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

W06

Donation Form

W06

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

In honor of _____

In memory of _____

Donor Name _____

Donor Address _____

Notice of donation—Name & Address _____

Payment Method

- Check Money Order
 VISA Mastercard Discover

Credit Card # _____

Expiration Date _____

Name on card _____

Signature _____

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

Gift Certificate Order Form

W06

Retailer	Qty	\$ Amount	TOTAL
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

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

W06

Item	Size	Qty	Description	\$ Amount	TOTAL
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____

Payment Method

- Check Money Order
 VISA Mastercard Discover

Credit Card # _____

Expiration Date _____

Name on card _____

Signature _____

Ship order to

 Phone _____

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

Subtotal \$ _____

Shipping \$ _____

Total \$ _____

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



Connect. Be a Part.

Help find a **CURE** for
**Spinal
Muscular
Atrophy.**

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

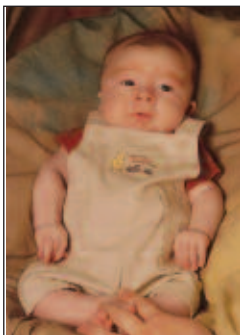
Patients have the opportunity to learn and receive information about the latest clinical trials and research studies for which they may qualify.

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

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

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

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



*In memory of Colin Robert Lynch
Born June 8, 2006
Home to Heaven Aug. 31, 2006*

Dear Colin,

It's Mommy and Daddy.

It's been three months since you left us, and our hearts sear with pain. We felt your spirit bless us the moment you entered this world.

Our love for you was instant, Boo-Boo. You were a beefy bundle, nine pounds, 12 ounces. You looked so perfect with your cherub-like face, and wide eyes. But looks were deceiving, as we quickly found out.

We were given the diagnosis, SMA 1. You were expected to live about a year. But you didn't even make that.

On the day of your funeral, your family and friends gathered at your home and released 85 balloons. One balloon for each cherished day of your life.

We will do it again June 8, 2007, which would have been your first birthday.

We will also plant you a tree, because you taught everyone around you how to grow. Colin, you inspired hundreds of people, many of them, complete strangers. You always had a brave heart, and a good-natured disposition even though you were so sick.

It would be easy for us to dwell on "what could have been." We had dreams for you that stretched to the sky. But you had a dream for us, a more meaningful one.

Helping to find a cure for SMA.

Colin Robert Lynch...we commit ourselves to fulfilling that dream. Son, we hope to make you proud.

Sharon & Brian Lynch



*Baylee Grace Peterman
04/27/05 - 04/17/06*

Our Little Baylee

*Our little Baylee went to heaven today
Though she is gone she is not far away
The angels escorted her into the presence of Jesus
Though we can't see her we believe she sees us*

*I'm happy with Jesus is what she would say
And forever in your hearts I know I will stay
I know you will miss me and I'll miss you too*

So don't miss heaven whatever you do

*I'm walking and running and safe in Jesus' arms
No longer bothered by earth's evil harms
No more am I hindered by sickness and disease
I'm doing just great so please be at ease*

*When you look to the heavens and see the stars twinkle in the night
That will be the twinkle of my eyes saying to you "Good night"*

*When you wake up each morning know I am with you
So don't you ever give up in whatever you do*

*Though my life on the earth was not a very long stay
Jesus promised we can be with each other forever one day
So for now it's "See you later" there are no good-byes
Remember I'll be watching you through heaven's eyes*

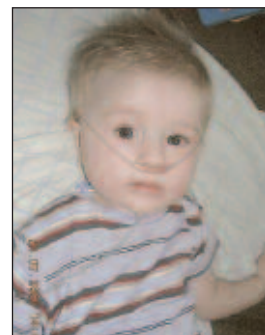
*Prayed for, longed for, rejoiced
for, then mourned...In our arms
briefly, in God's arms forever.*



**NATHAN PAUL
LIGGINS**
12/30/05-8/30/06

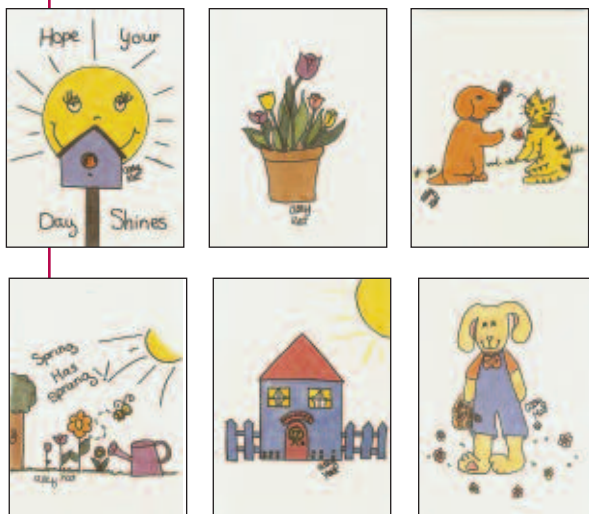


**OWEN
MICHAELIS BURNS**
12/28/2004-3/17/2005
**GRANT
WILLIAM BURNS**
12/28/2004-4/12/2005



GAVIN CAMPBELL
6/26/05-4/23/06

FSMA merchandise



12 Charlie Notecards | \$10

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



Cure SMA Bracelet | \$2

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

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



FSMA Golf Polo Shirt | \$24

Sizes: S M L XL XXL

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.



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

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



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

Mail your Orders to
FSMA National Office
or fax to 847-367-7623
Order form is on Page 16

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



SMA Awareness Pin | \$15

One design in sterling silver.

Angel Wing Pins | \$10



12 Window boxes Notecards | \$5

4 each of 3 designs (12 cards).



FSMA Lapel Pin | \$5

TOTES



Canvas Tote | \$15ea.

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



FSMA Tote Bag | \$10



FSMA Tote Bag | \$15

2-sided design.



Cotton Tote bag with Zipper | \$17

Together design.

Canvas Tote | \$10

CureSMA design.



FSMA Travel Mug | \$12

Keep your coffee hot!



SMA Sticker | \$2

Created in memory of Madison Vickers



FSMA Car Magnet | \$5

1 design.



