10 Tips: How to Use IDEA 2004 To Improve Education for Children with Disabilities

by Wayne Steedman, Esq.

1. Use the Findings and Purposes in IDEA 2004 to Establish a Higher Standard for a Free, Appropriate Public Education (FAPE).

Prepare Children to Lead Productive, Independent Lives. In “Findings” of IDEA 2004 (Section 1400(c)), Congress found that “30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by having high expectations for such children,” educating them in the regular classroom so they can “meet developmental goals and, to the maximum extent possible, the challenging expectations that have been established for all children and be prepared to lead productive and independent adult lives, to the maximum extent possible.” (Section 1400(c)(5)(A))

As a parent or teacher, you need to understand that when Congress reauthorized IDEA 2004, they raised the bar. To meet these new legal requirements in IDEA 2004, schools will have to use scientifically based instruction and provide more intensive special education services.

2. Use IDEA 2004 and No Child Left Behind (NCLB) to Obtain a Better Individualized Education Program (IEP)

When Congress reauthorized IDEA 2004, they specifically noted the intent to coordinate IDEA 2004 with the No Child Left Behind Act. (Section 1400(c)(5)(C)) Many definitions in IDEA 2004 come directly from NCLB, including the requirements for highly qualified teachers.

A “highly qualified teacher” has full State certification (no waivers), holds a license to teach, and meets the State’s requirements. Special educators who teach core academic subjects must meet the highly qualified teacher requirements in NCLB and must demonstrate competence in the academic subjects they teach. (Section 1401(10))

Attacking Low Expectations

Congress also found that implementation of the IDEA “has been impeded by low expectations and an insufficient focus on applying replicable research and proven methods of teaching and learning for children with disabilities.” (Section 1400(c)(5)) School personnel often assert that it is unreasonable to expect a child to achieve more than one year of academic progress in one year. School personnel assert this even more vigorously when they develop IEP goals for disabled children, goals that often reflect their low expectations.

But if a disabled child is two, three, or more academic years behind his nondisabled peers, the only way to “close the gap” is for the disabled child to make more than one year of academic progress in one year.

When children with disabilities receive intensive instruction from teachers who are skilled in the use of scientifically based instruction, it is not
We hope that everyone found the new Donations Listing publication that was recently sent out to be valuable. We would be pleased to hear any comments and feedback that you may have. In March we also began a regular monthly Eblast newsletter to announce upcoming events and noteworthy news, if you are not receiving the Eblast make sure to sign up on our website. Our next edition of Compass will be coming out shortly which will focus on the critically important area of our drug discovery programs. We look forward to updating you on our progress and results in this area.

A theme in this edition of Directions is education and transitions. We have included a number of articles and stories relevant to both students in elementary school and those looking to transition to college and beyond. We have tapped into our network of other organizations in order to bring you relevant, accurate information. If you are aware of other resources for families, let us know, we are always looking to expand the connections we can make to better serve your needs.

As mentioned in the last Directions, we are heading into Walk and Roll season. Since then we now have over 20 Walks scheduled throughout the US and Canada for 2007! We are well on our way to another banner year. Thank you to everyone involved in these and other fundraising events on behalf of Families of SMA. Your efforts and commitment to our cause make all the difference.

While we still have donations trickling in from our national holiday mailing campaign, so far we have received over one quarter million dollars in donations. Thank you for all of your contributions to support our programs in research and patient support.

We appreciate all of the holiday cards that were sent in to us. A selection of these are reprinted inside. We always enjoy hearing updates on how everyone is doing and seeing the great pictures. Unfortunately, due to space limitations, we are unable to include all of the photos in this issue…but we will add more to the Summer edition, heading to you in early June.

Sincerely,

Kenneth Hobby
Executive Director, FSMA

Mission Statement
Families of SMA is the largest international organization dedicated solely to:

· Eradicating spinal muscular atrophy (SMA) by promoting and supporting research

· Helping families cope with SMA through informational programs and support

· Educating the public and professional community about SMA

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

Submissions
To submit articles or make other contributions to our newsletter, please contact Lenna Scott at: newsletter@fsma.org.

Deadline for the next newsletter is: May 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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Update on Newborn Screening

Spencer Perlman, FSMA Legislative Affairs

Newborn screening remains an issue of significant importance to FSMA and a key component of our federal legislative agenda. While each state is responsible for determining the diseases and disorders for which it will screen, the federal government has taken an increasingly active role in this issue area in recent years. Congress took an interest in newborn screening due to the rapidly advancing fields of genetics and genomics. While some states were at the forefront of the human genome breakthrough, others lagged behind, leaving a wide disparity between the states’ newborn screening programs and the number of disorders for which various states screened, which at one point ranged from three (3) to 47.

As part of the Child Health Act of 2000, Congress required the Secretary of Health and Human Services (HHS) to create an advisory committee on newborn screening. The Advisory Committee on Heritable Disorders and Genetic Diseases in Newborn and Children (ADHDGDNC) was established in February 2004. It consists of leaders from medical, technical, public health, and scientific professionals with special expertise in the field of heritable disorders or in providing screening, counseling, testing, or specialty services for newborns and children at risk for heritable disorders.

As its first order of business, the ADHDGDNC worked with the American College of Medical Genetics (ACMG) to finalize a federal guideline listing those disorders and diseases for which it is recommended states screen newborns. The ACMG had been contracted by HHS to create such a list in 2001. The recommended list was released in 2005 and contains 29 disorders and diseases. In part due to the release of this list, several states have greatly expanded their newborn screening panels in the past two years and there is greater uniformity among the states regarding the disorders and diseases for which newborns are screened.

Presently, SMA is not on the federal recommended list, nor is it screened for in any of the states. This is due primarily to an historical bias against screening newborns for diseases and disorders for which there is no cure or treatment. FSMA has set out to alter this bias and have SMA included on the federal list, which will lead to the implementation of newborn screening for SMA in the states. Screening newborns for SMA will allow for the identification of SMA-affected children pre-symptomatically, which may have tremendous implications for the type of care that can be provided to those affected and with regard to ongoing clinical trials of potential future treatments or cures.

Since 2005, the ADHDGDNC has been working to develop a criterium and process by which the list of recommended disorders and diseases can be expanded. FSMA has been intimately involved in these discussions. Last year, we participated in an ADHDGDNC pilot program to test a draft nomination form by which the public may formally request a review of a disorder or disease for inclusion on the federal list. FSMA’s recommendations were considered by the ADHDGDNC, as were those of other patient advocacy groups, and the form has been streamlined, clarified, and improved. The updated nomination form is expected to be formally approved by the ADHDGDNC sometime this year.

With the nomination form nearly complete, the ADHDGDNC presently is working to develop the criteria by which a nominated disorder or disease would be judged for inclusion on the federal list. This represents a critical junction in the development of the process for expanding the federal recommended screening list.

FSMA is working to ensure that disorders or diseases are not categorically rejected for inclusion based solely upon the presence of a treatment or cure. We continue to work closely with the broader SMA community, other advocacy groups with similar interests, and the members of the ADHDGDNC which support newborn screening for SMA to remain engaged in the process and ensure that SMA has the opportunity of consideration for inclusion on the federal list.

The next ADHDGDNC meeting will take place in the Spring. We will continue to keep you apprised of our efforts in this area. If you would like to learn more about the ADHDGDNC, please visit its website at http://mchb.hrsa.gov/programs/genetics/committee.

Join the legislative action committee, email: lac@fsma.org
What Has Congress Been Up To?

Spencer Perlman, FSMA Legislative Affairs

The 1st Session of the 110th Congress convened in January with Democrats taking control from Republicans in the House of Representatives and the Senate following their victory in the elections in November 2006. The following is a brief primer on how Congress reorganizes itself and what it has been occupying itself with since the start of the year.

Congressional Reorganization

Congress reconstitutes itself every two years following a federal election. By law, Federal elections take place on the first Tuesday after the first Monday in November of even numbered years. Each new Congress convenes in January following an election. A “Congress” consists of two-year-long sessions: thus, the 1st Session of the 110th Congress will last through calendar year 2007 while the 2nd Session of the 110th Congress will occur during calendar year 2008. The 111th Congress will convene for its 1st Session in January 2009 following the November 2008 elections. According to Amendment XX of the U.S. Constitution, Congress must convene on January 3 of each year to begin its new session.

House of Representatives

While both the House of Representatives and the Senate reconvened in January, the two bodies of Congress are distinct entities that operate under different rules, precedents, and procedures. The House of Representatives consists of 435 seats, a number that is set by Federal law. Each Member of the House represents a congressional district that consists of roughly 600,000 individuals. Thus, the most populous states send more representatives to the House than the least populous states. California has the largest House delegation of 53 Members. Seven states (Alaska, Delaware, Montana, North Dakota, South Dakota, Vermont, and Wyoming) send just one at-large Member to the House. House terms are for two years, so each House seat is up for election every two years.

House seats are reapportioned among the states every 10 years following the decennial national census. The Constitution requires the Federal government to conduct a census every ten years in years ending in zero. The next census will occur in 2010. Reapportionment of the 435 House seats will occur shortly thereafter to reflect any population shifts. Some states will gain seats if they experienced significant population growth since the previous census of 2000 while other states will lose seats if they suffered significant relative population loss since 2000. Each state government will redraw their congressional districts in time for the federal elections of 2012 to reflect their new apportionment of House seats. Each newly drawn House district must encompass approximately the same population level.

Senate

The Senate consists of 100 seats, two for each state. Senate terms are for six years, though the terms are staggered so that one-third of the Senate seats are up for reelection every two years. Due to the fact that each state receives two Senate seats, regardless of population, the Senate is not affected by the decennial census.

Since every Member of the House is up for reelection every two years, the body must reconstitute itself every two years by passing new procedural rules, electing new political leadership, and reconstituting its committees and committee chairs. The Senate is a continuing body, meaning that it technically does not have to reconstitute itself every two years. However, by tradition the Senate also reviews the rules governing its functions and procedures, re-nominates its political leadership, and reconfigures its committee assignments and chairs on a biennial basis.

110th Congress

With the Democrats winning 30 seats in the House and seven seats in the Senate from Republicans in the November 2006 elections, they took control of both bodies. Presently, Democrats control 233 of 435 House seats and 51 of 100 Senate seats. These margins are historically very narrow, which limits the ability of Democrats to enact their agenda. However, as the majority party, Democrats control the legislation process and the committees within each congressional body. In practice, this means that the Democrats have the ability to decide which issues take priority and which legislation will receive attention and debate time. Republicans, who are now the minority party in both bodies, are able to react to and attempt to amend or block legislation proposed by the Democrats, but Republicans have little recourse to push their legislative agenda through Congress without compromising with the Democrats.

Appropriations

Since it convened in January, the 110th Congress has focused primarily on appropriations and budgetary matters. Each year, Congress must pass 12 appropriations bills that fund various aspects of the federal government for the coming fiscal year, which lasts from
SMA Carrier Screening Advocacy on Capitol Hill

Several members of FSMA participated in the Claire Altman Heine Foundation, Inc. advocacy day on Capitol Hill on February 12-13, 2007. The contingent visited with Members of Congress from California, New York, Massachusetts, Illinois, Florida, and Pennsylvania in support of pan-ethnic carrier screening for SMA. Their efforts helped to ensure the continued backing from key Members of Congress for a legislative effort to secure support from the National Human Genome Research Institute at the National Institutes of Health to improve SMA carrier screening technology and enhance education and awareness among the public and professional communities.

