



Serving Families Since 1972

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# GRSBA News & Notes

VOLUME 2, ISSUE 1

MARCH 2013

## UPCOMING EVENTS:

- **February 27:**  
**Board of Directors (BOD) Meeting**
- **May 22:**  
**BOD and Annual Meeting**
- **June 2013:**  
**Summer Picnic**
- **June 2013:**  
**American Legion Riders**

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## Letter from the President

Dear Friends,

Thank you for taking the time to check out all of the great things that have been happening at GRSBA!

As you can see, there are several events and activities scheduled and even more in the planning process for 2013 and beyond.

If you have the opportunity to join in the fun we would be happy to welcome you.

With all of the events

also comes the opportunity to volunteer. Being part of this group is very rewarding for everyone involved. Whether you are taking part in an event as an observer, supporter or an active participant, you are sure to have fun.

The 2012 Annual Appeal was a big success. We thank you for your continued support of your GRSBA!

Sincerely,

Doug Pease, President



Please consider designating GRSBA for your donations to the 2013 United Way Campaign.

## 2013 Annual Meeting & Elections

Coming up in May GRSBA will be holding it's Annual Meeting and Elections . Nominations are currently open for the following positions.

Anyone interested in running for the board should submit a "brief" description of themselves

and state why they would like to run. Please submit all paperwork to:

Doug Pease  
[dhp0220@gmail.com](mailto:dhp0220@gmail.com)

or

Jo Ann Armstrong  
[jarmst4459@aol.com](mailto:jarmst4459@aol.com)

**Position up for reelection:**  
(terms are for two years)

- Vice Chair
- Treasurer
- Medial Advisor
- (2) General Seats

**Vacant Seats:**

- SB Adult Representative
- Attorney

### 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"*

## Valentine's Pool Party



The GRSBA Annual Valentine's Pool Party was held on Sunday, February 17 at the Perinton Recreation Center. As always, there was good company, good food, and tons of desserts. A wonderful time was had by all.



*"I am motivated by my desire to encourage others to take on challenges and to give back to individuals and organizations that have made a difference in their lives, much like Stay-Focused has made a difference in my life."*



**Ryan Chalmers**

## Catching Up with Ryan Chalmers

### Paralympic Games/London 2012

Competing in track at the Paralympics Games as a member of Team USA was an experience I will remember for the rest of my life. It made me a better wheelchair racer and a better person. London opened my eyes to what disabled sports can become if we are successful in building enough awareness throughout the world. There were 80,000 people in the stands for almost every event, and millions of people in the UK watching on TV.

Even though I didn't hit my best times, or place where I had hoped I would in my events, it was an incredible experience for me. The experience has motivated me to work hard over the next four years, with the goal of doing my very best when I compete in Rio in 2016.

### My role in Stay-Focused ([www.stay-focused.org](http://www.stay-focused.org))

Over the past two years, I have had the opportunity to get more involved with Stay-Focused, a non-profit organization with which I learned to SCUBA dive in 2005. Roger Muller, the Founder/President of Stay-Focused, has enabled me to take on increasing levels

of responsibility in the organization, which has helped me to learn and grow as a person. I have attended meetings, further developed my interviewing and networking skills, and assisted in managing programs.

In the past year, I have been actively involved in all aspects of creating a major campaign, Push Across America, designed to build awareness for the potential of all persons with disabilities, as Stay-Focused celebrates its 10-year anniversary. I have traveled all over the US with Roger, meeting potential sponsors and donors, and I am totally committed to making Push Across America an overwhelming success. Roger and I have discussed my role in the organization going forward, and it is clear I will be involved with Stay-Focused for the long-term, both as a mentor for first-time divers, and as a member of the leadership team. I can honestly say, I could not be happier with the direction in which my life has taken me.

*Ryan Chalmers and his family have been active in GRSBA since Ryan was in grammar school. His mother, Linda, has served on the Board of Directors. His father, Gregg, is the Head Coach of the Rochester Rookies sports team.*

# Kirch Corner: Negotiating the Educational System

By: Lorna Patanella, RN

All families that have a child born with a developmental disability like spina bifida are suddenly thrust into a world of medical jargon and abbreviations. As a parent you quickly learn the terms that are most important at the time, but may not be aware of issues and concerns that develop down the road. Although it feels at the time that school is a long way off, it approaches quickly. The educational system adds another yet another system to negotiate and understand.

