



Serving Families Since 1972

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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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GRSBA

News & Notes

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Letter from the President

Summer has just begun and the GRSBA has been a busy group already. On June 11 we held our Annual Meeting and Board of Director's meeting. I am pleased to announce the following people as your Board of Directors for the upcoming year.



Officers:

Doug Pease, President
Julie Christensen, Vice President
Scott Cresswell, Treasurer (NEW)
Jo Ann Armstrong, Secretary

Directors:

Jillian Borkowski, SB Adult Representatives
Elizabeth Kulp, General Board Seat (NEW)
Kristin Marcott, Parent Representative
Sarah Merlau, General Board Seat
Steve Niles, General Board Seat
Lorna Patanella, Medical Advisor
Gerard Pritchard, SB Adult Representative
Holli Rissberger, General Board Seat
Robin Smith, Public Relations
Mark Williams, Web Site Administrator

We welcome Scott and Elizabeth to our Board! We are all very excited to work with you.

- Doug

2014 Colleen Gullen Scholarship Awards Announced

GRSBA would like to announce the five people who have received the Colleen Gullen Scholarship Award for 2014. We had a record number of applications this year. The Board is very excited to hear from these students after they complete their courses. Each applicant below received a \$500.00 award to assist in paying for their education.

Jillian Borkowski will begin classes at Monroe Community College in the fall.

Jennifer Faes will be completing her senior year at SUNY Geneseo.

Chase Marcott will begin classes at Monroe Community College in the fall.

Amanda Merlau will begin classes at Monroe Community College in the fall.

Zachary Pike will begin classes at Monroe Community College in Spring 2015.

This scholarship program was created in memory of Colleen Gullen by her parents and siblings. These students are receiving this financial assistance because of the generosity of the Gullen family. GRSBA would like to thank the Gullen family for helping our young adults further their educational training.

For more information about Colleen, please turn to Page 4 of this newsletter.

GRSBA Spotlight: Chase Marcott & Amanda Merlau



This edition of the GRSBA Spotlight series focuses on two of GRSBA's young adults that are graduating from high school this year: Chase Marcott and Amanda Merlau.

Chase Marcott

Hello, my name is Chase Marcott and I just graduated from Pittsford Sutherland - Class of 2014. I was born with Spina Bifida March 8th, 1996. Sports have been a huge part of my life, basically my whole life. I have been a part of the Rochester Rookies (track and field team) since the age of 5 and I have been competing with the team since the age of 6. I am

also a member of the Rochester Wheels (basketball) since the age of 13. Next year I will be attending MCC. I am doing the two plus two program. After two years at MCC I am thinking about

going to R.I.T but I am not 100% sure yet. I don't really know what I want to major in yet. I was thinking about industrial design but now I am thinking more about communications or broadcast journalism. I have no idea what I want to do yet though. I go through life day by day. I don't worry about what is going to happen tomorrow or what is going to happen next week. I live for today and I don't plan on changing it. "I don't need easy, I just need possible." – Bethany Hamilton.

Amanda Merlau

Graduating this year still comes to a shock to

me. I would NOT be the person I am today if I had never joined the Rochester Rookies. When I was little, I was very shy and didn't have many friends. Now I am kind, hard-working and a passionate person and have friends by my side. This year I am graduating from Hilton High School. I loved participating in our school's musical production and our drama club production. I also loved competing in track for the Rookies. Next year I plan on going to MCC and majoring in special education, and working with kids with autism.

Congratulations to Chase and Amanda as well as anyone else that has graduated this year, whether it be from high school, kindergarten or college!

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.

Meet Scott Cresswell, GRSBA Treasurer

Hi, I'm Scott Cresswell, a CPA with The Bonadio Group. I feel honored to have been asked to serve as Treasurer for GRSBA for the next 2 years. I was born and raised in Hilton, NY. Graduated College at St. John Fisher in 1988 and have been in public accounting ever since.

I have served as Treasurer for several organizations over the years with my goal to always not only keep accurate numbers but help move the organization forward so that it ends up in a better place than when I started. I look forward to meeting and working with you all.

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Non-Reimbursable Medical Expense Fund (NRME) Awards Announced

The GRSBA Board of Directors received and approved three applications this year for the NRME program. Nearly \$1,400.00 was awarded in June. We encourage all of our families and members to consider applying next year for the NRME program. Read future newsletters for more information on this program and to get an application.

Kirch Corner, By Lorna Patanella, RN

Sun is In! Vitamin D is a key nutrient for maintaining a healthy body. This vitamin plays a very important role in bone health specifically and possibly other roles within our bodies.

