

BLEEDING DISORDERS ASSOCIATION OF  
SOUTH CAROLINA

# ANNUAL GRATITUDE REPORT 2021

OUR MISSION: TO RAISE AWARENESS FOR AND ADVOCATE ON BEHALF OF PERSONS WITH BLEEDING DISORDERS AND THEIR FAMILIES; PROVIDE EDUCATION AND SUPPORTIVE SERVICES; AND PROMOTE ONGOING RESEARCH TO IMPROVE THE QUALITY OF LIFE FOR THOSE AFFECTED.



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[www.bda-sc.org](http://www.bda-sc.org)

# Board of Directors and Staff

*On behalf of the board of Bleeding Disorders Association of South Carolina, we want to thank you for all the support you have given us. We live in a world where everything was turned upside down these past couple years, but you chose to keep our bleeding disorders family together during these hard times. For that, we are so grateful for the time and support you have shown each and every one of our members. I can't lie, it was so great to finally be able to meet in person again in the fall this year!*

*I am so proud of our advocacy work and how we are raising awareness about Bleeding Disorders among our local and national leaders! Each voice is important, and we need to continue to make our concerns known, in order to bring about change! We are always trying to find stories to further educate our leaders and ensure they understand the importance their support means for our community; so, help keep us informed with what is going on in you and your family's lives!*

*Also, as we continue to grow as a community, we need everyone to let us know what you need from US. Please consider joining our board or getting involved in some other capacity, so that we can make BDASC even better!*

*Shelley Crisp, President*



*Dear friends, members, and partners in giving, It has been another fantastic year for us as we have now completed our transition in rebranding to a new more inclusive name of all whom we serve and we are grateful to everyone who continues to support our mission. We have grown tremendously over the past year with the strong partnerships of our treatment centers and state agencies, all working together to provide the best in access to quality healthcare, education, and supportive services. We have a strong commitment in supporting research, and have dedicated many hours and financial support in partnership with our national organizations.*

*Every day, our members and their families continue to inspire me. Together, with our donors, corporate partners, and our national organizations, we will continue to reach new heights. With your support, you allow us to grow our programs and services, while looking forward to limitless possibilities and bright futures. Thank you for being our partners in giving and an extension of our South Carolina family. I hope you enjoy reading about some of our many accomplishment this year! Highlights:*

- ▶ 48 families financially assisted with direct funding of \$23,437.81.
- ▶ Total of 60 community connections programs and events with over 2,391 volunteer hours.
- ▶ Robust grass root Advocacy Program with 55 active Coalition and Ambassador members.
- ▶ Outreach and communication to raise awareness with the general public and our members: \$53,590.07.

*Thank you for your continue support, love, and generous kindness. Because of YOU, we will continue to thrive. With warmest regards and heartfelt appreciation,*

*Sue Martin  
Executive Director*



## OFFICERS

Shelley Crisp, President  
Aaron Smith, Vice President  
Eric Duntun, 2nd Vice President  
Cristal Day, Secretary  
Patricia Tucker, Treasurer

## BOARD OF DIRECTORS

Wendy LeGrand  
Dr. Joey Krakowiak  
Ursula Sagot  
Christine Evans  
James Whitmire  
Robert Butler  
Ex-Officio Board Member  
Suzanne Martin

## STAFF

Suzanne Martin, Executive Director  
Jeremy Williams, Advocacy & Development Coordinator  
Jim Lane, Bookkeeper  
Richard Wright, Website



## ORGANIZATIONAL VISION

To be recognized as a leading organization providing valued services; as ambassadors of public outreach to enlighten and foster an understanding of what matters most to those affected by hemophilia and bleeding disorders; and to be our community's first choice in partnership to achieve their highest potential through empowerment, connection to their community and being part of the solutions that affect them the most, until a cure is achieved.