Snowman or Angels of Hope Cards | \$8

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

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%	Loehorn 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 Barrel	\$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%			

Mail your
Gift Certificate Orders to
FSMA National Office
or fax to 847-367-7623
Order form is on Page 16

Alabama Chapter (since 2005)

P.O. Box 680
Trussville, Alabama 35173
Phone: 205-661-6423
Ann Peterman, President—
alabama@fsma.org

Arizona Chapter (since 1997)

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

Chesapeake Chapter (since 1995)

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

Connecticut Chapter (since 2003)

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

Illinois Chapter (since 2006)

★ New Chapter
P.O. Box 684
Grayslake, IL 60030
Tel: (847) 373-3762
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Iowa Chapter (since 2000)

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Kansas City Area Chapter (since 2004)

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Tel: (913) 262-6468
Natalie Gibbs, President—
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Long Island New York Chapter
(since 2006)

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Louisiana Chapter (since 2005)

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Minnesota Chapter (since 1992)

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New England Chapter (since 1987)

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Chapter (since 2004)

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Beth Lockwood, President—
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Pacific Northwest (since 2006)

★ New Chapter
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Rick Jones, President
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Pennsylvania Chapter (since 2003)

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Rocky Mountain Chapter (since 1998)

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Texas Chapter (since 2005)

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Rhea Canfield, President—
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Western New York (since 2003)

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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

Chesapeake

The Chesapeake Chapter is proud to announce that the **12th annual CRM Golf Classic** to benefit FSMA raised over \$131,000!!! For the very first time, the event was moved to two adjacent courses to accommodate the demand of participating golfers. Over 50 foursomes participated. Golfers came from as far as California, Wisconsin, New York, and Florida. 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 our many volunteers who make it possible to pull off an event like this.

Iowa

The Iowa Chapter has been very busy the past few months.

For the 10th year the **BeaverDash Charity Run** gathered over 700 participants and over 100 volunteers and of course, "Dale the Beaver" to recognize Families of SMA. Once again it was a fantastic success, raising nearly **\$20,000** dollars for SMA research.

The Iowa Chapter would like to recognize the all the great volunteers from Wolfe Machinery, Inc. For the past nine years Wolfe Machinery has spent countless hours each September organizing and handling the registration and packet pick-up booth for our BeaverDash Charity Run. They also participate in several parades escorting "Dale the Beaver" to promote Families of SMA and the BeaverDash. Their enthusiasm and constant commitment are a vital contribution the success of the BeaverDash! Thank you Wolfe Machinery! You are amazing!

On Saturday, October 7th the Families of SMA Iowa Chapter held a fundraiser in conjunction with the annual Octoberfest at Earl May Nursery and Garden Center in Des Moines, Iowa. We were able to raise just over \$200.00 with our many activities such as the cake/book walk, lollipop tree, build a scarecrow,



Families of SMA Illinois members: Amy M. Marquez, Samuel Schoenborn, Ally Krajewski and Jungin Lee

pop toss and the toilet paper throw. Our heartfelt thanks go out to Mark Thoms, manager of EM for giving us the opportunity to raise money for research, get our information out and have fun!!!

The Iowa chapter also benefitted from the **6th Annual Beth Baily Bake Sale** (See info on page 26)

Illinois

Illinois is excited to be joining forces with the chapters of Families of SMA, and is looking forward to an active year in 2007. Established in October 2006, the officers representing the Illinois Chapter are as follows:

- President - Janet Schoenborn
- Vice President - Amy Marquez
- Treasurer - Edmund Lee
- Secretary - Tina Krajewski

Although specific dates for various chapter events and fundraisers are still in the planning process, Illinois members are advised to periodically visit the Families of SMA Illinois Chapter Website for the latest news and information. In the meantime, the Chapter Officers are available to assist the Illinois members of FSMA in any way possible, and can be reached by US mail, phone, and/or e-mail.



Kansas City Chapter held the 6th Annual RoeFest Cure SMA Race-n-Roll

Kansas City

The Kansas City Chapter has been very busy and successful in fundraising this summer and fall! First, the Chapter was, again, a charity recipient at the **2nd Annual Great American Barbecue** in Kansas City, Kansas during Memorial Day Weekend. This year, the chapter received \$10,000! We want to thank the Great American Barbecue Committee for choosing FSMA-KC Chapter as one of the beneficiaries of this great event.

On October 7, the Kansas City Chapter held the **6th Annual RoeFest Cure SMA Race-n-Roll**. This year, we had 475 par-



Constance Ramos, Charlie Sykora & Kim Sykora

5th Annual Cure New England Chapter FSMA Walk-N-Roll Across America

It was everything you could have asked for and then some!! September 24, 2006 was the date. First-time organizers BJ Mirabile and Kristine Pecora chose the date back in March of course not knowing what the weather would be. The week prior to the walk the biggest worry was the weather. Weathermen were forecasting torrential rain and wind – not a good day for a 2-mile walk around Horn Pond in Woburn, Massachusetts. That morning the clouds were thick and ominous but as the set-up began, the clouds began to lighten and eventually the sun made it's way through before registration began. (We're sure that Angel Rachel Rollinson had a lot to do with the beautiful sunshine – thank you!)

The sunshine was not the only good part of the day. Over 600 walkers and rollers came out to raise money to find a cure for SMA. Families from as far away as Vermont and Connecticut joined us for the walk. Live music created a perfect atmosphere for a fun-filled morning. Face-painting, tattoos, and games were available at each water table. At the end of the walking path, walkers and rollers were treated to pumpkin decorating, balloon animals, delicious bake sale treats and free ice cream and pizza. The Gaudreau family also worked tirelessly at the grills serving up hamburgers and homemade french fries.

And after enjoying the food, many people took their chances at the raffle & silent auction tent. Lucky winners went home with all sorts of prizes ranging from autographed Red Sox

memorabilia, a weekend in Maine, ski passes, gourmet food baskets, Life is Good items, an American Girl doll and LOTS more!!

There were many SMA families in attendance and it's always great to see old friends. However, what was amazing was the amount of attendees not connected with an SMA family. Many people came because of local advertising and word of mouth and they wanted to know more about SMA and how they could help find a cure. All of those newcomers won't soon forget about SMA after experiencing a day like that!

Of course, the best part of the walk is the amount of money raised for FSMA. When this project was started the goal was \$20,000 - an ambitious yet reasonable goal considering that BJ and Kristine were first-time organizers. The total, as of Oct. 31, is over \$72,000!! A good portion of that sum is from the attendees and their pledges and registration fees. Another large part is from the over 70 business sponsors. And the other large portion is from the donations collected as a team in honor of a child. The "River's Journey" team and the "Kate's Place" team each collected over \$6,000 toward the walk with team fundraisers. Kudos to River's and Kate's teams!!!