Vitamin D works to increase calcium absorption from our gut and then to bind calcium and phosphate together to form strong bones. It is important to have enough of both Vitamin D and Calcium to avoid soft bones (also known as osteomalacia) and then possibly fractures.

What is unusual about Vitamin D is that it comes naturally from the sun. The sun's UVB rays allow our skin to produce

Vitamin D and is then transported to the blood stream and ultimately to our bones where it binds with the calcium to lay down new bone. Our bodies are constantly losing bone and creating new bone, but in order for this to be effective the building blocks (Calcium, Phosphate and Vitamin D) need to be present in adequate quantities.

Ideally it only takes 20 minutes of strong sun exposure (between 10 am and 2 pm) to a large portion of exposed skin to get enough Vitamin D. Here is the catch, sunscreen interferes with the sun's UVB rays and the creation of Vitamin D and the sun in Western New

York is only strong enough in the summer. This is therefore a problem for most of us, but for people that do not walk and bear weight on their legs they are at higher risk for developing weakened bones. The process of putting weight on our bones helps them to stay strong and avoid fractures (breaks). For people with spina bifida this can become a serious health concern. The research has shown a fracture rate of 11-30% for children with spina bifida. Unfortunately the research is limited regarding standing programs for people with spina bifida that are not fully weight bearing. It is

important to ensure that everyone has adequate calcium intake especially during childhood and adolescence when most of our bone formation is made and adequate Vitamin D to aid in the bone development. Please speak with your medical providers about you or your child's risk factors for developing weak bones and their fracture risk and strategies to reduce their risk.



Did you know...

Radio flyer makes a very cool arm powered big wheel for kids ages 3-7. Its called the cyclone and you can find it in stores. If you call the manufacturer they will even send you out a FREE adapter kit that your child's legs can rest on.



Several members are also excited about the "free wheel". It attaches to your wheel chair and helps navigate many outdoor terrains. It fits on many different types of wheel chairs. Check it out at:

<https://www.gofreewheel.com/>

Swap your stuff...

A child's wheeled stander available. Free, great condition, just outgrown. Contact Holli for more information at hriissberger@gmail.com

If you have equipment that you would like to share or are looking for something please contact Holli at hriissberger@gmail.com and it will be included in our next newsletter as well as on our GRSBA Facebook page.



**Find GRSBA on
Facebook!**

Search for Greater Rochester
Spina Bifida Association.



“Her life was probably a better sermon than any preacher could put together. Her father said Colleen died at the crest of her wave. Only God could take her higher and He did ...”

***- Rev. James Moynihan,
pastor of St. Joseph's
Church, in his Eulogy
May 7, 1986***



Colleen Gullen: The Sharing of a Legacy of a Child

By Nancy Gullen

It is said the most difficult loss one can experience is the death of a child. Books tell us that one never quite recovers from the pain. However, let us not forget that even a child continues to live on in us. The very day we are born our legacy begins to build. It takes a lifetime. And no matter our age we leave a final gift to all ... our legacy ... true for a child as well. Never thought about it? Neither did I until our daughter, Colleen, died.

“Don’t tell me I can’t until I have tried. And when I have tried, I’ll show you I can.”

Colleen lived by those words for 19 years as she coped with the effects of Spina Bifida and Hydrocephalus. “She was really a miracle person,” said Sister Elaine Englert, SSJ, Principal of Nazareth Academy, where Colleen was soon to graduate. “They said she would not live past the age of 2 and that she would not be able to achieve in school but she lived to be 19 and was a B+ student.” While at Nazareth Academy Colleen was a member of the Perosian Choir and worked on the staff of the Gabriel, the school’s

newspaper; on the literary magazine, Spectrum and on the yearbook, Lanthorn. In the community she also worked as a volunteer “Candy Striper” in the mail room of St. Mary’s Hospital where she would insist every Saturday morning when I drove her that I drop her off at the main door and she would find her way to her job. Reluctantly I would drive away and not look back knowing she had to go to the basement. She laughed one day saying that she had trouble with the elevator and that a nice man not only assisted her but walked with her to the mail-room. He just happened to be the head of Administration! Colleen was not only a member of the Youth Group at St. Joseph’s parish in Penfield, where she was a member, but also worked as a receptionist twice a week in the rectory. We told Colleen early on that she had many gifts from God and they were hers to use. She was a person first with a disability second! Be true to yourself and don’t forget to smile!

