

# Newsletter / Member Update

## Letter From The President

Hello GRSBA Members and Happy New Year! The Board's focus in 2022, since our last General Membership Meeting, was around creating financial statements, reinstating the organization with the IRS as a 501(c)(3) charity, and restoring our relationship with the United Way. Now that each of those initiatives is complete, I'm pleased to inform you all that our organization is again on solid footing. Now, 2023 will be about making the GRSBA a vital resource for our members and the spina bifida community at large. This organization quite literally belongs to all of you.

We're now at a crossroads for all of us to define what exactly this organization should be.

### **We could...**

- Be a vital resource for new parents.
- Assist our adult members with resume building, honing interview skill, and job placement.
- Tell informative, and entertaining stories via social media, a newsletter, or on our website.
- Focus on building a tight community by fostering friendships and relationships among our membership.
- Design fun social events for families and the community.
- Assist families with their medical expenses.
- Have webinars hosted by experts on certain subject matter of interest.

... **and so much more!**

Clearly, the opportunities and directions are plentiful and there's more that we haven't even thought of yet. That's why we want to hear from you. I hope each of you will be able to attend our annual meeting and help define where we should go. Our possibilities are unlimited!



I look forward to talking to you and welcome your questions, ideas, and suggestions.

Moving forward together,

A handwritten signature in black ink that reads "Chris Muller". The signature is written in a cursive, flowing style.

**Chris Muller, GRSBA President**

Cell: 585-748-5697

E-Mail: [christopher.muller@gmail.com](mailto:christopher.muller@gmail.com)

*Although this document is lengthy and may be repetitive of previous letters and postings, we feel it is important to update members on the status of YOUR organization. We recognize that many members may not have received our electronic updates (Email and Facebook postings). Therefore, this version, which was sent by three methods of communication (USPS Mail, Email, and Facebook Posting), is all-inclusive of previous and current updates. If you have not received an email or USPS Mailing, please contact GRSBA to update your contact information. You can find the GRSBA mailing and email address at the end of this document.*

# IRS Revocation, Reinstatement and the Rebuilding GRSBA

As previously disclosed, the lack of tax filings for three consecutive years led to the organization's non-profit status being revoked in 2021.

The newly elected BOD met monthly and worked daily to file past-due federal and state taxes, which eventually led to the reinstatement of GRSBA's tax-exempt status. We were fortunate that the reinstatement dated back to the date of the initial revocation, which alleviated any concerns with contributions received over the past couple of years.

The BOD also worked to obtain authorized access to all bank accounts, which aided in the review of the organization's financial position and previous transactions.

Simultaneously, efforts were made to create a firm foundation necessary to rebuild the organization.

## COMMITTEES

We recognize that Committees are where the real work gets accomplished and are thankful for the members who have volunteered their service to help GRSBA serve people with spina bifida and rebuild a foundation for growth, progress and sustainability. The following committees were formed, which are focused on specific initiatives:

### EDUCATION AND AWARENESS COMMITTEE (EAC)

This committee is co-chaired by Kristin Ragone and Luke Schultz. The team's focus is on raising community awareness and ongoing education for GRSBA members.

A sub-committee will focus on Medical Needs Coordination, which will replace the previous responsibilities of the "Medical Advisor" position that was eliminated. Kristin Ragone will lead this effort. Sandra Burtner and Liz Kulp have also joined the committee.

## **COMMUNICATIONS COMMITTEE**

This committee focuses on social media content such as Facebook and Instagram, etc., Website updates, a “Welcoming” sub-committee and other forms of communication deemed necessary. The Communications Committee is chaired by Allie Ferington with Erin Briggs, Elizabeth Fox, Chase Marcott and Robin Smith serving on the team.

## **BYLAWS COMMITTEE**

The objective of this committee was to review the bylaws of GRSBA and recommend edits to ensure that we are centering around people with spina bifida and complying with current bylaws. The committee was chaired by Stephanie Woodward and included members Jessica Jones, Greg Ringelstein and Kristin Marcott.