Now that the walk is over for 2006, BJ and Kristine are left to wonder – "How are we going to top that next year?" Both BJ and Kristine welcome your comments and suggestions (positive and negative) to help plan for 2007! Contact them via email at: acureforkate@comcast.net or acureforkatie@yahoo.com

ticipants. The event was a huge success thanks to our sponsors, participants, donors and volunteers who came from all over the US. We kicked off the event by having Constance Ramos, original member of ABC's Extreme Makeover: Home Edition, sound our horn and start the 5k run/1 mile walk. Thank you, Constance, for helping make this event special! Many thanks to over 10 SMA Families who came to Roeland Park, Kansas from Kansas, Missouri, Iowa, Oklahoma and Nebraska. Our SMA Families participated, volunteered and raised funds to make this event such a success! This year, some families collected donations by using the FSMA Website. The families sent emails to friends with a link to their fundraising page. Three families collected \$8,500! This year our event total was close to \$45,000!! Thanks to all for helping us get closer to a cure!



Members of the Kansas City Chapter pose after the SMA Walk

Michigan

Here are a few things that have been happening in Michigan:

- The Fisher Fund, Inc. is a non-profit organization in Rockford, Michigan that holds several fundraisers every year. In summer of 2006, they held their annual Fat Bastard Wiffle Ball Tournament and chose FSMA as their organization of choice. They raised \$500 in honor of Malorie Fox (Ada, MI).
- In October 2006, Carrie Schofield with Silpada Jewelry donated a portion of her proceeds to FSMA in honor of Malorie Fox (Ada, MI) - contribution was \$80.
- In the summer of 2006, Byron Bank holds a run/walk event. This year they chose FSMA as their charity - in honor of Sydney Potjer (Byron Center, MI). They raised \$1000 for SMA research!

Minnesota

Thanks to everyone who helped and came to the Minnesota Chapter walk to make it a successful event. We have raised to date \$16,868. There are still funds coming in so our total will change.

The walk was held on September 17th and it was a beautiful day. The day started out on the chilly side but soon warmed up once the walkers and rollers started the event off. Everyone enjoyed a hotdog, chips and soda after they returned. We also sold nacho's, candy, and coffee and donuts. We had approx 150 walkers and rollers. Great time was had by all!

New England

The New England Chapter Fall Walk 'n Roll was an amazing success. Way to go New England! Again our thanks to each and every family/person who helped make this possible, and a special thank you to the Pecora and Mirabile Families for taking this event on and doing such an amazing job. Thank you Jack, Kris, Joe & BJ and their entire families.

A final thank you to remember where the birth of this walk came from: To a very special Angel up above, "Rachel Rollinson".

As the family database and chapter events continue to grow, it has become simply too much work for a few people to handle all the affairs of the chapter. So the officers and board members of the chapter would like to announce the appointment of Kolette Carleton as the assistant to the president, Silvia Murphy as the chapter's database administrator and Kristine Pecora along with BJ Mirabile as chapter meeting coordinators.

Kolette will assist the chapter in keeping existing families and members abreast of upcoming events, introductions of new families, and updating on the forums with regards to chapter events and functions. Silvia will assist the chapter in maintaining the existing family/member database along with updating and correcting the database for new families and new information (i.e. address, email and telephone number) and changes with existing families. And Kristine and BJ will take over the administration of making sure our regular quarterly chapter meetings are scheduled and planned out accordingly. We are excited about adding some more talent to our chapter administration and look forward to having Kolette, Silvia, Kristine & BJ further involved with FSMA. Thanks everyone!

As always, Michelle Rollinson will continue to handle incoming calls of newly diagnosed families and Mike & Paula Barrett will continue to handle the financial and other managerial components of the chapter. Thank you Michelle, Mike & Paula!

Also, "Thank You" to all our existing chapter families, board members and friends for all their continued help and commitment and to all our CT Chapter officers, board members and families/friends for their support and commitment as well.



The Morey family, pictured above: Lauralynn, & David Sr., with their four children; Meredith 1, Charlotte 3, David Jr. 5 and Jordyn 7, of North Chelmsford, has joined the fight to cure Spinal Muscular Atrophy (SMA) in a most generous and touching way.

Meredith and Charlotte shared a birthday party on Sunday September 3. Instead of presents for the girls, this wonderful family asked for donations to Families of SMA. The Moreys were inspired by the story of Rachel Rollinson, who died in 2000 from SMA at the age of 10 months. The Rollinson family is grateful to the Moreys for helping keep Rachel's memory alive, and for helping raise awareness about SMA. The event raised \$130.

Debbie Silveira held a spaghetti & meatball dinner at her restaurant in honor of Logan Watts. They raised \$1,900 for the New England Chapter!



Members of the Minnesota Chapter pose after the SMA Walk

Iowa



This was our second biggest year for the Beth Bailey Bake Sale. We raised \$1,700 this year, with a grand total of over \$9,000 raised in 6 years for research to find a cure. It was unfortunately our last year. We have enjoyed spending our time baking and packaging goodies for the bake sale. Our customers have also enjoyed eating our goodies. We've had many return customers for certain items. It has been a tremendous fundraiser for the memory of our daughter Elizabeth Bailey. Our family is now onto another fund raising project. An update on this exciting project will come in the next Newsletter. We are very excited to be moving forward in our fund raising efforts. Thank you to all who have donated and purchased our baked goods!

Tennessee

The Tennessee Chapter has been busy in recent months hosting 2 major fundraisers. In June our 3rd Annual Golf Tournament raised over \$13,000. Once again Centennial Golf Course in Knoxville was the site for a fun filled day. This year 25 teams participated and over 40 sponsors donated goods and services to make the event such a success. Thank you to Michele Silva and Ben Senger of WBIR (the Knoxville NBC affiliate) for hosting the awards ceremony; to Walter Mack III and Out-back Steakhouse of Oak Ridge for donating a wonderful dinner; to golf pro Louise Ball for pulling everything together; and to our Junior Volunteers Charlie Vogle (SMA II), Connor Murphy (SMA I), Gus Vogle, Chase Matlock and Andrew and Matthew Strader who raised over \$250 selling SMA awareness bracelets.

