

# GRATITUDE REPORT JULY 1, 2022 - JUNE 30, 2023

FOUNDATION for all bleeding disorders

### EXECUTIVE DIRECTOR LETTER Kelly Waters, LCSW, MSW

### **VHF MISSION**

Dedicated to serving and supporting the needs of those impacted by a bleeding disorder through **education**, **advocacy** and **community**.



We asked, you answered, and we listened. In the Fall of 2022, we sent out a strategic plan survey to assess the social needs of the constituents we serve. In many cases, modern treatments have changed what it means to live with a bleeding disorder, also the COVID-19 pandemic has changed our lives in many ways. With this in mind, we asked questions about how new and emerging treatments may have had an impact on your life, if your bleeding disorder needs had changed, and if you had feedback on the future relevance of VHF.

Your answers were thoughtful and insightful and of great value to our strategic planning process. Go here to read about the trends and themes that emerged from this survey.

VHF will roll out the new strategic plan this next fiscal year (July 1, 2023 - June 30, 2024) and we are counting on you to work with us as we continue to strengthen the Virginia bleeding disorder community through education, advocacy, and community. We are excited to explore new program ideas and develop resources to address unmet needs based on your feedback. However, we can't do it alone. I hope you will consider taking an active role with VHF by participating in an event, donating during bleeding disorder awareness month, volunteering at an event, becoming part of a committee, applying for one of our scholarships, or ensuring your voice is heard at an advocacy event.

I am so honored to be working with VHF for another year and hope to partner with you as we move VHF into the future. Thank you for all that you do. I look forward to seeing you at one of our many upcoming events in 2024.

### CONTACT VHF Mailing Address: 9702 Gayton Rd., Suite 277, Richmond, VA 23238 Phone: 804-740-8643 Email: info@vahemophilia.org Website: vahemophilia.org



## BOARD OF DIRECTORS

Thank you 2022-2023 Board of Directors for donating your time and talents



PRESIDENT Kathy Mortimer VICE PRESIDENT Amy Walker TREASURER Donald G. Smith SECRETARY Tory Gilliam

DIRECTORS Debbie Baugher, Tahnee Causey, Murai Johnson, and Vivek Kshetrapal

The Board of Directors is the governing body of VHF. Board members meet periodically to discuss and vote on the affairs of the organization, to support the work of VHF, and to provide mission based leadership and strategic governance. For information about serving on the Board of Directors, contact Kelly Waters at kelly@vahemophilia.org.



### **CONTRIBUTIONS** Fiscal Year July 1, 2022 to June 30, 2023

During Fiscal Year 2022 - 2023, 90 cents of every dollar went toward serving Virginians affected by inherited bleeding disorders through education, advocacy, and community. Your gifts to VHF empower all that we do. **THANK YOU!** 

VHF is grateful to the dedicated supporters whose gifts make it possible for us to serve the inherited bleeding disorders community. Go here to view the list of individuals and organizations who have made a financial contribution in Fiscal Year 2022-2023. VHF is so grateful to you all. VHF has taken care to ensure the accuracy of this list. If, however, there should be an omission or error, we express our sincere regret and ask that you bring it to our attention by emailing info@vahemophilia.org or calling 804-740-8643.



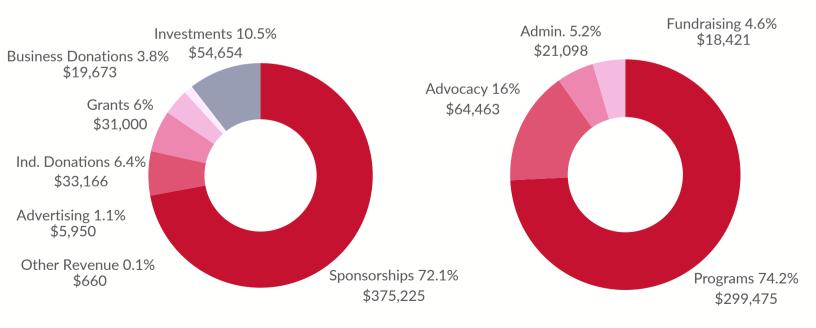
# REVENUE AND EXPENSE DETAILS

From Audited Financial Statements July 1, 2022 through June 30, 2023

### REVENUE

### NET ASSETS: \$1,709,508 Go here for additional financial details.

### **EXPENSES**



### WAYS TO GIVE

Thank you for your support of VHF and for helping us to serve the inherited bleeding disorders community in Virginia



