



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

BDASC

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 to 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 the visualization of our data within areas of the state. We will include as many diverse individuals and their families living with Bleeding Disorders with 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 all barriers or challenges, while also providing information and resources to community members that we currently can provide that can help in these access challenges.

Our 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 taken at each location.

The outcome goal of this project will be to share the data we discover with our HTC and healthcare agencies within South Carolina and look at ways to partner to help bridge any gaps we can achieve together. We also hope by having these small meetings that we can introduce community members to other members living in the areas for which they live.

***This program is sponsored by a generous
charitable grant from***

Genentech

A Member of the Roche Group

Survey Request

We would like to 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 HTC's and Hematologist offices. This is done 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 of any of your concerns. This information will be used to better serve the different regions of 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.

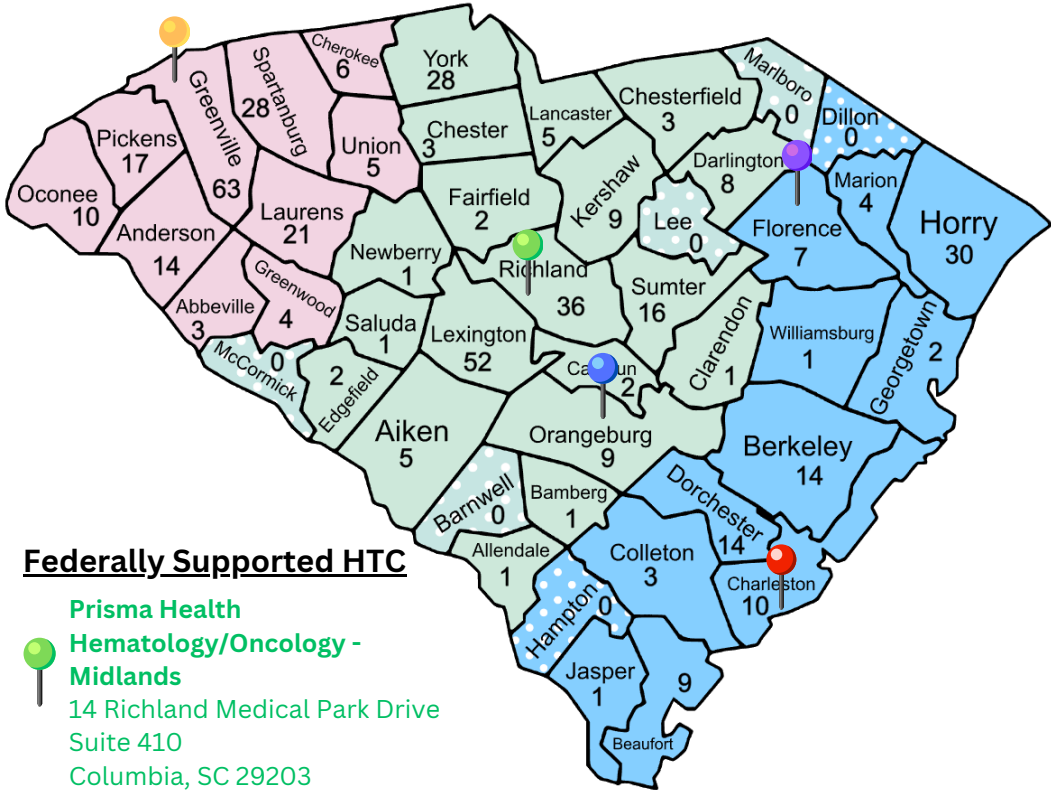
You may also visit this survey by entering the following URL into your browser: <https://tinyurl.com/46VoicesSurvey>

Survey Results

Survey results will be compiled as participants provide their feedback. The final report will be made available to all members of BDASC. The project will run throughout 2024. The final report will be published early 2025.

Your Voice matters and we thank you for taking the time to gather together and help us provide your voice as a platform for change.

