

JANUARY 2024



MEMBER EXPERIENCE & NEEDS ASSESSMENT FEEDBACK SURVEY REPORT



**Bleeding Disorders
Association of South
Carolina**

Serving All Bleeding Disorders
864 - 350 - 9941 | www.bda-sc.org

Our 2023 Experiences!



**NATIONAL BLEEDING DISORDERS
AWARENESS MONTH**



Camp Connections 2023



50TH ANNIVERSARY CELEBRATION



9th Annual Par For The Clot



**10TH ANNUAL STEP
FOR BLEEDING DISORDERS**



Community Connections Programs in 2023

BDASC

Member Experience Survey

On behalf of Bleeding Disorders Association of South Carolina, we are pleased to provide the results of the voices from our community from the 2024 Member Outreach Feedback Survey. While the number of respondents that took the survey was topped at 34, and we would have liked to have had more voices represented, these responses will be taken into consideration during this current year. The survey was open from November 15, 2023 through January 5, 2024 and was provided by QR Codes, mailings, within our newsletter articles, during events, within our E-blast newsletters, our social media platforms, Facebook and Instagram, our website, and was included within our e-mail signature for our employees. We strived to provide the survey in a quick format but wanted to also provide the opportunity for respondents to have open-ended questions so they can provide additional feedback.

This year we wanted to capture who was taking the survey and we thank you for providing the counties for which you live. The largest county representation was Greenville and Aiken County followed by Richland with a total of sixteen counties represented. Members impacted by hemophilia A had the largest number of survey results, with von Willebrand's Disease following, followed by hemophilia B, platelet disorders and other rare diseases. Our ethnicity of those who took the survey was predominantly represented by members reporting they are white, at 24 participants, with 8 participants identifying as black and one identifying as Hispanic. Our goal in the future will be to address having larger feedback from our minority communities.



2024 Membership Data Quick Glance

Members living in the Upstate - 167

Members living in the Midstate - 199

Members living in the Lowcountry - 95

Members living outside of South Carolina - 43

Membership by Bleeding Disorders

Hemophilia A - 296 (including women)

Hemophilia B - 49 (including women)

Women diagnosed as having Hemophilia A or B are not well reported and is something we will need to collect: Our records to date show 8 with hemophilia A, 6 with hemophilia B, most self-reported as mild.

Males with VWD - 54

Women with VWD - 92

Other Rare and Ultra Rare, Platelet Disorders are listed below - 17

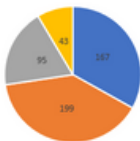
- Dysfibrinogenemia
- ITP Severe
- Delta Storage Pool Deficiency
- Factor Seven
- ITP
- Factor 11 (Hemophilia C)
- Qualitative Platelet Disorder
- Gray Platelet Syndrome
- Factor XIII
- Hypofibrinogenemia
- Factor Seven / Sickle Cell
- Hypodysfibrinogenemia / Platelet Aggregation Dysfunction
- Hypermobil Elher Danlas Syndrome / Platelet Dysfunction Unknown
- Platelet Function Disorder (unknown)
- Factor 1, Hypofibrinogenemia
- Platelet Function Disorder / May-Hegglin Anomaly
- Factor V Deficiency

Our member's ethnicity is something we are also now gathering, among many other data set, and we thank you for providing this information to us. As deidentified information, this data allows us to address all aspects within access to treatment and health care, educational and supportive services, while also helping us address health inequities, diversity, and inclusion. You can rest assured all personal information remains within the organization's data base and is never shared or provided to anyone.

Demographic Information

Demographic information is useful to the Board of Directors and the Executive Director when determining the needs of the community. This information is used to determine locations for events and which education topics to provide to the community. This information is vital in providing adequate services to the bleeding disorders community within South Carolina.

Member Demographics



■ Members living in the Upstate

■ Members living in the Midstate

■ Members living in the Lowcountry

■ Members living outside of South Carolina



In Which County Do You Live?

Of the member households who took the survey, the three counties that were most represented were **Aiken, Greenville** and **Richland**. Aiken and Richland counties fall within Region 2, whereas Greenville County falls within Region 1. Members were asked this question to identify that geographic area where events would reach the most community members. We received 12 responses from Region 1 (Upstate), 14 response from Region 2 (Midstate) and 8 responses from Region 3 (Lowcountry).