# MEMBER SPOTLIGHTS

## The Keith Family – Ambassadors Of The Year

I advocate on behalf of my husband, Ward, who has hemophilia A mild with an inhibitor. He was diagnosed at age 2, back in 1967, after being in the hospital with bleeding on the brain. He has grown up being in and out of the hospital for things like a bike accident, right-sided paralysis, and numerous hip surgeries. Due to these, he is not able to work and is on disability. I advocate because I want him to be able to have access to the proper medical care to ensure a good quality of life, not just for him, but for our daughter and our future grandkids (since our daughter Makayla is a carrier). I advocate because I want to educate people on what hemophilia is and the impact it can have on people, not just physically but also emotionally and mentally. Since Ward is not able to work he gets depressed. Thank God for the HTC. At his annual checkup, he saw the psychologist and got help for his depression. I advocate because I want to see the HTC continue to get the funding needed to stay open to serve our community. My husband is a wonderful man and having his hemophilia managed in a way that promotes his best life is why I advocate.

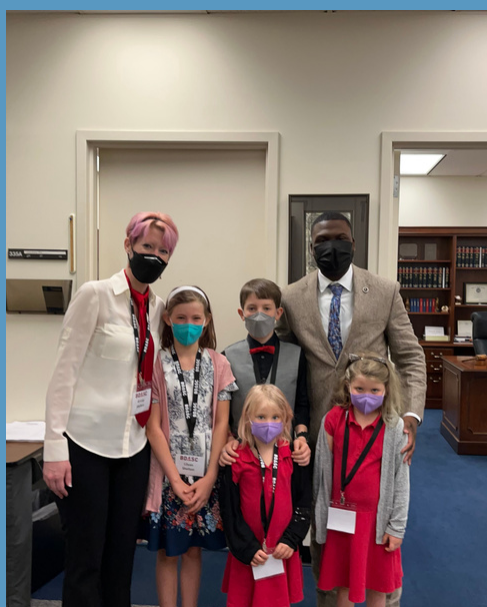


## Women With Bleeding Disorders Raise Awareness Kristen Shelton– Samantha Javorka

Being a caregiver for a daughter with a bleeding disorder can be a challenge. Outside of the everyday bleeding challenges it often feels as though we have to explain ourselves and advocate for ourselves frequently. Anything from meeting a new doctor, to setting up a 504 or applying for health insurance can be met with pushback. A lot of people have not heard of VWD or still believe that girls cannot bleed—even with a diagnosis. We live everyday encouraging our daughter to have strength and to advocate for herself. We've worked very hard to ensure that she receives proper treatment and care. We know that she can continue to advocate for herself, but at the same time we hope that she won't need to.

## Welcoming New Members to Our Family

New to BDASC, the Shelton family and Seth Morgan, join the organization and learn quickly how to advocate for access to quality healthcare and treatment for individuals living with bleeding disorders, always encouraging the youngest participants to join in.



# 2021 By The Numbers

## Events

**Annual Meeting Attendance:**

175 virtual participants (9 sessions and 1 awards ceremony)

