

PODS NEWSLETTER

Parents of Down Syndrome Support Group of NEPA

A Division of The Arc of NEPA

April 2009

Prepared by: Kristen Finnerty

Easter Egg Hunt 2009

The kids enjoyed their day hunting for eggs, making bunnies and visiting with the Easter bunny. Thank you to Cindy Holmes and Jen Cannizzaro for setting up this great event and to everyone else who chipped in to lend a hand!



SAVE THE DATE!

Annual PODS of NEPA Baseball Game,

Sunday, June 21st at 1pm (more details to come)

If you are interested in having your child with Down Syndrome throw out the first pitch, please submit your name to lincol97@aol.com

Your child must be 10 years of age or older.



PLEASE MARK YOUR CALENDARS FOR OUR NEXT MEETING:

Sunday, April 26th @ 6pm

Special Guest Speaker:

Danielle Burrier, Speech Therapist, Allied Services

I Can Do It!



Hello everyone! My name is Rose Catherine Holmes, but most people call me Rosey. I am 3 ½ years old and live in Clarks Summit with Mommy, Daddy, my little brother, Brady, my dog, Bo, and my cat, Rudy. I attend preschool three mornings a week and I love to swim. I get a big kick out of Curious George and I *never* turn down a French fry!

I celebrated a very important and exciting milestone in March - 2 years cancer-free. It was a wonderful day for my family and me! We celebrated with my doctors and nurses by having chocolate chip cake. We then went out for dinner to celebrate even more!

For those of you who may not know my story, I was diagnosed with Acute Myelogenous Leukemia or AML on August 5, 2006. Although I was acting like the same old Rosey my parents felt very unsettled about some unusual bruising on my body. Luckily they knew I had a much greater risk for leukemia than the average child. I think angels whispered in their ears that something was wrong.

To make a very long story short, I was diagnosed within 24 hours of my arrival at Janet Weis Children's Hospital in Danville, PA. The doctors have treated many children for leukemia and knew just what to do. I underwent eight months of chemotherapy and Mommy and Daddy tell me I was a champ and on many days I seemed like myself. I fought hard and with the help of my medicines and the outstanding doctors and nurses I was able to defeat the beast! The hospital was boring at times and I had some days when I felt really, really yucky. I watched a lot of Elmo and the hospital did so much to make my stay better, too. I especially loved when the therapy dogs visited me and when the volunteers brought me toys. My brother Brady was born in the midst of my treatments and he was wonderful distraction from all the medical stuff! My relatives helped out with Brady so that I had one or both of my parents next to me each step of the way.

I finished my last treatment on March 8, 2007 and so I am now in remission for two years. On behalf of my family I would like to thank all of you who so kindly supported my family and me during those eight months. We truly appreciated the many thoughts, prayers, gifts and words of encouragement. I ultimately did all the hard work, but my family, friends and even strangers helped to carry me along the way.

I can do it and I DID!

Special Education and Special Needs Trusts

Free Seminars

Heather M. Hulse, JD, MA, MS
McAndrews Law Offices

Seminar will include a presentation of Parents' and Students' Rights under the Individuals with Disabilities Education Act (IDEA). Parents will leave with an understanding of their child's eligibility to receive special education services and how to proceed through the evaluation and Individualized Education Program (IEP) process.

Seminar will further include a discussion of when and how to use a Special Needs Trust so that children (and adults) with special needs will remain eligible to receive necessary public benefits such as Medical Assistance (MA) and Supplemental Security Income (SSI).

Seminars will be held on:

- April 23, 2009 at 6:30pm, at Lackawanna College, The Lyceum at The Student Union, at the corner of Jefferson Avenue and Vine Street, Scranton, PA
- April 30, 2009 at 6:30pm, at Kings College, McGowen Hall, Burke Auditorium (Directions are available online at <http://www.kings.edu/directions/DirectionsToKingsCollege.pdf>)

Seminars on only Special Needs Trusts will be held on:

- April 7, 2009 at 7:00pm, at East Stroudsburg University in the University Center, Student Center Chambers (Directions are available online at <http://poconoautism.org>)
- April 15, 2009 at 7:00pm, at The Scranton School For The Deaf (Directions are available online at <http://sssd.neiu.org>)



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**2009 National Down Syndrome
Congress convention, July 31st -
August 2nd, in Sacramento, CA.**

Visit www.NDSCcenter.org to register
and to check out the list of keynote
speakers.

UPDATE YOUR CONTACT INFORMATION

If you would like to receive the newsletter via e-mail, or update your address, please contact Kristen at 585-2962 or finnertyk@comcast.net to add your name to our e-mail list.

The next session of swimming begins the week of 4/20, contact finnertyk@comcast.net if you are interested. Your child must be 3 years old and must be accompanied by an adult for the class.