The Knoxville Museum of Art was the perfect setting for our August event, "Someone's Miracle Awaits". Over 250 supporters attended, raising over \$57,000. Manny's Catering provided another fabulous meal. Over the years Manny has proven to be a true friend of FSMA. For the second year comedian Leanne Morgan of the Southern Fried Chicks (as seen on The View) entertained the crowd and introduced fellow comedian Brad Upton. They left everyone in high spirits for the live auction. Among the items up for auction was a guitar signed by country music star Gretchen Wilson. The bidding was brisk and made for an exciting end to a rewarding evening.

Texas

The last few months have been a busy time for Texas SMA Families and the Texas FSMA chapter. We started with our first official chapter fundraiser in June and raised over \$5,000. In August, the Rush family held their 4th annual Odds on a Cure in honor of Savanna Rush and raised over \$35,000. In September, the Hannah family held the 6th annual Lanie Hannah Benefit Scramble

golf tournament. To date, the Hannah family has raised over \$280,000 for SMA research! In October a chili and stew supper was held in memory of Braden Ray (Tumbleweed) Campbell who passed away May 5, 2004, at the age of 10 months. Profits from the fundraiser totaled approximately \$3,500. All proceeds will be donated to FSMA with 50% of the funds being directed toward research and the remaining monies directed to support TUMBLEWEED'S WAGON FUND of Families of SMA.

On October 22nd Steve Long ran the Chicago Marathon in honor of his son Jack Long. They exceeded their goal of \$3,500 and almost doubled that! In addition, Becky Long helped raise \$660 by selling shopping passes for Macy's Shop for a Cause.

Western New York

A Christmas gift wrapping table at their local Galleria Mall on December 2nd helped to raise funds and awareness. Chapter members asked for donations for the gift wrap to help fund a cure. They also had various SMA articles for sale including the new bead bracelets.

The Western New York Chapter of FSMA is hoping their next attempt at raising money is a success. With the help of KiPo Chevrolet we will raffle off a General Motors HHR. KiPo is giving us the vehicle at cost and we must sell at least 1,500 tickets to make money for a cure.

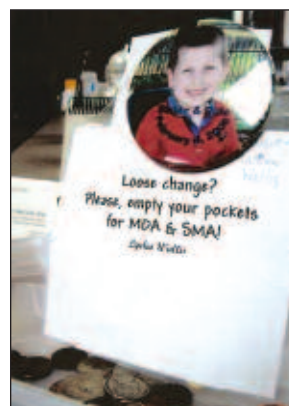
The Chapter is hoping to sell 2,500 tickets at \$20 each and offer the HHR as the Grand Prize. First, Second and Third prizes will be gas cards of \$1000, \$500 and \$250. The seller of the Grand Prize ticket will win \$250 if all tickets are sold. The drawing for the vehicle will take place at the Fourth Annual SMArt Walk for a Cure on August 4th, 2007.



Donald Faison from the hit TV show "Scrubs" wearing an FSMA T-Shirt during an episode of the show



Reagan Imhoff from New Berlin, WI. Left: Reagan wearing a Cure SMA Bracelet



A fundraiser by Lydia Wallis in honor of Matthew Wallis



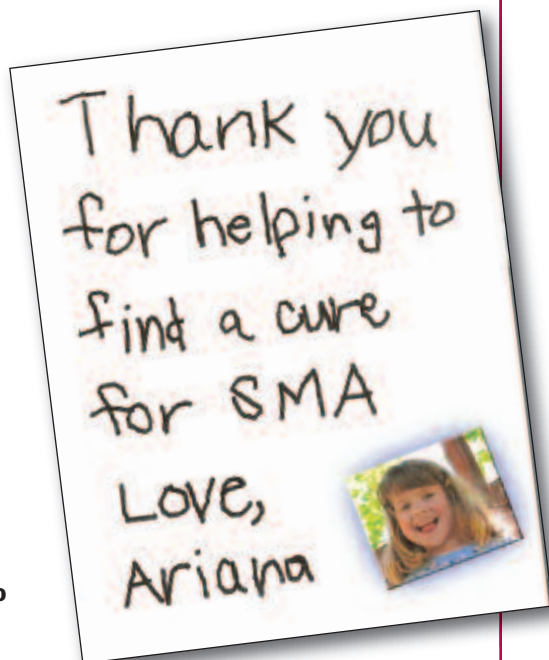
Piazza Family in Mets Dugout



Elizabeth Hallam eating cake on her 3rd birthday



Elizabeth Hallam's Make a Wish trip to Disney World "My princess after her big day at the Magic Kingdom...She went to bed two hours early. She was so mesmerized by her experience..."



SHARING page

www.curesma.org

I stumbled across this online and just wanted to share. "Celebrating Holland" is a follow-up to "Welcome To Holland" In the beginning, I think I read "Welcome To Holland" almost daily. Now that it's been six years since Joshua was first dx'd with SMA, we can honestly say that Holland is our home. For those of you who have helped us make Holland our home, we thank you. For those of you just landing in Holland, please know that Holland is not such a bad place to be. You will come to call Holland home one day, too.

Jennifer Tramontano

Celebrating Holland

by Cathy Anthony

I have been in Holland for over a decade now and it has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned. I reflect back on when I first landed in Holland. I remember clearly my shock, my fear, my anger, and the pain and uncertainty. In those first few years I tried to get back to Italy, my planned destination, but Holland was where I was to stay. Today, I can say how far I've come on this unexpected journey. I have learned so much more, but this too has been a journey of time.

I worked hard; I bought new guidebooks; I learned a new language, and I slowly found my way around this new land. I have met others whose plans changed, like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many encouraged me; many taught me to open my eyes to the wonder and gifts to behold in this new land. I discovered a community of caring – Holland wasn't so bad!

I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, assist and support newcomers. Over the years, I have wondered what life would have been like if I had landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and, at times, I would (and still do) stomp my feet and cry out in frustration and protest. Yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts. I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land; what is more important is what you make of your journey and how you see the very special, the very lovely things that Holland, or any land, has to offer. Yes, over a decade ago I landed in a place I hadn't planned yet I'm thankful, for this destination has been richer than I ever could have imagined!



Susan O'Neill's car license plate



Prasad Ghadi of Mumbai, India, accepting an international award for his artwork



The Lee family



Dani Pruitt 2½ yrs old



Colin O'Neill



Casey O'Neill



Samuel and Ethan Schoenborn



Sara Rose Greene



Gray and Riley Dougherty



Sydney Craven with her new brother Scott

You Don't Have To Walk to Lead a Great Life

by Jon Morrow

What do Franklin Delano Roosevelt, Stephen Hawking, and the majority of people with SMA have in common? None of us can walk, and none of us need to.