**Family Camp Attendance:** 157 in-person

**Winter Meeting Attendance:** 50 virtual

**Teen Retreat:** 25 virtual

**Camp Burnt Gin and Camp Courage**

**Support:** 176 children

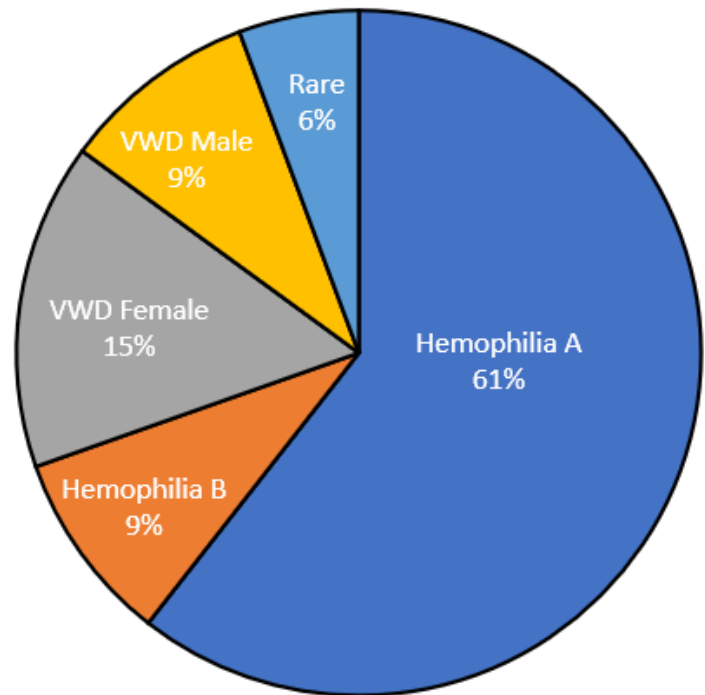
**STEP for Bleeding Disorders:**

**Participants:** 173 in-person

**Par for the Clot Attendance:** 172 (144 golfers; 23 volunteers; 5 guest speakers)

**Community Connection Programs:**  
Over 60

## Membership Served



**Communications Blast**  
Recipients: 17,436



**Website**  
Pages: 71



Households  
Directly Assisted:

**48**

**Financial Assistance and Scholarships**  
Total: \$23,437.81

## Social Media



**Hours Uploaded:**  
20:17:11



**Posts: 1905**  
**Reached: 11,652**



**Posts: 1,300**  
**Likes: 2,436**



**Tweets:**  
19



**Virtual Innovation Program**  
Managed  
Devices: 85

## Volunteer Hours

**Fundraising - 396**

**Board of Directors - 632**

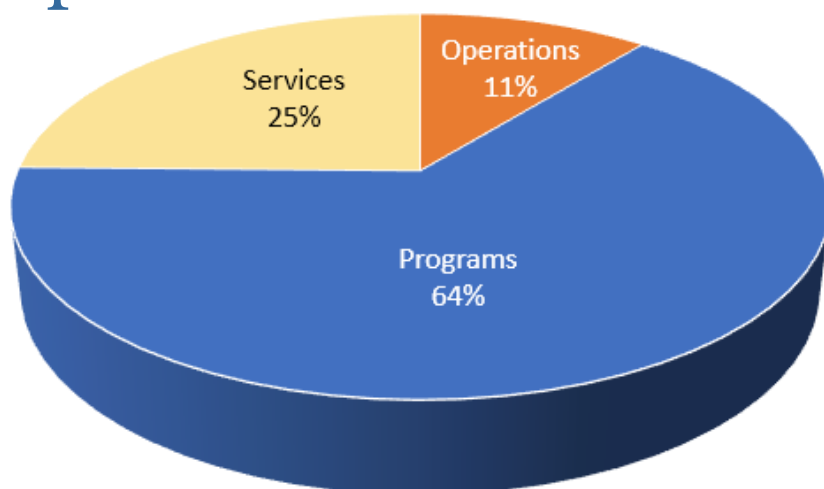
**Advocacy - 1620**



# Financial Report

## Expenses

Programs - \$219,789.36  
 Services - \$84,294.35  
 Operations - \$37,097.59  
 Total - \$341,181.30



## Program Expenses

National & Local Education:  
 \$35,396.77  
 Advocacy: \$17,173.34  
 Fundraisers: \$66,162.14  
 Camps: \$91,394.31  
 Support: \$9,662.80

## Services Expenses

Outreach and Communications: \$53,590.07  
 Financial Assistance: \$23,437.81  
 Research: \$3,530.00  
 Global and National Support: \$2,145.00  
 Organizational Development: \$1,591.47

## Operations

Management: \$15,136.92  
 Facilities and IT:  
 \$13,505.53  
 Legal, Bookkeeping:  
 \$8,455.14



