



“THE VOICES OF 46”
COMMUNITY RESOURCES & ENGAGEMENT
PROGRAM - RURAL COMMUNITIES
HEALTH EQUITY OUTREACH
PRELIMINARY PROGRAM RESULTS

BDASC

*This program is sponsored by a generous
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Outreach Program Summit*


Hemophilia Federation of America™

Project Background - Our Objective

To take a personal outreach approach to our rural communities and all 46 counties in South Carolina where we currently have members to map out access barriers to quality treatment and affordable healthcare, while providing resources for health equity. We will strive to discover healthcare disparities and lack of education within bleeding disorders care according to zip codes within the various counties in South Carolina. We will map our findings with a heat map to show a visualization of our data within different areas of the state. We will include as many diverse individuals and their families living with Bleeding Disorders within our survey outreach. Our goal is to take a broad look at all 46 counties in the state and discover barriers in access to care and treatment, graft the barriers or challenges we discover while also providing information and resources to community members.

The Plan

In an effort to meet our community members where they live, we will be traveling to local and rural counties where our members reside. As part of our discovery in our 2022 Health Equity Summit in Charleston, community members shared challenges of attending meetings and events where they have to travel far distances and asked for smaller meetings closer to some of the small counties outside the larger cities. These meetings will be casual events at local restaurants or facilities to engage in conversations between BDASC and the community. The gatherings, similarly to all BDASC events, will be offered free of charge to all community members in the designated targeted area. We will provide community members the opportunity to provide anonymous information with access to quality healthcare barriers and challenges through our outreach survey provided at each location and throughout the year within our online media platforms.

Survey Request

We ask each member family in attendance to take a moment and complete the following survey. This survey is completely anonymous and is designed to help our members have a voice in helping to identify a lack of education in treatment care needs and access barriers in their counties for which they reside. This information may be shared with the community and healthcare agencies within South Carolina including our Hemophilia Treatment Centers (HTCs) and local hematologist offices. This is in an effort to share the needs of our community with those who can provide change. There are no questions within the survey asking for identifying personal information. We ask you to be honest and provide as much information as possible about any of your concerns. This information will be used to better serve the different regions within South Carolina.



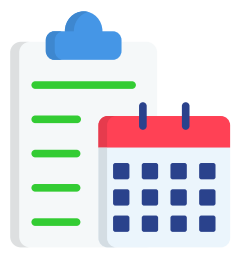
This survey may be taken by scanning the QR code to the left with your cell phone. This can be done using the Camera app on your phone. Once you get the camera to focus on the QR Code, the link will pop-up and allow you to click on it.

You may also visit this survey by entering the following URL into your browser: <https://tinyurl.com/46VoicesSurvey>



quick view

Total Number of Questions Asked: 23
Total Number of Respondents: 61
Represented Counties: 25



58%

see their hematologist annually

while **22%** see their hematologist multiple times a year



85%

seek care at a Federally Supported HTC

20%

drive between **90 and 200 miles** to see their provider

61% drive over **30 miles** to see their provider



Largest Barriers To Care

- “The distance to the nearest treatment center.”
- “The cost of traveling to the HTC.”
- “Taking time off of work.”
- “Childcare while I receive treatment.”
- “Insurance and out of pocket costs.”



30%

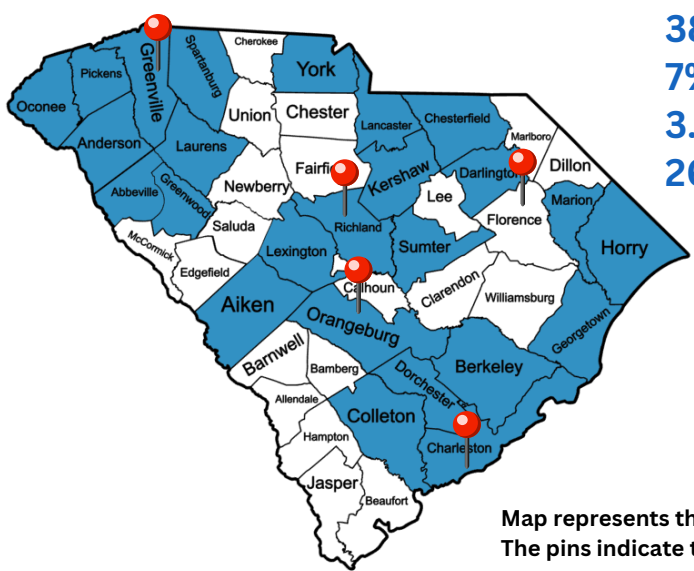
are not aware of the benefits of a Federally Supported HTC



5.8% seek care at MUSC - Charleston



- 38.5%** seek care at Prisma Health Midlands
- 7%** seek care at Prisma Health Orangeburg
- 3.8%** seek care at Prisma Health Florence
- 26.9%** seek care at Prisma Health Upstate



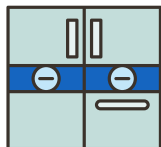
17.3% seek care elsewhere

Other results include: St. Jude, The Cancer Institute of Greenville, August University Children’s Hospital, Gibbs Cancer Center, Center for Blood Disorders, Penn University, Levine HTC in Charlotte

Map represents the counties that had respondents in blue. The pins indicate the location of the HTCs.

Where is the need for additional education/support?

EMERGENCY

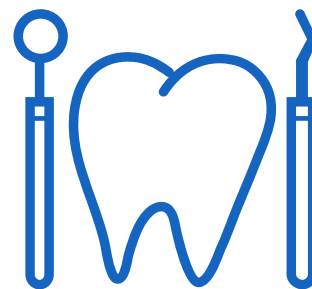


46% responded that the lack of bleeding disorders knowledge in the ER created challenges

29% responded that the lack of bleeding disorders knowledge in school settings created challenges



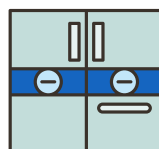
37% responded that the lack of bleeding disorders knowledge in the dentist/dental specialist office created challenges



Community members were most likely to be **denied** treatment because of their bleeding disorder at the **dental office/oral surgeon**, with **21%** of members saying they have been denied.

Community Members feel they did not receive quality care because of their bleeding disorders

EMERGENCY



51.5% responded that they did not receive quality care at the ER because of their bleeding disorder.

18% responded that they did not receive quality care at the Gynecologist office because of their bleeding disorder.



18% responded that they did not receive quality care at the dentist/dental specialist office because of their bleeding disorder.

Community Mental Health Needs

32% of respondents don't have access to mental health treatment, **4%** were denied care and an additional **4%** received unsatisfactory care.