Which diagnosis do you have within your household?

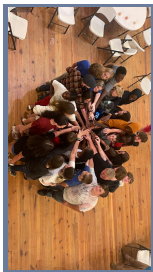
Of the member households who took the survey, the majority (16 responses) have members of their household living with Hemophilia A, with von Willebrand closely behind (12 responses). Additionally, in the "other" category, Hemophilia A Carrier was listed. Respondents were allowed to choose more than one diagnosis.

What is your ethnicity?

Of the member households who took the survey, the majority (24 responses) identified as White, while 8 respondents identified as Black/African American and the remaining 1 respondent identified as Hispanic/Latino.

What number of adults, teens and children living in your household?

Of the member households who took the survey, they identified 17 children, 16 teens and 30 adults within our community.



Support Services and Needs

With our continuous growth in membership these past few years and the high cost of increase event programming we asked the community if they would mind if we defrayed some of these costs at larger events by asking for a \$25 donation fee. Twenty-seven respondents said they were fine with helping to raise funds in this way while four respondents stated no. At this time, we would like to encourage our members to help us provide an **increase in our fundraising efforts, by donations, support, and your involvement** as opposed to charging for our events this year. While this is not something new to many of our national chapter organizations who do charge fees to attend larger events, we would like to not implement this option at this time. We encourage your support to help us continue to provide all events free of charge.

With our continuous growth of our membership and overall rising costs, would you be comfortable with a \$25.00 fee to attend our overnight events to help ensure our quality of events continue and also to help raise funds and defray the cost of our large events?

Of the member households who took the survey, **27 respondents** would be comfortable providing a \$25.00 fee to attend overnight events. This fee would help to offset the costs of these larger events and potentially deter last minute cancellations that have been happening at a more frequent rate, costing the chapter money. Of the respondents, 4 were not comfortable with this fee.

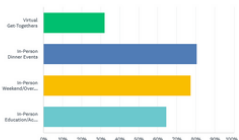
Which method do you prefer we use for communication with you? Due to the cost associated with purchasing a texting platform to communicate by text, at this moment it is not currently an option. (Multiple Choices Accepted)

With the rising costs in printing and postage, it is necessary for the chapter to determine if mailing content is still idea for the community at large. Of the member households who responded, 26 respondents prefer to be contacted via e-mail, while 9 prefer telephone and only 7 prefer to receive posted mail.

What types of events do you prefer to attend? (Multiple Choices Accepted)

What type of events do you prefer to attend?

Answered: 31 Skipped: 3

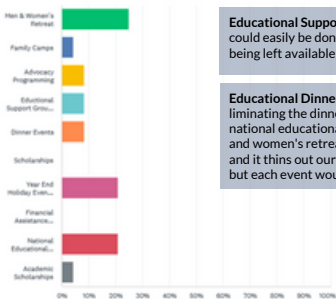


In communicating with our members, we were pleased that email was the number one mode they chose and far outweighed mailings which helps cut operations costs. In person dinner events and in person weekend or overnight events were viewed as most popular and our membership does not prefer the virtual option much with only 10 votes. This is consistent with what we have seen when hosting events, as these events are not well attended.

Rank what educational and support services you value the most important to you and your family?



If we had to cut back on some programs and services funding purposes, what would you chose and why?



Educational Support Group Events: Educational events could easily be done virtually with in person events being left available for larger endeavors.

Educational Dinner Events: I would be ok with liminating the dinner events, year end event, and national educational travel grants. Perhaps even men's and women's retreat. I think we have too many events and it thins out our involvement. I think we can do less but each event would be better attended.

