Greater Rochester GRSBA
Serving Families Since 1972
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GRSBA News & Notes

VOLUME 3, ISSUE 1 **MARCH 2014**

GRSBA Mission Statement

"We are a non-profit organization made up of Individuals with Spina Bifida, their families and other community members who work together to promote the physical, emotional and social well-being of all people with Spina Bifida, through programs, events and services in the Greater Rochester N.Y. region, that provide outreach education and advocacy."

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Letter from the President

Greetings everyone!

With the New Year underway and spring just around the corner, GRSBA has kicked off 2014 with a fun-filled pool party. The Mardi Gras themed event was enjoyed by "kids" of all ages, as you can see here.

Photo by: Doug Pease

The pool party is just the beginning of the fun and excitement that awaits us in the year ahead.

Watch your mail in the coming months for updates on what GRSBA is doing in your community and for the annual United Way letter. If you chose to donate to GRSBA through the United Way, I would like to thank you in advance for your support of this great association. I have had the pleasure of being the President of the Board of Directors for two years and I have been an active Board member for over seven years. I can say without a doubt that GRSBA is a family.

I invite you and your family to join us whenever possible for an event or a Board meeting. Your support of GRSBA, be it financial or otherwise, helps us continue our many programs and services to continue reaching new individuals and families in our community.

Thank you to all who have taken part in the Annual Appeal for 2013 and those of you who came out to support the association and each other. I wish you good health and happiness and I look forward to seeing you in the near future!

- Doug

GRSBA Annual Meeting and BOD Elections

On May 14, 2014 GRSBA will hold their Annual Meeting and Elections at the Al Sigl Center at 6:30PM.

We would like to strongly encourage everyone to attend as this is your opportunity to take part in planning the future of the Greater Rochester Spina Bifida Association.

Terms for the following positions are up for re-election:

- President
- Secretary
- Treasure
- Parent Representative
- Member at Large (2 positions)
- Lawyer*

We invite you to send us an email with a statement of why you would like to be part of the GRSBA Board or which position you would be interested in running for.

We are always looking for new faces and ideas!!

Please contact:
Doug Pease at
dhp0220@gmail.com
or Jo Ann Armstrong at
jarmst4459@aol.com

** We are looking for recommendations to fill this board position—please contact us if you have ideas!*

Family Spotlight: The Kulp Family

The Kulp Family

Photos by: Liz Kulp

We are the Kulp family. Shea is our 7 year old wheeled wonder, and the reason we are connected with the GRSBA. Shea's dad is Dan, and his mother and scribe for this article would be me…Liz. Also running around our home you will find Shea's siblings - Simon 9 yrs, Danielle 11 yrs and Emily 2 yrs old. We live in Macedon, NY which is about 30 minutes east of downtown Rochester.

Shea enjoys Rookies, horseback riding, rough housing with friends and anything that involves being social and getting dirty! He is also loves going to summer camp. He cried when he had to come home, not when we dropped him off there!

Dan and I had a calling, or passion if you will, to build our family through adoption. With so many kids needing a home or just a way to survive, it just seemed natural for us. Because of our family history and my job as a Physical Therapist, special needs was not out of our comfort zone. Simon was our first adoption 6 years ago. He has down syndrome and also later we learned that he has non-verbal autism. He gives super-duper hugs and kisses though! Danielle joined our family 4 years ago. We Initially thought she also had down syndrome but after she was home we learned she had a rare 9th chromosome deletion syndrome. Who knew!? That saying about learning something new every day is certainly true in our home. Shea joined our family about 2 ½ years ago…he was adopted from the Ukraine. He is quite the comedian, socialite and very motivated in regards to living life to the fullest… but he could certainly pass on homework if given the chance! Shea can walk with HKAFO's and a walker, but he definitely prefers his wheels. He does have a VP shunt, has had a few surgeries, but overall is in pretty good health. Knock on wood he hasn't succumbed to nearly as much respiratory illness this winter as he did the last 2 years. Last but not least is Emily. She is 2½ years old… and well I think that says it all. She is a handful and then some! She was a lovely surprise addition to our family! Dan currently works as a comedian/story teller, as well as being the pastor of a church. He does a good amount of traveling for his work also.

We learned of GRSBA shortly after we adopted Shea in the autumn of 2011. I can't remember exactly how we learned about the group, but if I had to wager it probably had something to do with meeting Jo Ann at a Kirch clinic day!

Hmmm what would I like from GRSBA?? Do you have nannies? These kids are exhausting! Ha ha. But seriously, I think one of the most important parts of GRSBA is having other parents to talk to who "get it" and understand all of the joys and challenges of loving and caring for an individual with spina bifida. Probably even more important than that is the fact that Shea now has many friends with wheels who have some similar functional and cognitive levels. That is so important for him as he grows, finds his way, and learns to accept and embrace his differences in life. I'm so glad we found you guys…

Interested in being featured in an upcoming Spotlight? Contact Robin Smith via e-mail at rmsmith3025@gmail.com or via phone at (585) 944-8811.