October 1 - September 30. Thus, federal Fiscal Year (FY) 2007 began on October 1, 2006 and will end on September 30, 2007. If Congress fails to pass appropriations by the start of the fiscal year, it must pass a so-called continuing resolution (CR), which is a stop-gap bill that provides temporary funding for the affected government agencies at the previous fiscal year’s funding levels. If a CR is not enacted, the affected portions of the federal government would be forced to shut down since it could not receive funding from the federal treasury.

**FY 2007 Bills**

The 109th Congress failed to pass all but two of the appropriations bills for FY 2007 prior to adjourning. The vast majority of the federal government was left to operate under a CR which ran until February 15, 2007. This is highly irregular. Thus, the 110th Congress was left to address FY 2007 funding levels. It passed an omnibus appropriations bill just prior to the February 15 deadline to fund the government through the end of FY 2007. Work on the omnibus bill took up much of the Congress’ time and energy for the first month and a half of the year. The omnibus bill was relatively kind to programs of concern to the SMA community. For example, the National Institutes of Health (NIH), which funds most of the nations biomedical research, received a $600 million increase in funding over FY 2006 levels.

**FY 2007 Supplemental Appropriations**

Over the past month, Congress has turned its attention to a so-called supplemental appropriations bill for FY 2007. This bill will provide additional funding for various government programs (the vast majority related to the wars in Iraq and Afghanistan) through the end of FY 2007 that require additional funding above the regular FY 2007 funding levels. This includes emergency funding for various military efforts, recovery from Hurricane Katrina, farmers affected by drought, and other similar items.

**FY 2008 Budget and Appropriations**

Additionally, Congress has turned its attention to FY 2008; it has begun the process of putting together a budget resolution for FY 2008, which will begin on October 1, 2007. The budget resolution will determine how much money may be spent for various government functions (e.g., health, defense, education, etc.). The 12 appropriations bills for FY 2008 will divvy up this funding among the various government programs during a process that will take place over the summer and into the fall.

While a highly effective and accurate SMA carrier screening test has existed since 1996, it is not well utilized due to a lack of awareness and understanding of SMA among OB/GYNs and genetic counselors. Sadly, this means that couples seeking genetic counseling while planning a family rarely are screened for SMA. With some straightforward technical enhancements to the existing test and greater awareness, a pan-ethnic carrier screening program for SMA is achievable, which will allow individuals of childbearing age to make informed reproductive decisions.

If you would like to learn more about carrier screening or the Claire Altman Heine Foundation, please visit the website at www.preventsma.org or send an email to deb@preventsma.org. FSMA is pleased to partner with the Heine Foundation to support carrier screening.

Looking Ahead

Budgetary and appropriations matters, along with the war in Iraq, are likely to take up the majority of Congress’ attention this year, and 2008 is likely to be overshadowed by the Presidential election. This marks the first Presidential election since 1928 that neither a sitting President nor a sitting Vice President is pursuing the presidency. Thus, the nominations for both parties are wide open and likely to capture much of the national and congressional attention. Several Senators are pursuing the White House, which will have an impact on the ability of that body to legislate, in part because the presidential candidates will be particularly sensitive to casting politically difficult votes and in part because their travel schedules will limit their time in the Senate.

FSMA will continue to closely monitor Congress’ work and to advocate on behalf of the activities that are of importance to the SMA community. This includes newborn screening, biomedical research funding, special education and possibly an SMA community bill. I will provide a report on congressional activities related to these items in the next newsletter.
**UPCOMING events**

**Jacob’s Run, Walk & Roll**
Congratualtions to the Jacob Isaac Rappoport Foundation on an amazing walk, March 4th. The preliminary totals indicate over $97,000 was raised.

**2007 Upcoming Events**

**April 14** - Cure SMA Walk ‘N Roll in Norwood, OH - bethml@fuse.net

**April 21** - 5th Annual Kale Shiesley Volleyball Challenge in Tonawanda, NY - wmy@fsma.org

**May 5** - 5th Annual SMA Race ‘N Roll in Baton Rouge, LA - louisiana@fsma.org

**May 5** - Cure SMA Walk ‘N Roll in Lansing, MI - hollyschafer@comcast.net

**May 5** - 8th Annual Wyatt Sutker Foundation Walk in Tonawanda, NY - info@wkswithsma.com

**May 7** - 2nd Annual Steven’s Swing for a Cure SMA Golf Classic in Magnolia, DE - jnjmoyer@comcast.net

**May 12** - 2nd Annual Benefit Ride to fight SMA in Horsham, PA - MJMC-AlvaryRiders@verizon.net

**May 12** – “The Human Race” in Santa Rosa, CA - ncalif@fsma.org

**May 19** – 7th Annual Cure SMA Walk ‘N Roll in Hingham, MA - silvia@fsma.org

**May 19** – 2nd Annual “Steven’s Walk” to drum out SMA in Haddon Township, NJ - m.potter9@verizon.net

**May 20** – 6th Annual CT Chapter Walk ‘N Roll in Hamden, CT - conn@fsma.org

**June 2** – Cure SMA Walk ‘N Roll in Colorado Springs, CO - carengreen@msn.com

**June 3** – 4th Annual Walk ‘N Roll to Cure SMA in Philadelphia, PA - pennsylvania@fsma.org

**June 9** – Cure SMA Walk ‘N Roll in Dracut, MA - jeppmdffr@comcast.net


**June 24** – Illinois Chapter Walk ‘N Roll in Schaumburg, IL - illinois@fsma.org


**July 15** – Jimmy’s Swim & Swing for the Cure in Mt Laurel, NJ -

**Meet the new Fundraising Events Coordinator for FSMA**
As we look ahead to 2007, I wanted to introduce myself as a resource for you in the National Office. While I am not new to Families of SMA, having been involved for about two years, I have embraced the opportunity to take on more responsibility regarding fundraising efforts! I will be helping to support you in any way that you need for existing events, as well as providing resources for families looking to kick-off their very first walk. I will also be working to list all fundraising events on our web site, set up on-line registrations for your event and will be working to help you publicize your event in FSMA publications.

I look forward to speaking or corresponding with each of you personally over the coming months. Please don’t hesitate to contact me with any comments or questions.

Let’s Walk ‘N Roll to Cure SMA together!

Jill Dauergedas
Fundraising Events Coordinator
walk@fsma.org
800-886-1762

**FSMA has purchased 15 new vinyl banners for use at your event. Call or email the office for details.**
Families of SMA Collaborates with the Broader SMA Community

Over the last year, Families of SMA has been working with the general SMA community on multiple projects to enhance awareness about SMA and to help enable the best SMA research, drug discovery and clinical trials.

1. Co-funded the “Neurology in Disease Of Children” Symposium at the Child Neurology Society Meeting.

With the NIH, Claire Heine Altman Foundation, and Child Neurology Society. This day-long event focused entirely on SMA, and helped educate child neurologists about the most up-to-date research and clinical care practices for SMA.

2. Co-sponsored a satellite symposium at the Society of Neuroscience meeting.

With the SMA Foundation. This meeting is the premier neuroscience research conference with over 25,000 researchers attending. This was a great forum to raise awareness about SMA in the basic science community.

3. Collaborating with the NINDS sponsored SMA Project.

The NIH has generously provided FSMA with a testing slot to assess the FSMA/deCODE compounds for therapeutic benefit in SMA mouse models.

4. International Coordinating Committee for SMA Clinical Trials.

The mission of the Committee is to facilitate the conduct of fast, efficient and effective clinical trials in SMA that lead to new treatments, and ultimately improve care for people living with SMA.

a. The voluntary ICC consists of 4 main groups: The Patient Advocacy Group, the Clinical Trial Outcome Measures Group, the Clinical Trial Protocol Design Group, and Standard of Care Group.

b. Jill Jarecki is the chair of the Patient Advocacy Group. This group also includes Cynthia Joyce of the SMA Foundation, Sharon Hesterlee of MDA, Chris Lorson representing FightSMA, Richard Green of the Jennifer Trust, and Tonya Mason as the parent representative.

c. The PAG helps fund and facilitate ICC projects, including a Standard of Care Conference for SMA and the document that resulted called “Consensus Statement for Standard of Care in Spinal Muscular Atrophy”. The article will help physicians internationally provide the best possible clinical care to SMA patients.

d. The PAG is organizing and helping fund the "SMA Summit on Drug Development" to be held September 28th and 29th, 2007 in the Washington DC area. The goals are:

- To gain a better understanding of the regulatory requirements for SMA drug approval.
- To inform stakeholders about the status of SMA drug development.
- To identify gaps in our current development efforts.

5. The oversight of the Indiana Registry is now done by a neutral oversight committee.

The committee is appointed by the PAG. This facilitates registry access to investigators. Clinical trial recruitment is done directly through the registry and the individual site clinical coordinators for each clinical trial. None of the advocacy groups, even when funding a trial, has any role in patient recruitment or even learn the names of patients enrolled in trials.

VISIT www.curesma.org and link to the clinical trials tab. There you will find a list and links to all of the research studies and clinical trials taking place. You will also find the information needed to register for the

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.
In an exam room in Indiana, researchers work to identify early signs of Huntington’s Disease in subjects participating in a research study. The hope is that these little clues will lead to the development of new and better treatments, delaying the onset of this debilitating disease or curing it all together. In hospitals across the United States, doctors work to build better ways to detect and treat cancer in children. And in Missouri, data is being collected to help unravel the mystery of autism.

As diverse as these studies are, they all have one thing in common: they are using medical registries to aid in the advancement of medicine.

In 1986, Families of SMA founded a database which is known today as the SMA International Patient Registry. In the twenty years it has existed, the registry, maintained at Indiana University, has come to house data for over 1,000 individuals with SMA. The registry has been used in studies ranging from new treatment trials to survey studies which seek to identify all of the issues faced by families with SMA. Registries (also known as databases) are an essential tool that concentrates information in one place so that people with a certain disease or problem can be connected with researchers who are looking for treatments and cures. Different registries collect varying types and amounts of information, from basic demographics (age, gender, etc.) to more detailed information that comes from things like physical exams and tissue samples.

There are two types of research that can be conducted using data from the SMA International Patient Registry. The first type is statistical/demographical research. This type of query does not involve the use of any identifiable information and can be easily released to researchers.

The second type of research request would require identifiable information. In this situation, researchers and clinicians who are interested in conducting research into SMA are required to submit a research request. The request is then evaluated by a panel of experts to ensure that it is both a sound study and that all appropriate measures are in place to protect potential subjects. Once a request is approved, IU searches the database to find the people and/or data that fit the request. We would then send an information letter about the study and an informed consent form for that specific study to each person who meets the study criteria. No information would be released to the researcher without your explicit, written permission to do so. You are never under any obligation to participate in any research project and if you choose to participate in a study you can withdraw at any time with absolutely no consequences.

The registry is creating connections between people with SMA and the researchers who are trying to solve the puzzle of SMA. Please read on to discover how you might be able to help put the next piece of the puzzle in place.

Who can join the registry? The registry is open to any person who has any type of SMA. There are no other requirements!

How do you join the registry? Joining the registry is easy. There are several forms to fill out, all of which can be found at http://www.iupui.edu/~medgen/heditary/sma.htm or by contacting Connie Garland at (317) 274-5745.

In order to participate in the registry, you will need to fill out:
• a consent form for information to be collected and stored in the database
• a consent form that allows protected health information to be collected
• a patient questionnaire

When you have completed the questionnaires, you will mail them to Connie Garland at Indiana University. They are then entered into the registry. At IU, great pains are taken to make sure that data is kept secure and private. We have extensive security safeguards in place to protect all of the information that we gather.

