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11<sup>th</sup> Annual STEP for Bleeding Disorders 5K Walk/Run Fundraiser May 11, 2024 Saluda Shoals Park 6071 St. Andrews Rd Columbia, SC 29212

Dear Friends, Supporters and Sponsors:

Imagine receiving news about your health or the health of a loved one that will impact you for the rest of your life. You have a bleeding disorder. Your career, hobbies, where you live, family planning, and many other life decisions are now all affected. Your doctor can prescribe a treat regimen, but where do you turn for support in between office visits. Who has the most relevant experience or practical knowledge to help you navigate life with a rare and life threating chronic disorder?

Being part of a community that shares experiential knowledge often means the difference between effectively managing a chronic disorder like Hemophilia or von Willebrand Disease, or being debilitated by it. Patient education and empowerment, public awareness, support services, and advocacy for those affected are the principals at the core of our organization. We are *The Bleeding Disorders Association of South Carolina (BDASC)*, and we would love to have your support!

As South Carolina's leading resource for children and families affected by bleeding disorders, the BDASC maintains close relationships with our community, providing them the opportunity to network with other families experiencing the same situations, seeking guidance and emotional support for an often anxiety-ridden and frightening diagnosis. We support our families from the initial diagnosis throughout their lifetime. We serve the entire state of South Carolina, over 1,200 individuals and their families, and we are a tight-knit community family. Hemophilia and other bleeding disorders are rare and the occurrence of knowing someone in your lifetime with the same disorder is highly unlikely. BDASC helps our members develop a strong support system that will benefit the emotional health of individuals within the family unit. Having a bleeding disorder can be an extremely isolating experience and the feelings of knowing you are not alone in this chronic health struggle are unmatched in importance.

**Bleeding Disorders Association of South Carolina** is a 501(c) 3 non-profit organization which serves the state of South Carolina and is a chapter of the *National Bleeding Disorders Foundation (NHF)* and a member organization of *Hemophilia Federation of America (HFA)*. BDASC is proud to present our <u>"STEP for Bleeding Disorders 5K Walk/Run Fundraiser"</u>. The event will be held at the Saluda Shoals Park in Columbia, South Carolina, on May 11, 2024. This event is our Chapter's largest fundraising event and is made possible by the generous support of our donors and sponsors. The funds raised will support the educational programs, advocacy initiatives, and supportive services we provide to those affected by bleeding disorders in South Carolina. A small portion of the walk proceeds will be provided to the research of the National Bleeding Disorders Foundation. Walks such as ours occur each year throughout the nation to support local chapters.

Persons with bleeding disorders, like hemophilia, have clotting factors or proteins in their blood that are missing, low or do not work as they should. The lack of a specific clotting factor prevents the blood from clotting normally. This can lead to bleeding into joints, muscles, and internal organs. Bleeding into the joints and muscles is extremely painful and causes long term damage. Certain internal bleeding episodes such as bleeding in the brain, can be life-threatening. Treatment is *expensive* and can be complicated. Currently, there is no cure.



For the past 51 years, **Bleeding Disorders Association of South Carolina** has provided support services and educational programs to the South Carolina bleeding disorders community. Below are just some of the programs and services that your sponsorship dollars will support and ensure to continue. Our advocacy efforts have improved the lives of many in our community.

We provide the following support services, free of charge:

- 1. An Annual State-Wide Annual Meeting and Educational Conference
- 2. Support groups, workshops
- 3. Bleeding Disorders Summer Camp support for children and teens affected by bleeding disorders
- 4. College Scholarships
- 5. Virtual Technology Managed Devices Programming (VIP), IPads
- 6. Financial Assistance Program
- 7. Patient Advocacy Training
- 8. A state legislative day in *March, the National Bleeding Disorders Awareness Month*, to raise awareness of bleeding disorders and advocate for the needs of those affected.
- 9. Patient Advocacy *Coalition* and Ambassador Program
- 10. Teen & young adult support / educational events
- 11. Walk and Golf Fundraiser to raise awareness and funds
- 12. An outreach and referral program in collaboration with our Hemophilia Treatment Centers
- 13. Annual year-end winter meeting and Holiday gathering
- 14. *Quarterly newsletter* for our members, all affiliations of our organization, state hospitals, state agencies and HTC's.
- 15. *Educational and social dinner outreach programs and events* throughout the state to assist families in their *local areas*
- 16. Educational Family Gatherings and Adult Retreat Weekend
- 17. Local, regional, and national training and travel sponsorships
- 18. Participation at Washington Days at the Nation's Capital.
- 19. *Research Funding* to support the *NHF Judith Graham Pool Research* Fellowship, The *National Research Blueprint* and funding to *world projects* for underdeveloped countries for treatment.

We hope we can count on you to support our mission. Hundreds of families in South Carolina will benefit from your support and on behalf of **Bleeding Disorders Association of South Carolina**, we thank you for your consideration. Should you have any questions, please don't hesitate to call or e-mail me at the below contact information. Additional information on the walk, participation and sponsorships packages can be located on our website at <u>www.bda-sc.org</u>

Warmest Regards,

Sugarme Martin

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