Discover the Magic!
Joint us for the
40th National Conference at Disneyland
June 29 - July 2, Anaheim, California
Register today at www.spinabifidaconference.org

Kirch Corner, By Lorna Patanella, RN

I would like to take the opportunity to thank Mrs. Jo Ann Armstrong for her long standing and significant contribution to the care of children and their families that are seen by the medical providers at the Andrew J. Kirch clinic.

Photo by: Angela Huss

Jo Ann has been a presence in our clinic for over 18 years. As many of you know she literally is our Kirch Corner. She strategically sits at the corner in our clinic to help the various providers stay organized and timely when possible. We often ask Jo Ann to stop into a room when a family would benefit from her support and knowledge.

Recently we had 2 new families come to clinic with their child. One of the families wrote this note to JoAnn and I think that this summarizes exactly why Jo Ann is so important to our office and our community "It was so great having a friendly face at our first spina bifida clinic. I was a little nervous and over-whelmed thinking about meeting with so many new docs at once, but catching up with you helped put me at ease. We had great appointments, thanks for all you do for our local Spina Bifida family!

The other family was new to our area and the girl said that Jo Ann was the only other person she met that also had spina bifida. I am sure that Jo Ann has been that first connection for so many others too.

Not only has Jo Ann had a great impact on our families, she also educates our team and the many student doctors that come to our clinic. She is a tireless advocate for people with disabilities in our university and the community.

We have a consumer advisory board in our division that she has been an active member of for many years. She is also a board member of the Al Sigl and Easter Seals organization.

Thru these roles she advocates for services and programs for people with disabilities both adult and children. Jo Ann's efforts were publically recognized last year with the Rochester Business Journal's Health Care Volunteer of the Year award. I believe that our medical care, our families and our community is a much better place as a result of the thoughtfulness and insights of Jo Ann Armstrong, thank-you!

How to Apply for NRME Reimbursement

The Non-Reimbursable Medical Equipment (NRME) fund was set up over 20 years ago by Donna Willome, a nurse practitioner and parent of a young man with spina bifida. The purpose of the NRME fund is to provide financial support for families who have medical expenses that are not reimbursable trough Medicaid waiver or other funding sources.

Requests for funding are made by way of completing and submitting the NRME application. The application is reviewed for dates, applicability (e.g., sinus medicine co-pays are not related to spina bifida), and completeness. The fund generally covers 80% of the request up to $500.

Requests are reviewed by the GRSBA Board of Directors. However, the name of the requestor is not provided to the Board to ensure fairness in distributing funds. Once approved, the Board Treasurer is provided with the appropriate contact information to arrange for payment.

The following are some helpful hints when filling out the NRME application:

1. Save receipts in a separate file throughout the year.
2. Watch the GRSBA Newsletter or e-mail for the yearly application and deadline information.
3. Follow all directions on the form.
4. Complete the application and send copies of all receipts directly to Donna Willome (contact information provided on the application form).
5. Add any explanations that you think might be helpful.
6. Call or e-mail Donna to let her know that the application has been sent so that she keeps an eye out for it.
7. Remember that you are sending last year's receipts (think of this like filing out your taxes!).

Questions? Contact:
Donna Willome
dwillome@rochester.rr.com
(585) 248-8973

Applications are now being accepted for non-reimbursable medical expenses (NRME). The application is included in this issue of the newsletter!

Find GRSBA on Facebook!
Search for Greater Rochester Spina Bifida Association.

Scott Niles Selected as Boy Scouts Youth Delegate

"I can do anything other Scouts can do. I just do it differently."
- Scott Niles

Scott Niles is a 13-year-old from Williamson, N.Y., and the son of Laurie & Steve Niles. He has 2 sisters, Carolynn & Rachael. He also has a niece, Sophia that he loves so very much.

Scott is a member of Boy Scout Troop 125 in the Seneca District with Seneca Waterways Council, headquartered in Rochester, N.Y. He began his Scouting participation at age 6 and has been involved for the past seven years. While in Cub Scouts he earned the Arrow of Light, the only award from Cub Scouts that can be worn on the Boy Scout uniform.

Scott also competes regionally and nationally with the Rochester Rookies Wheelchair and Ambulatory Track and Field Team. His hero is a 2012 U.S. Paralympian, Ryan Chalmers, who pushed across America in his racing wheelchair, Ryan was also born with Spina Bifida.

Scott's best Scouting memory was completing a four-mile hike to & from Marcy Dam in the Adirondacks. He said it was a really hard hike, but to break it up he would take 300 steps then he would take a 5 minute break. When we got back to our base camp all of his fellow Scouters gave him a standing ovation. Obstacles do not seem to stop Scott from achieving what he sets out to accomplish.

