



Serving Families Since 1972

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GRSBA News & Notes

VOLUME 2, ISSUE 2

AUGUST 2013

UPCOMING EVENTS:

- **Sept. 7:**
GRSBA
Family Picnic
- **Sept. 25:**
Board of
Directors
(BOD)
Meeting
- **Dec. 11:**
Roc the Day
- **Dec. 18:**
BOD and
Annual
Meeting

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Letter from the President

Greetings,

Summer has begun and so have the great activities and events of the GRSBA. The Annual Meeting in May was a great success. We had a record number of attendees and participants in the meeting. The Board discussed the continuing development of the new GRSBA Web site, which is up and running. The list of social events for the year was discussed and each Committee Leader gave a report on the status of their events. All of the events planned for 2013 are in this issue, so please be sure to check them out and mark your calendars. Please plan on coming out and joining us in the fun this summer and fall, as each and every Committee member has been working diligently to make these events fun and exciting for each of us to enjoy.

The Colleen Gullen Scholarship Award recipient was also announced at the Annual Meeting. Jennifer Faes received the award and will be returning this fall for her senior year. Jenn has worked hard over the summer to complete classes which will allow for her to graduate early. We are all very proud of Jenn and we wish her the best for the upcoming year.

Finally, GRSBA will be participating in the Roc the Day Campaign again this year. This one-day fundraising event will take place on 12/11/13.

I would like to thank Amy Faes for her years of dedicated service to the GRSBA. Amy has served as a Board member, Committee Leader, President, and most recently as Vice President of the Board of Directors. Amy, I personally want to thank you for your years of devotion and hard work for our group and I know the rest of the Board and the members feel the same. Thank you Amy! You are a dear friend and I know you will continue to be involved with the GRSBA for many years to come.

Thank you, Amy Faes...



I wish each of you a safe, healthy and happy rest of your summer. See you all on Facebook!?

Peace,

Doug Pease, President

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"

“GRSBA is an awesome local support system that families need to know about as soon as possible.”



The Smith Family

Spotlight on the Smith Family

Hey there! We're the Smith Family—Jason, Robin and Jackson. We live just outside of Gorham. Jason and I have been together for over 13 years (married for 6), but have known each other since Middle School. We graduated in the same class! When we're not busy working, playing or going to school/therapy, we can be found riding motorcycles, killing time on Facebook, Blogger and/or Pinterest, or throwing our dinner on the floor for our Great Dane, Duke. We'll let you decide who does what!

Jackson just turned two in May and is obsessed with the word “No.” He enjoys anything that has to do with water, balls or the Disney Jr. Channel. He was born with L5 myelomeningocele and hydrocephalus (VP shunt placed at 1 month old). He's currently a commando-crawler, but does have a wheelchair and a mobile stander. He also has AFOs and a TLSO to help correct his scoliosis. And let's not forget the infamous eyeglasses that spend more time on the floor than on his head!

We've been members of GRSBA for a little over two years—since Jackson was

born—but have only recently become more involved in the last year or so. Robin was just elected to the Board of Directors this past May.

We learned about GRSBA at one of our prenatal visits at Strong Hospital. It was the day that we took the tour of the NICU and met the staff at the Kirch Center (including a very special volunteer, JoAnn, who added us to the GRSBA email list!).

We'd love a larger online presence—something that can be found easily by a parent who has just found out that they are having a child with spina bifida. We want parents to know about GRSBA as soon as they've received a diagnosis, not months down the road. GRSBA is an awesome local support system that families need to know about as soon as possible.

The GRSBA Individual/Family Spotlight is a new feature of the newsletter aimed at helping GRSBA members get to know each other better.

Interested in being featured in an upcoming Spotlight?

Contact Robin Smith via e-mail at rsmith3025@gmail.com or via phone at (585) 944-8811.



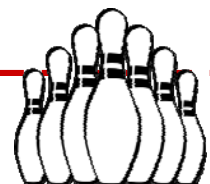
Upcoming GRSBA Events!!!

GRSBA Annual Picnic!

Join us on **Saturday, September 7th, from Noon-4pm**, at the Stevens Pavilion at Veterans Memorial Park in Henrietta (595 Calkins Road). There will be games, crafts, and much more. Lunch will be provided, please bring a snack or dessert to share. Please R.S.V.P. to Holli at hriissberger@gmail.com or 585-329-0038 by Aug. 24.