If you have any questions about the registry or are thinking of joining the fight, please don’t hesitate to get in touch. If we connect, we can solve the puzzle!
Most sports for people with disabilities are restricted to manual chairs. Therefore, someone who is required to use a power chair, has to sit on the sidelines and just dream that one day the time would come when they could be a world class athlete. That time is now. Powerhockey is a sport that is designed for people who use power chairs. It is a sport that can be adapted so that everyone can play and really contribute to the team, regardless of a person’s upper body strength.

For many years some form of Powerhockey has been played all over the world. In the United States, Powerhockey began to become organized in the early 1990s. The United States Electric Wheelchair Hockey Association (USEWHA) was started in Minnesota with the mission of providing a quality hockey program to those who use an electric wheelchair in daily life. In 2001 the USEWHA hosted its first Powerhockey World Cup, with 11 teams from around the world participating. Later, Canada and the United States combined to form the North American Powerhockey Association (NAPA), which has hosted tournaments in 2004 and 2006. NAPA is the governing body over smaller organizations throughout North America.

One of the newer organizations is the North Carolina Electric Wheelchair Hockey Association (NCEWHA), which has been represented at the 2004 and 2006 Powerhockey World Cups. The NCEWHA currently has 1 team, the Carolina Fury, and is looking to sign up more players throughout North Carolina. When asked about the growth of the NCEWHA, Jonathan Greeson, the organization’s President, said, “I truly believe the sky is the limit for our program. It is our goal to have at least 4 teams across North Carolina, so we can compete against each other and be well represented at the World Cup tournaments. However, personally I would like to see the organization spread up and down the east coast. Growing up with SMA, I know what it is like to watch all of your friends participate in sports and have to sit on the sideline. I want to make sure that other kids don’t have to deal with that and I know the leaders of the other hockey leagues feel the same way. Playing hockey has really had a positive impact on my life. I have made life long friends and developed the confidence needed to be successful in life. This game can give the same results to anyone who tries it.”

Josh Cranfill, the NCEWHA Vice-President, says he loves playing the game because “This sport has allowed me to act on my competitive nature, while at the same time has given me the chance to be independent. Powerhockey gives those who are confined to a power chair the opportunity to be involved in a team sport which allows them to meet new people. Socialization is a major benefit of Powerhockey. By allowing participants to meet and interact with people of similar situations, it provides a sense of comfort for those who are skeptical about their disability. As I continue to play and be involved with the NCEWHA and Powerhockey, I gain an enormous amount of self-confidence about myself and about my disability. Powerhockey is truly more than just a sport, and I am glad that I am a part of this organization.”

The USEWHA is really looking to expand across the nation. If you are interested in Powerhockey, please visit www.powerhockey.com. They will put you in touch with your closest league representative. Greeson says, “If there is not a league in your state, the USEWHA and other league representatives will help you start your own. Remember every league started with just a few people who wanted to be a part of a team, there is no reason why you can’t do the same. It is definitely worth the effort and you will make a difference in so many lives, including your own. We look forward to all of you joining the Powerhockey family!”

Contributed by North Carolina Electric Wheelchair Hockey Association (NCEWHA)
Pen Pals

Did you ever want to connect with another parent who is going through a similar situation? Does your child wish to get to know other kids with SMA? If your answer is yes, FSMA may have the solution—FSMA Pen Pals.

We will highlight various members looking for pen pals in each issue and then you can mail/email us and ask to be their pen pal. We will help connect you together.

For more information email info@fisma.org

Sibling Support Group

Announcing the SibKids and SibNet Listservs. The Sibling Support Project of the Arc of the United States is pleased to announce SibNet and SibKids. SibNet and SibKids are the Internet’s only listservs for and about brothers and sisters of people with special health, developmental, and emotional needs.

Both SibKids (for younger brothers and sisters) and SibNet (for older siblings) allow brothers and sisters an opportunity to connect with their peers from around the world. Both listservs have members from the US, Canada, Australia, England, Japan and elsewhere. SibNet (started in 1996) and SibKids (started in 1997) are remarkably warm, thoughtful, and informative communities where young and adult brothers and sisters share information and discuss issues of common interest.

Anyone who has email can subscribe to SibKids and SibNet. For a no-cost subscription and to learn more about SibKids and SibNet, please visit the Sibling Support Project’s Web Page (see address below). Finally, if you have further questions about SibKids, SibNet, our Sibshops, or the work of the Sibling Support Project, please contact:

Don Meyer, Director
Sibling Support Project
6512 23rd Ave NW, #213, Seattle, WA 98117
206-297-6368 • www.siblingsupport.org


2007 FSMA Family & Professional Conference

Planning for the conference is set…lots of fun for the whole family

Registration forms are available online at www.curesma.org
Please register by May 10th

Hotel Accomodations: Hotel reservations can be made by calling 800-233-1234. Please reference Families of Spinal Muscular Atrophy.

The weekend is filled with numerous workshops including: Genetics, Fundraising, Respiratory Issues, Physical Management, Housing, Recreation and Therapy, Nutrition, Grieving, Self Help & Wellness, Open Discussion and One-on-One Consultations.

Conference agenda includes:

• Thursday night welcome with researchers
• PJ Party Movie night for kids and parents
• 2 days of workshops
• Kids’ program
• Continental Breakfast both Friday & Saturday
• Annual Full Banquet Dinner & Silent Auction
• Luncheon –adults only – Research Q&A
• Annual Kids Carnival, a favorite with the kids

Khi 9yr old girl with SMA II

Khi loves to play all sorts of video games, she enjoys watching TV, playing with her Goody Girl and Bratz dolls, she also enjoys talking on the phone to her friends. Khi wants to be a scientist when she grows up.

I’m Crystal, 23 and my son Socrates (Junior) has SMA type II and he is 3.

We would like to write to others with the same limitations. Junior loves cars, movies and McDonalds chicken nuggets and he just got his little power car (W/C) a couple months ago and is still learning.

Hope to hear from someone soon

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Thank you Families of SMA.

Instead of giving each other Christmas gifts this year, we decided to donate money to Families of SMA, in honor of Kennedy Montoya, my son who has SMA type II (raised $1,185). Only the kids got gifts. The picture is him in his first ever school picture and as you can tell by his big smile, he loves it. This was the first Christmas that he really got into it, so that was enough of a present for my husband, my family and myself, just to watch him and his sister rip open their gifts. Thanks so much for all that you do for our family and the many others out there. We are so blessed to have such a big family in the SMA family. You have helped me and my family get over some big emotional hurdles, and I probably would have never made it without this extended family. Thanks for all you do, we can’t say that enough.

Rick, Autumn, Juliet and Kennedy Montoya of Stanton, CA

CIBC WORLD MARKETS MIRACLE DAY RAISING AWARENESS FOR CHILDREN IN NEED

Thank you to all those who participated in the CIBC World Markets Corp. annual Miracle Day campaign on December 6, 2006. Miracle Day is an effort to raise awareness for children who are underserved, at-risk or in need and occurs on the first Wednesday in December each year. On Miracle Day, 95% of CIBC World Markets’ net commissions from trades made through the firm that day are donated to over 350 participating Miracle Day charities located throughout the United States. CIBC has donated over $175,000 to FSMA over the last 6 years through the Miracle Day Campaign.

To our friends at FSMA,

It is with great happiness that we send you checks totaling $11,000 from this year’s 3rd Annual Lukie’s Fall Festival. It always amazes me how much support we are getting, year after year, and how much the festival is growing! This year, we added a hay ride to the festivities, along with opening space for local crafters. We had lots of entertainment, bands, DJ, singers and a Karate demonstration. We also had a local K-9 unit from the State Police, therapy dogs, caring clowns and a blood drive. -Along with lots of great food (Joe is a chef)! It was truly a wonderful day and thank God, no rain!

Thank you for all of the support that you lend to us and all of the families affected by this terrible disease. I feel that with all of our efforts combined, a cure is attainable!

God Bless!

Tara, Joe, Kadyne and Anna Maida, along with the Maida and De Crescenzo families of Roseto, PA

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Dear FSMA,

On January 24, 2005, shortly after birth it became evident that Logan had a serious problem. They questioned SMA but all tests came back inconclusive. So we hoped and we hoped. But in April of this year the diagnosis of SMA was confirmed for Logan “Boo-Boo.” We had a fundraiser for a van for Boo-Boo and boy did family, friends rally around us. I have a jar on the counter of my restaurant and my customers give & give dollars, quarters, & pennies.

In October we were approached by Al Cote “Karaoke Al” about having a fundraiser for our grandson. We decided however, to have a spaghetti dinner in his name for research of SMA. The fundraiser was called Logan’s Hope for SMA and was held on October 22nd.

The jar remains on our counter and little by little the funds come in. Manny & I feel strongly that we should inform as many people as possible about SMA.

Sincerely,
Debbie & Manny Silveira, of Assonet, MA, raised $1,355 for Families of SMA

In honor of Logan Anthony “Boo-Boo” Medeiros

Chuck and Megan Hernandez, of Lutz, FL, raised additional funds from the Annual Maluko Charity Golf Classic. They raised a total of $32,000 for Families of SMA, in honor of Tyler Hernandez.

Chris and Lana Hannah, of Weatherford, TX, held the 6th Annual Lanie Hannah Benefit Scramble Golf Tournament. The Event was on September 22nd at the Canyon West Golf Club, in honor of their 6 year old daughter Lanie. They had the help of many family members and friends, as well as the support of many businesses. As usual, their tournament was a huge success, raising $30,000 for Families of SMA!

What started out as a 40th birthday gift in 1996, from Kevin Arnold to his wife Linda, has become one of the most successful fundraisers for Families of SMA! In 1996, Kevin asked his wife what she wanted for her 40th birthday. Since Linda knew that Kevin was an avid golfer, she asked him to have a golf outing for Families of SMA, in honor of their son Eric. They have hosted this golf outing every year since then! The event is always held on the 2nd Monday in October, which was October 9th this year. They have received a tremendous amount of support from the local community and businesses. Their son Eric is now 21 years old, attending the West Virginia University, as a double major in journalism and psychology.

This year’s event was held in South Charleston, WV and had over 90 golfers. Eric gave out the awards to the golfers. He also putted again to raise extra funds! They have family members that run the raffle board, help with the putting and registration, as well as make the raffle baskets. This year’s golf outing raised $18,500 for Families of SMA, bringing the total amount raised for Families of SMA, since 1996, to over $220,000!!!

Jim & Catherine Giroir and the James Patrick Giroir Fund held the 4th Annual Party for a Cure. This September event raised over $17,000 for Families of SMA in memory of James.

The Alabama Chapter hosted the “First Annual Swing Fore a Cure Golf Tournament” in memory of Piper Olivia Willingham and Baylee Grace Peterman on Thursday October 19, 2006. They raised $16,400.

Joseph & Jenny Imhoff, of New Berlin, WI raised additional funds from “Rally for Reagan – Golf for A Cure”. They have raised a total of $12,150 in honor of their daughter Reagan.

Kevin & Karen Rummel and A Cure for Connor, of Roslyn Heights, NY, hosted their 4th Annual Golf Outing on October 5th. The “A Cure for Connor” event raised $10,000 in honor of their son Connor.

Ann and Keith Crews and family, of Warrington, PA, hosted a “Walk Away SMA” in loving memory of their son Gavin Patrick Crews. They raised $9,000 for FSMA and had a great time doing so. Gavin’s brothers and sisters still take an active roll in fundraising for the hope that someday a cure for SMA can be found. A special thanks to all of their friends and family for their help in keeping Gavin a part of their family.

Dear Families of SMA,

The triathlon was a huge success! I had 93 participants compete and we raised approximately $4,450. We had a blast too! The weather was perfect and everything that could have gone wrong didn’t, I definitely had some help from above.