The Boy Scouts of America has since 1916 held a congressional charter under Title 36 of the United States Code. As part of fulfilling the obligations of that charter, the organization hand-picks Scouts and Venturers to visit our nation's capital and deliver a recap of Scouting's previous year.

It's a great way to remind Washington leaders that Scouts do meaningful work in their constituencies and that Scouting is preparing young people for a character-filled life.

This year Scott was selected to represent the BSA and Seneca Waterways Council during a High-Profile Trip to Washington, D.C. Scott was one of only nine youth delegates selected from nearly 2.5 million youth Scouting members to present the Boy Scouts of America's Annual Report to the Nation to Congress. It's basically a summary of another great year for Scouts

How are the delegates chosen?

Each fall, all 300 U.S. Boy Scout councils are asked to nominate a Scout or Venturer to be considered. The National Council then sends these names to a committee that reviews all nominations. Five or six young people are hand-picked to be a representative group of all programs from all four regions of the country. Care is taken to ensure the ethnic diversity of Scouting is showcased.

Three more delegates get "automatic" selections: the National Sea Scout Boatswain, the National Order of the Arrow Chief and the National Venturing President. Serving as a member of the Report to the Nation delegation is one perk of office. They've earned it.

The BSA has no political affiliation, so delegates make sure leaders from both major political parties get copies of the official report. What a great opportunity for these delegates to see firsthand the inner workings of our government. And what a great opportunity for our government leaders to meet some outstanding Scouts! Scott spent 6 days in Washington visiting different historical places, meeting with top national leaders before presenting the Boy Scouts Report to Congress. Scott was able to meet Speaker of the House John Boehner, Representatives Nancy Polosi, & Dan Maffei, and Senators Harry Reid and Mitch McConnel.

The delegation's schedule while in D.C. included scheduled visits to the U.S. Cabinet, House, and Senate leadership, as well as the Secret Service, Pentagon, Goddard Space Center, Tomb of the Unknown Soldier, Supreme Court, and more.

According to the Boy Scout's Seneca Waterways Council office and Troop 125 – "Scott is a great example of the Scouting

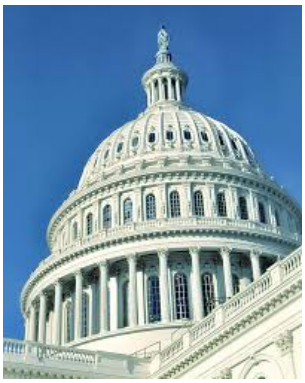
Niles Selected as Boy Scouts Youth Delegate, continued

spirit. He draws upon his abilities versus letting physical challenges stop him from participating in every aspect of Scouting and benefiting greatly from the skills, the confidence building, and the independence gained through Scouting. He is an example of the Scout Oath as he pushes forward, breaking down barriers to do his best and to help others. He has helped his fellow Scouts understand the broad concept of diversity and to welcome and respect all people regardless of their differences"

Scott's mantra: "I can do anything other Scouts can do, I just do it differently" Scott's favorite part of the trip was going to the Pentagon and meeting the Chairman of the Joint Chiefs of Staff, General Martin E. Dempsey. Oh yeah, and also being able to share the whole experience with his Dad.

You can see more pictures at: http://www.flickr.com/photos/boyscoutsofamerica/sets/72157640876703413/

Article written by: Scott & Steve Niles
Photos by: Steve Niles



Thank you!

We would like to thank those of you who donated to GRSBA through the United Way's ROC the Day campaign on December 11, 2013. GRSBA is able to do what we do only because of your kindness and generous donations of time and financial support!

Scholarship Information

Greater Rochester Spina Bifida Association

Colleen Gullen Scholarship Fund

GRSBA is now accepting applications for the 2014-2015 school year.

Applicants must:

- Have spina bifida
- Provide proof of educational institutional registration and mailing address
- Be an active member of GRSBA

Applications are due April 30, 2014
(see application form included in this newsletter)

National Scholarship Opportunity:

180 Medical College Scholarship Program
offers five $1,000 college scholarships to those with spina bifida, spinal chord injuries, transverse myelitis, and/or neurogenic bladder.

Students attending a two-year, four-year, or graduate school program full time in the fall are eligible to apply.

Applications are due June 1, 2014.

For more information, visit: http://www.180medical.com/scholarships

Upcoming Events:

May 14: Annual Mtg. & BOD Mtg.
Sept. 9: Family Picnic
Sept. 24: BOD Mtg.
Dec. 3: BOD Mtg.

GRSBA
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GRSBA Mardi Gras Pool Party (2/23/14)

Everyone had a "swimmingly" good time at the annual SB pool party at the Perinton Recreation Center! Kids and adults alike enjoyed donning masks and beads for the Mardi Gras theme. The afternoon was spent meeting new people and catching up with familiar ones while enjoying pizza and lots of yummy treats. The kids especially loved chasing each other in AND out of the pool. We are already looking forward to the next one!







Photos by Angela Huss