

JANUARY 2023

MEMBER EXPERIENCE FEEDBACK SURVEY REPORT



**Bleeding
Disorders
Association of
South Carolina**

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

Our 2022 Experiences!



**NATIONAL BLEEDING DISORDERS
AWARENESS MONTH**



Camp Connections 2022



HEALTH EQUITY SUMMIT 2022



8th Annual Par For The Clot



**9TH ANNUAL STEP
FOR BLEEDING DISORDERS**



Community Connections Programs in 2022

BDASC

Member Experience Survey

As Bleeding Disorders Association of South Carolina now moves into 2023 and beyond, a survey was conducted of its membership to light the path they wish to see the organization follow. The survey was concentrated in focus areas of programs and services, research, advocacy, and community connections. The survey ran from December 2, 2022 to January 13, 2023 and members were reached through email, social media posts, BDASC's website, and for VIP members, a web clip added to their iPads. While no identifying questions were asked of the survey, households were asked for demographic information including what county they are from. Many users chose not to provide this information as it was optional.



Member Experience Survey

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

Of the member households who took the survey, the general responses were advocacy and connection. With six responses including advocacy, and "being together" and education following closely. Because this was an open ended question, it was intended for the community to share their comments. We have provided excerpts from some of the survey responses.

I think that the thing that will unite our community is knowledge. I'm a firm believer that knowing each others stories and learning more about our bleeding disorders will absolutely bring us together. Just having an understanding of what people go through often brings more empathy and kindness to people's lives, and at the end of the day, everyone needs the support of others.

What do you consider to be BDASC's greatest accomplishments, or what you would like us to accomplish as your member organization?

The most consistent response was to create and foster community. Sharing the community's stories and ensuring that people know that they are "not alone" was a common response. It was also mentioned that BDASC's greatest accomplishment was being inclusive of all bleeding disorders.

Reaching families who deal with bleeding disorders and bringing them together in a way of knowing they are not alone.

In looking ahead with our strategic plan-What are the core BDASC events, activities, services that you would like to see us keep and that you feel are the most beneficial?

The responses that were received indicate that the programs we provide are beneficial. The most highlighted activities/services are the educational events, financial assistance, and advocacy work.

"Education, support groups, and all advocacy work you do today"

If we had to eliminate an annual event for funding purposes, what event would you chose and why?

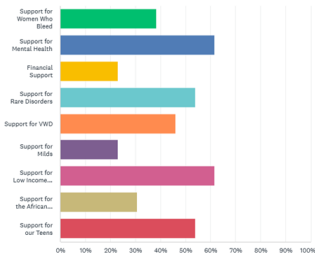
Family camp was the most suggested event to eliminate. One responses was to eliminate the annual meeting, which is not possible as it is required to maintain our non-profit status. The annual meeting was listed because they indicated that it did not have enough time for making connections. On the flip side, others mentioned that they appreciated the annual meeting and all the educational opportunities it provided and connections to the community.

Family camp. I like the Annual Meeting because the Chapter honors individuals in the community, board members, and others.

The Annual Meeting location could be better and the fact that it doesn't give much time for making connections.



What would you like BDASC to offer in the next 2-3 years if we could? What are you in need of that we may not offer our members, or do you think the Chapter could be providing that would help you and your family?*



Consistent with what we have been hearing from the SC community, as well as the National community over the past few years, Support for Mental Health and Support for Low Income Families are key needs.

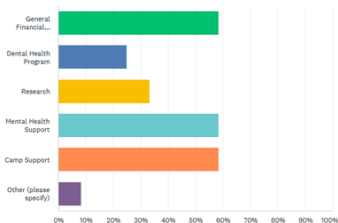
62% of the responses indicated the need for both. Additionally, 54% of responses indicate that there is a need for supporting Teens and the Ultra Rare Disease community.

Continue to do what you do but include other topics besides advocacy.

*Please note that users were allowed to choose multiple responses to this question.

