



WNYFSMA Newsletter

**WNY Chapter
Families of Spinal
Muscular Atrophy**

WNYFSMA
Winter 2007

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SMArt WALK for a CURE

Once again we are actively getting our thoughts and energy in gear for our 4th (can you believe it) annual WALK for a CURE.

The permits and insurance for the walk are all in place and we are waiting for the final ok from the park commissioner for the ok for free parking for the event. It will, once again, take place at Beaver Island State Park. This year it will be at a more secluded shelters (2) with ample parking and drop off facilities close by.

The corporate sponsorship letters are scheduled to be mailed by the end of February. The Walk registration forms will be mailed in May. We are hoping for an early response from our past dedicated supporters. We have been very fortunate, in the past, thanks to a few sponsors to have a good financial start for our walk. Along with the many walkers with pledges our walks have been more than we could have hoped for.



2006 SMArt Walk Families at Beaver Island Park

Once again, we are asking for everyone's help and support. We are asking for ideas, manual help, more corporate sponsors etc. The more help we can get, the more successful we will be.

In the past we have raised over \$130,000. This money, combined with all of our other fund raisers, has the Western NY Chapter recognized as one of the most successful new chapters of Families of SMA.

Please note that all of the fund raisers, The Girl Scout garage sale, candle lighting ceremony, volleyball tournaments, chowder sales, Teddy Geiger concert and the donations from individuals all add up to our Chapter being successful. We are able to contribute all this money to National for research and family services. The more we help, the quicker a treatment and cure for this horrible disease will be found.

We have all been touched by this devastating disease and we will find a cure!

Wyatt Walk

The Wyatt Kyle Sutker Foundation, LTD was started by Steve and Julie Sherman Sutker, after the death of their first born Wyatt Kyle to Spinal Muscular Atrophy Type I at the age of 5 and 1/2 months. At the time of Wyatt's death little information and support was available to families dealing with Type I, the #1 killer of infants. Gathering and distributing information regarding SMA, providing support to families and professionals, educating the public, raising funds to support research directly related to SMA Type I have become the goals of this unique foundation. The Wyatt Kyle Foundation is run by 100% volunteers. More information can be found at the website www.wkswithsma.org please check it out.

One of the major fund raisers for the foundation is Wyatt's Walk for SMA Type I. The eighth annual walk will be held this year on May 5, 2007 (it is always held on the 1st Saturday in May). The Walk is co-chaired by Wyatt's grandparents John and Sally Sherman. It is a 3 mile walk along the beautiful Niagara River in Tonawanda, New York and includes a gift, raffle, prizes, and lunch. Around 200 people attend each year and along with sponsors are able to raise over \$20,000 each year. We hope many of you will join us or contribute this year.

Upcoming and Ongoing Events

- **2/18/2007 - Valentine's Ice Cream Social**
- **4/21/2007 - 5th Annual Volleyball Challenge Court**
- **Alessi Fitness Body Fat Contest benefiting Spinal Muscular Atrophy Contest begins January 15, 2007 & ends April 14, 2007**
- **5/5/2007—Wyatt Walk—Niawanda Park**
- **8/4/2007— SMArt Walk for a CURE & Car raffle**

Kale's Sled Hockey

This September Kale tried something new, Sled Hockey. Needless to say I was very worried about the whole thing. Would it be safe, would he be too cold, would he catch a cold; would he fit in? Seeing him smile melted away all my worries, he loves it!



Kale during one of his Saturday practices. "Trash Talking Kale" is a good name for him!

The organization is called the WNY Physically Challenged Youth Sports, Inc. or AKA Buffalo Sabres Sled Hockey. The President of the organization is Norm Page. He is a very kind person and assured me that if there is a will there is a way and he would do whatever Kale needed to get on the ice, which he did. Kale has a specially fitted sled and sticks for his size that were adapted to his needs. He was matched up with a pusher to help him move on the ice with ease and assist him with whatever he needs. Kale is on the novice team which is coached by a wonderful young man, Brad Emerson, who is also physically challenged. You would never know it as he flies by you like a bullet on his sled. He is very experienced as he is a member of the US Sled Hockey Team and won a bronze medal in the 2006 Paralympics in Turin, Italy. He has a very gentle way about him and is very encouraging with Kale and the other team mates.

It is great to see Kale playing a team sport, to be apart of a team. It is something that I thought I would never get to see. He has a blast out on the ice even "trash talking" like a big kid. He even played a game at HSBC Arena.

A lesson learned here for me. Never let your worrying prevent your child from experiencing life. For more information please feel free to contact myself or Norm Page directly at 681-3552 or go to www.buffalosledhockey.com

"A dream is in the mind of the believer, and in the hands of the doer"
 "You are not given a dream, without being given the power to make it come true."

Angelica Catalano—Youth Award Winner

The National Federation for Just Communities of Western New York (NFJC) honored three organizations and 38 individuals for their service to others in the Buffalo area during the 2007 Community Leaders Awards Luncheon held January 18th in the Buffalo Niagara Community Center.

Community Leader Youth Award—Angelica Catalano (Cousin to Alex Blair)

Angelica Catalano is a senior at Williamsville East High School where she is Student Council Secretary and Editor in Chief of the Yearbook. She became involved in researching and community service for Spinal Muscular Atrophy after her cousin, Alex, was diagnosed with the disease.