### **LEGACY SOCIETY**

You can be a part of VHF's Legacy Society by remembering VHF in your estate plan or will. In doing so, you will directly impact the lives of people living with inherited bleeding disorders. You will also touch the lives of those who might someday be affected – your special gift to us will have a lasting impact. For more information call 804-740-8643 or email kelly@vahemophilia.org.

### **HOPE SOCIETY**

Make a monthly gift to be part of our Hope Society - a special group of people whose commitment to the ongoing operations and the future of VHF help give hope to those living with inherited bleeding disorders. Your monthly gift will make a difference - no matter the amount. Sign up for a monthly donation and see other ways to give back at vahemophilia.org. Hope Society Donors 2022-2023: Lamont Banks, Sarah Waniewski Eckhart, Therese Ihrig, Jeff and Christine Krecek, Donald and Beth Smith, Steve and Sarahbeth Spasojevich, Kelly Waters, and Barbara Wheatley.

### **CHC: CREATING HEALTHIER COMMUNITIES**

VHF is a member of CHC: Creating Healthier Communities workplace giving campaign in Virginia. To donate to VHF with the state employee campaign (Local Government and Schools United Way), direct your donation to #06043.

Thank you to the 2022 United Way South Hampton Roads CHC donors: Mandy Baker, David and Heather Brinkley, Taryn Denham, Shelly Evans, and Kamala Lannetti. Thank you to the 2022 United Way Workplace Giving Donors: Wayne Grindle (National Capital Area) and Marty and Natalie Kaszubowski (South Hampton Roads)



#### **UNITE FOR BLEEDING DISORDERS**

The VHF community came together on October 16th. 2022, in support of our Unite for Bleeding Disorders Walk. Thank you to everyone who contributed to the success of this event. Because of YOU we surpassed our goal and raised an amazing \$38,889! A big congratulations to our Top Team fundraising winners - 1st place: Star City Bleeders with top fundraisers Colin Davidson and Matthew Lee, 2nd place: Severe With No FEAR! with top fundraiser Zack Bordone, 3rd place: Team Lukasz with top fundraiser Monika Eiden and, 4th place: Team Stone with top fundraiser George Stone. Amazing job to all our Factor Club recipients, who each individually raised over \$500 for the walk: Zack Bordone, Cody Davidson, Monika Eiden, Vivek Kshetrapal, Matthew Lee, Don Smith, and George Stone. Go here to see photos.



#### BLEEDING DISORDERS AWARENESS SEASON OF GIVING

On March 1st, 2023, in honor of Bleeding Disorder Awareness Month (BDAM,) we kicked off our season of giving and wrapped-up with over 85 friends, family members, and supporters on May 7th at the BDAM Education Celebration at the Virginia Zoo! Go here to see photos. It was heartwarming to see so many of you at our BDAM events at Topgolf in Richmond and Virginia Beach, at educational dinners throughout the state, at the World Hemophilia Day program, and at our Annual Meeting in Norfolk. Because of your participation, your donations, your Facebook fundraisers, your sponsorships, and your t-shirt purchases, we were able to raise \$62,828 during our campaign period March 1st to May 7th! We look forward to starting the celebration and awareness raising season again in March 2024. Stay tuned!

### **EDUCATION** Your gifts have an impact on the lives of those affected by bleeding disorders

The Lyman Fisher Scholarship was established to honor Dr. Lyman Fisher, a teacher, researcher, and clinician in hemostasis. For many years, he directed the adult hemophilia program in Virginia. Because of your generous donations, two deserving members of the bleeding disorders community received a Lyman Fisher Scholarship in the amount of \$2,000 in the Spring of 2023.