More guidance for children - how to manage anxiety in kids with bleeding disorders, how to help unaffected siblings, how to setup a 504/IEP/IHP (what options are there in SC), navigating the ER with a child, learning how to advocate in health care settings (knowing our rights when it comes to healthcare)."

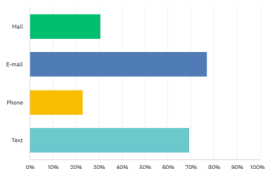
What are the top things you would like financial contributions from our donors to be used for?*



*Please note that users were allowed to choose multiple responses to this question.

Accessibility

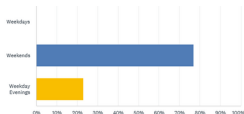
Which method do you prefer we use for communication with you?*



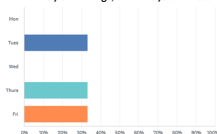
*Please note that users were allowed to choose multiple responses to this question.

When is the best time for you and your family to attend events/education/fundraisers?

Weekends continue to rank highly as the best time for events for our community. This is not surprising as we are entering into a post-covid time. We are noticing that people are resuming their "normal" and that often means they are busier. As for the week nights that are best, these are the same as last year - Tuesday, Thursday and Friday.



If Weekday & Evenings, which days are best?



Please provide any suggestions on how BDASC can be more accessible.

Honestly I think BDASC is completely accessible. I wouldn't change what you do.

I believe it is available to all. Maybe add a day at MUSC clinic appointments like you do at the other HTC's. Encourage community members to volunteer for events.

The job has been done . Keep up the outstanding work.

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

Continue to create a family environment.

I think that BDASC is headed in the right direction. I would love to see more camp support (more info on camps, when they are, what they do at camp, maybe have a booth at events with information on camps). I would like to see continued support for the VWD and Ultra Rare communities. Those two groups have been widely underserved in the past and I know it has made me feel excluded.

Advocacy, with the Advocacy Group and Advocacy Days and a break out about it at the Annual Meeting. Not all the time. Continue education and awareness. I realize how important advocacy is but community and building togetherness as a family is most important. Try to get the Holiday Winter Meeting back to an evening event, Family Camp back to Myrtle Beach. I love the new times for the STEP Walk and The Par for the Clot works out better. Continue to ask community for fundraising ideas to help fund events and there is nothing wrong with charging for some things with the availability for scholarships to help those that can't pay. No one should feel entitled, we are equal and should work together. You will also find those that will help pay for others if needed.



ANALYSIS

Based on the responses of the membership, a focus on the themes of Advocacy, Health Care Access, Mental Health & Low Income Families, and In-Person Support Activities is desired. Services including, Financial Assistance, Scholarships, and Camp and Teen Support remain popular across the board. In-person programs both large and small as well as event programs are highly rated.

The focus on diversity over the last few years and changing the organization's name to being less hemophilia centered has paid dividends as the vast majority of respondents feel that the Chapter reflects and supports them. The continuation of the VIP program has also given members a sense that the Chapter is accessible to them.

Generally it seems as though the chapter's needs are being met. Multiple responses said "keep doing what you are doing." The respondents indicated that we are very accessible to them, although it was suggested that having a day at the MUSC Clinic appointments may be beneficial.

As the bleeding disorders community nationwide has begun to feel the effects of the current economic climate, we are strategizing for the potential need to make changes in our annual programs and services. There were multiple suggestions from respondents regarding which programs they would choose if cuts had to be made. The staff and board of directors will continue to monitor the needs of the community and do our best to serve the membership.

REPORT NOTES

This report is based on the 14 responses the Chapter had received by January 13, 2023. Members who feel that the results so far don't reflect their feelings should take the survey by visiting <https://www.surveymonkey.com/r/2022BDASCMemberAssessment>. Equally, members who do agree with the results so far should also take the survey to reinforce the results. The survey will remain open until January 31, 2023. You may also contact the Chapter at any time to provide additional comments, concerns or suggestions!



**BLEEDING DISORDERS
ASSOCIATION
OF SOUTH CAROLINA**

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