Current Membership By Region and County



Federally Supported HTC

Prisma Health

Hematology/Oncology - Midlands

14 Richland Medical Park Drive
Suite 410
Columbia, SC 29203

Satellite Office - Prisma Health

Hematology/Oncology - Upstate

900 W. Faris Road
2nd Floor
Greenville, SC 29605

Prisma Health Hematology/Oncology - Florence

101 William H Johnson Street
Suite 400
Florence, SC 29506

Prisma Health

Hematology/Oncology - Orangeburg

172428 Village Park Drive
Orangeburg, SC 29118

Non-Federally Supported HTC

MUSC Pediatric Hematology

125 Doughty St., Suite 520
MSC 917
Charleston, SC 29425

Member Families By County

Lowcountry (13 Counties): 92 Families

Midstate (24 Counties): 202 Families

Upstate (10 Counties): 170 Families

South Carolina Members of BDASC

(46 Counties): 512 Families

Out of State: 48 Families

South Carolina Federally Funded HTC's

HTCs are specialized health care “Centers of Excellence” that bring together a team of experts in the field of bleeding disorders care and treatment; to include doctors, nurses, and other health professionals experienced in treating people with bleeding disorders.

A CDC study of 3,000 people with hemophilia showed that those who used an HTC were 40% less likely to die of a hemophilia-related complication compared to those who did not receive care at a treatment center. Similarly, people who used a treatment center were 40% less likely to be hospitalized for bleeding complications.

Each HTC may provide access to multidisciplinary health care professionals:

- Lab medical technologists and pathologists
- Hematologists
- Orthopedists
- Physical therapists
- Nurses
- Social workers and other mental health professionals
- Other specialists available by referral, (e.g., dentist, nutritionist, genetic counselor, gynecologist referrals)



More Information can be found at the Prisma Health Website

Prisma Health HTC Midlands:

Dr. Stephanie Ambrose

Columbia

14 Richland Medical Park Drive
Suite 410
Columbia, SC 29203
Phone: 803-434-1028

Orangeburg

172428 Village Park Drive
Orangeburg, SC 29118
Phone: 803-434-1028

Florence

101 William H Johnson St., Suite 400
Florence, SC 29506
Phone: 803-434-1028

Prisma Health HTC Upstate:

Satellite Office

Dr. Leslie Gilbert

Greenville

900 West Faris Road, 2nd Floor
Greenville, SC 29605
Phone: 864-455-8898

MUSC Pediatric Hematology - Non

Federally Supported:

Dr. Shayla Bergmann

Charleston

125 Doughty St., Suite 520,
MSC 917
Charleston, SC 29425
Phone: 843-792-2957

BDASC Member Resources

Scan the QR Codes with your phone to learn more about each of these Member Resources. Please note, that with rising costs we have limited the number of flyers that we mail to member homes. All of our flyers and event information can be found on our website, in our newsletters, our e-blasts, and on social media.



BDASC
Website




Member
Services




Newsletter


Calendar of Events

 Being a member offers benefits that go well beyond raising awareness for, and advocating on behalf, of those with bleeding disorders. We provide education and networking opportunities, along with support services while promoting ongoing research to improve the quality of life for those affected. Throughout the year we keep our members abreast of these opportunities as well as the latest news and developments in the field of bleeding disorders through a variety of high-quality programs and events, with most events at no charge to our registered members.

Summer Camps

 We believe summer camps for children and teens living with bleeding disorders are very important. Summer camps help develop self-independence skills and allow for the opportunity to build lifelong friendships with individuals who understand what it is like to live with bleeding disorders. We will provide summer camp support to families who have children attending summer camps upon request. The Chapter will provide travel grants or other needed items to help offset the cost of sending a child to camp. We partner each year with Camp Burnt Gin and the Hemophilia Treatment Center staff, and Camp Courage from the BIL0 Charities Children's Cancer Center in Greenville to provide mentoring and self infusion support for campers.