Sincerely,
Holly Friede of Seeley Lake, MT (in honor of her son Brandon)

www.curesma.org
Each year at the holiday party for the W.R. Berkley Corporation, in Greenwich, CT, they hold a gingerbread house auction, whereupon employees can volunteer to create gingerbread houses. Each gingerbread house is auctioned off individually among the employees in attendance, with the baker of each house selecting a charity to donate the monies of the winning bid to. Each gingerbread house winning bid amount is also matched by W.R. Berkley Corporation and donated to each charity. Carol LaPunzina, of Demarest, NJ, selected Families of SMA as her charity of choice! The winning bid for her gingerbread house was $4,400, which was then matched by W.R. Berkeley Corporation! They raised a total of $8,840 in honor of Laura Nellen.

Mike and Abbie Dougherty, Maria Stone, along with their friends and family in Charlotte, NC, held the 8th Annual SMashing Kickoff on Saturday November 4th. The event was at the North Carolina State vs Georgia Tech game. They raised $7,500 for Families of SMA.

Marge Shively, of Los Altos, CA, held another successful “Trick or Treatment for SMA” campaign! She raised $6,905 for Families of SMA, in memory of her granddaughter Jessica Fernandes.

Bruce and Delores Fry, of Winchester, VA, held their 8th Annual Golf Tournament in memory of Derek Smith. It was another successful May tournament, which raised $4,175 for Families of SMA.

Hope Lutheran Church, in Comanche, TX raised an additional $3,398 from a chili supper and sausage sales in memory of Braden Campbell and in honor of Tambryn Campbell, through the Tumbleweed Wagon Fund benefiting Families of SMA.

St. Germain Elementary School, in Saint Germain, WI raised $1,766 from their “Project Vinnie Penny Challenge”, honoring 5th grader Vinnie Kadlubowski.

The Staff of Shongum Elementary School, in Randolph, NJ, chose Families of SMA as the charity to support during the holiday season. In lieu of holiday gifts, the 23 participating teachers asked students to donate to FSMA, which raised $1,760.

On Tuesday, February 13th, the Waukesha North Girls Basketball Team, in New Berlin, WI, hosted a “Rally for Reagan” fundraiser to support former teacher and basketball coach Jenny (Larson) Imhoff’s daughter Reagan in her fight against SMA. Fans could buy tickets for the 50/50 raffle and other half time events to win prizes. The night’s big winner of the 50/50 raffle was Cathy Ludwig, who so very generously donated her winnings to FSMA. Before tip-off of the game, The Imhoff family was surprised with a check for $500 from the Waukesha North High School Key Club and Interact Club’s lunch time sundae fundraiser. The night was very enjoyable and a great success raising $1,360 for Families of SMA. Thanks to Kaitlyn Cooper, Arica Ludwig, Coach Gilmore, Nancy Billingham and the Key/Interact Clubs for all of their hard work!
Amy Albrecht and Tiffany Benzal, from Hanover, PA, made pink and brown beaded bracelets. The bracelets have a charm with the letter E, which stands for Emmy Rose Baugh. They sold the bracelets to family, friends and strangers and raised $810 for Families of SMA, in memory of Emmy.

Eileen Lerner, of Delray Beach, FL hosted a “Holiday Sale” on December 6th, at Convery’s, in honor of her grandson Zeke Lerner. Several of her co-workers created items, such as holiday center-

pieces, jewelry or fudge, which are appropriate for gift giving. They raised $806 for Families of SMA. Over the last few years, the proceeds from the holiday sales and ongoing book sales have raised over $5,500 for Families of SMA!

Miss Kilian’s second grade class, in Ridgefield, CT, raised funds in honor of their classmate Cubby Wax. They raised $750 for Families of SMA.

Margaret Behm, of Libertyville, IL raised $546 hosting a “Pampered Chef” party in honor of Leo Kullander.

Grubb & Ellis Management Services, in Southfield, MI raised $260 from the proceeds of a “Book Fair” held in honor of Sydney Grace Potjer.

USAopoly, Inc, of Carlsbad, CA, raised another $125 in honor of Skylar Bahrenburg. The funds are raised from the royalties of the sales of “USA’s Finest Cities” edition of the Monopoly Game.

Each year the Greater Clark County Schools, in Jefferson, IN, draws a name from the list of employees at the Administration Building. The person whose name is drawn chooses a charity to raise funds for. During that year, funds raised from their “Casual Fridays” go to the charity. Families of SMA was chosen for their “2006 Casual Fridays”. They raised $119 in honor of Colby Russ.

Barb Lewis, of Morehead, KY, held a Longaberger Fundraiser in honor of Adora Lewis. She raised $100 for Families of SMA.

The employees of Hanover Pediatric Associates, in Hanover, PA, paid $5 each to wear football jerseys to work as a fundraiser. They raised $91 in memory of Emmy Baugh.

Karlene Henshaw, of Homewood, IL placed a “Collection Container” at her physical therapy facility and raised $76 in honor of her granddaughter, Chloe Ochoa.

Michael Derass, of Duluth, MN put out a donation can at his coffee shop. He raised $50 for Families of SMA.

Lana Weisenberger, of Mosinee, WI, made “Tessa’s Angels” ornaments with her siblings, to raise funds for FSMA. They raised $200 in honor of her daughter Tessa.

The 5th Annual Jack Rabbit Run took place in Kirtland, Ohio on September 10th. The run was dedicated to the memory of William Scott Blumensaadt who passed away at nine months of age. His mother, Jennifer, spoke about how he taught them more about love, humility, and the importance of a strong loving family during his short life.

Many families were involved and helped to raise funds in honor of Vinny Rini, Tylar Michalski, Bryce & Alexis Wilson, Halima Truesdale, Alivia Kobal, Jack Kotheimer, Tommy Testa, Michael Brodsky, Brandon Johnson, Kylie Gerhardstein, Dan Darkow; and in memory of William Blumensaadt, John Turner, Madison Vickers, and Jack Karpanty.

In addition to the run/walk there was a large raffle, clowns, music, lots of food, booths sponsored by Starbucks Coffee, Wild Oats Natural Market and Canine Companions, kids fun run, awards, and much more. The Inlet Dance Theatre performed to a piece called “Ascension”. The dance concluded with a symbolic release of butterflies that carried prayers and wishes for a cure. The Jack Rabbit Run/Walk raised over $60,000.
MEMBERSHIP form

**Suggested Annual Donation for Membership**

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

**Payment Method**

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

$ Amount enclosed or to be charged

Credit Card #

Expiration Date

Name on card

Signature

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

SP07
**Donation Form**

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

In honor of

In memory of

Donor Name

Donor Address

Notice of donation—Name & Address

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

Credit Card #

Expiration Date

Name on card

Signature

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

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**Gift Certificate Order Form**

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

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

Subtotal $________

Shipping $________

Total $________

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

Credit Card #

Expiration Date

Name on card

Signature

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

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**Merchandise Order Form**

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

Subtotal $________

Shipping $________

Total $________

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

Credit Card #

Expiration Date

Name on card

Signature

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

Many of you may already know that Rebecca was the Wisconsin Families of SMA Vice President, and unfortunately passed away in October due to breathing difficulties related to SMA. This has been a very difficult time for her friends and family. We all want everyone to know who she was and her important contributions to society. I knew her as my little sister and best friend. Here are some words I wrote for her obituary that describe who she was and just a few of her accomplishments:

Rebecca J. Diels, age 28, passed away the morning of Thursday, October 26, 2006 at UW Hospital in Madison. She was born on April 7, 1978 to parents Gary and Jeanette Diels. Rebecca lived with type I/II SMA that challenged her physically, but not mentally. She did not require an able body to live life. In fact, Rebecca was currently attending college and taking courses in web design, and was well on her way to starting her own web design business. We remember Rebecca as a kind, compassionate, flirtatious young woman with a fiery spirit and a brilliant mind. She had a passion for the arts—poetry, writing, graphic design, music, theater and film. Beck had a great sense of humor, calling herself, “a tad sarcastic,” and referring to her stomach tube as a “belly piercing.” Rebecca had strong opinions and made it clear that she, and any other physically challenged person, deserved respect and the ability to make their own decisions about health care and daily living. Her hope was to educate the ignorant—she was disappointed in the lack of interest in Spinal Muscular Atrophy and went to great lengths to change this. Beck has dedicated the past several years of her life to connecting those afflicted with SMA by creating an SMA friends list that currently has 400 members. They now have a forum to, in her own words, “chat, laugh, learn, cry, relate, and help,” which will continue forever in her memory. Beck also helped organize SMA fund raising events.

I was not aware of this at the time, but her brother Brian discovered that she had been offered a full-time position as a Wisconsin Quality Home Care Commissioner. Kathleen Falk (Dane County Executive) appointed four advocates to serve as Commissioners and work together to improve home care in Wisconsin. Rebecca passed away before receiving this notification. Months earlier, Beck had sent a letter expressing her support of the Commission and describing her own personal experiences as evidence of the need for the Commission. On November 2, 2006, the Dane County Board observed a moment of silence during their meeting in her honor and expressed regret that they did not get the chance to work with her.

We all miss her so much…those big beautiful brown eyes, sarcastic wit, incredible generosity, and a desire to change the world for the better. I believe she did change the world for the better and I hope we can at least attempt to continue positive change in her memory.

Miss you Beck…Ma Soeur, Mon Amie, your sister Tracey
FSMA merchandise

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

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

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

Angel Wing Pins | $10

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

FSMA Tote Bag | $10

Cotton Tote bag with Zipper | $17
Together design.

FSMA Tote Bag | $15
2-sided design.

Canvas Tote | $10
CureSMA design.

SMA Sticker | $2
Created in memory of Madison Vickers

FSMA Travel Mug | $12
Keep your coffee hot!

FSMA Car Magnet | $5
1 design.

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

License Plate Frame | $7

FSMA Lapel Pin | $5
Spring Note Cards | $6
Alyssa Silva’s “Working on Walking” note cards. 6 different cards.

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

Donation Gift Card | $10 ea., 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.

Cookbook for a Cure | $14
The FSMA cookbook contains almost 400 recipes from SMA families all over the world!

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

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

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

Cure SMA Bracelet | $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.

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.
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
Janet Schoenborn, President–illinois@fsma.org

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

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

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

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

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

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

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

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

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

Pacific Northwest (since 2006)
* New Chapter
P.O. Box 173
Galvin, WA 98544-0173
(206) 861-3587
Rick Jones, President–pacwest@fsma.org

Pennsylvania Chapter (since 2003)
Box 4307
Philadelphia, PA 19118
(866) 647-8113
Karen McCrory-Negrin, President–kmcnegrin@comcast.net

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

South Jersey/Delaware Chapter
(since 2002)
PO Box 538, Medford, NJ 08055
Tel: (866) 774-9533
Jessica Moyer, President–jnjmoyer@comcast.net

Southern California Chapter
(since 1999)
1070 E. Orange Grove
Burbank, CA 91501
Tel: (818) 846-6589
Rosemary Roope, President–scalif@fsma.org

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

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

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

Are you interested in starting a new chapter for Families of SMA?
Please contact our Chapter Coordinator, Barb Trainor at fsma-chesapeake@comcast.net
**Long Island Chapter**

The Long Island Chapter will host its annual Walk N Roll on Saturday, September 15th on the Long Beach Boardwalk at 10am. Details will be on the chapter website. There will also be a meet and greet in May where there will also be a demonstration from Canine Companions.