Bowling Event

Join us on **Sunday, October 20, from 1-4pm**, at Clover Lanes (2750 Monroe Ave.) for an afternoon of bowling, food, and entertainment. A special raffle will be included. Please R.S.V.P. to Gerard at gprit12@gmail.com by October 6.



Kirch Corner: The Dangers of Latex

By: Lorna Patanella, RN

It is summer and time for parties and balloons. For parents of children with spina bifida there is an everlasting vigilance about touching the latex balloons and the possibility a latex reaction. I recall the beginning of the latex concerns when I was a nurse in the late 1980's. Until this time people were not aware of the connection between latex and children with spina bifida. It is well recognized now that people with spina bifida have a higher rate of latex allergies than any other group of people, even those with similar complex newborn malformations like omphalocele and hydrocephalus (per the 2006 article: Early exposure to latex products mediates latex sensitization in spina bifida but not in other diseases with comparable latex exposure rates). The degree of reaction can vary from mild to severe. It is often thought that early and frequent surgeries expose children to latex and predispose them to the allergy. Since the discovery of this reaction hospitals have implemented several changes to reduce a child's exposure, no longer do we use red rubber catheters or latex gloves and in general most hospitals have eliminated latex whenever possible. As a result of these changes the rate of latex allergy has gone from 37% to 0.8% (per the 2010 article: Effects of latex avoidance on latex sensitization, atopy and allergic disease in patients with spina bifida). People born prior to the mid 1990's that had multiple surgeries and used rubber catheters are still at an increased risk for allergy.

The Spina Bifida Association keeps an updated list of latex containing items on their web site:

<http://www.spinabifidaassociation.org>

This is a helpful resource for everyone including your child's summer camp and school nurse. The current recommendation for all people with spina bifida is to avoid latex exposures use "Latex Precautions", but universal allergy testing is not recommended. Enjoy the summer, the parties, the sun but avoid the latex balloons and use latex free band-aids for all those cuts and bumps.

Lorna Patanella is a Pediatric Nurse Practitioner and is the coordinator of the Spina Bifida Clinic at the Kirch Clinic at Golisano Children's Hospital.

For appointments, contact the Kirch Clinic at:
585-275-2986
disabilityinfo@urmc.rochester.edu

News from the Rochester Rookies

The Rochester Rookies Track, Field, Swimming, Archery and Weight Lifting teams experiences a very successful season. The full team—consisting of **Tucker Hauser, Shea Kulp, Max LaMonica, Chase Marcott, Elizabeth Martin, Amanda Merlau, Scott Niles, Luke Schultz, and John Spinks**—brought home numerous Gold, Silver, and Bronze medals from the New Jersey Regional Games. Special congratulations to **Luke Schultz**, who was the recipient of the "2013 Coaches Award" which is presented to the athlete that represents the best overall effort in his/her field.

A special thank you to all the people who made it possible for our athletes to attend, including our coaches, volunteers, sponsors, and parents.

Announcing the 2013 Board of Directors

As part of the Board meeting / Annual meeting, voting was held to elect the GRSBA Board of Directors. Please welcome the incoming Board of Directors for your GRSBA:

- Doug Pease, President
- Julie Christensen, VP
- Larry Wilcox, Treasurer
- Jo Ann Armstrong, Secretary

- Gerard Pritchard & Jillian Borkowski, Co-Chairs/SB Adult Reps
- Kristen Marcott, Parent Rep
- Sarah Merlau, Social Events
- Steve Niles, Social Events/Newsletter
- Lorna Patanella, Medical Advisor/Newsletter
- Holli Rissberger, Social Events/Newsletter
- Robin Smith, Public Relations/Newsletter
- Mark Williams, IT Specialist/

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Spokes for Spina Bifida (Poker Run)

On Saturday, June 22, GRSBA joined with the Chili American Legion Riders in a motor cycle Poker Run fund raiser. "Many thanks" go out to our board member Sarah Merlau for the endless hours of preparation that she and her committee put in to make this a great day. Sarah's committee along with Barbara Williams from the Chili Legion Post provided us with a day of fun, food and yes, even Mother Nature cooperated in providing us with wonderful weather. The final results are not in yet, so we will be reporting back to you in the next issue of this newsletter.

