# BDSSC

# BLEEDING DISORDERS ASSOCIATION OF SOUTH CAROLINA

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.



# REPORT 2024

## Welcome 2025



#### Welcome from our President, Shelley Crisp

Becoming President of the South Carolina Bleeding Disorders Association is incredibly meaningful to me. I've been involved with this chapter for 10 years, ever since my son, Lucas, was diagnosed with severe Hemophilia A at just a year old. He'll be 12 this July, and watching him grow into a strong, compassionate, and resilient young advocate has been one of the greatest joys of my life. He's

learning about the importance of speaking up and is already beginning to participate in advocacy himself. This organization has been a lifeline for our family, and I'm so grateful for the people we've met and the strength we've found through this community. Taking on this role feels like a full-circle moment, and I'm excited—and deeply committed—to giving back and helping other families feel seen, supported, and empowered.

#### **2025 OFFICERS**

Shelley Crisp, President Taylor Upton, Vice President Cristal Day, Treasurer

#### 2025 BOARD OF DIRECTORS

Christine Evans
James Whitmire
Sharlene Maloy
Candi Mitchum
Eric Townsend
Virginia Maxwell
Ex-Officio Board Member
Suzanne Martin

#### STAFF

Suzanne Martin, Executive Director
Samantha Javorka, Engagement & Development
Manager
James Romano, Legislative Coordinator
Jim Lane, Bookkeeper
Richard Wright, Website



#### Gratitude from Sue Martin, Executive Director

It has been another fantastic year for us with tremendously growth in membership from our outreach efforts and strong partnerships of our treatment centers and state health agencies. Working together, our mission is to provide the best in access to quality healthcare, education, and supportive services for our bleeding disorders community in South Carolina. We have a strong commitment in supporting research and innovative treatment therapies in partnership with our national organizations. While our revenue growth was the highest ever, our supportive services and all our mission resources and higher costs had us going slightly over our budget. However, with Legacy investments, we are assured to continue serving our members well into the future. Within our growth, we proudly continue serving our community having 89% of every dollar spent with our mission. We are grateful to those who give for the future and will need

to secure additional funds in companies and individuals who want to invest in an organization that serves a mission for hope. 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 our community to thrive with dreams of limitless possibilities and bright futures.

#### Highlights:

- 88 financial assistance, disaster relief, and emergency and compassionate care requests filled with direct member services of \$26,006.00.
- Hosted over 75 virtual and live community engagement connections programs, services, fundraisers, awareness campaigns and events.
- Enhanced our robust grassroot Advocacy Coalition Program with 43 active Coalition and Ambassador members, residing in 24 counties throughout South Carolina.
- Outreach and Communication to raise awareness with the general public and serve our members: \$41,820.00.



Thank you for your continued support, love, and generous kindness. Because of YOU, we will continue to thrive. Thank you for being our partners in giving and an extension of our South Carolina family.

# 2024 Member Spotlights

Congratulations to our 2024 Chapter Award Recipients!

Board Member of the Year - Sherlene Maloy

Legislative Advocate of the Year -Representative Jason Elliot, District 22 (R), Greenville County & Representative Kevin Hardee, District 105 (R), Horry County

Coalition Advocate of the Year - Whitney Galloway

Coalition Ambassador of the Year - Michelle Krakowiak

Junior Advocacy Ambassadors of the Year - Natalie Mitchum and Adonis Rabb

Appreciation and Partnership Award – Lt. Governor Pamela Evette

Making a Difference Award - Malerie Hartsel, Program Manager & Interim Director, DHEC

Hemophilia Assistance Program

Volunteer of the Year "The Fisher Award" - Patricia Tucker

Aaron Eugene Gossett Pillar of Strength Award, "On the Shoulder of Giants" - Warren Ingram

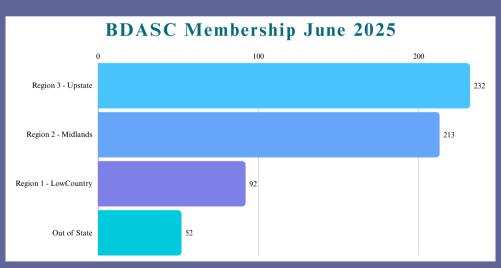




## Welcoming Over 60 New Member Individuals and Families



Welcome Max Krakowiak
Proud Parents Joey & Michelle and
proud big brothers Sam & Thomas



Welcome to all of our new members and families!