**New England Chapter**

The Massachusetts Chapter is excited about their upcoming Sports Night hosted by Little Battlers Foundation, (www.littlebattlers.org) an organization dedicated to helping others fight infant and childhood disabilities and diseases, to help FSMA with their fight against spinal muscular atrophy. All proceeds raised will go directly to FSMA. (www.fsma.org) The event is being held at the end of March at the Sports Zone in Dracut MA (1734 Lakeview Ave, Dracut, MA 01826) with local boxing legend Micky Ward in attendance.

On Wednesday, December 27th, 2006, alumni hockey players from North Country Union High School in Newport, Vermont, gathered to battle it out at the Stanstead Hockey Arena. According to Ed Gaudreau, event coordinator, over 30 alumni hockey players registered to play and the stands were filled with longtime hockey fans.

Approximately $1000 was raised from registration fees and donations. Ed Gaudreau is unclad to Jennifer Gaudreau and Eric Binette, who also played in the game. FSMA thanks all those who participated and donated. Your efforts are greatly appreciated!

**OKI Chapter**

**Xavier Students Provide Valuable Assistance to OKI Chapter**

Students at Xavier University are lending their skills, experience, and enthusiasm to help raise awareness of SMA and to assist us in promoting our “Walk-n-Roll” which will be held on the Xavier Campus on Saturday, April 14. Elizabeth Lockwood and Rosemary Hilston made a presentation to the Public Relations Student Society of America (PRSSA) in October. The students offered to form a committee to explore ways in which they could use their public relations skills to help our organization. PRSSA students then attended our “Walk” meeting on January 15 and, while observing our planning, offered ways to help. First, they will assist us in a “Crosstown Roll Out,” a promotional event which is scheduled for Thursday, March 29 during the lunch time on Fountain Square. The idea, proposed by Caitlyn Brown, is to hold a wheelchair relay competition between the PRSSA of Xavier University and the PRSSA of the University of Cincinnati to draw attention to the disease that is SMA and also to promote our “Walk” which is two weeks later. Caitlyn also feels this is a great way to educate the XU and UC students about what it’s like to be in a wheelchair. The obstacles they face in the relay represent the obstacles people in wheelchairs face in their everyday lives. Jen Dalton and Bob Herzog — our Honorary Chairpersons from Channel 12 — will emcee the event on Fountain Square and, hopefully, Channel 12 will cover the activities. The PRSSA of Xavier has also offered to donate an iPod Shuffle as one of the prizes. In addition, the PRSSA will help us to develop a better press kit and assist us in obtaining more feature articles in local publications. The October presentation to the PRSSA, led to an invitation to our OKI Chapter from the Senior Seminar - Public Relations Management to be their client to work on solving public relations problems being experienced by our Chapter. A few from the Chapter will attend the Senior Seminar on February 12 from 6:00 p.m. to 7:30 p.m. to outline the challenges of raising SMA awareness. The Senior Seminar students will work on the project throughout the semester with Chapter members attending some sessions and, otherwise, communicating by e-mail. At the end of the semester, the teams will present solutions and offer resources to help the OKI Chapter better communicate with the community and hold more effective fundraising campaigns. The Occupational Therapy students and alumni of Xavier University continue to support the activities of the OKI Chapter as they did for last year’s “Walk.” OKI members are working with the O.T. students and alumni to outline ways in which they can, again, add valuable interest and activities to the “Walk-n-Roll.” The O.T. students are hoping that more SMA children will attend the April 14 “Walk” so they can interact with the children and demonstrate some O.T. strategies and techniques.

Kennedi Vondrak in her new manual wheelchair (Iowa Chapter)
Rocky Mountain Chapter
Our 8th Annual 5K Walk-n-Roll For Our Angels held on September 9, 2006 was another tremendous success raising over $18,500!

Caren and Jesse Green started this event in memory of their daughter, Emily. Norma Green, SMA Type I. The Green family continues to be a tremendous support to our chapter. Caren has served as vice president of the Rocky Mountain Chapter since our inception. It has been Caren’s mission to help fight SMA so future families won’t have to face the challenges and heartache that come with this disease. Thank you, Caren and Jesse, for starting something great in Colorado!

The Annual Walk-n-Roll has always been held in Colorado Springs. With research at new heights, the need to raise SMA awareness and more funds brings us to expanding this event to two cities. The 9th Annual Walk-n-Roll for Our Angels — Colorado Springs will be held in June 2007 and 1st annual Walk-n-Roll for Our Angels – Denver will be held on Sunday, August 26, 2007 at Clement Park, Littleton, CO.

Both events need your help through committees, volunteers, sponsors…do your part for SMA and join us!

Zoe Grisz got a surprise of a lifetime when she met Ace Young and the entire American Idol crew at their concert in September, 2006!

South Jersey/Delaware Chapter Update
It has been another busy year with many families becoming involved and hosting their own fundraisers. This past fall and winter, Ann Crews and family hosted Walk Away SMA and raised over $9,000 for SMA in memory of Gavin Crews. The Halabura/Contento family ran the SMA booth at Indian Acres Tree Farm in Marlton, NJ and brought in over $1500 in donations through children’s games, crafts, baked goods and auction items. Jeff and Lisa Wood hosted their Third Golf Tournament in Hamburg, NJ and raised about $30,000 for the chapter in honor of their daughter Elizabeth. Way to go! Steve Moyer hosted the fourth annual SMA golf tournament in PA and raised $2,000. Thanks Dad, in memory of Steven! In December Trish Rudisill, a friend of the Potter family, held a gift wrapping table at Barnes and Nobles for 10 nights and raised over $250 in honor of Steven Potter. In December the Zdep family did a letter campaign in memory of their son Alex and donations are still coming in. Also, Michelle Apgar, a friend of Anna Zdep, donated sales from a pampered chef party and donated over $600 to the chapter. Lastly, Francine Eisenmann hosted a Pampered Chef party and donated many items for an upcoming fundraiser and in addition collected gifts and donations from friends the past year for Steven’s Gala. Thank you Francine!

We have a busy fundraising season coming up starting with Steven’s Gala for SMA on Feb. 23rd at the Crowne Plaza in Cherry Hill. On Feb.24th Young Children’s Center for the Arts will partner with FSMA in memory of Camryn Kepple to raise money for both charities at the National Constitution Center in Philadelphia. Special guest The Soup Nazi from Seinfeld will be there. On Monday, May 7th, we will host the second annual Steven’s Swing for A Cure at Jonathan’s Landing in Magnolia, Delaware. Please contact Jason Moyer at 866-774-9533 or email jnjmoyer@comcast.net for more details. On May 12th, the Second Annual Benefit Ride to Fight SMA will be in Horsham PA. For info please contact Chris at 215-674-1475 or email MJMCalvaryRiders@verizon.net . On May 19th, the Potter family will host Stevens Walk for SMA at Newton Lake Park in Haddon Township. Registration begins at 9:00am. Please contact Terri Potter for details at 856-869-9072 or email m.potter9@verizon.net. Lastly, on July 15th Jimmy’s Swim & Swing for a Cure Families of SMA Fun & Fund Day will take place at Ramblewood Country Club in Mt. Laurel, NJ. For more info contact Corinne Halabura at halcontent@comcast.net .

Back in July, AHMD honored Jessica Moyer, president of the chapter, with their annual Wellness Award and raised over $12,000 through company donations. Thank you to Bill Previdi and Jackie Hill for nominating FSMA and coordinating this noteworthy event. An SMA Oldies night in September brought in over $2,000 for the chapter. Thank you to Cheryl Cirelli and Diane Wolf for coordinating this fun event.
For questions regarding any of the above fundraisers or information on the chapter, please contact 866-774-9533 or email jnjmoyer@comcast.net. Please check the FSMA calendar for additional events.

Southern California
The Southern California Chapter’s Walk-n-Roll event was held for its second year at Johnny Carson Park, November 5th in Burbank. It was the perfect Southern California day—sunshine and mild-to-warm temperatures. Add to that dozens of generous volunteers and almost 400 walkers and rollers raising more than $41,000!

The 4th annual Zeke Lerner Celebrity Bowl-a-thon, benefiting Families of Spinal Muscular Atrophy, continues to get bigger and better. This year’s event took place Oct. 28th at AMF Rocket Lanes in Chatsworth, California and raised an all-time high of $33,000!

Western New York
The WNY Chapter is busy getting ready for the 4th Annual SMArt Walk on August 4th. Our corporate letters will be mailed late February or early March and the walk flyers will be in the mail by the end of May. All the park permits and insurances are in place and we have once again been able to get free parking at Beaver Island State Park. At our walk this year we are also planning a car raffle to help raise money for a cure. The vehicle, a GM HHR van, has been donated at cost from KiPo Chevrolet.

Also, as part of the raffle, we will be giving away gas cards for 1st, 2nd, and 3rd prizes. We also plan on our basket auction and 50/50 split.

The 5th Annual Kale Shiesley Volleyball Challenge will take place on April 21st. The challenge is organized by Kale’s uncle Rob Litten and every year it is a success. The event has grown from the first year when just a few players showed up to last year when players had to be turned away. A dinner and raffle follow the event.

The Wyatt Walk is scheduled for May 5th in Niawanda Park, Tonawanda, NY. This will be the 8th annual walk sponsored by the Wyatt Kyle Sutker Foundation, LTD. The foundation was started by Steve and Julie Sherman Sutker after the death of their son, Wyatt to SMA Type 1. The goal of this foundation is to raise funds to support research directly related to SMA Type 1.

The Wyatt Walk is co-chaired by Wyatt’s grandparents Jon and Sally Sherman. About 200 people attend each year and along with sponsors are able to raise over $20,000 each year.

Mary Bognuh has initiated a Parents Advisory Council at Women’s and Children’s Hospital of Buffalo. The goal is to improve the model of care in the Neuromuscular and MDA Clinic. The council will work as a liaison between hospital, medical staff, and families to improve the care, outcome and quality of life for patients with pediatric neuromuscular disorders.

Mary has also established a list of websites that offer valuable information on ways to cope with issues involved with SMA. These sites can be found on our website, www.wnyfsma.org.

Angelica Catalano, cousin to Alex Blair, has been awarded the Community Leader Youth Award from the National Federation for Just Communities of WNY. She became involved in researching and community service for Spinal Muscular Atrophy after her cousin was diagnosed with the disease. Since then, Angelica has joined FSMA and participated in the SMArt Walk several times. She collaborated with the WNY Chapter of FSMA to organize a benefit concert featuring her cousin, recording artist, Teddy Geiger. This concert raised $4,400 for research, family services and awareness programs.

On February 18th, the WNY chapter hosted a Valentines Day Ice Cream Social. The kids were able to make their own sundaes after a lunch of pizza and wings. Games and crafts also were available along with Build-a-Bear. Proceeds from Build-a-Bear were donated back to FSMA.

Pacific Northwest Chapter
The Pacific Northwest Chapter just completed our second meeting and Valentines Day party.

Because our territory is so large, our fundraisers this summer will include growing an existing golf tournament in central Washington, growing an existing Walk and Roll in Forest Grove, Oregon and starting a brand new Walk and Roll event in Seattle.

We have established a nice solid core of 8-10 families, but would like to get many more families involved.
The most recent edition of The Jeffrey Journey is now available from author Helen Baldwin. Helen wrote the book as an “honest account of our family’s introduction to SMA, its rounds of destruction, and the unexpected blessings.” It also includes a CD of music, Dreams for Jeffrey, written by Helen’s mother, JoAnn Derden. There is a special dedication in the book to honor and remember those with SMA. For more information about the book, or to add your child’s name to the list contact Helen at jeffreyb@skybest.com.