Children with spina bifida automatically qualify for Early Intervention (EI) services from birth. A child's gross motor, fine motor, social, communication, intellectual and daily living skills are assessed by trained therapists or other professionals. If it is found that they have delays in any of those areas, an Individual Family Service Plan (IFSP) is developed and services are put in place to help your child develop. This is a family directed program, and services are provided in home or day care. The family and team meet to review your child's progress every 6 months. This program starts at birth and continues thru age 3.

When your child reaches age 3 the services change from a community based program to a school district directed program. Your child is still assessed and services are provided based upon need similar to EI, but the district's Committee on Preschool Special Education (CPSE) is now the organizing body. If your child is eligible to receive services they will develop a plan to provide services called an Individualized Education Plan (IEP). Based upon the IEP, services will now be provided in the Least Restrictive Environment (LRE), this may still be at home, daycare or a preschool setting. Officially parents meet with the CPSE annually to review progress and plan for the next school year. A child has a formal re evaluation every 3 years unless your child's condition changes, or it is requested by a teacher or parent. Parents are provided a copy of all testing and the IEP with all the recommendations. If a

parent does not agree with the results and recommendations they are within their rights to disagree and seek an independent educational evaluation (IEE) paid for by the district.

By the time your child reaches age 5 and transitions to kindergarten the Committee on Special Education (CSE) assumes responsibility for planning services for your child in a similar manner as in preschool. Now, with few exceptions, the services are provided by the school personnel within the school setting. It is important for children with spina bifida who may also have a learning disability to have that recognized by the CSE so that educational modifications, if needed, can be put in place.

Often children with spina bifida are identified as a child with an orthopaedic disability and their learning needs may be overlooked or underestimated. All services and therapy must be educationally relevant and directed at promoting a child's educational progress. It is important to include specific goals for the IEP, which both the parents, child and school team can identify. By age 12 your child will receive an assessment to determine vocational skills, aptitudes, and interests and by age 14 the CSE will begin discussing post high school goals as part of Transition Planning. A child that receives special education services under an IEP diploma is entitled to stay in school and receive services thru age 21. Students that graduate with a Regents diploma and have received services can access adult directed supports upon graduating to help with college or work related needs.

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](mailto:disabilityinfo@urmc.rochester.edu)

## Thank You...from the GRSBA Scholarship Winner

I would like to thank the GRSBA for the scholarship that I received in June this past summer. Currently I am an Education major at SUNY Geneseo and plan on becoming a teacher after I graduate. I used the scholarship money to pay for all my textbooks and materials for two semesters at Geneseo. Receiving the scholarship has really helped make a difference. It has been a huge help in assisting in covering my college expenses and is greatly appreciated.

Sincerely,  
Jenn Faes (2012 Scholarship Winner)



Jenn Faes visited a Rochester Rookies practice during a fall break from SUNY Geneseo

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## GRSBA Youth SCUBA Dives in Grand Cayman

Amanda Merlau of Hilton, NY recently completed her first diving program with Stay-Focused, an organization that offers teens and young adults with disabilities the opportunity to become certified SCUBA divers. The 16-year old returned from her week-long trip to Grand Cayman with PADI certification (PADI is the Professional Association of Diving Instructors) and a renewed sense of confidence in her abilities. The Stay-Focused program is a unique one, using SCUBA diving as a medium for leadership development and empowerment, and to encourage unlimited possibilities for disabled youth and young adults.

The belief in unlimited possibilities is nothing new to Amanda, who also recently returned from a successful showing in the 2012 National Junior Disabilities Championships (NJDC) in Edison, New Jersey. A member of the Rochester Rookies Wheelchair and Ambulatory Sports Program since 2003, Amanda is an experienced athlete who competed in numerous events, including shotput, discus, swimming and power lifting.

Amanda looks forward to continuing to pursue athletics

and unleashing her potential, both with the Rochester Rookies and with Stay-Focused. The Rochester Rookies will gear up to start is 2012-2013 season in September, and in the summer of 2013, Amanda will return to Grand Cayman for a Reunion trip with her Stay-Focused SCUBA certification class.

**Amanda and her  
Stay-Focused SCUBA team**