The Waiting List

The
Arc

The Arc of Luzerne County in cooperation with The Arc of Northeastern Pennsylvania and The Arc of Wyoming County are conducting a regional event which will bring public and legislator attention to the Waiting List in Pennsylvania.

Don't miss this event if you want your voice to be heard!

Please join us:

Mohegan Sun at Pocono Downs
Highway 315, Pittston, PA

Friday, May 8th, 2009

9:00 a.m. - Registration
followed by Breakfast,
Speaker and Questions

This event will provide an opportunity for those concerned and affected by the waiting list to highlight the critical need for services for families and people with intellectual and developmental disabilities. "Event made possible with resources from Disability Rights Network of PA."

RSVP by: Friday, May 1st, 2009 to The Arc-NEPA - (570) 346-4010

ACTION ALERTS

The **Achieving a Better Life Experience Act (ABLE) of 2009 (S 493/HR 1205)** has been introduced in both the Senate and House. The ABLE Act will give individuals with disabilities and their families the ability to save for their child's future just like every other American family, and help people with disabilities live full, productive lives in their communities.

The **ABLE Act** will allow individuals with disabilities to create a disability savings accounts or 'ABLE Accounts' that would accrue interest tax-free. The account could fund a variety of essential expenses for the individual, including medical and dental care, education, community based supports, employment training, assistive technology, housing, and transportation. The legislation prohibits amounts held by, or paid or distributed from any ABLE accounts from being treated as income or assets when determining eligibility for benefits provide by any Federal benefits program.

Asset development is one step toward improving economic self-sufficiency, and the legislation's focus on encouraging asset development will greatly incentivize people with disabilities to live more productive lives through earning and saving resources for their future. **Action Required:** If your Representative and/or Senators are not already a cosponsor of S. 493/H.R. 1205, please call them to cosponsor this important legislation (*a list of Members who have already signed on to the bill is included below*). **Talking Points to Call Your Senators and Representative:**

I am calling to ask my [Senator/Representative] to cosponsor the **Achieving a Better Life Experience Act (ABLE) of 2009 (S 493/HR 1205)** led by Senators Casey (D-PA), Hatch (R-UT), Dodd (D-CT), Kennedy (D-MA), Brownback (R-KS), and Burr (R-NC) and Representatives Crenshaw (R-FL), Meek (D-FL), Kennedy (D-RI), and McMorris Rodgers (R-WA).

The legislation encourages persons with disabilities to save in order to live an independent and meaningful life while reducing their dependency on public benefits.

This legislation allows for the establishment of tax-exempt financial security accounts for individuals with disabilities to pay certain expenses, including: medical and dental care, education, community based supports, employment training, assistive technology, housing, and transportation.

If your boss is interested in signing on as a cosponsor, please contact:

Bryn McDonough (202-224-6324) in Senator Robert Casey's office Dustin Krasny (202-225-2501) in Representative Ander Crenshaw's office

*Source 4/6 NDSS & NDSC e-mail

The Arc PA Action Alert - Special Education Bill Needs Cosponsors Before April 27 Special Education Funding Reform Needed Now

[Take Action!](#) Original Cosponsors Needed for House Bill in April

In 2007, a report commissioned by the General Assembly found that the state's share of overall per-student spending in Pennsylvania was inadequate. As a result of that study, the Pennsylvania General Assembly passed legislation in 2007 that increased state funding for general education. However, special education was left out of the legislation.

The consultants who authored the original 2007 "Costing-Out Report" (Augenblick, Palaich, and Associates - Denver, CO) published a separate report earlier this year focusing on the adequacy of state funding for special education in Pennsylvania. The study's conclusions reaffirmed that adequate funding per special education student should equal 230 percent of a general education student (for example: general education = \$8100 per student; special education = \$18,673 per student). The study found that 391 school districts out of 500 have inadequate levels of spending for special education, and that \$380 million in new funding is needed annually to achieve adequate funding.

Legislation has been drafted with support from disability advocacy groups to reform special education funding based on the results of this study. The legislation proposes the following: To close the \$380 million adequacy gap over a period of 6 years; to base state funding to school districts on a district's 5-year average of actual students enrolled in special education; provide increased funding to districts that do well including students with disabilities in their neighborhood schools and general education classrooms; consider a school district's level of poverty; and, consider whether a school district's current tax effort demonstrates (or fails to demonstrate) a commitment to adequately funding their educational programming.

In addition to funding adequacy, the proposed legislation includes new accountability requirements. For example, the bill would require a district's special education plan to explicitly include a budget for special education. It would also direct the PA Department of Education to measure a school district's performance against published performance indicators, and it would authorize PDE to withhold up to 5% of a district's funds for non-performance.

Representative Mike Sturla has agreed to champion the bill. He expects to introduce the legislation the last week of April. He has circulated a "co-sponsorship memo" to his colleagues in the PA House of Representatives. The Arc of Pennsylvania urges its members to contact their state representatives and ask them to sign-on as original cosponsors before the bill is introduced.