In her growing years as her parents we focused on helping Colleen to reach her maximum

potential. We taught her that in order to achieve in a tough world independence was her key and a positive attitude would be her saving grace assuring her we would be beside her all the way. So it was at the beginning of her school years with the reluctance to accept her in the mainstream and when after months of dialogue with the Penfield School Superintendent Colleen was the first person with a physical disability to ever ride a Penfield School Bus. As a young child she mastered the long leg braces along with Canadian crutches and as an enrolled Blue Bird rode her adapted bike in the 4th of July parade along with her troop. Colleen had just been accepted to the Fall term at Nazareth College two weeks prior to her death. To live on campus would have been her first opportunity for independent living. She was thrilled! Another achievement for a determined young woman!

What has been our inspiration over the past 28 years since Colleen died? The answer is very simple. The Madaglia Pontificia Medal mentioned in the above caption and placed in my

Colleen Gullen, continued

hand by Pope Paul VI showing his profile on one side and on the other the figure of Christ with outstretched arms below the inscription "Christ ... the Way, the Truth and the Life". Confusion with tickets for a 1969 audience with the Pope placed my husband and I in the first row. Upon conclusion of his Papal address Pope Paul descended the stairs walking toward us with the Pontifical photographer and guards at his side. Hands reached out from everywhere to touch him and people shouted his name. Frightened by the crush Colleen, in my arms, screamed. Pope Paul gently lifted her into his arms and kissed her. Taking my hand he then placed in my palm his medal folding each finger over the purple velvet bag. Softly smiling his eyes

were piercing as if to say, "this will inspire". Upon returning home the medal was framed along with the picture so that Colleen would have it for her lifetime. After Colleen died we realized that the medal was now meant to inspire us. It continues to do so with the Colleen Gullen Spina Bifida Association Scholarship Fund given out each year for Post Secondary and/or Training School opportunities.

It has been 28 years since Colleen passed away and words still do not come easy. Although at birth her wrappings had a slight tear known as the birth defect Spina Bifida, inside the child was perfect and over the 19 years of her young life she taught us and others the true meaning of love, of accepting people as they really are, of reaching out



Pope Paul VI gives a medal to Colleen Gullen, then 2, with her mother, in a papal audience of 500 people in Rome. (Vatican photograph, appeared in the Democrat & Chronicle, May 10, 1986)

to others and how to most of all, to lean on our Faith during periods of struggle, trial and loss.. In their letter of condolences the Rochester Eye and Human Parts bank stated, "We hope you will find comfort in the knowledge that the gift of Colleen's eyes has restored the sight of two young people."

We have reluctantly given back part of God's gift of Colleen – the

person, but the other part – all that she gave to each of us known as her Legacy, will remain with us forever. The spirit never dies! It takes courage to live ... to grieve ... to survive as well as to be a person physically challenged or the parents of a child born to fight the odds. Like the gold medallion we must hold our courage in the palm of our hand. It is then that we will find our way, our truth and our life.

Save the Date: GRSBA Family Picnic



Saturday, September 6th, 2014

12-4 pm

Steven's Pavilion at Veterans Memorial Park

595 Calkins Road, Henrietta

Face painter, massages, Magic Joe,, food, friends, and more!!!

We will provide lunch and drinks, feel free to bring a snack to share .



Upcoming Events:

Sept. 9: Family Picnic
Sept. 24: BOD Mtg.
Dec. 3: BOD Mtg.

Push Like Me! By Chase Marcott

I graduated from Pittsford Sutherland High School on Saturday June 21st. For my English class this year, I had to do a "Passion Project" When I got the assignment I thought to myself "Oh boy, this is going to be hard... what am I passionate about?" After a few day of thinking about it I got it! My whole life I have wanted to teach as many people as I could about spina bifida and what it is like to be on a wheelchair on a daily basis. So I decided to hold an event called "PUSH LIKE ME!" I wanted to have several students be in wheelchairs for part of their school day so they can get an idea of all of the struggles I go through on daily basis at school. I contacted Monroe wheelchair to see if they could donate 6 wheelchairs for the day and I explained what I was doing. The people at Monroe were so excited that they said yes. I had a sign up for the event in the main office at Pittsford Sutherland High School for a week and at the end of the week I had over 50 people who wanted to take place in the event. Since there was such an interest in the event I decided to pick 12 students to be on a wheelchair for a day. I had 6 students for the morning classes and 6 students for the afternoon classes. Then after the event was over I made up a few reflective questions and gave them to each student who took part in the "PUSH LIKE ME!" event. All of the responses were amazing. It was very cool to see what other students had to say about the whole thing. I hope I can some day take this event to other schools around the country and maybe one day make it into a fundraiser for awareness for persons with "disabilities".



Please if you have any questions at all email me and I would be happy to respond to you.
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