Illustrator, father of Tori, and FSMA member Jeff Wissman is proud to be a part of a new project “Snowball the Amazing Duck” with authors Dr. Donald Burnell and Garrett Burnell. It deals with a family that foster parents an orphaned duck. A portion of it is fiction while the other portion is non-fiction. A small child and his father are bonded closer together in the way that they feed and care for Snowball. Later in the book the duck comes to the rescue of a drowning girl. To those around him he is considered a hero. However, he simply states, “I saved her because it was the right thing to do.” Many of life’s lessons can be learned from this 45 page story. A percentage of every book sold will be given to FSMA. The book is available from Barnes and Noble.com

In “What Lies Behind His Eyes” you will find inspirational messages from 25 year old Buddy Bryan, who has Spinal Muscular Atrophy, and has lived in a nursing facility since the age of 6. In this book he shares his inspirational messages of how his spirituality has helped him cope with his life and grow into who he is today. He has advocated to the State of Florida on different occasions for people with physical disabilities to have more opportunities to live a normal life. He doesn’t let his disabilities get in his way, and he attributes all of this to his spirituality. The book is available on Amazon.com.

Families of SMA is now a Mission Fish eBay seller!

It’s easy to use
Any seller can donate to FSMA while listing an item on eBay. Sell anything from collectibles to cars and donate a portion through eBay Giving Works.

You control what to give
Give as little as 10% or as much as 100% from anything you sell ($5 minimum donation required). And with eBay’s generous fee credit policy, a percentage of your insertion and final value fees equal to the percentage you’re donating will be credited back to your account!

Your listings stand out
This icon sets your eBay Giving Works item apart on eBay as an authentic charity item, and the giving bar tells buyers how much you’re giving away. Plus, your listing shows up in the category you pick, on eBay Giving Works, and on the nonprofit’s MissionFish page: it’s like getting three categories for the price of one!

It’s tax-deductible
Every donation made from an eBay Giving Works listing is completely tax deductible. MissionFish collects your donation, delivers it to FSMA and provides you with a tax receipt.

Tumbleweed’s Wagon Fund
We would like to thank each of you who have requested and received a wagon via Tumbleweed’s Wagon fund for SMA. It is indeed a bittersweet emotion that so many of you have found the wagons to be useful and helpful versus the fact that we are still without a cure and that a need still exists. As of this writing, the wagon fund has received over $20,000 from donations in memory of Tumbleweed (Braden Campbell) or in honor of Tambryn Campbell. Currently, over 95 wagons have been sent to families. We will continue to fight for a cure by directing 50% of all donations toward research and by supplying type I’s with wagons from the remaining monies.

We need your help in filling a void that Jenny and I harbor in regard to Tumbleweed’s Wagon Fund. That void is our inability to see pictures of your child and family enjoying the Radio Flyer Wagons. It would warm our hearts if you would submit such photos to us and grant us permission to place on our “yet to be established website” and to use them on a DVD designed for use in fundraising activities. If you are interested, please entitle your e-mail “Wagon Photos” so we can recognize them in order to avoid accidental deletion or being lost in the “junk mail” folder. Submit your photos, or contact us at dvcroket@hotmail.com or bcampbell29@msn.com

Brad, Jenny, Tambryn (type I), Braelyn & ^i^ Tumbleweed
Transcript of SMA Clinical Trials Chat on Thursday, February 15, 2007

The following is an abbreviated version of the Chat with Dr. Sandra Reyna and Dr. John Kissel. Dr. Reyna is the project manager for Project Cure SMA in Salt Lake City and Dr. Kissel is a researcher and specialist in SMA at the Ohio State University and a Project Cure SMA Team Investigator. A full transcript is available on the FSMA web site.

sp: Hi Dr. Kissel, is any SMA trial test specifically crafted by type (1, 2, 3) or is it generic?
sl: What are the inclusion and exclusion criteria for the valproic acid study?
dr_kissel: Most trials of SMA are targeted specifically to one group, and up to this point, most studies have focussed on the type 2 and 3 patients. We don’t have space to go into inclusion/exclusion criteria for all studies, but they are available on the Project Cure SMA web site www.projectcuresma.org. Since the genetic defect is the same for all three types, we are hoping that what helps one type will help the others. Project Cure is also planning on future trials in adults, as well as patients with other types as well.
dr_reyna: Project Cure SMA submitted an adult SMA study proposal to the FDA for review and it has been approved and we are in the last stages of IRB and other regulatory final approvals. We expect to be able to announce this new clinical trial in few weeks. It will be a single site study and Dr. John Kissel is the principal investigator at Ohio State.
dr_kissel: All of our regulatory documents are in, and we have funding from FSMA! We are waiting for final approval of the IRB (human subjects) protocol! The study is part of the Project Cure initiative!

ll: If one has taken valproic acid in the past can they be allowed in the study?
dr_reyna: First you must meet all inclusion criteria in order to be considered a possible study subject. Then, as long as you are not taking Valproic Acid at the time of study enrolment, yes you may be able to participate in a clinical trial using Vaproic Acid as the study drug. If you are taking the medication currently, you will need to go through a wash out period when you are not taking any medication.

f: Do you know when the SMA Carni-val clinical trial will be wrapping up? Is there anything you can share with us so far?
dr_reyna: The SMA CARNI-VAL’s last study visit is scheduled for Nov 2007. We are working towards data analysis with the intention of being able to present these findings at FSMA meeting in June 2008.

z: What are the most promising details related to CARNI-VAL tests, and which types of SMA benefit most?
dr_kissel: I am not sure exactly what you mean, in that the CARNI-VAL trial is blinded, so we really have no results, and not even any “hunches” yet. We, like our patients and families, are simply waiting for the study to be finished and data analyzed.

ll: I have read and get a little confused about the different phases of clinical trials. Is the current trial looking for efficacy?
dr_reyna: SMA CARNI-VAL is a phase II trial which means that its main focus is to define a therapeutic dose range and to establish efficacy, side effects, and clinical toxicity of the study drug. Most clinical trials are designated as phase I, II, or III, based on the type of questions that study is seeking to answer:

• In Phase I clinical trials, researchers test a new drug or treatment in a small group of normal volunteers or to a carefully defined subject population under controlled conditions to obtain preliminary data on drug safety, to determine a safe dosage range, and identify side effects.

• In Phase II clinical trials, the study drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety.

• In Phase III studies, the post marketing studies delineate additional information including the drug’s risks, benefits, and optimal use. These phases are defined by the Food and Drug Administration in the Code of Federal Regulations.

f: Assuming there are positive results seen in the SMA CARNI-VAL Clinical Trial, when will patients excluded from the trial have an opportunity to receive treatments?
dr_reyna: Clinical trials are traditionally classified into four phases (Please see the classification above in one of the other questions). SMA CARNI-VAL is a Phase II study. Each phase of development leads to a greater understanding of the attributes and uses/indications of the compound in question. Our goal is to continue to follow through all phases of clinical research to analyze the effects of the test treatment and do so through FDA approval.

f: Is it true the SMA CARNI-VAL clinical trial is focusing on younger children because younger children have a greater response to this particular drug? If so, what funding and research efforts focus on the search for a cure for anyone over the age of 8 years old?
dr_reyna: New clinical trial designs for SMA children are always a concern to Project Cure SMA investigators. We are constantly looking for potential study drug(s) that can be used safely in all age groups, as well as other clinical trial designs to include different study SMA groups (i.e. age groups, SMA types, inclusion/exclusion criteria, the use of other functional motor scale as a test scale, etc.)

f: We have heard that there are some clinical trials with hydroxyurea and phenylbutrate. Are you involved in these or do you know if any of them have shown promise thus far?
dr_kissel: A study of phenylbutyrate in children with type 2 disease was just published and was negative, but it was a relatively short duration study (13 weeks). Studies in hydroxyurea are ongoing, although a preliminary study was not encouraging.

sl: Who will be able to participate in the drug study at OSU?
dr_kissel: The Project Cure adult study is for ambulatory type 3 and 4 patients over age 18 with DNA proven disease. Patients need to be able to walk 30 feet without assistance such as a cane, crutches, or braces.

ll: Will the adult study be placebo controlled?
dr_kissel: For the first six months, it will be placebo controlled, and then everyone will get the drug.

hv: Are there any clinical trials planned involving oligonucleotides?
dr_kissel: To my knowledge, there are no clinical trials currently planned with oligonucleotides, but there is much basic research going on in this area. It is really a “hot” area of research now for all of the genetic diseases.
My Cousin Kiley

By Steffany A. Sweet

I have a very special cousin, and her name is Kiley McClay. She is four years old and has Spinal Muscular Atrophy (SMA). Kiley cannot walk and she is in a wheelchair.

Kiley is a caring, funny and unique cousin who is fun to be around. Every time we’re with her, she always has something to say that makes us laugh. She is also very kind and sweet.

Apple is Kiley’s pet cat. He is black and very shy. Whenever we see him, he always runs away.

My cousin has nicknames for my sister and I, and these are what they are: Britty (my sister Brittany), and Steffy (me).

Kiley lives in Centralia, Washington and is in preschool. She has a brother and his name is Quinn. He is two years old.

Kiley lives with her Mom, Dad and brother.

She goes to California to get medical treatment, and she flies on an airplane every time she goes. She also has water therapy in a swimming pool. She really enjoys the water.

Their van is equipped with a ramp, so Kiley can get up and down easily. I help to raise and lower the ramp with a switch.

She likes to have fun just like the rest of us. When she comes to my house, we all go outside for a walk. She loves to cruise around in her wheelchair. She is a great driver and can go almost anywhere.

Kiley is going to be getting a new wheelchair, and she will be able to stand up in it. It is called a Standing Danny.

This past Halloween Kiley dressed up as a cowgirl, and Quinn dressed up as a cowboy. They had a party for the kids with SMA. There was one boy who made his wheelchair look like a boat, and he was dressed up as Sponge Bob. He won the prize for the best costume.

One of my favorite stories about Kiley was when we were at an SMA garage sale fundraiser. My aunt Rozie asked me to watch Kiley and walk with her around the neighborhood. One of the neighbors thought she was so cute and wanted to give her a corndog to eat. I had to be in charge and say that she could have the corn dog. But the good part is I got one too! Everyone was surprised when we came back from our walk with lunch in our hands!

So as you can see, my cousin is a very special person. Even though she can’t do some of the things other kids can, she’s just like any other person. So if you see someone who is in a wheelchair, get to know them. Play with them. Have fun with them. I bet they are special just like my cousin Kiley!

About the author

Steffany is eight years old and lives in Tumwater, Washington. She lives with her Mom, Dad, and older sister. Steffany is in the third grade and likes to play basketball.
Dear Families of SMA,

On September 19th of 2006, our son’s preschool the “Kathy Herwood Center” in Andover, MA, held a mini Walk and Roll event. The teachers talked to the students in the classroom about SMA and what its effects are. They then walked a quarter mile around the school parking lot. They did this to show support for our son and their fellow student Joseph Miller, age 4 who has SMA type II. The school used the event to help teach good citizenship and the value of helping others. The school is going to try to make this an annual event. My wife and I were surprised to say the least when the school approached us with the idea. The event may have been used by the school to teach a lesson to the students, but I can’t say enough about what it did for us. It was a real shot in the arm to see all the children doing what they can to help support our son and raise money to find a cure. They raised $358.

The Miller Family – Dena, Joseph and Eric

Vent Camp

By Jack Freedman, age 11

This summer I went to Camp Victory, a vent camp near Scranton and Harrisburg in Pennsylvania. It was a long drive. It took five hours. Camp was from Sunday to Thursday. I did not bring shoes because it was summer. Mom and Dad brought medical equipment and taught the nurses how it worked. Two of my nurses were Ellen and Emily. Some of the helpers were Lori and Brian. Brian poked on my nose and made me laugh.