## **NEED ASSESSMENT COMMITTEE (NAC)**

This committee is an Ad-Hoc committee. It operates with the intention to solicit feedback from all members and will hold open-

door meeting sessions. The team is chaired by Allie Ferington, with the assistance of members: Jenny Sterner, Robin Smith, Louis Day, and Gregg Chalmers.

## **GOVERNANCE COMMITTEE**

The purpose of this committee is to organize, coordinate and facilitate the GRSBA Annual Meeting, BOD Member Nomination Process and the election process, as set forth in the recently updated By-Laws.

The committee is chaired by Gregg Chalmers and consists of members Sandra Burtner, Louis Day, Jean DiNoto, Kristin Fien, Chase Marcott, Kristin Marcott, Missi Rickett and Shawna Lee Ryan. This committee will disband upon completion of the Annual Meeting and elections.



# The Bylaws of The Greater Rochester Spina Bifida Association

One of the first initiatives that the current BOD acted upon was the review of the Bylaws (last amended was on March 25, 2015) to determine if any potential updates should be considered.

The Bylaws Committee, led by Stephanie Woodward, spent much time, focus and energy to thoroughly review and propose changes that the committee felt necessary.

The BOD reviewed the changes proposed by the committee and unanimously approved the amendment dated June 2, 2022. The updated Bylaws took effect immediately upon approval.

A copy of the Bylaws of the Greater Rochester New York Spina Bifida Association can be found on the GRSBA Website. It is also available upon request.

## Medical Reimbursement Fund

The BOD has unanimously agreed to reinstate the Medical Reimbursement Fund. The grant criteria, application, review and approval process will fall under the responsibility of a sub-committee (of the Education and Awareness Committee), led by Kristin Ragone, who will work quickly to make this program available to our members. You can expect an update on the committee's progress soon.





## GRSBA New Logo

The BOD has secured the service of GRSBA Member, Nico Santiago, for the creation of a new logo. Nico will graduate in the Spring from RIT with a degree in Industrial Design and has presented several logo options, which are currently being considered. The final selection will be revealed in the near future. Thank you, Nico, for sharing your creativity and talent with GRSBA! This is the first step in the updating of the organizations new look and brand.



## Website

Inline with the BODs objective of creating a new look and brand for the organization, all agreed that efforts should be made to create a

new Website, which will serve as a vehicle for communication and resource for members.

This project will fall under the responsibilities of the Communications Committee.

## Bowling Event

The first social event since the organization's non-profit status reinstatement was a fun gathering of bowling. The day was filled with laughter, smiles, conversations, games ... and a few strikes. Future social events will be announced soon!



# Financial Stability and Fiduciary Responsibility

Due to the fact that previous GRSBA Financial Statements and transaction registers were not available, Treasurer, Kristin Fien, devoted a significant amount of time recreating financial statements dating back to January 1, 2022.

Previous year's Bank Statements and transactions were obtained from the financial institutions and reserved for future review and reference.

Funds were transferred from the checking account to savings account, which earn a higher rate of interest.

Currently, ALL financial transactions are presented during the "Treasurer's Financial Review," which occurs at all BOD meetings.

Basic Accounting Principles were implemented to ensure fiduciary responsibility is held to high standards, and that the BOD act as Stewards of trust and in good faith for the good of the organization,

placing the interest of its members first and foremost.

## United Way

The loss of GRSBA's non-profit designation led to the freezing of the United Way funds, which had been designated to GRSBA.

The success with the reinstatement of the IRS non-profit status and consistent communication with the United Way were successful in retroactively releasing the 2020 and 2021 funds which were withheld.



GRSBA had to resubmit an application to be a United Way "Donor Designation Agency" which, after much communication and correspondence, was eventually approved.

The United Way Donor Designation Agency number for the Greater Rochester Spina Bifida Association is #1044.

## GRSBA'S Sustainability

A primary goal of the BOD is to build the organization's ability to maintain and support the organization over time. Many processes, procedures and safeguards were implemented to ensure the sustainability of the organization.