Since then, Angelica has joined Families if Spinal Muscular Atrophy and participated in the SMARt Walk for a Cure several times. She collaborated with the Western New York Chapter of FSMA to organize a benefit concert featuring her cousin, recording artist, Teddy Geiger, which raised \$4,400 for Research, Family Services and Awareness Programs.

She works tirelessly and selflessly to increase student action and awareness of this condition and it was with honor that the NFJC Community Leader Youth Award was presented to Angelica Catalano.

Over 800 people were in attendance, along with Angelica's parents and grandparents. GREAT JOB, Angelica!!!

What We Learned in Our First Trip to the Hospital

Unfortunately, our luck ran out and Alex was hospitalized for the first time in January for 18 days. Although it was a very long stay, we feel that some good things did come out of this adventure. Below are some things we experienced during this time. What I do want to say is every child is different and has different needs so we did what we thought was best for Alex. Everyone parent has his or her own way of handling the stressful situation of taking your child to the hospital. So this information is just to let you know how we tried to handle the situation with the information we read and what we chose to do with it.

Alex ended up having Para influenza and pneumonia. The one thing I did remember the day he was admitted into Children's Hospital was that Alex should not be given oxygen. I just remember reading that somewhere at sometime and while the ER doctor was insisting on it, I waited until Dr. Sheehan, his lung doctor, saw Alex to determine what steps to take. During the wait, I did allow Alex to have the oxygen mask placed by his mouth/nose for minimal support. I believe giving an SMA child oxygen masks the true problems they are experiencing with breathing. After seeing Dr. Sheehan, he was pleased that Alex was not given full oxygen support – he even thanked the ER doctor for holding out until he came by!

Prior to arriving at the hospital, Alex's doctor insisted on going by ambulance. At first, we didn't see the need but I will tell you, upon arriving at Children's and Alex being assessed, we were admitted immediately to an ER room. Alex needed a chest x-ray and the tech came right to Alex to have it done. No waiting around with the other sick kids. That was really important. While arriving by ambulance is not a guarantee that you will be given a room right away, it certainly doesn't hurt. And I have waited in the past for a chest x-ray – it can take a while.

Fortunately, the hospital had a cough assist machine available, so we didn't need ours. But in some areas, it might be a good idea to bring that along and any other equipment you might need for a stay. Alex just started using a V-pap machine which the hospital did not have available so we brought in ours.

While Alex was using his cough assist with various Respiratory Therapists, I noticed some keep changing the settings on it! So this is something you should watch out for. We made sure that his inhale/exhale/pause were where they should be each time they came in. We also made sure his pressures were at the right settings – some tried to change those too. Some therapists have their own way of doing things so it is important to be there when you can for each session. But the good thing is, most were able to offer different suggestions on when to do the cough assist, why they prefer certain methods etc. So, it is good to hear what they have to say and use it to what works for you and your child.

When Alex is in pre-school, he gets all of his therapies there. While in the hospital, he was also entitled to having therapy sessions which we weren't made aware of right away. So when you think your child is up to some stretching, ask to have some sessions set up so they don't get stiff. Obviously, you would want whatever therapies done that your child will tolerate and not cause any unnecessary discomfort. But it also isn't good to let them get real stiff because getting them back to the point they were before being admitted may take a long time.

Alex was in so long this time because the decision was made that he should have a G-tube. While we were trying very hard at home to feed him orally, it proved very difficult to get in all the calories he needed each day. For Alex, the surgery was about 2 ½ hours long and we were home within a week after that. So far, it is working well for us BUT that can be a story for the next newsletter.Until then I hope the rest of your winter season is uneventful!

If anyone has any questions about our stay, I would be happy to hear from you.

You can reach me at blair89@verizon.net or 648-1044.

Diane



You Could Win This Car!

Our car raffle to benefit FSMA is underway. We are attempting to sell 2500 tickets @ \$20 ea for the chance to win a 2007 HHR General Motors van. We must sell at least 1500 tickets for the vehicle or a 50/50 split will take place. Again, we need your help. We have about 2/3 of the tickets left. If you know of an event where the vehicle can be displayed and tickets sold, please let us know. We are in the process of having a booth at the Canal Fest in June. Please call or e-mail if you would like raffle tickets to buy or sell. Karen @ 716-693-7149 or ksbiesley@aol.com.

The drawing for the vehicle will take place at the SMArt Walk on August 4th.





**WNY Chapter
Families of Spinal Muscular
Atrophy**

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Together We Will Find A Cure!.

WNY Chapter
of FSMA



Websites to help Cope

The Independence Founda-

tion: www.independencefoundation.org

Families of SMA - National: www.fsma.org

Dr. John Bach: www.doctorbach.com

SMA Foundation: <http://www.smafoundation.org/>

Parent to Parent of NYS: <http://www.parenttoparentnys.org/>

These sites offer valuable information to the newly diagnosed and also how to cope with day to day issues involved associated with Spinal Muscular Atrophy.

There are also links on www.wnyfsma.org that deal with nutrition etc.

If you have a story or thoughts you would like to share or see published, please send it to our PO Box in care of "Newsletter" Thanks

Improving Neuromuscular Care in WNY

Women's and Children's Hospital of Buffalo and parents of children with neuromuscular disease are teaming up to form a Parent Advisory Council. Our 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.

If you are interested in participating or for more information, please contact Mary Boguhn at marybog@msn.com or 681-2728.