Congratulations to our families who welcomed

new babies this year!

# 2024 By the Numbers

#### 2024 Major Events Memberships Outreach

Advocacy Program: (year round - 700 attendee outreach)

Adult Connections Retreat: 76 attendees

STEP for Bleeding Disorders Fundraiser and Awareness Campaign: 155 attendees

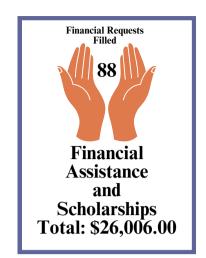
**Annual Meeting & HELLO Conference:** 162 attendees

Community Connection Outreach Programs & Support Groups: over 500 attendees

Teen Camp and Kids Camp Support: 250-300

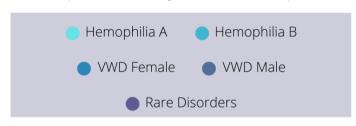
Par For The Clot Charity Golf and Awareness Campaign: 175 attendees Fall Family Advocacy Camp and Medical Symposium: 80 attendees

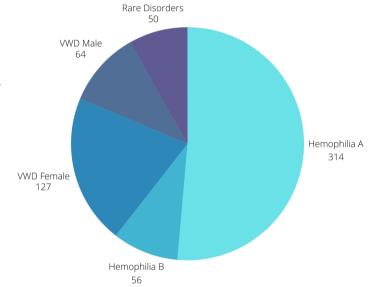
Winterfest Statewide Meeting: 80 attendees



# Membership Served

(2025 Data by Disease State)





# Hours Uploaded: Posts: 1,049 Reached: 15,419 Reached: 5,700 New Followers: 47





#### **Hundreds of Volunteer Hours**

Volunteers are the heart of this work. You are the reason we can offer hope, connection, and care to so many. From the bottom of our hearts, thank you—for showing up, for giving your time, and for believing in our mission. You make a difference, and we are deeply grateful for all that YOU do.

# Financial Report

## 2024 Expenses

**Programs** - \$265,810

**Services - \$73,120** 

**Operations** - \$54,667

**Fundraisers** - \$63,780

**Camps** - \$58,225

**Total Expenses - \$515,602** 

## **Program Expenses**

National & Local Education: \$147,626

Advocacy: \$74,699

Medical Symposium: \$21,098

**Community Outreach Support: \$22,388** 

## **Services Expenses**

Outreach and Communications: \$44,059

Financial Assistance: \$26,006

**Research: \$1,000** 

Global and National Support: \$2,055

## **Operational Expenses**

Management: \$23,660 Facilities and IT: \$20,329 Legal, Bookkeeping: \$8,439

**Organizational Development: \$2,239** 

## **Fundraising Expenses**

Step for Bleeding Disorders: \$22,409

**Par for the Clot: \$41,372** 

**Total: \$63,780** 

#### 2024 Revenue

**Individual Donations - \$12,624** 

**Fundraisers** -\$116,706

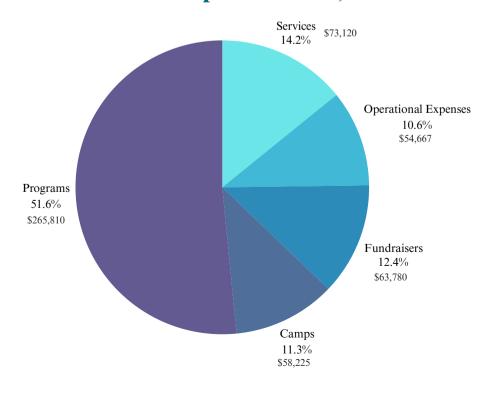
Foundation, Corporate, and Grant Support - \$356,961

**Legacy Investments - \$205,108** 

**Total Revenue - \$691,399** 

Our expenses outpaced our general revenue by \$13,820 this year. With our growing membership and the costs of events and overhead growing, we have had to utilize our investment savings to cover these additional expenses. We need to increase our revenue to avoid pulling funds from our future legacy investments.