A shared Google Drive was created to maintain all GRSBA Financials, Bank Financial Statements, BOD Meeting Minutes and Committee Reports, IRS and NYS Tax Financial Forms, which include detailed instructions for completion and filing deadlines, Membership



Contact Listings and ALL other organizational correspondence and relevant documents.

The objective to create a smooth and informative transfer of responsibilities as changes in officers occur is a key step to ensuring continued growth and progress of GRSBA. Steps are underway to facilitate this process.





# Annual Membership Meeting

## Save The Date!

Please mark your calendar for our upcoming Annual Membership Meeting and Election. We look forward to a night of fun, which will include an update on the progress of the organization, great food, beverage / open bar, and GREAT raffle prizes! We have worked hard to create processes and procedures that will speed up the election vote tally!

Please see official “NOTICE of Annual General Membership Meeting and Elections”, which is attached to this update letter.

Date: **Thursday, February 16th**

Time: **6:30 PM**

Place: **Strathallan –  
Downstairs Ballroom**

## Membership

The Board of Directors has agreed to waive the 2023 Membership Dues, therefore, ALL current and new members are considered active and eligible to vote. A drive to increase membership will occur throughout this year.





# Purpose of our Upcoming Board of Directors Election

The entire Board of Directors (BOD) was elected to a two-year term during the last Annual Membership Meeting and Election. This was due to the fact that the organization had lost its Non-Profit Status and all terms for the previous officers had expired. In an effort to establish a staggered election cycle for BOD positions, some Directors have volunteered to serve a one-year term, while others will complete a two-year commitment.

The current election, based on a change to the by-laws, will be for a three-year term. The “President and Secretary” will complete their two- year commitment and the “Vice President and “Treasurer” positions are up for reelections. Half of the BOD has also volunteered to offer their positions for re-election. This will provide continuity and align with the terms of the by-law requirements.

The following positions are voluntarily up for reelection:

**- Vice President**

**- Treasurer**

and

**- Three (3)**

**Director Positions**

Please find the Board of Directors Nomination Form and Self Addressed/Postage-Free envelope enclosed.

If you did not receive a hard-copy mailing, please contact GRSBA to confirm your address is correct in our membership database.

# — Current Board of Directors —



**Chris Muller**  
*President*



**Stephanie Woodward**  
*Vice President*



**Kristin Fien**  
*Treasurer*



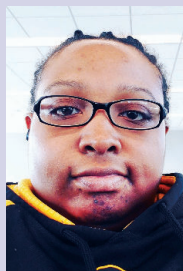
**Gregg Chalmers**  
*Secretary*



**Sandra Burtner**  
*Parent Representative*



**Allie Ferington**  
*Director*



**Jessica Jones**  
*Director*



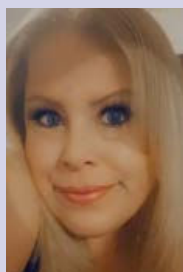
**Kristin Marcott**  
*Director*



**Kristin Ragone**  
*Director*



**Nick Ragone**  
*Director*



**Shawna Lee Ryan**  
*Director*



**Luke Schultz**  
*Director*

# — GRSB Contact Information —



## **Mailing Address**

P.O. Box 3 • Fairport, NY 14450

## **Email**

GRSBA.NY@Gmail.com

## **Phone**

Chris Muller, President: 585-748-5697

## **Enclosed Materials**

- » **Annual General Meeting and Election Notice**
- » **Call for BOD Position Nominations**
- » **Nomination Form**
- » **Membership Application (For NEW Members only, existing members are not required to renew their membership.)**
- » **USPS Mailing includes Self Addressed/Postage-free Envelope for the return of Nomination Forms**



# *Where should we take the* **GRSBA?**



## **We're Back and We Want To Hear From You!**

The Greater Rochester Spina Bifida Association (GRSBA) is quickly gaining ground in strengthening our ability to provide resources, educational opportunities, job seeking resources and social gatherings for our members!

We've consistently sought and received feedback from our members, offering suggestions on how we can better serve our members and community. We strive to act on these recommendations and to build an organization that better serves ALL members.

Please continue to provide feedback, as we want to keep the momentum going!