In asking our community what was the most important educational and supportive services we provide, general education ranked highest, followed by support groups for ultra rare, vWD, women with bleeding disorders, included with supportive activities, with advocacy training ranking equal. The question of cutting back on any type of program or services was ranked with our year-end holiday event and national grants support as the highest program that could be cut if needed, just under our men and women's retreat. While it is not within our knowledge as to whether those who chose the men and women's retreat as something that could be eliminated were ranked by individuals with children, it is understandable that an adult retreat is more difficult for members to attend if they have small children and no other support services to care for their children in their absence, IE: family, caretakers, babysitters. The adult retreats were combined into an event to support many groups together within the past few years, all which were very well attended, allowing for our adult men, women, those with vWD, rare bleeding disorders, couples, and individuals to take time away from their kids (if possible) if they have any. Last year's event was ranked the highest of all events for the year with 100 percent highest evaluation satisfaction.

Community Thoughts and Feedback

In your view, what is the most common purpose or mission that unites our South Carolina Bleeding Disorders community within the Bleeding Disorders Association of South Carolina organization?

I believe the purpose should be to provide education and an opportunity for the community to come together to learn from each other. A common place where the community can learn of new and upcoming advances in treatment and can learn about opportunities available to them - scholarships, educational experiences, etc.

To make sure that the bleeding disorder community is not only informed of new things arising- insurances, medicine, and other treatment option. It is also a main purpose to help provide the need of the bleeding disorder community.

Providing opportunities for the affected and their families to connect with others to build lasting, supporting, and educational relationships to strengthen our overall bleeding disorders community.

What would you like BDASC to offer in the next 2-3 years that we are not currently providing, if we could?

More support for the women within the bleeding disorders community, particularly regarding mental health and self advocating for women with bleeding disorder symptoms who are facing challenges receiving proper diagnosis.

Spanish sessions at events like annual meeting.

Family Camp with more outdoor activities and less lectures/education /training (build that into the outdoor activity)

Additional comments you would like to add/provide for BDASC to consider as we update our strategic plan for the next 3-5 years?

Keep up the great work. We couldn't do this without you

Please keep doing what you are doing, as far as communications and outreach. Meeting together and travel is important, but I feel constant communication is valuable, whatever the stage. Budget friendly options could include more virtual interactive sessions to keep up the engagement, folks being willing to host smaller dinners in their homes, etc.

At least one meeting super close to where all families get a chance to attend and enjoy without traveling so far each time.

Looking ahead, financial assistance, support for our women who bleed, and support for our teens ranked the highest in this survey and is in line with our strategic planning. Support for mental health ranked just under the aforementioned. We would like to highlight a few comments under what you would like us to offer in the next two to three years that we are not currently providing. As far as gene therapy education, we will continue to update our members and provide educational and advocacy support for our women who bleed within the bleeding disorders community. We would love to have an app for members to stay informed as was suggested, but the cost and availability may be out of our reach. Small meetings at someone's house to go over things and provide support is something our members could always do on their own once they engage with others, but could not be sanctioned by the organization due to liability. We are working on Spanish events as we supported a few this past year and having Spanish sessions at our big annual meetings. Family camp was brought up a few times and if funding were to cover all aspects and we find a new location, that is something we would love to provide to the community. Mental health workshops have been provided at most our large events and will continue, as well as advocacy support. Social Security benefits and accessing them is something we can look at and provide virtual meetings, or provide information during small breakouts. Additional comments for the next three to five years were heartwarming and we thank you as we try our best to meet the needs of our unique large community, however, we are not without limitations. Communication, outreach, and budget friendly options with virtual interactive sessions was suggested and is very important to the organization, however our virtual events in the past have not been very successful with attendee participation.



In closing, more fundraising events and engaging major corporate donors aligns with our strategic planning for the next three to five years. Our landscape for support is changing and more challenging, confirming this year with our first ever shortfall in our revenue of \$49,000. We will need to be strategically planning for this revenue shortfall and membership growth for us to meet the needs of the South Carolina Bleeding Disorders community. We asked, and you responded, what is the most common purpose or mission that unites us. We thank you for taking the time to provide your voices within this Member Feedback Outreach Survey as we plan for our future.

Please continue to stay connected and engaged throughout 2024. We have many support programs and events to meet everyone's needs. Should you need more information at any time, please reach out to the chapter or visit the chapter's website at <http://www.bda-sc.org>. We welcome your volunteer services too!

If you missed the survey and would like to provide feedback, we always welcome your thoughts, call or email us at info@bda-sc.org.



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