# Financial Report

## Revenue

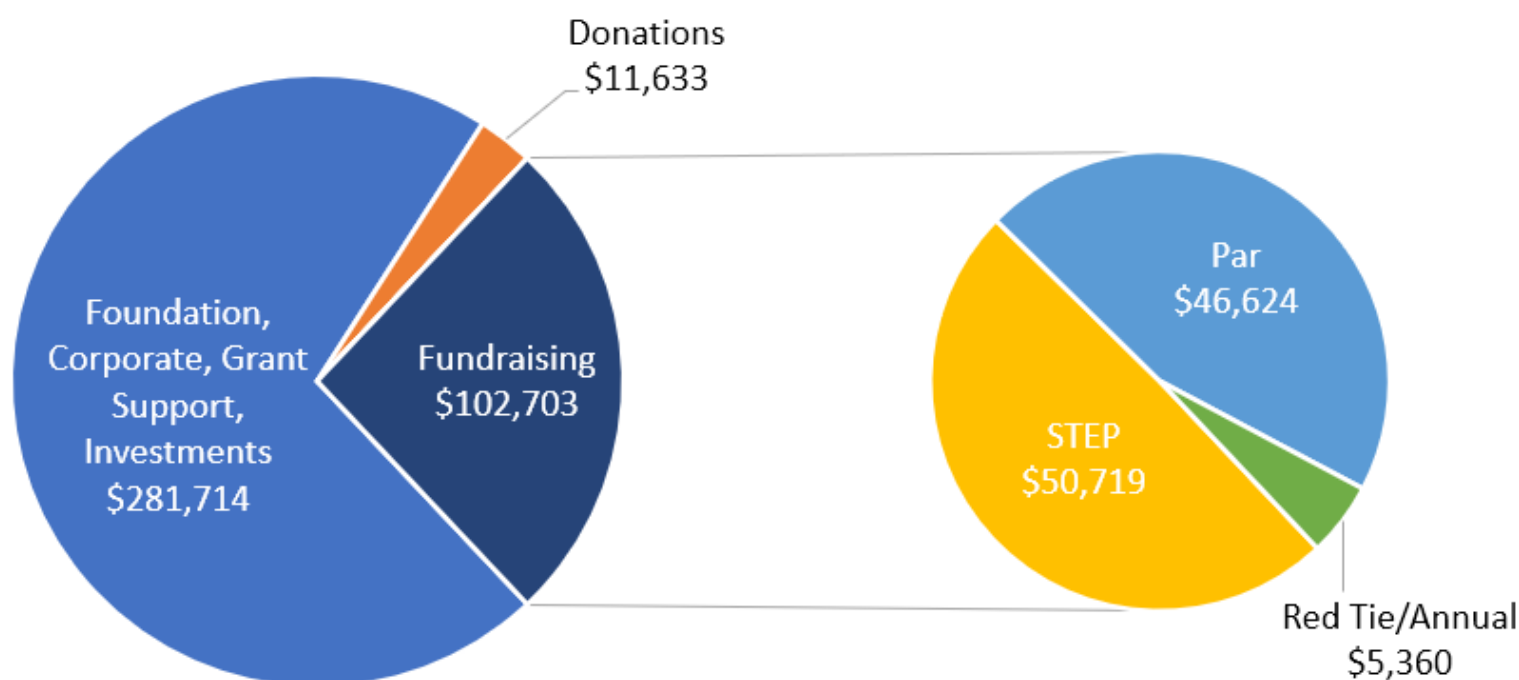
**Individual Donations**  
\$11,633.19  
**Fundraisers**  
\$102,703.56  
**Foundation, Corporate,  
and Grant Support**  
\$281,714.89  
**Total Revenue**  
\$396,051.64



## Fundraising

**Par for the Clot Golf Tournament:**  
\$46,624.36  
**STEP 5K Walk:** \$50,719.56  
**Red Tie Campaign:** \$5,075.00  
**Annual Appeal:** \$285.00  
**Total:** \$102,703.92

## Revenue



# PACE REPORT

## Public Outreach

In 2021, we hosted a Bleeding Disorder Awareness Month campaign at Falls Park in Greenville including lighting the Liberty Bridge red. We held a kickoff for the Red Tie Campaign with city and county proclamations recognizing March as national Bleeding Disorders Awareness Month. We held a virtual World Hemophilia Day event, hosted a STEP for Bleeding Disorders fundraiser (that was open to the public), and held our annual Par for the Clot Charity Golf Tournament.