When FDR nearly died of polio, everyone thought his political career was over. Even after years of therapy, he couldn't walk without someone supporting him.

But he became President of the United States. He was elected to four terms—the most of any President in history.

When Stephen Hawking contracted ALS, he rapidly lost the ability to speak. Even with a speech synthesizer, no one wanted to give him a job as anything but a research assistant.

But now he is probably the most famous scientist alive today. He's written more than half a dozen books—all without speaking or typing.

Only FDR and Stephen Hawking are special, right? They never had to go through what you go through.

Well, no. No one has experienced exactly what you have.

Each of them did, however, go through periods of depression. Both experienced moments when they felt weak and helpless.

Yet they kept going. Why?

Because they realized they were still human. They could still think. They could still communicate. They could still connect with the world and other people in a meaningful way.

They realized that they were good for something. And so are you.

The next time you start feeling depressed and useless, think about their example. If FDR and Stephen Hawking can change the world, then what can you do?

My guess: anything you want.

Don't Be Afraid to Fly!

Rocco Arizzi

One of the greatest challenges that people with physical disabilities face is that of getting from point A to point B. As if getting from home to work or school is not difficult enough, traveling longer distances presents its own set of obstacles. I have done a great deal of traveling over the course of my life, especially in recent years, and I have taken just about every form of transportation imaginable. Airplane travel is the most difficult experience I have had, and is invariably what I get the most questions about. Traveling by air requires a good amount of patience and planning, but after some experience becomes a bit less of an ordeal.

When possible, I try to book my flight well in advance, so that I will have better choices of flights and seating, both of which are important. I try to book direct (non-stop) flights whenever they are available. Direct flights are important because they minimize the need to transfer in and out of airplane seats, and they lessen the number of times my wheelchair is transported by baggage handlers. The less time my wheelchair spends in baggage handling, the less chance of damage. If I am unable to book a direct flight, I make sure that there is sufficient time (1 hour is best) during the layover to get transferred to the next flight.

I try to book a seat as close to the front bulkhead area as possible, because this shortens the distance I have to be transferred from the airplane entryway to my seat. If the flight does not book seating, or if the bulkhead area is already booked, I occasionally am able to talk the airline into moving me to the bulkhead after explaining the situation to them.



After booking the flight, I immediately call customer service for the airline and ask for their "special needs" department. I let them know that I am traveling with a wheelchair, and they log it into the system. Doing this goes a long way toward making things easier on the day of the flight. They ask me questions about the type of wheelchair I am traveling with, what type of batteries, if any, are used, and what assistance I may or may not need boarding the plane.

If you are flying with a motorized wheelchair, it is important to ask about battery transport regulations during this conversation with customer service. In the past, I have made assumptions about transporting batteries that turned out to be wrong once I got to the airport. In general, wheelchair batteries can stay in the wheelchair as long as they are dry cell or gel cell batteries. Any battery that is classified as a wet cell will have to be taken out of the chair and

packed in special boxes. Most modern wheelchairs, however, no longer use wet cell batteries. Some airlines have required me to disconnect the battery cables from the terminals.

Before I go to the airport, I take anything off the wheelchair that may be a problem either going through security or in baggage. I take off backpacks, bags, or any other easily detachable item (some may have cup holders, mirrors, flags, etc.). This makes the security screening process go faster and cuts down on damaged or lost items. If you have a bag or container that is a permanent part of the chair, or not easily detached, be sure to empty it out completely.

When possible, I try to get to the airport 2 hours in advance of my flight time. If everything goes smoothly, I end up waiting around for a long time at the gate, but there have been a few occa-

sions in which those two hours were just barely enough. When I get to the ticket counter, I explain that I am traveling with a motorized wheelchair and the agent fills out a special tag. You can decide whether or not you want to take the wheelchair to the gate, or to transfer to an airport wheelchair and let the baggage handlers take the chair right there at the ticket counter. Since I, personally, do not like to sit in the airport wheelchairs, I usually take my own wheelchair to the gate. It is important to note, however, that taking your own wheelchair through security takes a little bit longer.

I have a different experience going through security each time I fly. Some airports will cut wheelchair passengers ahead of the security line, because often the rope mazes are inaccessible. Generally, the security personnel will give a typical pat-down and usually require me to have my shoes off. I explain that I cannot lift my arms, and give them permission to move my limbs as needed. Also, they swab the wheelchair in various places with a dust wand, then run the swab through a machine to check for explosive residue. The whole process just takes a few minutes, but is generally longer than that of a typical passenger.

Once at the gate, I let the gate agent know that I am there and that I will need to speak to the baggage handlers about how to properly lift the wheelchair. If you have a wheelchair with a lot of extra motors (for seating, etc.) or other parts that can come loose or detached, like armrests or footrests, you need to explain to them in detail how to best lift the chair to prevent damage. Also, I explain how to put the wheelchair into “freewheel” mode and how to lock it.

Like most people who use a wheelchair on a daily basis, I am very uncomfortable when I am sitting anywhere but in my own wheelchair. Unfortunately, airline regulations and airplane architecture require that you sit in an airplane seat, with the wheelchair stowed in baggage. In the rare cases that I have flown

myself, airline personnel have transferred me onto the plane using a narrow “aisle chair”. Two workers lift me into the aisle chair, push it to the airplane seat, and then transfer me to the seat. I typically travel with a PCA or a family member, however, who just carries me to my seat (a more difficult task when I put on my holiday weight). Wheelchair passengers are seated first, to allow the extra room and time needed to board.

I find airplane seats very uncomfortable, especially on longer flights. If you are used to very specific seating positions, you may want to bring along a pillow or any other seating aids (cushions, wedges, etc.) that you think would make you more comfortable on a longer flight. Since there are carry-on item limits, though, you should call ahead and explain what you are bringing and why. Since most flights are just a couple of hours, I usually just gut it out and I don’t bring any cumbersome seating items. If I’m in too much pain I’ll ask the flight attendant for a pillow, or a couple of those tiny bottles of Jack Daniels.

Getting off the plane takes a while because it takes some time to get the wheelchair out of the plane and up to the gate. If you are using an airport wheelchair and getting your wheelchair at baggage claim, you still generally have to wait for the other passengers to disembark before you do.