I cried Sunday and Monday nights because I missed my Mom and Dad, but not on Tuesday or Wednesday. I woke up at 7:00 a.m. and had breakfast at 8:00 a.m. every morning. I yelled, “Wake up, everybody it’s morning!” Sometimes I made Tarzan sounds to wake everybody up.

I liked to hang out in the activity room. One time I was pretending to eat chips and use two remotes while I was watching “Lilo and Stich.” I had fun swimming in the pool with my respiratory therapist, Tomi. I swam with a float. We swam in the rain because it rained for three days! Kelly, a girl in a neighboring cabin, swam with me.

On Monday night, there was a talent show. My friend, Mason, and I hung out in the rain, having fun relaxing on the porch. I knocked over trash cans with my wheelchair. I had a good time.

We had a carnival in the cafeteria on Tuesday night, and I stayed up late. Kids were getting rides in a dog sled. I watched them. Emily helped me throw a ball at a throwing ball game as Ellen watched. I tried to hit the piñata but it was too hard for me. We had a big thunderstorm after the carnival. I was afraid of the storm and I didn’t cry, but I felt like it.

The rain finally stopped on Wednesday. It was a beautiful day. We did lots of playing in the soccer fields. I tried to push the ball with my chair but it hurt my toes.

At night we had a luau. DJ Big Dog played music in the cafeteria but it was too loud for me. Stephanie (who took care of Mason) danced with me. We did the “Hokey Pokey” with Brian.

Thursday, another beautiful day, was when Mom and Dad and Cara picked me up. The pond outside had a fountain in it. I really liked that. I was happy. I want to go to camp every year.

To learn more about the Pennsylvania Vent Camp at Camp Victory www.campvictory.org Held annually the last week in June go to www.hmc.psu.edu/ventcamp

Congratulations to Allegra Keys. We just learned that last year Allegra won a City of Seattle scholarship for kids who improve their community! Thanks for showing that kids with SMA can really make great contributions!
Julie and Grace Crews, of Warrington, PA, provided face painting and made bracelets raising $200 in memory of their brother, Gavin Patrick Crews.

The Stars Team, of Longview, TX wrote:
First of all we want to thank you for all that you do. Everyone appreciates it. Here’s a donation of $125 for research. I also want you to know that we are praying for all of you everyday. We got all of this money through donations. We got these donations by putting boxes out and kindly asking for money for SMA, we also had a picture of Matthew Wallis. Thank you for all that you do!
With hope, The Stars Team
P.S. Did you know that Matthew is 7 years old?

Dear Families of SMA,
In an effort to help raise money to find a cure for SMA, I have sold SMA bracelets at my local schools. I am enclosing checks totaling $1,483. Selling the bracelets not only helped me raise money, but also helped raise awareness in my local area. In December, I will be speaking at one of the elementary schools about SMA and living with it everyday. It made me feel good to see the generosity of both the students and their parents.
I hope to be speaking more on behalf of Families of SMA and raising more money in the future. I want to thank you for all the help that you have provided both my family and me over the last 13 years, since my diagnosis at age 2.

Love to all,
Laura Nellen of Demarest, NJ

Dear Families of SMA:
I really hope the doctors are able to help children with SMA. I would really like them to find a cool weapon that makes the children not have SMA anymore. For my 5th birthday, I collected money to help the doctors with this instead of getting presents but I still got lots of presents. All the money I received is with this letter - $280. I hope the babies get the shots so they can get better for ever and ever. My cousin, baby Colin (Lynch), died from SMA and he didn’t get to celebrate his birthday. When he was sick with SMA, people had to hold him and I got to take my picture with him.
I hope we can do more things to help the doctors stop SMA.

From your friend, Luke Fenstermaker of Philadelphia, PA –
DO YOU SEE THE ANGELS?

Sometimes when I see you look up at the sky
It's as though you see angels, fluttering by.
You smile and you laugh with your eyes all aglow,
Do you have your own secret that none of us know?
Do you see the angels sent from above?
Are they here to remind us of God's true love?
I'll never forget that cold winter day
When they said you would never walk, run or play.
Little hope for a cure existed they said.
But you took our hand, down this path we were led.
Do you see the angels guiding our way?
Do they know we are thankful for each precious day?
Some people search their whole lives and they ask,
What is my purpose, my reason, my task?
But when you are given an angel on earth
The mission is clear, it defines your self-worth.
Do you see the angels lighting the night?
Do they give you the strength to go on with this fight?
The things you have taught us are endless you know.
The love that we feel just continues to grow.
We are lucky and blessed to have every day,
An angel from heaven to show us the way.
Do you see the angels sent from above?
Do they know that you taught us the meaning of love?
The ache that I feel in my heart every day
Is from knowing that someday you'll be taken away.
To know you and love you is worth all the pain,
And if given the chance, do it over again.
Do you see the angels leading the way?
To God's kingdom, where we'll hold you someday.

Debby & Bob St. Onge
Veronica Rose, Type 1 SMA, 2 years old

Eloise Pillarella recovering from Spinal Fusion surgery with her sisters, Jamilla & Samantha, and service dog Kenwood.

Eloise Pillarella in her first 5K (Tunnel to Towers) to honor 9-11 victims in NYC.

Eloise Pillarella competing in the 25 meter freestyle event (with no assistive floats/devices!) at the Empire State Games, Long Island, NY.

Debby & Bob St. Onge
Veronica Rose, Type 1 SMA, 2 years old

Eloise Pillarella recovering from Spinal Fusion surgery with her sisters, Jamilla & Samantha, and service dog Kenwood.

Eloise Pillarella in her first 5K (Tunnel to Towers) to honor 9-11 victims in NYC.

Eloise Pillarella competing in the 25 meter freestyle event (with no assistive floats/devices!) at the Empire State Games, Long Island, NY.
Lydia Wallis’ donation box at her dad’s dermatology office.

Marianne, Michael & Sara Middlebrook

Joshua and Daniel Tramontano

Ally Krajewski on her first birthday.

Hannah & Alex Marshall

Mitchell, Jack, Leah and Will Kotheimer

Weston Gehman

Sophia Salus

The Martineau-Andrade Family proudly announce the birth of Nicolas, February 16th. He was 8 lb. 11oz. and 20 1⁄2 in.

Marianne, Michael & Sara Middlebrook

John, Krista, Joshua & Anna Rose Scurria

Kennedy Verbsky

Kyle & Natalie DeAndrade

Braelyn & Tambryn Campbell.
Because of space limitations, we are not able to feature all the holiday cards in this issue. Our next newsletter will feature the remainder of the cards.
10 Tips: How to Use IDEA 2004 To Improve Education for Children with Disabilities

unusual for these children to make more than one year of progress in an academic year.

Parents and teachers must learn about the requirements of NCLB and IDEA 2004 to ensure that these legal requirements are met. Although there is no private right of action under NCLB (i.e., parents cannot sue schools when they fail to meet NCLB’s requirements), the failure to meet NCLB requirements can be used as evidence that a child did not receive an appropriate education. (To learn more about No Child Left Behind and IDEA, see Wrightslaw: No Child Left Behind, published by Harbor House Law Press.)

3. Include Research Based Methodology in the IEP

This language in IDEA 2004 creates new requirements for schools to use scientific research based instructional practices and interventions that are based on accepted, peer-reviewed research, if such research exists.

School officials often refuse to write educational methodologies into the IEP. They argue that teachers should be free to use an “eclectic approach” to educating children with disabilities, and should not be forced to use any specific methodology.

Congress rejected this practice when they reauthorized IDEA 2004.

By including frequent references to the need to use scientific, research based instruction and interventions, Congress clarified that methodology is vitally important. By requiring the child’s IEP to include “a statement of special education, related services and supplementary aids and services, based on peer reviewed research …” (Section 1414(d)(1)(A)) Congress clarified that IEPs must include research based methodology.

Including methodology in the child’s IEP will benefit the child’s parents and teachers. As participants in developing their child’s IEP, parents will benefit by having input into the instructional methods used to teach their children. The teachers who implement the IEP will benefit by having guidance from a team of professionals who are familiar with the child and who have reviewed the research to determine the interventions and instructional methods that are most likely to provide the child with educational benefit.

This is a win, win situation for all – especially for children who will benefit when they receive effective instruction from teachers who are trained in research-based instructional methods.

4. Ensure That Annual Goals are Comprehensive, Specific and Measurable

Short Term Objectives

The problem is reminiscent of the game “Whack a Mole” where one knocks one mole down, only to have another mole appear in a different location. Since Congress eliminated short-term objectives and benchmarks, this information will now have to be included in the annual goals.

Eliminating short-term objectives creates as many problems for educators as it does for parents. Short term objectives and benchmarks are steps that measure the child’s progress toward the annual goals in the IEP. When written correctly, short-term objectives provide teachers with a roadmap and a clear mechanism to evaluate the child’s progress.

If the IEP goals are not specific and measurable and do not include academic and functional goals, the IEP is defective and open to a challenge that it denies the child a FAPE.

Parents must be vigilant. The danger is that the IEP team will propose annual goals that are not specific and measurable, do not meet the child’s academic and functional needs, and do not describe how the child’s progress will be measured.

5. Use New Evaluation Procedures to Monitor Academic Progress and Progress on IEP Goals

When conducting an evaluation, the school shall use “a variety of assessment tools to gather relevant functional, developmental, and academic information, including information provided by the parents. (Section 1414(b)(2)) The child’s academic achievement or functional performance may necessitate a reevaluation. (Section 1414(a)(2))” These references to measuring and improving the child’s academic achievement and functional performance are new in IDEA 2004. The IEP team must now consider functional, developmental and academic information in developing an IEP that provides a child with a free appropriate public education (FAPE).

School personnel often claim that grades and performance on IEP goals are separate, and that academic failure does not mean that the child was denied a FAPE.

IDEA 2004 rejects this claim. If the child is making progress on his IEP goals, but is receiving failing grades or is not making adequate progress in academic areas, this may be evidence that the child is not receiving a free appropriate public education.

To meet the threshold requirements for a FAPE, the school must ensure that the child with a disability makes adequate progress in academic achievement and functional performance, and on the IEP goals. If the child’s academic achievement and functional performance are not commensurate with the child’s progress on IEP goals, the child’s IEP needs to be revised. The parents and educators need to determine what adjustments need to be made to the child’s special education program and IEP.
6. Give Consent Only for Evaluations or Portions of the IEP to Which You Agree

IDEA 2004 requires the school to obtain parental consent before the initial evaluation and before implementing special education services in the IEP. Although the wording of the statute changed in IDEA 2004, the substantive effect is no different for initial evaluations.

Parental Consent for Special Education & Related Services

The parent is also required to give consent for special education and related services. If the parent refuses to provide consent for services, the public school “shall not provide special education and related services to the child…” (Section 1414(a)(1)(D)(ii)(II)) This language represents a significant change from IDEA 1997 which required schools to seek mediation or due process to obtain parental consent for services.

This new language may create problems for parents who want their child to receive special education and related services, but disagree with part of the IEP and/or how the school plans to provide services in the IEP. The law does not prevent parents from consenting to parts of the IEP that are acceptable, while refusing consent for those parts of the IEP with which they disagree. There is some support for this approach in the IDEA 2004 statute.

IDEA 2004 maintains the “stay put” provisions of IDEA 1997. (Section 1415(j)) Under the “stay put” provision, the child can remain in the then-current educational placement and continue to receive the same services during proceedings to challenge the IEP, unless the parents and school agree otherwise.