## Advocacy

In 2021, five BDASC members participated in NHF's Annual Washington Days for virtual meetings with the offices of both South Carolina U.S. Senators and four of the seven members of the House of Representatives. We held completely virtual state Advocacy Days with 22 Zoom meetings. We advanced H3956 to create a Rare Disease Advisory Council in the state, passing it out of the House of Representatives and pushed to have it created via proviso at the end of the session.



## Community Connections

In 2021, we continued to develop our support groups including our M.E.N.S., C.A.R.E. (women's), and Y.E.S. (children's and young families') support groups, as well as continued teen programming. We held myriad meetings, programs, and activities for each of these groups throughout the year. We also continued our Virtual Innovations Program (VIP), utilizing iPads to keep members connected and informed about ongoing BDASC activities.

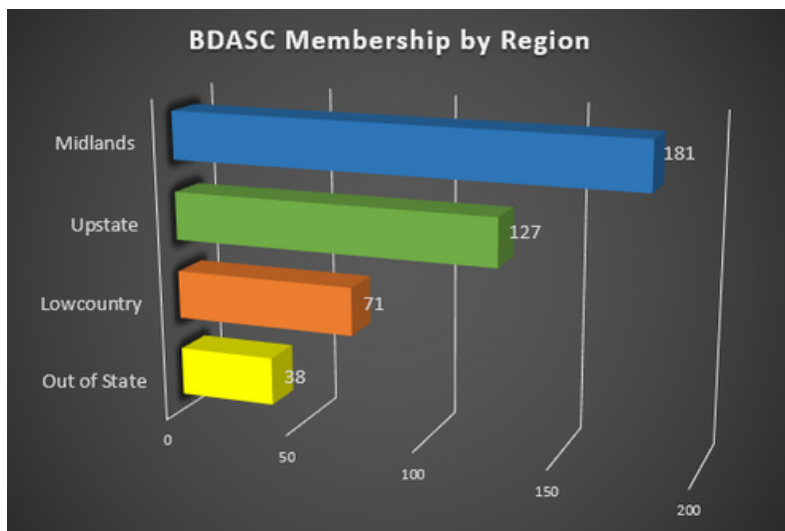


## Education

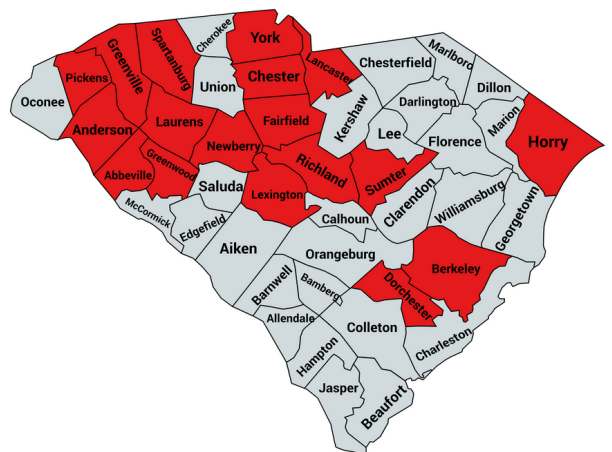
BDASC hosted a number of events this year including our Annual Meeting and H.E.L.L.O. Conference and Annual Family Camp. BDASC also had the privilege to attend, present, and be honored at three national conferences in 2021. We hosted more than 40 Educational Outreach Programs with more than 500 member families in attendance throughout the year.



In 2021, we held over over 60 connection programs for our members and provided multiple service resources in six major areas. Thank you for all YOU did to support our mission.



## Coalition Members in 18 Counties



Green Gate Office Park  
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CELEBRATING  
**48**  
YEARS

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