Once I get my wheelchair back the very first thing I do is check it for damage. I do this right in front of the baggage personnel. If you find any damage to the chair that you are certain did not exist before the flight, ask immediately for the paperwork for filing a claim. It may take a bit of fighting, depending on the nature of the damage, but the airlines will pay for any damage that they cause to your wheelchair.

I have had good and bad experiences flying, and the whole process can be very intimidating if you have never been through it before. After a few runs, though, it all becomes fairly routine.



Heather Jaclyn Cuevas and big brother Dylan



Isaac Postma in Kindergarten at Byron Center Christian School.



Jenna Boguhn on her 2nd birthday.



Hannah Macellaro

Joshua's Story

(It's a little long. The past seven years have been an incredible journey!)

By Jennifer Tramontano

We welcomed Joshua Adam Tramontano into this world on December 14, 1998.

Joshua was born two and a half weeks early. We had our Christmas tree up and decorated, but I didn't have my bag packed for the hospital! After a very easy and short delivery, we were thrilled to finally meet our little boy, our first baby. He was absolutely beautiful.

Aside from the unbelievable colic, Joshua seemed to be developing like your average, healthy baby. He reached the very early milestones of rolling and being able to sit up on his own.

Around nine months, we began to notice that Joshua was no longer meeting some of his gross motor milestones. He never crawled. He never tried to pull himself up to a stand. We noticed that his legs seemed very "floppy." He also developed a fine tremor in his hands that became worse if he became nervous or excited.

As first-time parents, we were concerned; however, we were repeatedly getting reassurance that everything was fine.

After Joshua's 12 month checkup, we were referred to a pediatric neurologist, as well as sent for some bloodwork. The bloodwork did not include a test for SMA. We were relieved when the bloodwork came back normal.

We left our first visit to the neurologist with a referral to Birth-to-Three and an appointment for an MRI. Again, we were relieved when the MRI came back with normal results. Once again, we were reassured that with a little encouragement and early intervention services, Joshua would be off and running very soon, and that he would walk.

Joshua started receiving physical and occupational therapy in our home two times a week.

After Joshua's 15 month checkup, our pediatrician admitted that he was "stumped." Joshua was not making any progress toward reaching his gross motor milestones. In fact, his percentiles had dropped considerably and he had very low muscle tone. Our follow-up visit to the neurologist was moved up a couple of weeks earlier. The reassurances that everything was going to be okay seemed to be fading away.

At this next visit to the neurologist, we were referred to Boston Children's Hospital for some testing. The doctor wouldn't tell us specifically what she was looking for. We live in Connecticut. We were being sent to Boston for testing. The words "neurological disorders" and "neuromuscular diseases" were being thrown around. We knew this was serious. Our perfect little world seemed to be quickly falling apart....

So, on May 16, 2000, we set out for Boston Children's Hospital. I can still hear Joshua screaming as he was being poked and prodded during the EMG testing. This was the day we learned that Joshua had Spinal Muscular Atrophy, Type II. This was the day the neurologist looked us in the eyes and told us our beautiful little boy was going to die – the same neurologist who, four months prior, told us Joshua would be off and running in no time at all.

This could not be happening to our beautiful little boy. This was not what we had hoped and dreamed for. It is impossible to put into words what we were feeling at this time.



We had never heard of Spinal Muscular Atrophy. There is no history of this disease in our family. Of course we began to try and find out all that we could about SMA. We began by contacting the National Office of Families of SMA. I can still hear Audrey Lewis' voice. I can still hear her saying that our son is type II and he is not going to die before his second birthday. Although Joshua would never walk, we learned that the prognosis was not as grim as the neurologist portrayed it to be.

So, this is where our journey of life with SMA began. Little by little we started learning all that we could about SMA. We started by visiting Dr. Bach in New Jersey. We left our first visit with Dr. Bach with prescriptions for a pulse oximeter and a Cough Assist.

Next began the equipment... Because Joshua cannot walk, it is important for him to stand and weight bear on his legs. Joshua's very first piece of durable medical equipment was a manual "Sprout Standing Dani." He got this stander when he was only 17 months old. Joshua was so very proud to be able to move about in his stander. In June of 2003, Joshua got a new power Standing Dani.

Next came his power wheelchair. Joshua was fitted for his power wheelchair when he was two years old. It was truly amazing to watch Joshua in action in his "wheels." Within five minutes, he was off and running. His first set of

Raising Funds for Friends

“wheels” was delivered to us in September of 2001 – September 11, 2001, to be exact. We were not anxiously awaiting the arrival of a power wheelchair for our two-year-old little boy. The look on Joshua’s face was absolutely priceless when he took off in his wheels. He was thrilled to be independent. This was the day we got to experience the joy of Joshua taking his first steps. In the end, September 11, 2001, turned out to be such a sad day for reasons other than Joshua receiving his first power wheelchair. I remember tucking him in that night, giving him an extra hug and kiss, and being so thankful he was safe at home with both mommy and daddy.

Like most kids with SMA, Joshua was a pro at driving his wheels in no time at all. When you’re out in public with an adorable little toddler in a power wheelchair, it seems as though you become public property. Boy, if we had a dollar for every time we heard, “Boy, he sure is a good driver,” or “You better slow down, or you’ll get a speeding ticket,” we could have raised lots of money for SMA!

Joshua, however, was truly amazing. He just loved his new-found independence. Soon enough, the wheels became part of our everyday routine. This is what’s normal for us. Some parents chase after their kids who run around on two feet, we just chase after Joshua in his wheels.

Soon it was time for Joshua to go to preschool. Once again, Joshua was truly amazing. The first day we dropped him off, he was like, “Bye, mom. See you later.” Within two weeks, he wanted to take the bus. I remember that first day sending our three-year-old little boy off to preschool on a bus with his power wheelchair and my heart being ripped out of my chest as the bus pulled away. Now, Joshua is in second grade at West Woods School. Going to school is part of his everyday routine like any other seven-year-old. Joshua has many friends, goes to many birthday parties, goes on field trips, and participates in everything that all of the other kids do.

Soon after Joshua was diagnosed with SMA, we became actively involved in

fundraising and spreading awareness about SMA. We attended our first Families of SMA conference three weeks after Joshua was first diagnosed. We spent the weekend walking around like deer with their eyes caught in the headlights. As difficult as it was to attend this first conference so soon after being diagnosed, we were so grateful we did. We met so many remarkable families and formed many friendships.

In September of 2002, we started the Connecticut Chapter of Families of SMA. I was president for two years and a half years. Joshua’s dad is currently the vice president. We have helped raise over \$150,000 since Joshua has been diagnosed and will continue to be part of the effort to find a cure for SMA!!!! We will fight the fight until WE WIN!!!!