46 Voices Survey Results

January 2, 2025

Total Number of Questions Asked: 23

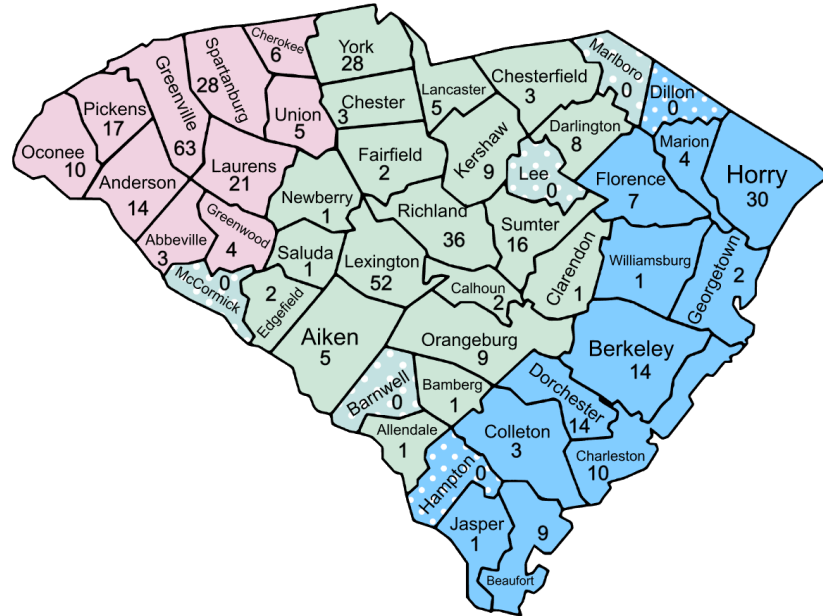
Total Number of Respondents: 61

BDASC Community Members throughout the state of South Carolina were asked to participate in a brief survey regarding access to treatment care and services throughout the state of South Carolina. This survey requested non-identifiable demographic questions as well as questions regarding access to treatment care and education related to their bleeding disorder. This survey was taken by individuals immediately affected by bleeding disorders themselves or within their immediate family. Respondents were caregivers, siblings, grandparents and people living with bleeding disorders. **Of the 46 counties in South Carolina, respondents represented 25.**

Demographic Information

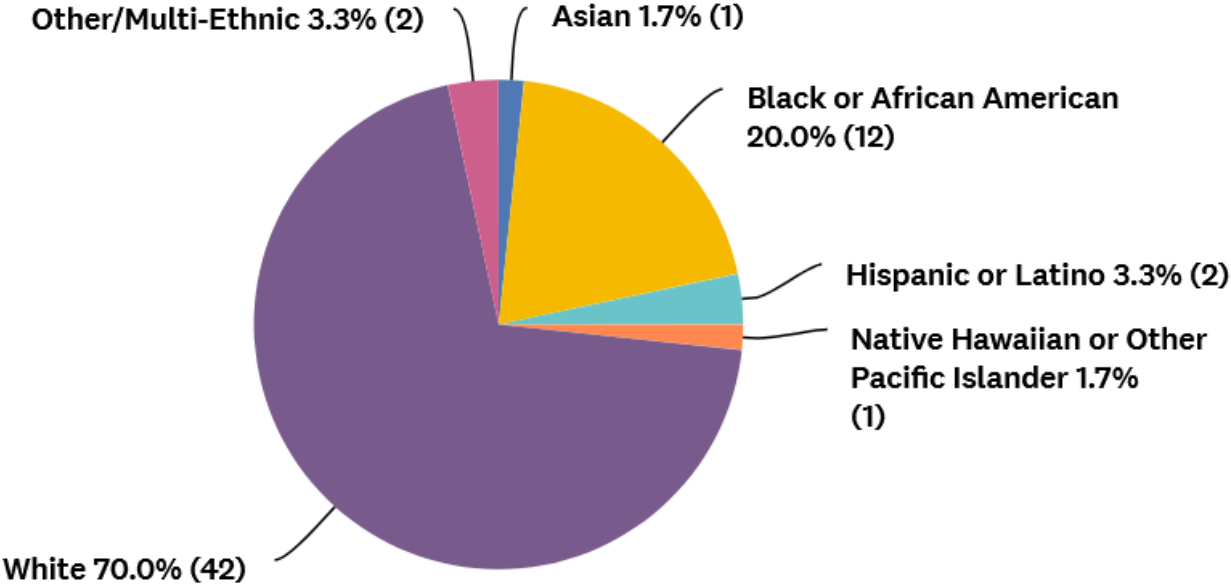
Community members were asked which county they reside in. All 61 participants answered the question with the following results:

Abbeville	1.64%	1
Aiken	8.20%	5
Anderson	3.28%	2
Berkeley	6.56%	4
Charleston	4.92%	3
Chesterfield	3.28%	2
Colleton	1.64%	1
Darlington	3.28%	2
Dorchester	3.28%	2
Georgetown	1.64%	1
Greenville	6.56%	4
Greenwood	1.64%	1
Horry	4.92%	3
Kershaw	1.64%	1
Lancaster	1.64%	1
Laurens	14.75%	9
Lexington	3.28%	2
Marion	1.64%	1
Oconee	3.28%	2
Orangeburg	1.64%	1
Pickens	8.20%	5
Richland	1.64%	1
Spartanburg	4.92%	3
Sumter	3.28%	2
York	3.28%	2



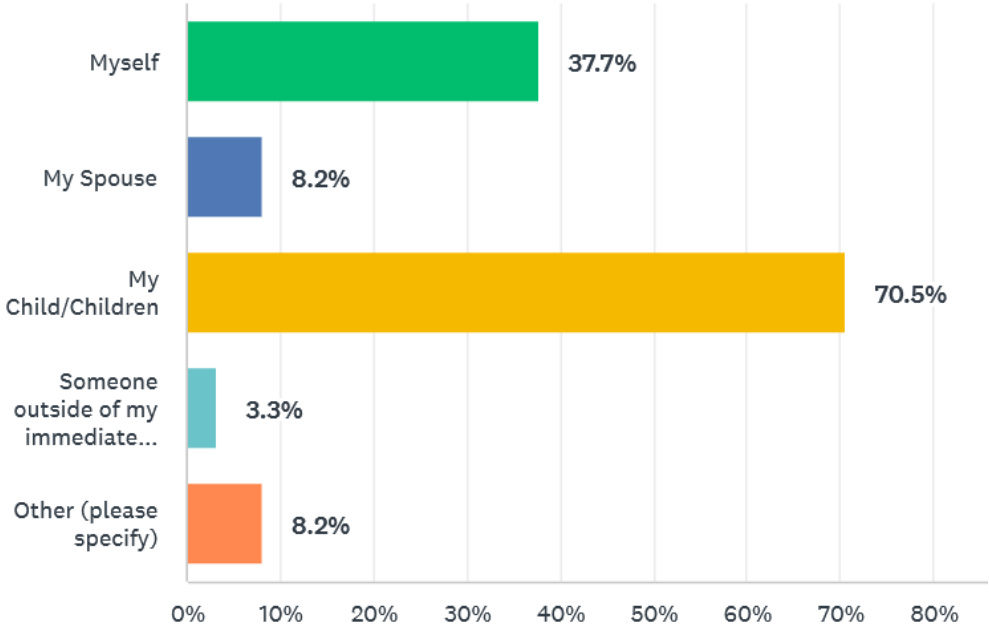
BDASC Community Member Distribution within South Carolina counties for reference upon the initial program start, June 2024.