**Soren Johnson** is a senior at Old Dominion University and is majoring in fashion merchandise. Soren has been an active member of the VHF community most of his life, attending Camp Youngblood, volunteering as a teen leader, participating in the Gettin' in the Game Junior National Championship (JNC), and traveling to the National Bleeding Disorders Conference in 2016 to receive a teen impact award. "I would like to thank the VHF Scholarship Committee for rewarding me with this scholarship. This scholarship will take me to places I have never been to before and allow me to take my education to heights I never knew I could reach. Thank you for showing that you believe in me and my future. "

Jackson Spasojevich is a student at James Madison University and is studying Modern Foreign Languages with a focus on French. Jackson has been an active VHF volunteer helping with numerous events and has gone to the Capitol on multiple occasions to advocate for legislation that is important to the bleeding disorders community. "Advocacy, both for my own needs and the needs of others, is vital to the functioning of our society today. Everyone has obligations to their communities, whether they actually fulfill them or not, but I know that in my life, I will never forget the support and care that I have received from VHF and will never stop trying to repay it in any way I can."





The Terry Lamb Enrichment Scholarship can be used for any program that enhances one's self-esteem, overall health, leadership skills, areas of interest, development of life skills, and volunteerism. Program examples include Camp, National Meetings, Educational Programs, Life Skill Classes, Fitness Activities, etc. In November of 2022, Matt Berg applied for the Terry Lamb Scholarship to help offset the costs of one on one personal training. *"I would highly encourage everyone, hemophiliac or not, to see a good dietician and get into an exercise program. I cannot even describe how good I felt losing 60 lbs. I felt like I had a new lease on life, and I paused considering getting my ankles done. Things like this scholarship do more than keep Terry alive for those of us who knew him, but also help live life as Jim White puts it "really, truly fit"."* Go here to read the rest of Matt's inspirational story.



### **ADVOCACY** VHF continues to advocate on the behalf of those with bleeding disorders

VHF continues to advocate on behalf of those with inherited bleeding disorders, and we encourage you to join us in this effort, if you would like to learn more about how to get involved email info@vahemophilia.org.

### IN VHF's FISCAL YEAR 2022 - 2023

VHF advocate, Steve Spasojevich, attended and shared his family's story at Rep. Abigail Spanberger's Inflation Reduction Act Press Conference (August 25, 2022.) "I was honored to represent VHF, and all members of the bleeding disorder community, at the press conference on the Inflation Reduction Act hosted by Representative Spanberger. I shared how vital the extensions of protections in the Affordable Care Act are to members of the community in order to access the healthcare needed to survive. It was a great experience, and I am so glad that the voices of the bleeding disorder community are being heard."

6 VHF members attended the Hemophilia Foundation of America (HFA) Fly-in (September 17-19, 2022), participated in education and visited legislators in DC advocating for HR 5801 – All Copays Count and encouraged legislators to find a path for healthcare for those 2.2 million Americans who are in a coverage gap in the states that have not expanded Medicaid. VHF constituent and volunteer Sam Petty had this to say "At the HFA Fly-In I had the pleasure of advocating for the Bleeding Disorder Community, of which I am a part. I learned of a few predatory practices of Insurance Companies and how we can go about protecting ourselves from them. I stood in a room with mothers and fathers of patients, as well as fellow patients testifying of the struggles we face and the actions we need from our representatives. The power of the words said in these meetings was immense. I'd like to thank HFA for this opportunity to represent my community. Thank you."

VHF held numerous advocacy educational opportunities in partnership with the Hemophilia Association of the Capital Area (HACA), which included the Advocacy Stakeholder and Education Meeting (November 9, 2022), 4 weekly meetings during the 2023 General Assembly, a General Assembly re-cap, and Advocacy Education Meetings (October 20, 2022 and January 24, 2023.)

Virginia bleeding disorder advocates along with nearly 400 representatives from across the country joined with the National Bleeding Disorders Foundation (NBDF, formerly NHF) for Washington Days (March 8-10, 2023) to make our voices heard. VHF is pleased to offer travel grants to attend national meetings and this past fiscal year we were able to assist Pat DeRatto with her trip to Washinton Days. Go here to read more about her experience.

VHF attended meetings including - Virginia Bleeding Disorder Program (VBDP) Annual Stakeholder meeting, Healthcare for All Virginians Coalition (HAV) meetings, and Virginia Quality Healthcare Network (VQHN) Touchpoint Healthcare events. VHF also worked closely with Virginia's Hemophilia Treatment Center's (HTC's), HFA, and NBDF, to ensure information is shared on Medicaid, Medicaid unwinding, open enrollment, etc., as well as to continously advocate for access to comprehensive and affordable health care.