In March of 2004, Joshua became a big brother, welcoming Daniel Ryan Tramontano into the world. Daniel is now two years old and is SMA free.

Joshua is now seven years old. We can’t believe seven years have gone by. He seems to be growing up so fast. Joshua is a happy a little boy. He is living a happy life.

These past seven years have been an incredible journey. After receiving such a life-changing diagnosis, we soon discovered a new-found happiness. We no longer sweat the small the stuff. We celebrate every accomplishment! We realized Joshua was sent to us for a reason. He is truly a gift. He has taught us more these past seven years than most people will ever learn in a lifetime. Naturally, if given the choice, we don’t think we would have chosen this path of life with SMA. Some days it seems like a long, uphill journey. While other days, it’s smooth sailing. One thing’s for sure, we have been blessed to meet some truly incredible people along the way that make the journey that much easier!

Please be sure to keep us in your thoughts and prayers – praying for a miracle, because we sure could use one.....

■ Two third graders from Westwood View Elementary School in Westwood, Kansas raised nearly \$1,500 for Spinal Muscular Atrophy. For their birthdays, **Lucy and Chloe** decided that instead of accepting gifts, they would ask for donations to fight SMA, which afflicts their friends and classmate Claire Gibbs and her sister Lauren Gibbs. Chloe and Lucy invited the entire third grade class to join in a celebration at park. The kids had hot-dogs, cake and ice cream. Chloe and Lucy passed out Cure SMA bracelets as party favors. Chloe and Lucy collected nearly \$1,500 in donations which they presented at the RoeFest Cure SMA Race-n-Roll on October 7th.

■ Eight year old **Matthew Strader** of Knoxville, TN has been busy building bird houses. To date he has raised over \$800 selling his birdhouses to find a cure for his friend Connor Murphy. Word of his efforts reached local reporter Michele Silva, resulting in Matthew being featured on the evening news!

■ **Cubby Wax** celebrated his 7th birthday in August, and once again asked his friends to make donations to FSMA instead of bringing gifts. His friends responded generously raising \$420 in his honor. Happy Birthday Cubby!

■ **Brannan Gerard** celebrated his 4th birthday. His cousin, Alex, has SMA type I, Instead of presents Brannan wanted to share with his cousin and asked for donation to FSMA! What A Guy!

■ **Veronica St. Onge** recently celebrated her 2nd birthday and her family asked for donations in lieu of gifts, a donation of \$130 was made in her honor. Happy Birthday!

Q: Is assisted coughing the best way to help keep the lungs clear of congestion? Any long term problems with pushing too hard etc?

Dr Schroth: Yes, assisted coughing or using a Cough Assist machine is the best way to keep the lungs clear of congestion. Generally there have not been long term problems with the manual cough assist as long as it feels ok to you.

Q: We had difficulty with the cough machine - he is 18 months, does he need to be a little older to breathe with it? Is CPT and bipap enough to help him when he is sick until he gets used to the cough assist?

Dr Schroth: I encourage you to work with your child to get them used to the Cough machine. What I have parents do is to coach your child by saying "take a big breath in" while the machine is doing the inhale. And when the machine is on the exhale mode, say to your child "now cough." If you set the time on the modes the same your child will learn the rhythm of the machine especially if you coach them through it with directions.

What I mean by setting the time modes the same is that inhale is always 1 or 2 seconds, exhale mode is always 1 or 2 seconds and pause is always 1 or 2 seconds.

Q: Considering that our son seems to have asthma, is it possible that the use of a cough-assist machine (In-ExSufflator) causes bronchial obstruction? What are the suggested parameters (pressure and time) for a SMA type 2 kid with and without a cold?

Dr Schroth: If your child has a cold the only way to clear secretions is to cough them out. In my opinion, the Cough Assist does not contribute to airway obstruction. The settings I recommend are inhale pressure 25 to 40 cm of H2O for 1 second, exhale pressure -25 to -40 for 1 second and pause time 1 to 2 seconds. Four to 5 breaths are taken continually followed by suctioning the mouth to remove secretions coughed

up and a rest period of 1 to 2 minutes. We do 4 sets of 5 breaths. The goal is to gradually increase the pressure to 40 on inhale and exhale.

Q: Is there a significant difference between using a nebulizer with saline and Xopenex and if so what would indicate the uses of both during CPT prior to a cough assist?

Dr Schroth: Xopenex is a medication that contains a form of albuterol. It is not clear to me whether Xopenex or albuterol make a difference for children with SMA before CPT or coughing. My rule of thumb has been to try it especially if there is a history of asthma in the family or the child has had asthma type symptoms. However, it does not seem to help every child. I am convinced that coughing and chest PT helps every child. You are so busy taking care of your child that I recommend that we determine what works and do that. And if it does not make a difference then it may be a waste of your valuable time.

Q: I do have Cough Assist and Bipap, and we use then both. The problem is that my son seems to have asthma and is hyper reactive after RSV. What can we do to help him??

Dr Schroth: If your child seems to have asthma, then he may benefit from albuterol and/or an inhaled steroid, medications we use in asthma. These may help keep his respiratory status "more even."

Q: So far we have use the BIPAP only when he is sick since his sleep study turned out well (97% O2 all night), so my question is: What signs should we look for to decide if our son needs to use NIV (BiPAP) during nights?

Dr Schroth: If his sleep study is ok and you are using BiPAP only with illness this is ok. If you start to see his chest sink in at the sternum, he may benefit from BiPAP every night.

Q: Our 16-year old daughter has restrictive airway and asthma with some loss of oxygen as determined

by her sleep study. She will not wear her C-Pap mask nightly (she says it interrupts her sleep). She currently wears it about twice a week or sometimes every 3 nights, but she removes it sometime during the course of the night. What protocol do you recommend?

Dr Schroth: There are multiple issues to consider when your child dislikes their mask. There are lots of different styles of nose masks and I suggest you contact your home care company to try some others. There are some that are nasal pillows or canulas that do not block vision while they are on. Another issue to consider is whether the BiPAP settings are optimal for her. Possibly the settings should be evaluated by her doctor. If she is only on CPAP this may be the problem. I suggest switching to BiPAP from the C-Flex. The CPAP will not provide her with enough support for her breathing during sleep.

Q: My son's bi-pap is like the cough machine mask - is it ok if it covers his mouth and nose?

