

JANUARY 2022

PRELIMINARY MEMBER EXPERIENCE FEEDBACK SURVEY REPORT



**Bleeding
Disorders
Association of
South Carolina**

Serving All Bleeding Disorders

864 350 9941 | www.bda-sc.org

Our 2021 Experiences!



**NATIONAL BLEEDING DISORDERS
AWARENESS MONTH**



Camp Connections 2021



**KEEPING IT COASTAL 2021
EDUCATIONAL FAMILY CAMP & ADULT RETREAT**



7th Annual Par For The Clot



**8TH ANNUAL STEP
FOR BLEEDING DISORDERS**



Community Connections Programs in 2021

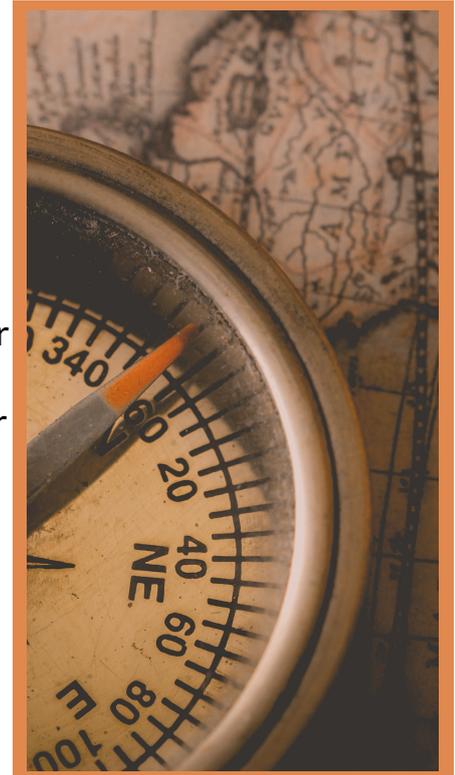
BDASC

Member Experience Survey

As Bleeding Disorders Association of South Carolina now moves into 2022 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 November 23, 2021 to January 21, 2022 and members were reached through email, social media posts, BDASC's website, and for VIP members, a web clip added to their iPads. A palm card with the web address and a QR code leading to the survey was also sent out as part of the year end newsletter and winter holiday mailing to every address on our master list.

The total return rate of the survey was 6.8. While no identifying questions were asked of the survey, households were asked for demographic information including what bleeding disorder their household lives with to make sure we have fair and equal representation.

DEMOGRAPHIC QUESTIONS



1. Do you live in South Carolina?

The vast majority of members of BDASC live in South Carolina at 96%, with Richland County having the most respondents. Some households who have moved out of the state and still participate in Chapter events did take the survey. Additionally, with our new virtual capability to reach members beyond our boundaries and a growing membership, these extended members were also able to voice their opinions.

2. How do you identify?

Of the member households who took the survey, only two categories were chosen, African American and White, with 20% for the former and 80% for the latter. It should be noted that in this regard, the population of the survey submitting households is not a fully accurate reflection of the known makeup of the membership community.

3. What Bleeding Disorder are you or your household affected by?

Those living with Hemophilia A make up the majority of the households that participated in the survey with 60%. This was followed by Hemophilia B at 24%, then VWD, with other Platelet Disorders making up the last percentage. No other Rare Bleeding Disorders members took the survey.

4. What severity of Bleeding Disorder do you have?

For severity, those with severe disorders had the decisive majority at 68%, with those mildly affected coming second at 24%, and moderately affected at 8%.

1. How do you prefer to connect with the Chapter and its members?

With many of the communication systems developed during COVID still in place, we wanted to see how the membership preferred to interact with the Chapter. Larger and Small In-Person Events won out with **76%** and **64%** of members preferring them respectively, followed by Small Virtual Events at **36%**. Large Virtual Events was a distance last with **12%**.

2. Please rate the importance of being a member and the direction of our future planning? What is most important to you? (On a scale from "Not important at all" (-3) to "Very important" (+3))

3. Advocacy: Access to care and treatment; health care.

Advocacy was by far the highest rated effort the Chapter works on. On the weighted scale, Advocacy had a total of **66** points, a **1** point lead over the second highest rated effort.

4. Research: Advancing research in treatments care, IE: gene therapy, new treatment therapies, and research to finding a cure.

Research was fourth with **56** points.

5. Education: Programs to support different disease states, IE: VWD, Hemophilia, Platelet Disorders, others rare bleeding disorders.

Education was last with only **52** points.

6. Support Services: Services we provide.

Support Services came in a second with **65** total points and only **3** points ahead of third place.

7. Community Connections: Activities that provided you connection to other members.

Community Connections came in third with **62** points.

8. Do you feel that BDASC is accessible to you, where you live?

The vast majority of member **88%** feel that the Chapter is accessible to them where they live.

9. Do you feel that BDASC reflects and supports you, your family, and your Bleeding Disorder?

The vast majority of member **92%** also feel that the Chapter reflects and supports their bleeding disorder.

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

Advocacy, Access, and Support were the theme of the most answers to this question.



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

Our advocacy efforts and being inclusive of all bleeding disorders were highlighted the most to this question.

12. What are the top three things you would like financial contributions to our organization to be used for?

Advocacy, Health Care Access, and Support were again the top themes.

13. Which method do you prefer we use for communication with you? (You can choose more than one)

Email and texting were the most popular with **50%** and **25%**. Traditional mail came in at a low **13%**, and phone calls barely broke **11%**. With so few members preferring traditional mail, the Chapter should shift away from this channel as postage and handling times are increasing significantly.

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

I think it would be fantastic if at some point BDASC would be able to host events for specific bleeding disorders. So many times when we attend events (nationally as well) they are geared towards hemophilia. Even events that are not specifically for hemophilia almost always center around hemophilia.

Build on youth and young adult growth and investment, they are our future and we'll depend on them. Community outreach. Continue community live events. Continue education and advocacy. Work to build external connections for income.

Keep up all you are doing! Fantastic organization!



ANALYSIS

Based on the responses of the membership, a focus on the themes of Advocacy, Health Care Access, and In-Person Support Activities is desired. Services including, Financial Assistance, Scholarships, and Camp Support remain popular across the board, second only to Advocacy. In-person programs both large and small as well as event programs are highly rated but a desire for educational programs are less expressed.

The focus on diversity over the last year 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, despite the limited in-person events held around the state.

As we move into our new normal of a post-vaccine society, a rebalancing between virtual and in person events will be necessary. While small or highly focused virtual events are still well regarded, larger virtual events may not be as well received as they once were.

One interesting spot in the survey is that for the most part, many of the membership no longer wants to receive event notices via traditional mail, preferring email and text instead. This is good for the the Chapter to know as postal rates are projected to continue to increase while handling time will be slower. A reliable and cost efficient texting service will have to be chosen to access this preferred line of communication. In future surveys, social media, and the News Infusion should be considered as a preferred communication method.

PRELIMINARY REPORT NOTES

This report is based on the 25 responses the Chapter has received by December 27, 2021. Members who feel that the results so far don't reflect their feelings should take the survey by visiting tinyurl.com/BDASC2022MFS1 Equally, members who do agree with results so far should also take the survey to reinforce the results. Both will need to take it by January 21, 2022 when the survey closes.



BLEEDING DISORDERS ASSOCIATION OF SOUTH CAROLINA

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