Community members were asked what their racial or ethnic background is. 60 participants answered the question with the following results:



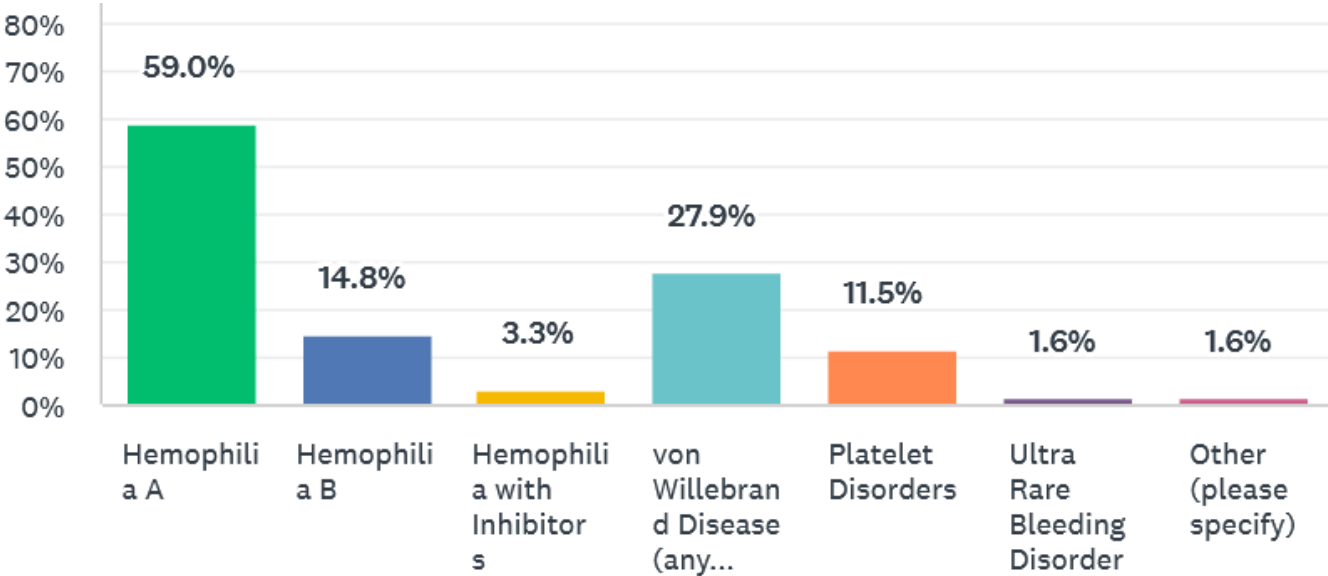
Bleeding Disorder Information

Community members were asked who in their family was affected by a bleeding disorder. 61 participants answered the question with the following results:



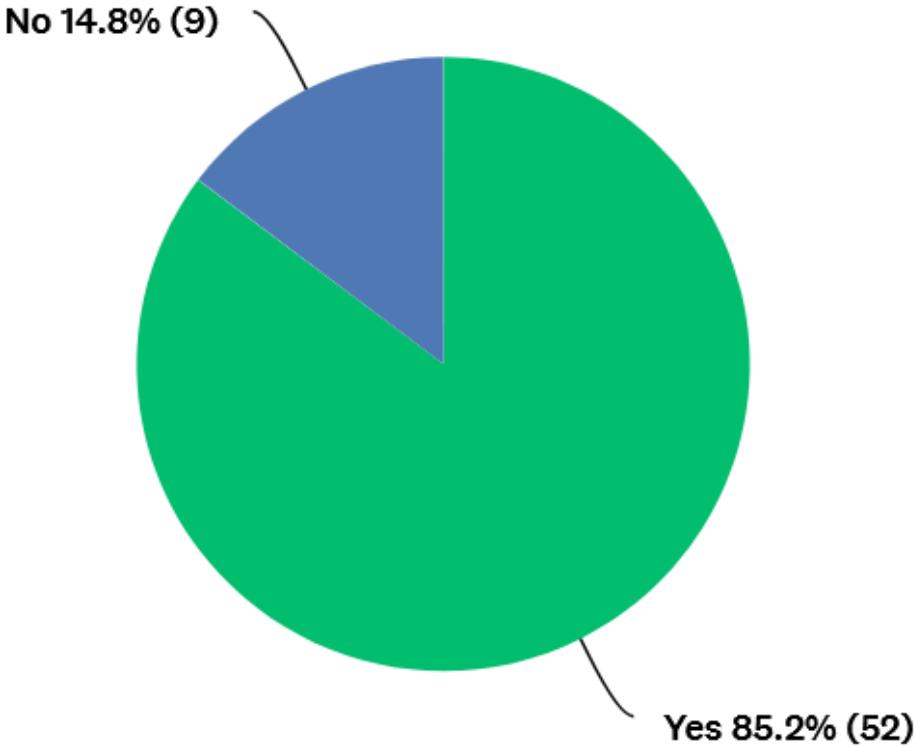
Other results include: Brother, Girlfriend's son and Grandson

Community members were asked which bleeding disorders they were impacted by. 61 participants answered the question with the following results:

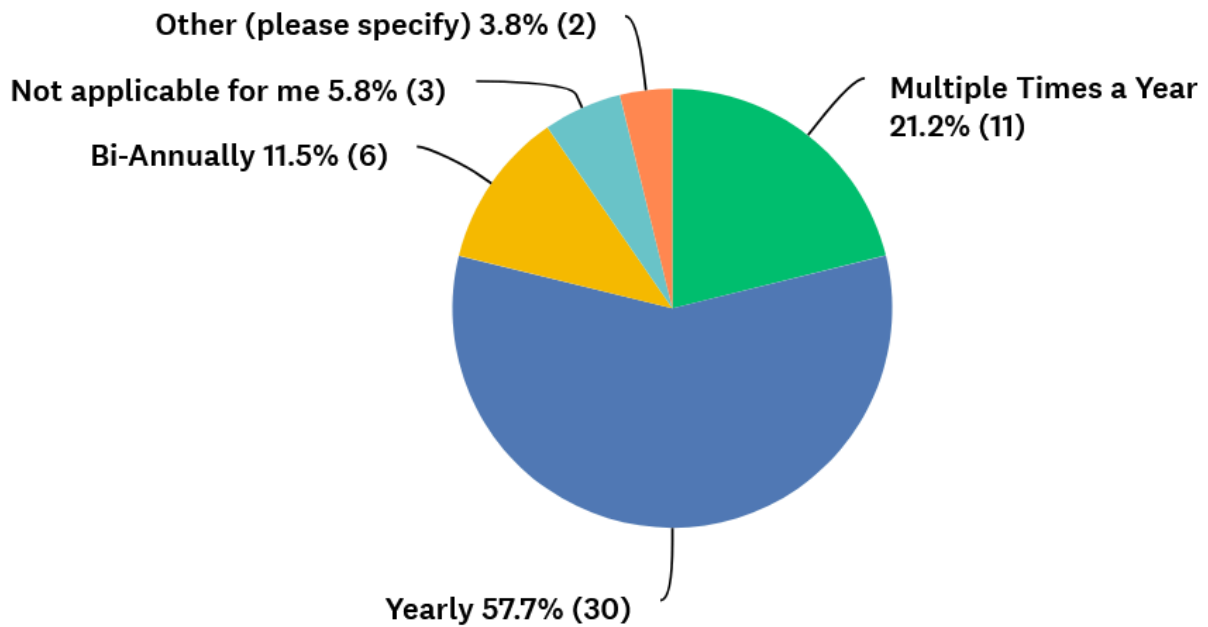


Other results include: Essential Thrombosis

Community members were asked if they currently seek care at a Federally Supported HTC. 61 participants answered the question with the following results:

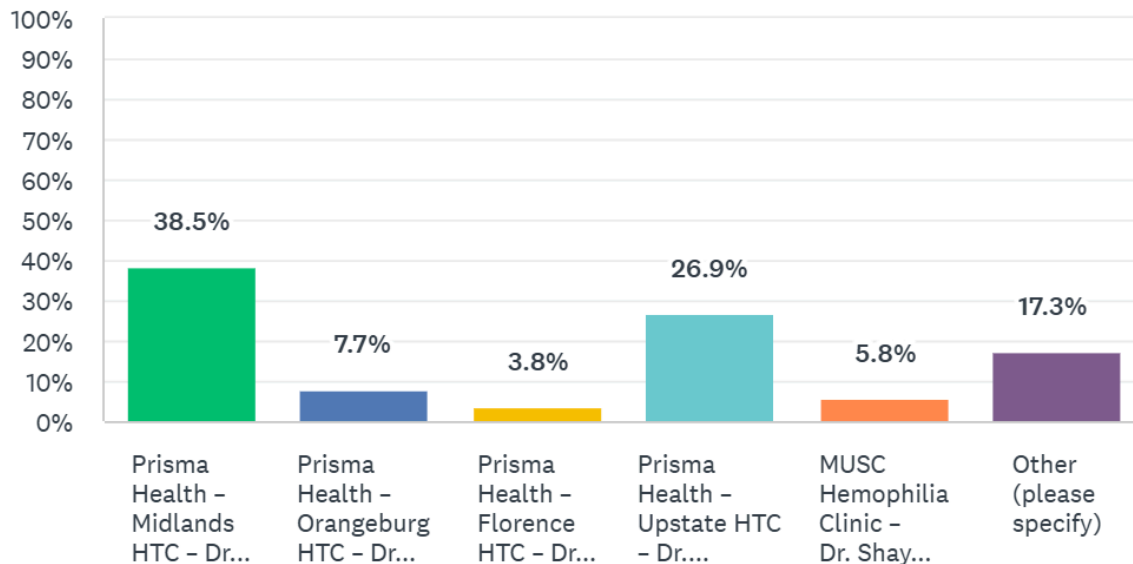


Community members were asked how often they see their Hematologist at a Federally Supported HTC. 52 participants answered the question with the following results:



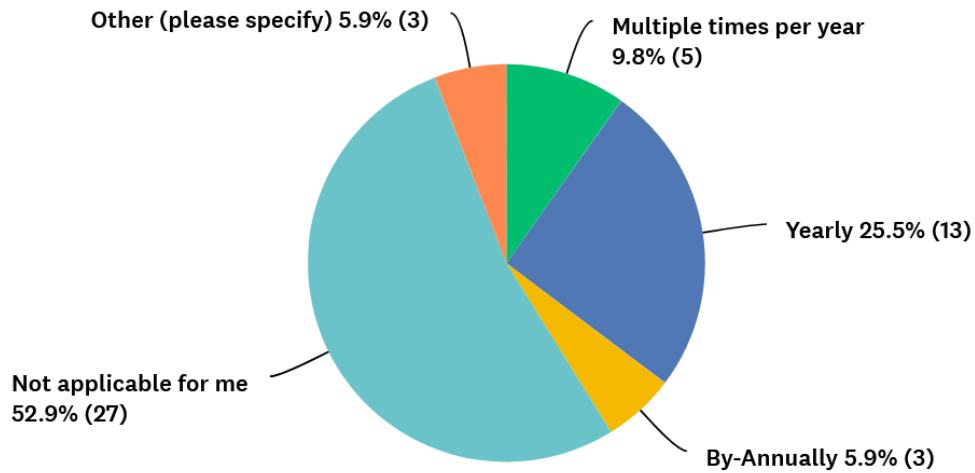
Other results include: As Needed

Community members were asked where they currently seek care for their bleeding disorder. 52 participants answered the question with the following results:



Other results include: St. Jude, The Cancer Institute of Greenville, August University Children’s Hospital, Gibbs Cancer Center, Center for Blood Disorders, Penn University, Levine HTC in Charlotte

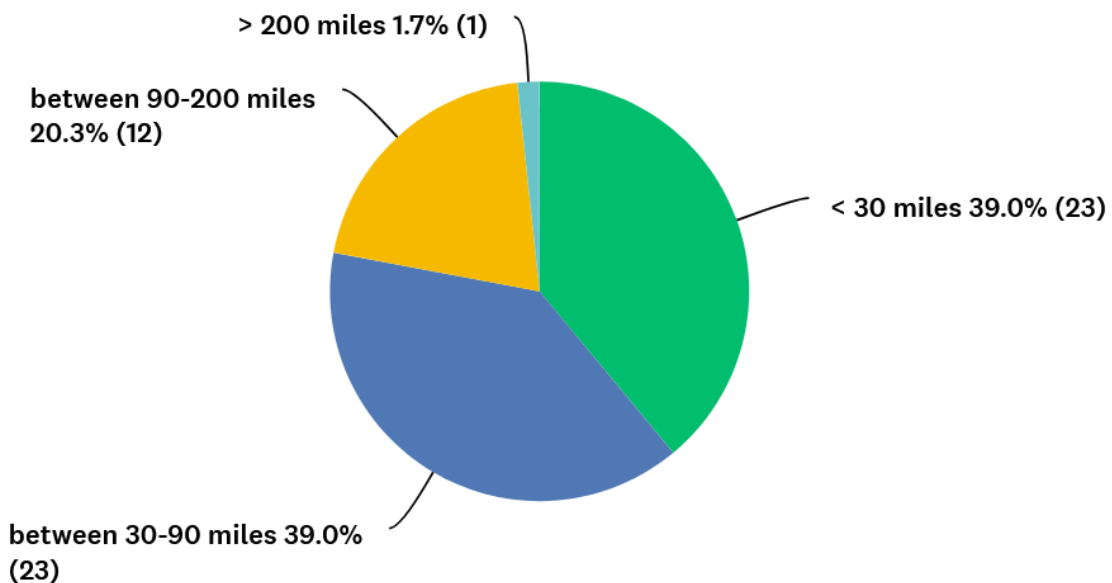
Community members were asked how often they see their Hematologist not within a Federally Supported HTC. 51 participants answered the question with the following results:



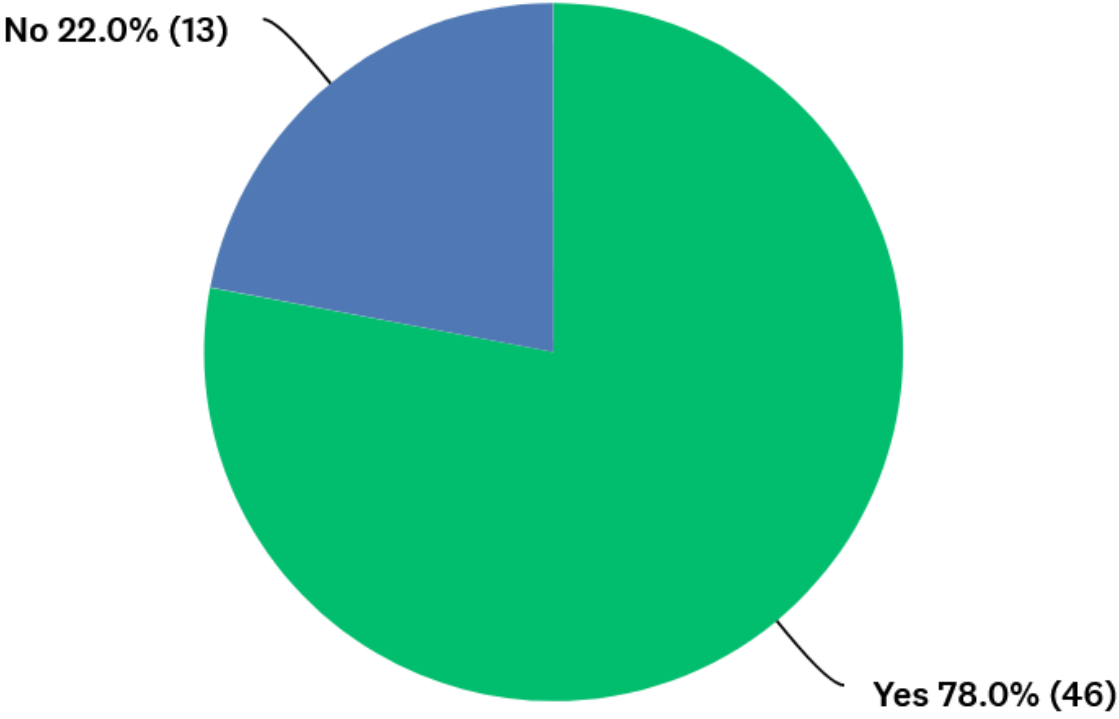
Community members were asked what barriers prevent them from seeing a Hematologist at a Federally Supported HTC. 30 participants answered the question with the following results:

- The distance to the nearest treatment center.
- It was not offered as an option to me and I am still unsure how to access these services in Upstate, SC. I was referred out to the Cancer Institute of Seneca by my ENT, who suspected an issue after a surgery with complications of the treatment busting back open and then being sent to Greenville for a more experienced opinion. However, the lack of time and consideration for my care has been horrendous, and at times detrimental.
- The cost of traveling to the HTC.
- Insurance dictating where we have to go.
- Taking time off of work.

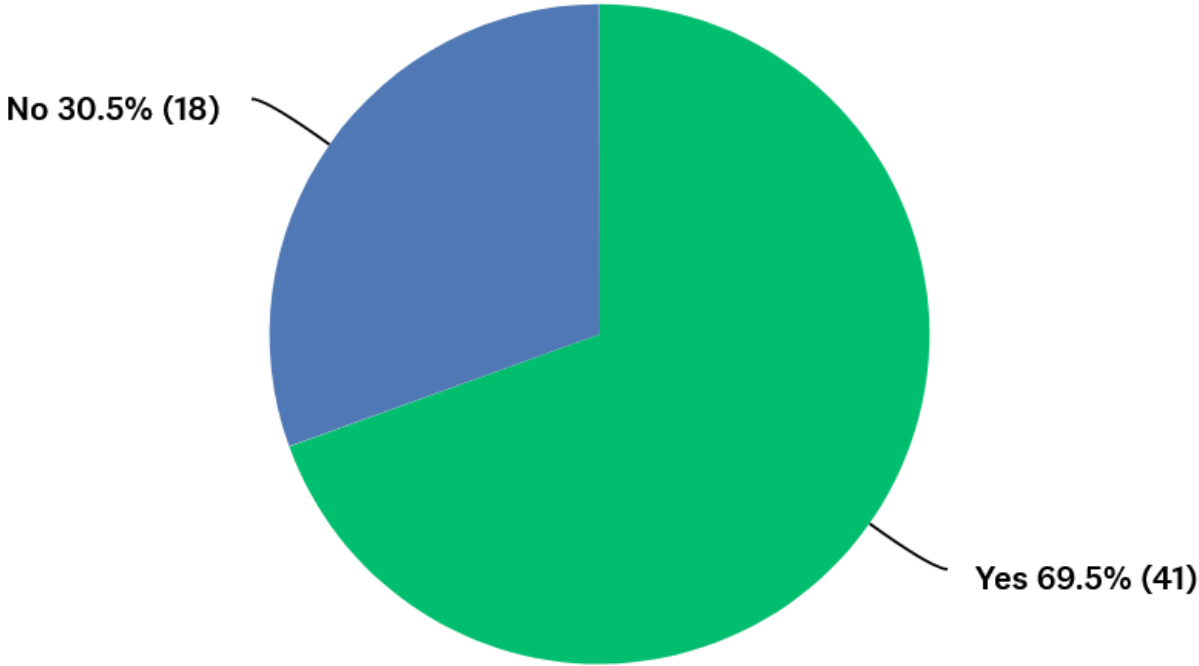
Community members were asked how far they travel for care for their bleeding disorder. 59 participants answered the question with the following results:



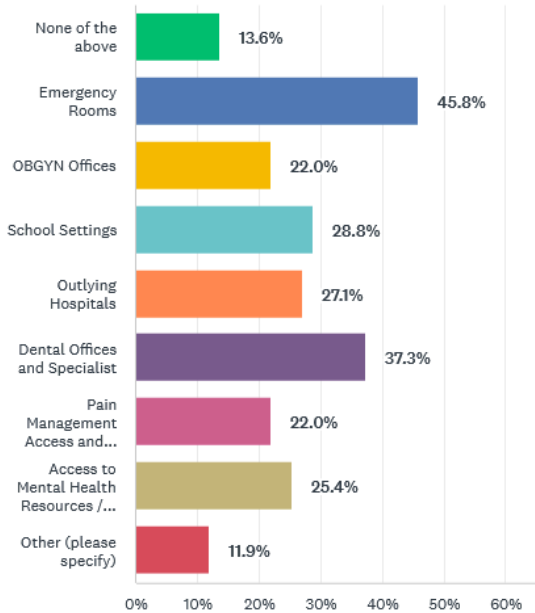
Community members were asked if they were aware of all the locations of South Carolina's Federally Supported HTC's. 59 participants answered the question with the following results:



Community members were asked if they were aware that Federally Supported HTC's are part of a network of national comprehensive care treatment centers dedicated to treating bleeding disorders. 59 participants answered the question with the following results:



Community members were asked what other challenges they have in caring for a loved one, or having a bleeding disorder themselves, and what causes them stress. Additionally, they were asked where they find a need for education and support in understanding bleeding disorders. 59 participants answered the question with the following results:

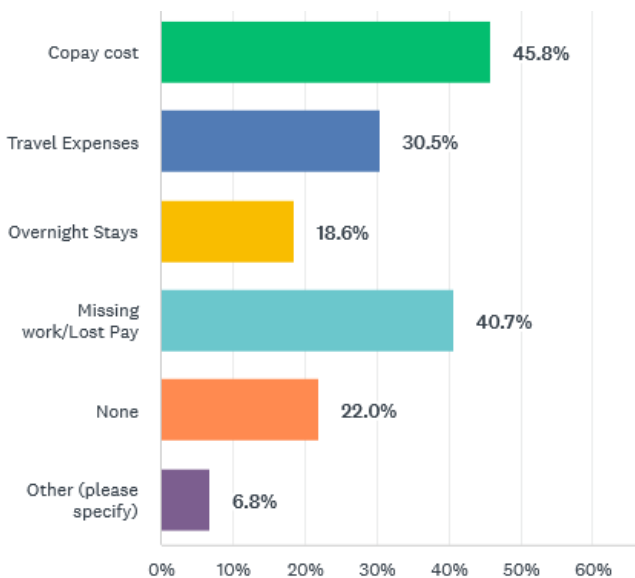


Other results include:

- Insurance companies trying to switch drugs.
- ENTs: It took two ENT doctors, multiple generic tests, and surgery with complications to finally be taken seriously on all the bleeding issues that I was having.
- PCPs: Despite VWD being a common bleeding disorder, it is uncommon for them to run necessary testing in order to properly diagnose VWD of any type. I was told to "stop running into things." When it came to unusual bruising and 18 + days of menstrual bleeding at an Urgent Care, I was told "If I was in the middle of the desert, what OTC medicine would I take, yeah take that." For frequent half dollar blood clots coming out of my nose, face pain, and migraines that were happening for over a month, I ended up with four sinus surgeries that busted open and only then, was I taken more seriously on the other bleeding issues I was having.

- Understanding state insurance programs and how they are run.
- Having the confidence to reach out and knowing what to reach out for.

Community members were asked what financial aspects of having a bleeding disorder they struggle with. 59 participants answered the question with the following results:



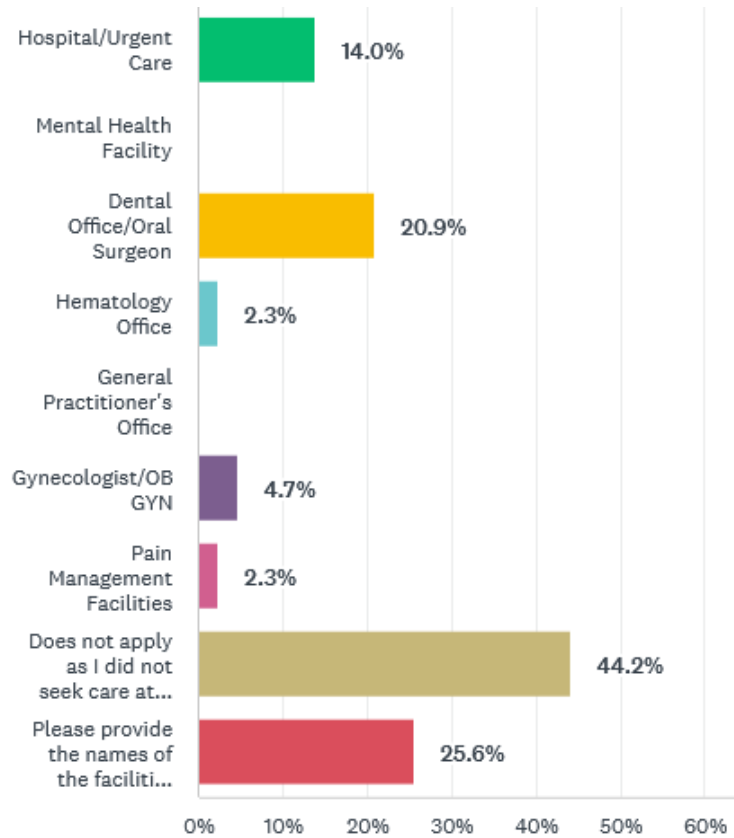
Other results include:

- Childcare while I receive treatment.
- Insurance and out of pocket costs.

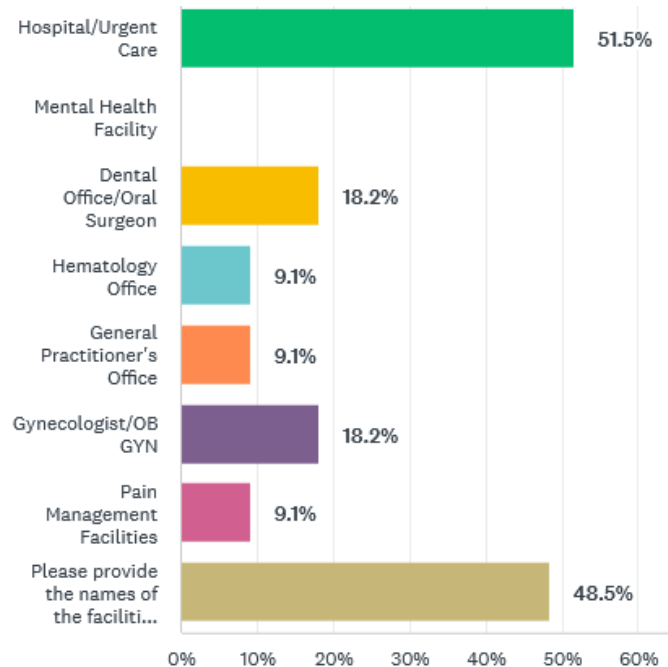
Community members were asked how the chapter can make seeing the hematologist more accessible. 59 participants answered the question with the following results:

- We are lucky to live close to the MUSC center and have no issues seeing the Hematologist. However, Our son will be going to College soon and we are concern about HTC in other parts of the country. That is becoming a part of the decision as to where he should go to school.
- Continue to be there if needed.
- I need a hematologist that gives me the time of time of day and actually cares. My current hematologist wanted me to travel 3 hrs round trip after having a hysterectomy and medical Labiaplasty, for infusions. I went into that surgery not knowing what my plan was for infusions after I left the hospital. It was only after I had already had the surgeries without knowing my plans for infusions with limited childcare, that staff was told I could have infusions on a weekend at Oconee. When my husband called to confirm about the infusions, he was told they did not do infusions at Oconee on weekends via Oconee Infusion Center at the hospital. When we relayed that to my hematologist via MyChart, the hematologist was out golfing and could not be reached. We were then later told that the nurse at Prisma- Greenville Hospital was the one who had to set up infusions. When we asked her and other staff, she stated she was not the one who was supposed to set any of this up. That poor nurse worked hard to make sure I had infusions when I left the hospital. I ended up having to stay an extra day to make sure this was was set up where I would have no issues getting infusions on a weekend. I had messaged and went in to be seen before the surgeries to get this resolved and I was treated less than important by my doctor. I was even told Oconee could not do infusions for Humate- P even though after I had the surgery I was told otherwise. As someone who has PTSD and has an extremely hard time advocating for themselves, I find this care detrimental to any blood disorder patient. The level of incompetency and malpractice could cost a patient their lives.
- Providing education which is already being done.
- Instead of having a clinic day, have it any day so I don't have to miss work.
- Help with the costs of seeing the HTC for care.
- We are blessed to be able to have a flexible schedule to accommodate treatment for our son and currently we have private insurance and Medicaid for him so financially we are ok. I think other than advocating for an HTC in Horry or Georgetown, we are in good shape.
- Continued growth with chapters and clinics in local areas (rural).
- Keeping them invited to events.

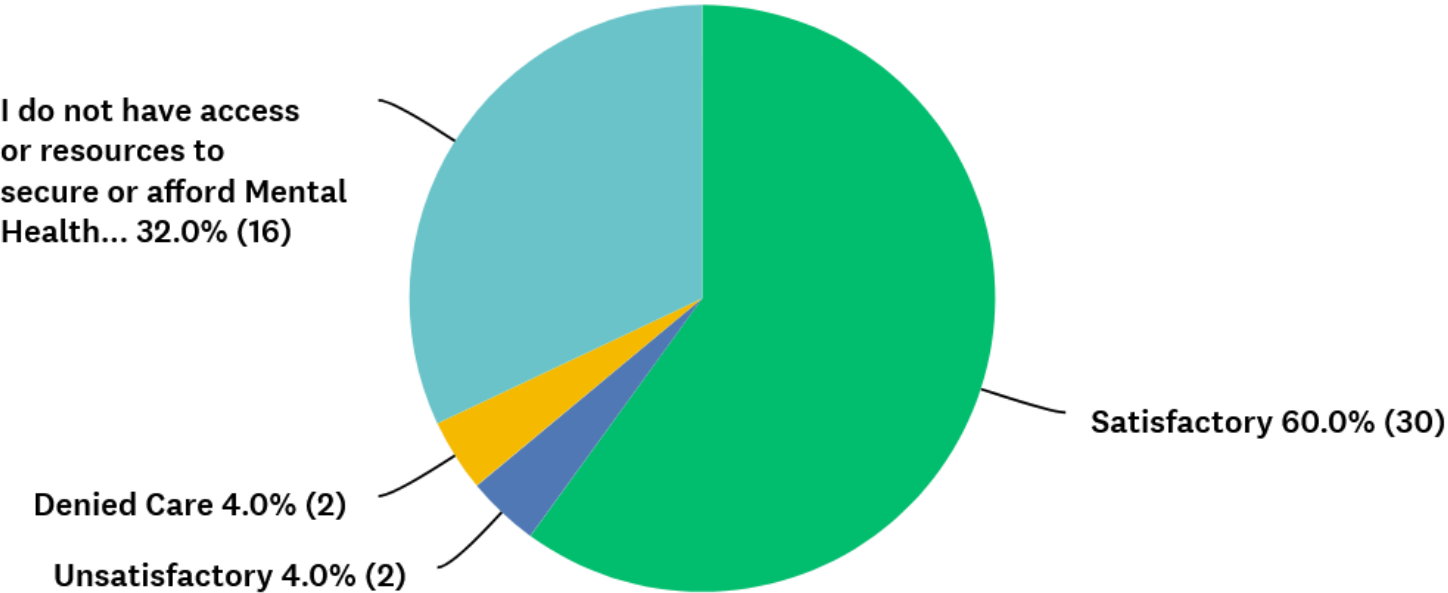
Community members were asked if they were ever denied treatment because of their bleeding disorder. 43 participants answered the question with the following results:



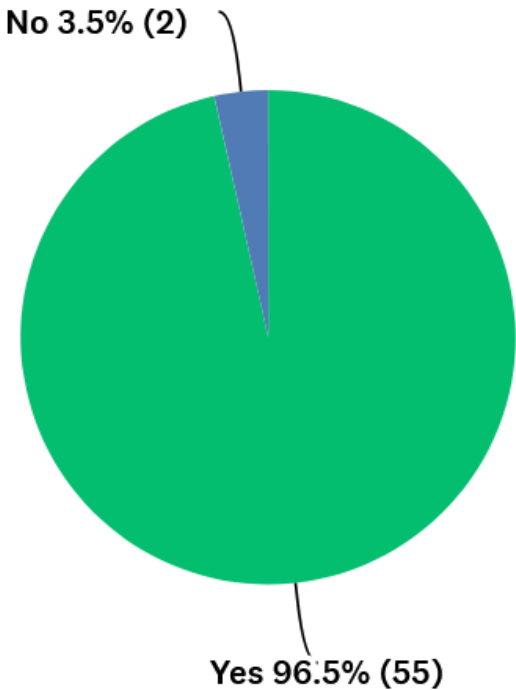
Community members were asked where they believe that they did not receive quality care because of their bleeding disorder. 33 participants answered the question with the following results:



Community members were asked to rate the care they have received when seeking mental health assistance related to their bleeding disorder. 50 participants answered the question with the following results:



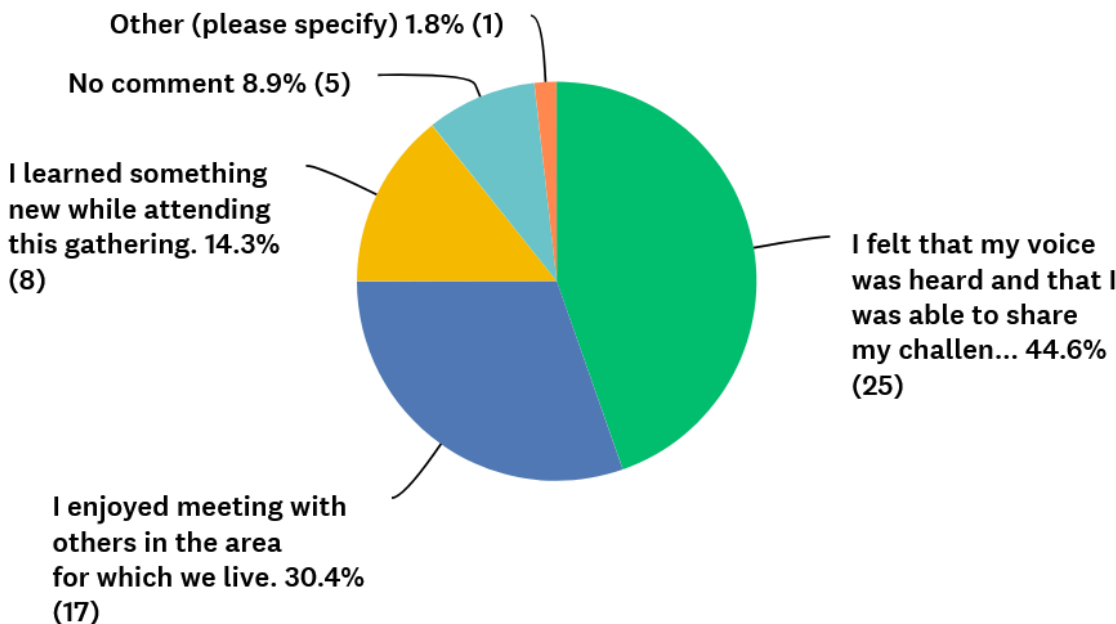
Community members were asked if they attend chapter events. 57 participants answered the question with the following results:



Community members were asked what is the largest barrier keeping them from attending chapter events. 57 participants answered the question with the following results:

- Distance to events & the driving cost to get there, travel expense.
- Work Schedule.
- The Zoom call that I attended was discontinued for lack of participants, I believe. I am still new to this as I have had my diagnosis about a year, yet I have had many issues in care and do not know how to resolve the issues I am having. I also am unsure if events are free or are child friendly to know if I can participate in them. Unless events specifically state it, as someone who deals with a black and white thought process, I will not attend.
- Sometimes I am in a lot of pain & can't attend all the events and because there is a policy to attend all classes in the events, I tend not to go.
- Transportation
- Other outside , family commitments to attend.
- Getting time off of work to attend.
- Life logistics, and weeknight events are hard.
- Childcare and traveling with a baby, small child.

Community members were asked if they found the 46 Voices Outreach Program events helpful. 56 participants answered the question with the following results:



Project Summary

During our 2022 Health Equity Summit in Charleston, SC, we gained valuable insights from rural community members about their needs for improved local education on bleeding disorders, better treatment care, and stronger community connections. In response, we created “The Voices of 46” Project, designed to amplify the voices of community members and identify their concerns regarding treatment care and services.

The project aimed to gather concrete data on the barriers to care in South Carolina’s rural bleeding disorders communities. Running from June 1 to December 31, 2024, the program included in-person events across the state and an online survey. The survey was shared widely through social media, print materials, and our website, inviting participation from our entire membership. The results aligned with our expected community sentiment, while also providing additional insights into how we can better serve the community.

While financial barriers to care were identified as a significant issue, the survey uncovered multiple factors affecting access to treatment. Beyond the cost of travel to clinics, respondents highlighted the financial strain caused by lost income from taking time off work and the added expense of childcare. These often-overlooked factors can prevent patients from receiving the care they need.

Additionally, it became clear that many healthcare providers, particularly in Emergency Departments, Urgent Cares, and dental clinics, lack a comprehensive understanding of bleeding disorders. This knowledge gap not only results in lower-quality care but also in instances where patients are denied care altogether.

Through “The Voices of 46,” we have gained critical insights that will guide us in addressing these challenges and improving care for our rural communities.

Plans & Goals

With the completion of the 46 Voices program, our first step is to share the valuable data we gathered with South Carolina’s Hemophilia Treatment Centers (HTCs) and the broader South Carolina Bleeding Disorders community. We will present our findings during the 2025 HTC Patient Advisory Meeting in January.

Immediate Goals:

1. Create an Emergency Care Brochure: This brochure will be distributed to individuals with bleeding disorders to present when visiting any Emergency Department or Urgent Care Facility. It will include:
 - General emergency actions for individuals with bleeding disorders.
 - Specific care instructions for patients, with a customizable section for the patient to complete.

Plans & Goals Continued

2. Develop a Travel Letter:

- Educate the community on how to obtain a travel letter and when to request an updated version.
- Provide guidance on how and when to use the travel letter, both for patients and caregivers.
- Include critical information such as the patient's diagnosis and treatment plan.

Long-Term Goals:

1. Expand Education for Healthcare Providers:

- Offer additional education on bleeding disorders to outlying hospitals and urgent care facilities.
- Provide targeted education for dentists and oral surgeons to improve understanding and care for patients with bleeding disorders.
- Continue to work in partnership with our HTC's and other medical facilities to seek ways to improve the quality of care and treatment our the bleeding disorders community needs in South Carolina.

We will continue to work in close partnership with our HTC's and other medical facilities to explore and implement strategies that improve the quality of care and treatment for South Carolina's bleeding disorders community. By fostering collaboration and ongoing dialogue, we aim to identify and address gaps in care, enhance patient education, and ensure that every individual has access to the resources and support they need for optimal health outcomes. Through these partnerships, we are committed to advancing the standard of care and creating a more inclusive, informed, and supportive healthcare environment for all those affected by bleeding disorders in South Carolina.

We would like to extend our deepest gratitude to everyone who played a role in making the "Voices of 46" survey a success. Your time, effort, and dedication have been invaluable in helping us gain crucial insights into the needs of our community. To the members of our South Carolina Bleeding Disorders community, thank you for sharing your experiences and concerns with us so openly and honestly. Your voices are what drive our work and will guide us as we continue to advocate for better care and services.

A special thank you to the organizations, sponsors, and individuals who supported this project. Your collaboration, trust, and willingness to engage in this important work have been essential in ensuring that the survey reached the right people and that the information we collected will have a meaningful impact. Together, we are making a difference, and we are grateful for each of you who contributed to this important initiative. We look forward to continuing our work with all of you to improve the quality of care and support for the bleeding disorders community in South Carolina. Thank you for your commitment to this cause and for being a vital part of this journey.



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