Dr Schroth: It sounds like your son is using a full face mask with the BiPAP. I prefer a nose mask, because you can hear him talk around the nose mask. If he is doing well with the full face mask, this is ok too.

Q: When my son has a cold and his nose is stuffed up, is it safe to use the mask (we use the mini me) for the bipap? Does he just know to breathe through his mouth?

Dr Schroth: When your son has a stuffy nose it is ok to use the mask. I suggest cleaning his nose out of secretions as much as you can before using the BiPAP.

Q: I'm an adult with SMA type 2. Could you please discuss the effectiveness of LVR (lung volume recruitment) exercises for the group? I've been doing it for two weeks and have seen impact already. It's basically stacked breathing with an ambubag, it stretches lungs, helps cough and improves ventila-

tion. (More info at: <http://www.ottawahospital.on.ca/rehabcentre/servicesclinics/respiratory-e.asp#2>)

Dr Schroth: The lung volume recruitment exercises are great for older children and adults who can cooperate. In younger children, I use the Cough Assist on the inhale mode (turn the exhale time to 0).

Q: How does IPV work?

Dr Schroth: IPV uses an air source like a air pump to deliver air into the lungs by mask or mouth piece at a set frequency and pressure. It sounds like a choo-choo train. It essentially does CPT from the inside using air to shake up the secretions. Some people do not like it, even less than the cough machine.

Q: Should we get an antibiotic every time he has a cold or just when he has a fever? Sometimes the colds last 3 weeks and the antibiotic is just for five days - can they become immune to the antibiotic if we give it every time he has a cold?

Dr Schroth: The purpose of the antibiotic is to prevent a bacterial infection, which can contribute to pneumonia. Colds are caused by viruses and in general there is no cure, we have to wait them out. But viruses cause a lot of secretions in the lungs and nose and colds make everyone weaker. I generally treat with an antibiotic only at the beginning. I generally do not treat with an antibiotic the entire illness.

Q: My 3-year old son has SMA type 2. We live in Chile, South America. This year he has been in hospital 4 times due to pneumonia, all of them requiring mechanical ventilation, once intubated and the others with NIV (BIPAP). My question is: Is it a good practice to use antibiotics as soon as he presents signs of a cold? What type of antibiotic will be more appropriate to start with?

Dr Schroth: The most important thing to help keep your child out of the hospital is the equipment we have been discussing. Do you have a Cough Assist machine and BiPAP for your child? The

antibiotics only help if you are helping your child to clear all the secretions from their lungs that they are too weak to cough out by themselves.

Q: Is it safe to give our kids products like Airborne Jr. or Mucinex to add extra protection against catching colds?

Dr Schroth: Yes I think Airborne Jr is safe to use. I have looked at the ingredients and I am not concerned. I think Mucinex has less to offer and contains an ingredient that is very common in most cold over the counter medications, guaifenesin.

Q: Do you think Airborne ingredients would actually help prevent anything?

Dr Schroth: I do not know whether the ingredients in Airborne will help to prevent anything. I can't recommend one way or the other.

Q: Our 2 1/2 yr old daughter has had 2 bouts of "sudden apnea", are there any signs that would tell us whether or not they were caused by plugs vs. vasal galag response?

Dr Schroth: The 2 sudden episodes of apnea are sometimes difficult to figure out. My suggestion is to cough her and see whether anything comes up or clears from her airway. There is a concern among those of very interested in SMA as to whether there is autonomic dysfunction and we are all trying to figure out the best way to sort this out.

Q: When a child is sick - breathing fast - increased heart rate, etc what immediate tests should we request at the hospital to determine if it's pneumonia, collapsed lungs, or just a bug?

Dr Schroth: The most important thing is for someone to listen to her lungs. Generally we can hear where the problem is. Oxygen saturation check is also important and a chest xray to see where there may be areas of mucus plugging.

Q: With the x-ray we've been told they can't really tell the difference between pneumonia or collapsed portions - is that true?

Dr Schroth: Yes, it is difficult sometimes to tell whether it is pneumonia or mucus plugging on an initial chest xray. But we also make a determination about that based on what the lungs sound like and how the child is doing.

Q: My daughter is 3 years old and type III. When do you feel is the appropriate time for us to get her set up with a Pulmonologist? Should we do it now although she hasn't had any problems yet or wait a little longer?

Dr Schroth: For a child with SMA III, now is good time to meet with a pulmonologist to get acquainted. They may only need to see your daughter once per year, but it helps to establish that relationship before there is any respiratory difficulty.

This chat is part of an ongoing schedule of chats by various experts on topics that are important to families. Previous topics are located on our web site:

http://www.fsma.org/chat_transcripts.shtml and they include chats on nutrition, insurance, genetics, physical therapy. If you have a topic that you would like to see covered, please let the FSMA office know, and we will try and schedule it.

Join us online for our next chat:

"Clinical Trials for SMA"

with Dr Sandra Reyna
& Dr John Kissel
of Project Cure SMA.

Thursday, February 15th
7pm CST—sign up online at
www.curesma.org



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Plans for the conference are set!

Chicago, Chicago... Our kind of town and home to FSMA. We return home for a top rated conference. Come to Chicago and make a family trip out of it. From Navy Pier to Millennium Park, world's largest and most complete Tyrannosaurus Rex at the Field Museum, American Girl Cafe, The Magnificent Mile and Lake Michigan to Lincoln Park Zoo... there is something for the entire family to enjoy! Most importantly, what brings us to Chicago is the annual trip to network with other families, experience a kids' program where wheelchairs are the norm, and get research updates first hand from the researchers.

Separate conference packets will be sent early February which will include full conference registration information with details on the agenda. Forms will be included to register and mail to FSMA or complete online.

Hotel accommodations: Hotel reservations can be made by calling 800-233-1234 for a special rate of \$115 per night. Please reference Families of Spinal Muscular Atrophy Conference. See Hyatt Regency site for more information about the hotel and area guide:
<http://woodfield.hyatt.com/property/index.jhtml>

- 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.

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.

Conference agenda includes:

- Pre registration Meet & Greet
- PJ Party Movie night for kids and parents
- 2 days of workshops
- Kids' program
- Continental Breakfast before Opening Session
- Annual Full Banquet Dinner & Silent Auction
- Luncheon –adults only – Research Q&A
- Annual Kids Carnival, a favorite with the kids

Conference fees:

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

*Children over 10 subject to additional charge for Banquet

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