

Families of SMA

# WNY Families of SMA

## Car Raffle for a CURE

2006 Fall Edition

October 2006

Hi All,  
 I am sending you a web-site created by Elizabeth Lockwood, a grandmother of 2 children with SMA in the OKI chapter who has made some great "Cure SMA" purses to sell to raise funds for FSMA. Each purse is a limited edition and there will be new designs regularly. She also has other items for sale. Please check out the site [www.curesmasite.com](http://www.curesmasite.com)  
 Thanks,  
 Nicole Haake  
 OKI Secretary

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WIN THIS CAR!

The Western NY Chapter of SMA is embarking on a new idea to raise money to find a cure. With the help of KIPO Motors, who has generously donated the vehicle at cost, we are going to sell 2500 raffle tickets at \$20 ea. We will be able to make almost \$30,000 to help in our quest to raise awareness and money to find cure.

This may seem like a monumental task but with the help of everyone who has been touched by this devastating disease, we can do it.

The idea is to sell the tickets now or as soon as possible and have the drawing at the 4th Annual SMArt Walk for a Cure on August 4th, 2007. We must sell at least 1500 tickets for the vehicle or a 50/50 winner will be awarded. Grand prize will be a 2007 HHR General Motors vehicle. 1st prize will be a \$500 Noco gas card. 2nd prize will be \$250 Noco gas card and 3rd prize a \$100 Noco gas card. The seller of the grand prize ticket will

be awarded a \$250 gas card. Taxes will be paid by the winner of the grand prize.

Also, Keith Lucas, owner of KIPO Motors has offered to donate to WNYFSMA \$150 for the purchase of a new GM vehicle by any member of the WNY FSMA family. He also noted that GM makes available a \$1000 vehicle handicap package at no charge.

Anyone interested in purchasing or selling the Car Raffle for a Cure tickets please call Karen @ 716-693-7149 or e-mail [karen@wnyfsma.org](mailto:karen@wnyfsma.org).



General Motors HHR 2006  
 (\$18,500 value)

### 3rd Annual WALK is a success!!!!

The 3rd annual SMArt Walk for a Cure was held on August 5th at Beaver Island State Park. It was a perfect day for a walk in the park.

With the help of almost 400 people we were able to raise over \$52,000!!! The money was raised through corporate sponsors, walk pledges, basket raffles, and from the many aunts, uncles, grandparents and parents, friends and neighbors of those somehow touched by SMA. Special recognition has to go to the Matthew Reilly Team with over 70

members that raised over \$10,000.

The children were able to sit in a vintage racing truck owned by Tom my "Boots" Karabin. The truck has the FSMA logo printed on its side to help raise awareness. Next year's walk will be on



August 4th and we would love to have more help.

Bonnie, Diane & Nick Pickolas

## Jen's Story—Living with SMA



Jen and her niece  
Cheyenne

Hello,

A few months back, Chris Muller and I asked for input on Children's Hospital Neurology. Some of you answered where you and your children are seen for neurology and why. In the ongoing effort to improve care locally, what changes would you like to see in Children's Hospital Neurology and/or the MDA Clinic? Any other thoughts and comments are welcome.  
Mary Boguhn  
marybog@msn.com

First let me introduce myself. My name is Jennifer Kariman. Most people I know call me Jen. I am 27 years old and been married 4 years to my husband Doug, who is a Nurse at ECMC. I have SMA

Type 111. Most of my life doctors diagnosed me with MD, when I was a child. In Kindergarten, teachers noticed I was getting up from the floor slower than the other children. That was the start of many tests to come. Around the year 2000 is when tests shown that I had SMA.

Most my childhood was pretty normal. Even before I started school, I was running up stairs and hiding on my family. When doctors diagnosed me with MD, I always had therapy in school up to about my 10th year in high school. Even though I hated it, I now

know it was only doing me good. Middle school was the worse.

Kids found anything to make fun of someone. But somehow someway I got through it. High school was my best years. I had many friends and most knew there was something wrong with me. But they never looked down on me for it. After I graduated, I found a great job and met Doug. At this point in my life I was able to walk far and do much of everything. Some things were hard but I always found ways to work around them so that I could do them.

Doug and I got married on August 10, 2002. I had a lot of family and friends praying for my strength that day. I was nervous, like any bride would be on that day. But for me I was most nervous if I was going to have the strength for the whole day. That was the

first time in my life I felt God all around me. I had strength to climb a mountain. It surely was a beautiful day.

Now that 4 years have gone by, I noticed a change in strength. I get my bad days but I always force myself to keep going and to never give up, even though the thought has crossed my mind many times. I believe if I stay active throughout my day it will keep me going.

To sum up my life living with SMA, I would have to say that I had a great life so far. There's someone out there worse off than me. I believe my purpose in life is to encourage others. Someone once told me, we can do anything, we just do it differently.



## Baby Caine

We're happy to announce the arrival of baby Edward Joseph Caine weighing 9# even and 21 3/4" in length. He made his arrival on Aug 27th to parents Dorothy and Doug Caine.

Doug & Dorothy organized the Paddle for a Cure last August in memory of their daughter Audra, who lost her battle with SMA in 2004.

As noted by his parents he is already showing his personality in quiet moments and not so quiet moments.