Although there is no “then-current educational placement” when there is a dispute between parent and school over the initial IEP, the fact that the parent and school agree on some part of the IEP creates an obligation for the school to implement those parts of the IEP to which the parent provided consent.

If you want to consent to part of the IEP, here are some suggestions:

- Initial each part of the IEP to which you agree
- Next to the signature line, write that you do not consent to any part of the IEP that you did not initial
- Think about how you want to resolve your dispute or disagreement with the school.

If you want to consent to part of the IEP, then fill in the spaces provided. Follow the steps provided in the IEP form. The school may not refuse consent for services, the public school “shall not provide special education and related services to the child…” (Section 1414(a)(1)(D)(ii)(II)) This language represents a significant change from IDEA 1997 which required schools to seek mediation or due process to obtain parental consent for services.

7. Insist that the Child’s Regular Education Teacher(s) Participate in IEP Meetings

IDEA 2004 lists the individuals who are required members of the IEP team:

- The parents
- Not less than one regular education teacher
- Not less than one special education teacher
- An individual who can interpret the instructional implications of evaluations
- A representative of the school district who has supervisory responsibilities and is knowledgeable about the general education curriculum and agency resources. Section 1414(d)(1)(B)

Congress changed IDEA 2004 to allow members of the IEP team to be excused from attending IEP meetings, even when their area of the curriculum or related service will be discussed. As a parent, you do not have to consent to this. Before a team member can be excused, the individual must submit a written report to the IEP team and the parent must consent in writing. (Section 1414(d)(1)(C)) The demands placed on a teacher’s time are great. In the end, the time spent developing a comprehensive IEP that addresses the child’s unique needs will save time. More important, input from all the child’s teachers will benefit the child. Regardless of whether

the parent consents to a regular education teacher being excused from an IEP meeting, the law still requires that at least one regular education teacher attend the meeting.

If the child receives any educational services in a regular education class or may receive educational services in a regular education class, the regular education teacher(s) should attend the IEP meeting.

Although the law only requires one teacher to attend, all regular education teachers with whom the child has or will have contact should attend the IEP meetings. If the child’s teachers do not attend an IEP meeting, it is likely that important information will be missed or overlooked. Without input from the child’s teachers, other members of the IEP team, including the receiving teachers, will not understand the child’s unique needs and how to address these needs.

The parent should not consent to team members being excused from IEP meetings unless the circumstances are exceptional. If a team member’s area will be discussed, the teacher or related services provider needs to attend the meeting to provide information and answer any questions that arise. If you encounter a problem getting the required members of your child’s team to attend the IEP meeting, write a letter to request that all of your child’s regular education teachers and related service providers attend the IEP meeting. (To learn how to write effective letters to the school, read the chapters on letter writing in Wrightslaw: From Emotions to Advocacy published by Harbor House Law Press.)

8. Avoid Three-Year IEPs Like the Plague

Anyone who thinks that parents and school personnel can develop an IEP that will meet a disabled child’s needs for three years is ignorant about child development and education. Fortunately, three year IEPs are a pilot program that will be available in no more
Ten tips that may help ease your child’s transition to adulthood

By Marcia Kelly

Planning for your child’s transition from adolescence to adulthood is one of the most important things you can do to pave the way to a successful future. In Minnesota, special education transition planning and services begin when your child with a disability is 14. From then on, you and your child will start learning new skills side-by-side. Your child will begin to take on more responsibility, and you will find new ways to provide support.

It can be a challenge. Depending on your child’s disability, you may need to consider everything from postsecondary education to employment, from housing to finances. As you and your son or daughter plan for the future, consider these tips to help build a successful transition.

1. **Help build your son’s or daughter’s self determination and self-advocacy skills.** All young people should have a strong sense of their strengths, abilities, and interests. If students have a disability, they should also be aware of how it might affect them at work, in the community, and in their educational pursuits. Transition is a wonderful time to explore how youth will talk about their disability in different settings and ask for any support or accommodation they will need.

2. **Help develop your child’s social outlets.** Social relationships and recreation are more than fun; they are important tools that help tie people into the community and provide a wider network of support. Although social isolation can be an issue for many young adults with disabilities, transition planning that addresses opportunities for social relationships and recreation can build a bridge to success.

3. **Expand your network and explore community supports.** As children with disabilities become adults with disabilities, they may need support from a variety of sources. Start now to develop helpful networks for your child. Who do you know in your family, social group, professional circle, religious community, or other sphere who could help provide social, recreational, work, or volunteer experiences for your young adult? Look, too, at adults in the community who have the same disability as your child to learn what kinds of support they use.

4. **Make sure your son registers with Selective Service at age 18.** All males—including those with disabilities—must register with Selective Service within 30 days of their 18th birthday. (Exceptions are made for young men in institutional care.) Failure to do so can affect a person’s ability to receive federal and state benefits, including student loans, job training, and government jobs. Learn more at www.sss.gov or link through PACER’s site at www.pacer.org.

5. **Explore post-secondary accommodations.** Students who receive academic programming and support in high school through Individualized Education Programs (IEPs) and 504 plans will not automatically have the same support after they graduate. Although post-secondary institutions are required to provide reasonable accommodations to students with disabilities, they are not required to modify course work, if it would substantially change program requirements. When you and your student visit a prospective school, visit the campus’s Disability Services Office to:
   - explore how to document your student’s disability;
   - ask if you can talk with other students and families about their experiences in this particular program;
   - inquire about what accommodations are available. In addition to note takers, extended time, and alternative testing environments, are other, less common services offered?

6. **Investigate SSI programs.** Financial planning is an important part of transition. Many people with disabilities are beneficiaries of Supplemental Security Income (SSI), a federal program that provides a monthly benefit check that can help pay for living expenses. A lesser-known program of SSI, called Plan for Achieving Self-Support (PASS), may be helpful to some SSI recipients. It allows a person with disabilities to set aside income and resources in order to reach a work goal. These goals could include such things as enrolling in an educational or training program; obtaining supported employment; starting a business; or purchasing a vehicle to commute to work. PACER Center published parent briefs on SSI in conjunction with the National Center for Secondary Education and Transition (NCSET). The briefs are at www.pacer.org/publications/transi tion.htm. Social Security information on SSI is at www.ssa.gov/work/ResourcesToolkit/pass.html.

7. **Encourage your child to build a résumé by volunteering.** Many young people struggle to find work experiences that help them compete...
in the job market. Volunteering is a great solution. Young adults can gain skills and build a résumé that shows a prospective employer their abilities, initiative, and dedication to work. Volunteering can also help develop additional social skills, especially if it is done along with a parent, friend, or group of peers.

8. Help your child learn “soft” employment skills. In addition to the work skills people need for their jobs, they also need “soft skills.” These include such things as being able to accept direction, ask for help, deal with conflict, and engage in interpersonal communication. They also include being prompt, having appropriate hygiene, and dressing properly for the workplace. An employer is more likely to be patient with an employee learning the technical aspects of a job if soft skills are in place. You can help your young adult develop these skills by practicing them at home.

9. Plan for health care management. Like most people, young adults with disabilities need to manage their health care and insurance. You should develop a clear plan on how to address health care needs once your child reaches adulthood.

10. Call PACER Center for information and resources. The transition staff at PACER Center can help you prepare your son or daughter for the adult world. Trained advocates can help you understand your rights and find resources to help with all aspects of transition. To speak with a transition expert, call (952) 838-9000. You may also visit www.pacer.org/publications/transi- tion.htm for online transition resources.

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than 15 states. (Section 1414(d)(5)) If your state submits a proposal and is approved for the three year IEP pilot program, the IEP team must obtain your consent before they develop a three-year IEP. Do not grant consent.

You are not limited to one IEP meeting a year. Parents and teachers can request an IEP meeting to review and revise the child’s IEP more often than once a year. IDEA 2004 provides that the IEP team shall revise the IEP to address:

• Any lack of expected progress toward the IEP goals or in the general education curriculum,
• The results of any reevaluation,
• Information provided to or by the parents,
• The child’s anticipated needs, and
• Other matters. (Section 1414(d)(4))

9. Challenge Suspension or Expulsion if Child’s Behavior was a Manifestation of the Disability, or if the Alternate Placement Does Not Provide FAPE

IDEA 2004 permits the school to suspend a disabled child from the current program or place the child into an interim program for up to 10 days if the child violates a “code of student conduct.” (Section 1415(k)(1)(A)) If the school wants to suspend the child for longer than 10 days, they must convene an IEP meeting to determine whether the child’s behavior is a manifestation of the child’s disability. If the school concludes that the child’s behavior was not a manifestation of the disability, the school can discipline the child in the same way and to the same extent that a non-disabled student can be disciplined. (Section 1415(k)(1)(C))

This means the school could provide a child with an inappropriate special education program and placement, and could expel the child from school. There are several strategies you can use to ensure that the school does not use behavior problems as a way to deprive your child of an appropriate education.

IDEA 2004 still requires school districts to provide a free appropriate public education to all children with disabilities, including children who have been suspended or expelled from school. (Section 1414(k)(1)(D) and Section 1412(a)(1))

10. Avoid Due Process Hearings if Possible

Due process hearings should be your last resort, after you have attempted all other methods to resolve the dispute. Due process hearings are often an expensive and lengthy process. There are few absolutes in the law, and perhaps even fewer absolutes in the context of special education disputes. The adversarial nature of due process hearings often creates a wound in the relationship between parents and school personnel that never heals.

Try to resolve your dispute through IEP meetings, mediation, and/or the Resolution Session before you request a due process hearing.

The URL for the complete article is at www.wrightslaw.com/idea/art/10.tips.steedman.htm

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The thought of going away to college can be a scary thought for anyone, especially if you are a person with a disability and rely on family members or personal assistants to assist in daily living. My name is Shannon O’Brien and I have SMA type III. I know this thought definitely crossed my mind a few times when I thought about college but I never let it stop me from achieving my dream of actually going away to college!

Since I was a little girl, I always knew I wanted to go to a big university and move away from home. As I began to grow older and start thinking about college, my choices ranged from Illinois (my home state) to Iowa to California and even Arizona. After beginning to look into schools, I realized right away that the University of Illinois was the right choice for me!

Not only is it a top ranked school for academics but it is one of the most accessible schools in the nation. How could I not choose it? I am now a sophomore at the University of Illinois in Champaign and I am studying to become a speech therapist. One of the main reasons I picked U of I was because they offer an entire dorm for people with disabilities. They also help you by prescreening and training personal assistants, who you then get to pick and choose the ones that work well with you. They also have a floater on call 24 hours a day. They can help you do little things throughout the day or in case your personal assistant does not show up. This helps out a lot because going away to school can be very stressful and adding on the stress of finding your own personal assistants that are reliable is a whole other story! I know for myself, I have never had anyone else take care of my personal needs other than family and friends, therefore it took some adjusting and getting use to. But trust me, it did not take long!

Once I was moved in and my parents left, I felt like a whole new person. Instead of being scared and upset, I just felt really independent. I no longer had to rely on them to take care of my personal needs or to take me anywhere I needed to go. Living on a big college campus makes life a lot easier, especially one that is really accessible.

I think the best part about living away from home is the freedom you have to do whatever it is that you want. Whether it is taking the bus to the mall, meeting friends at the library to study or even walking down the street to hit up the different campus bars, there is always something to do and it is no longer impossible for me to do it without the help of someone else.

The best advice I can give to anyone who is looking into going away to college is to explore all your options and make sure you feel comfortable with your decisions. Even though it may seem hard to move away from home and be on your own, it is also rewarding and can give you a new found independence!