## 2024 Expenses \$515,602



# Financial Report

## 2024 Revenue

Individual Donations - \$12,624
Fundraisers -\$116,706
Foundation, Corporate, and Grant
Support - \$356,961
Legacy Investments - \$205,108

**Total Revenue - \$691,399** 

#### **Fundraising Revenue**

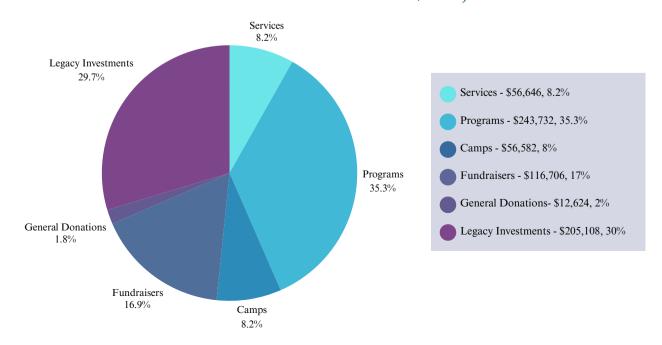
Par for the Clot Golf Tournament: \$64,937 STEP 5K Walk: \$51,749 Bleeding Disorders Awareness Month: \$20 Annual Appeals (Giving Tuesday): \$0

Total: \$116,706





#### 2024 Net Revenue & Legacy Investments \$691,399 General Revenue Funds - \$501,782



# 2024 PACE Report

#### Public Outreach

In 2024, we proudly hosted our annual Bleeding Disorders Awareness Month campaign, which featured a variety of impactful events and advocacy efforts. The campaign kicked off with city, county, and state proclamations officially recognizing March as National Bleeding Disorders Awareness Month. Key highlights included our State Advocacy Days in Columbia, the launch of a national von Willebrand Disease Awareness Day, and a special event in honor of World Hemophilia Day. We also hosted our annual Men's & Women's Retreat, the public STEP for Bleeding Disorders fundraiser, and the Par For The Clot Charity Golf Tournament. Our advocacy extended beyond state lines, with dedicated efforts in Washington, DC, and a presence at the South Carolina School Nurses Conference where we helped raise awareness and provide vital education.



#### **Advocacy**

In 2024, ten members of our Advocacy Coalition took part in NBDF's Annual Washington Days, meeting with the offices of both South Carolina U.S. Senators and five of the state's seven U.S. Representatives. Back home, we held our Annual State Advocacy Days, conducting 38 legislative meetings. We also hosted our annual legislative breakfast for all members of the South Carolina General Assembly where we advocated for co-sponsorship of our House bill aimed at ensuring all copays count towards a patients out of pocket cost shares when using patient assistance programs. We testified on behalf of those with bleeding disorders.



#### **Community Connections**

In 2024, we continued to develop our support groups including our M.EN.S., C.A.R.E. (women's), VWD and Rare Bleeding Disorders support groups, as well as continued our 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 virtually and informed about ongoing BDASC activities.





#### **Education**

In 2024, BDASC hosted a wide range of educational events, including our Annual Meeting and H.E.L.L.O. Conference, a Medical Symposium, the Fall Family Advocacy Summit, and our Winterfest Gathering. We also had the honor of attending, presenting at, and being recognized during three national conferences. Throughout the year, we held 16 Educational Rural Outreach Programs, reaching more than 400 members across the state.

As we look ahead, we know that we can't do this alone. Your continued support is essential to deepening the impact of everything we do for our community. Our mission goes beyond raising awareness—it's about creating a strong, compassionate network where no one feels alone in their journey.





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