## Question & Answer

I've been meaning to communicate some info to the other parents whose children may be having difficulty adjusting to the use of a respiratory therapy vest or even bi-pap. The pulmonary doctors and hospital respiratory therapists (because they do not take the muscle weakness aspect of the disease into consideration) tend to set the vest pressure too high, which makes it uncomfortable and basically impossible for a child with weak lungs to take a deep breath. When Matthew was having difficulty adjusting to his vest pressure increase, I called The Vest company directly and they assured me that this (pressure setting) was "strictly a comfort

issue and had absolutely no effect on the quality of the therapy". Matthew only tolerates a pressure of 2 with his front-only inflating vest. I believe the same can be true of the expiratory pressure on the c-pap or bi-pap. Weak lungs cannot breathe out against a high expiratory pressure and therefore, the child may be uncomfortable and unable to rest. As I'm sure you know, the best settings for bi-pap are an inspiratory pressure of 16-22 and an expiratory setting as low as possible (no more than 4) per Dr. Bach's recommendations. Also, this procedure (which was recommended by Dr. Bach as well) has worked great for us in our effort to keep Matthew out

of the hospital. Whenever Matt is sick, even if no cold symptoms are present, we put him on 24 hour pulse oximetry. If his oxygen level dips below 95%, we put him on his bi-pap or ventilator to let him rest because he fatigues of breathing with fever or vomiting. Of course, if cold symptoms are present, we make him use his cough assist when he dips below 95%, if he is awake, and put him on non-invasive ventilation to sleep.

I'm not sure if anyone else has had experience with these issues so could you please pass on this info to the other parents as they are not likely to get it from the local doctors.

Thanks, Cathy Minderler

**What's Happening in WNY** - A comprehensive list of workshops, events and ongoing support groups in the WNY area. *Updated on September 15, 2006.*

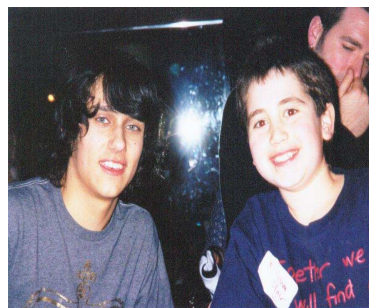
Project Cure SMA is still looking for Type 2 and non ambulatory Type 3's ages 2-8 to participate in the Valproic Acid, Carnitine trial. If you know of any families that are interested please ask them to contact either Jeff Horn at 801-581-4544 or [jhorn@genetics.utah.edu](mailto:jhorn@genetics.utah.edu) or Dr. Sandra Reyna at 801-581-3551. There are further criteria that need to be met and will be discussed at the time of inquiry. [Salt Lake will facilitate gathering info for other sites.](#)

### Teddy Geiger

#### SMA's Favorite Singer Helps Again

Some exciting news from the Teddy Geiger Team. On Teddy's official web site, [www.TeddyGeigerMusic.com](http://www.TeddyGeigerMusic.com), there will be a page dedicated to SMA. This will be listed under "Teddy's Causes". A paragraph on SMA and the FSMA charity will be listed along with a link to the FSMA web site and the donation page. Teddy's web page usually gets about 30,000 visitors each week.

A big thank you goes out to Torre Catalano (Alex Blair's Godfather) who helped to get this project rolling. Torre has been in constant contact with Audrey Lewis to work on getting some celebrities involved to help bring awareness to SMA. We wish Torre much success in this endeavor because we need to share information on SMA in hopes of finding a CURE!



Teddy & Adam

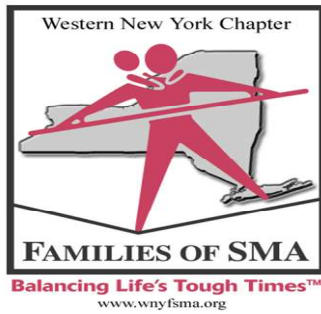
Correction from last edition: Volleyball total \$2800

*The WNY Chapter FSMA is in the process of starting a Loan Closet to assist families that are in need of help. We have some supplies and equipment, but it is only a start. If you have any equipment or supplies you do not need and wish to donate, please contact Mary Boguhn at [marybog@msn.com](mailto:marybog@msn.com) or 716-681-2728 for more information.*

People Inc. still has Family Reimbursement dollars available for families. Family Reimbursement can be used for necessary goods and services for individuals with developmental disabilities residing at home with their families, including funding for respite. If you would like more information, ask your service co-coordinator to call 880-3700 and ask to speak to the Family Reimbursement department. You do not need to have service coordination from People Inc. to be eligible for this funding.



WIN THIS CAR!!!!



WNYFSMA  
PO Box 444  
N Tonawanda, NY 14120

Phone: 800-886-1762  
Bonnie Shiesley—President  
Diane Blair—Vice President  
Joanne Hallmark—Treasurer  
Karen Shiesley—Secretary  
Mary Boguhn—Correspondent  
Rob Litten—Webmaster

*Together we will find a cure*



WIN THIS CAR!

## Toys and Books Garage Sale



Allie and Meghan and  
Jessica Weisner

On June 3<sup>rd</sup>, 2006 Brownie Troop 305, out of Chili, NY held a Toy and Book Sale with all proceeds going to FSMA.

The sale was held in memory of Meghan Emily Wiesner (06/03/03-06/27/03) on what should have been her third birthday.

SMA free twin sisters, Allison and Jessica Wiesner (8 years old) came up with the idea after watching Extreme Home Makeover with the Johnson family. They wanted to do something to help those living with SMA and to remember their baby sister.

The Wiesner family is active members of the Western NY Chapter.

All the brownies and parents chipped in to make the day a success and even on a gray rainy day \$457.40 was raised with the sale of toys and books. The brownies also had a Brownie Special of brownies and lemonade for sale.

The leaders and parents are very proud of the girls and the Wiesner family feels very blessed to have the love and support of these special friends.