### COMMUNITY

When you make a donation to VHF, you are supporting programs and services that directly impact individuals living with inherited bleeding disorders.

VHF's programs and services help meet the needs and challenges facing the inherited bleeding disorder community. Since bleeding disorders affect not only an individual, but also their entire family, VHF offers programs and services for every member of the family such as:

- Over 30 education sessions during this past fiscal year (both in-person and virtual) that included programs such as Family Day Camp, Medical Symposium at Great Wolf Lodge, Annual Meeting, and Women's Day Out.
- An e-newsletter sent to over 1,000 people each month with chapter updates and timely resources on topics like financial assistance, emerging therapies, and mental health and shareable resources for schools and healthcare providers.
- Financial Assistance Program that provides financial support, based on availability of funding, to help pay for expenses incurred in the care, treatment, or prevention of an inherited bleeding disorder. This fiscal year VHF has been able to offer over \$4,000 in financial assistance to benefit individuals and/or families in covering transportation to clinic, gas cards, rent, utility bills, and medical bills.

"I feel a sense of belonging participating in Family Camp. It is a special place where families can have fun together and share stories, resources, and experiences with other families impacted by hemophilia, building a strong community of support at camp and in our everyday lives." ~ Eileen Bunn, VHF Community Member

"It was so evident to me how much love and work was put into making such a fun and educational community event! Thank you so much for all your hard work! And I wanted to tell you that the kids' program was great, too! Malcolm and Kaylee showed me their resilience coloring books, and what a fantastic educational tool that is!! Malcolm told his homeschool co-op class on Monday about his weekend at the program at Great Wolf Lodge, and he was able to tell them all about his hemophilia. Seeing how comfortable and confident he was made my heart so happy." ~ Beth Sterner, VHF Community Member



### VHF 2024 CALENDAR

#### Changes to the calendar are possible, go here to view the most up to date calendar.

#### JANUARY

General Assembly Weekly Check-in (every Tuesday @ 4:30 pm during the 2024 session) 5th - National Meeting Travel Grant Application Deadline (HFA Symposium & NBDF Washington Days) 18th - VHF/HACA Camp Youngblood Information Session (Virtual) 29th - Advocacy Education Meeting (Richmond)

#### **FEBRUARY**

General Assembly Weekly Check-in (every Tuesday @ 4:30 pm during the 2024 session) 10th - Women's Retreat (TBD)

### MARCH BLEEDING DISORDERS AWARENESS MONTH

2nd - Community Education - BD Month Kick-off (Topgolf, Virginia Beach)
3rd - Community Education - BD Month Kick-off (Topgolf, Richmond)
6th - 8th - NBDF Washington Days (Washington DC)
14th - Education Dinner (TBD)
21st- Education Dinner (TBD)
28th - Education Dinner (TBD)
29th - Lyman Fisher Scholarship Application Deadline

### APRIL

10th - Camp Youngblood Application Deadline

11th - 14th - HFA Symposium (Indianapolis, IN)

17th - World Hemophilia Day

20th - Annual Education Meeting (Natural Bridge)

21st - Bleeding Disorders Awareness Education & Celebration (Natural Bridge)

### MAY

18th - New Family Support & Education (TBD)

### JUNE

3rd - National Meeting Travel Grant Application Deadline (NBDF BDC) 29th – Community Event (TBD)

### JULY

14th - 19th - Camp Youngblood at Camp Holiday Trails (Charlottesville) 27th - Community Event (TBD)

AUGUST 17th - Community Event (TBD)

### **SEPTEMBER**

12th - 14th - NBDF Bleeding Disorders Conference (Atlanta, GA) 28th – Medical Symposium at Great Wolf Lodge (Williamsburg)

OCTOBER TBD

NOVEMBER 2nd – Adult Retreat (TBD) 7th - HACA/VHF Advocacy Stakeholder & Education Meeting (TBD)

**DECEMBER** 7th - Winter Gatherings (TBD)