Financial Assistance & Travel Grants

 The Bleeding Disorders of South Carolina Emergency and Financial Assistance Fund is intended to improve the quality of life of individuals and families affected by bleeding disorders. The assistance fund provides funds to eligible individuals and families who need emergency financial assistance and non-emergency aid for; basic living expenses emergencies, medical and living expenses incurred due to the medical care associated with a bleeding disorder, mental health, and more. Travel Grants for educational and supportive BDASC and national events are also available.

BDASC Member Resources

Virtual Innovations Program



In response to the COVID-19 pandemic and subsequently rolled out as part of our 2020 Statewide Annual Meeting & HELLO Conference, Bleeding Disorders Association of South Carolina launched a new initiative, our Virtual Innovation Program (VIP). The mission of the VIP program is to provide continuing education, support services, and to connect with members with the use of managed educational tools, such as iPads. Enrolled with the service of a Mobile Device Management we can provide virtual connections to web clips, videos, apps, and URL's, all of our choosing, and provide zoom virtual meeting capabilities. The program was well embraced by the 60 families or individuals who first enrolled. We now have 85 members enrolled in the program. With the huge success of this educational pilot program, we are opening it up to all the members of BDASC as funding for additional educational tools becomes available.

BDASC SC Resource Guide



During the COVID-19 pandemic, the Bleeding Disorders Association of South Carolina, developed our first South Carolina Resource Guide. The resource guide has been redesigned and updated to include up-to-date information and additional resources. The Resource Guide can be found on the BDASC Resource webpage.

Medical Alert ID Bracelets



Bleeding Disorders of South Carolina believes one way to protect yourself or your loved ones with bleeding disorders is to be sure a Medical Alert ID is worn at all times. The information you provide on these ID's will help the emergency medical providers and medical teams identify your condition and medical needs should you not be able to speak for yourself. These ID's can very well save your life. Medical IDs come in Rugged Sports bands to Pedant Necklaces and are more than just a piece of jewelry; they provide you with constant access to the world's largest emergency-support network. The Chapter can provide assistance to help purchase a Medical Alert ID for South Carolina's Bleeding Disorders registered members of the Chapter.



scan here for
our Instagram
account



scan here for
our Facebook
account

BDASC Member Resources

National Organizations



National Bleeding Disorders Foundation

1230 Avenue of the Americas
16th Floor,
New York, NY 1002
Phone: 212-328-3700
<http://www.hemophilia.org>



Hemophilia Federation of America

999 N Capitol Street NE, Suite 301
Washington, D.C. 20002
Phone: 202-675-6984
<https://www.hemophiliafed.org/>



NORD[®]
National Organization
for Rare Diseases

National Organization of Rare Diseases

1900 Crown Colony Drive
Suite 310
Quincy, MA 02169
Phone: 617-249-7300
<https://rarediseases.org/>

COPAY Assistance for Out-of-Pocket Costs

Accessia Health

P.O. Box 5930
Midlothian, VA 23112
Phone: 800-366-7741
<https://accessiahealth.org/>

PAN Foundation

P.O. Box 30500
Bethesda, MD 20824
Phone: 866-316-7263
<https://accessiahealth.org/>

The Assistance Fund - TAF

8427 Southpark Circle
Suite 100
Orlando, FL 32819
Phone: 855-845-3663
<https://tafcares.org/>

Catholic Charities - South Carolina

<https://charitiessc.org/>

Hemophilia Assistance Program (HAP)

The South Carolina Hemophilia Assistance Program (HAP) is a state-funded program provided by the Department of Health and Environmental Control (DHEC) in partnership with [Accessia Health](https://accessiahealth.org/). The HAP program was established to assist state residents with Hemophilia and von Willebrand Disease. The program offers insurance case management and financial assistance for private health insurance costs as well as co-payment assistance. The program was established to assist eligible patients with obtaining health insurance by funding premiums and co-pays. This insurance will cover blood disorders healthcare needs as well as comprehensive and preventive services. **To apply:** Call Malerie Hartsell, Director of the HAP Program – (803)- 898-2966.