

JULY 1, 2021 - JUNE 30, 2022 GRATITUDE REPORT



EXECUTIVE DIRECTOR STATEMENT

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.



It is hard to believe that we have wrapped up another fiscal year filled with transition as we shifted back to in-person events and learned more about all the new bleeding disorder treatment developments coming our way. Yet, what remains constant is the support, strength, and energy of the Virginia Hemophilia Foundation (VHF) community.

VHF certainly had a lot to celebrate this past fiscal year including receiving all six Chapter of Excellence awards from the National Hemophilia Foundation (NHF) and the Member Organization Spotlight Award at this year's Hemophilia Federation of America's (HFA's) Symposium. VHF also continued the successful advocacy education partnership with the Hemophilia Association of the Capital Area (HACA) that includes virtual advocacy chats throughout the year, weekly check-ins during the General Assembly session, and an annual advocacy stakeholder meeting in the fall. Furthermore, there was a record number of Lyman Fisher Scholarships awarded, financial assistance to individuals and/or families in need were provided, involvement in national research activities increased, and

over thirty educational and community building programs were offered.

I am excited to work with you, VHF's amazing community members, donors, supporters, and volunteers, during this rapidly evolving time for the inherited bleeding disorder community. As we move forward with assessing the environment, identifying strategic objectives, and figuring out next steps, we welcome your input! There will be formal opportunities for you to participate through surveys, focus groups, and/or individual meetings. However, don't hesitate to reach out at any time. The best part of my job is personally connecting with you.

Thank you for all that you do and look forward to seeing you at one of our many upcoming events in 2023!

CONTACT VHF

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BOARD OF DIRECTORS

Thank you 2021-2022 Board of Directors for donating your time and talents



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

DIRECTORS Debbie Baugher, Kate Breitbeil, Murai Johnson, Vivek Kshetrapal, Sarahbeth Spasojevich, Sarah Waniewski, Megan Whiteaker

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, 2021 to June 30, 2022

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 2021–2022. VHF is so grateful to you all. If we inadvertently omitted or misspelled your name, please accept our apologies.

When you make a donation to VHF, you are supporting programs and services throughout the year that directly impact individuals living with inherited bleeding disorders and their immediate family members.

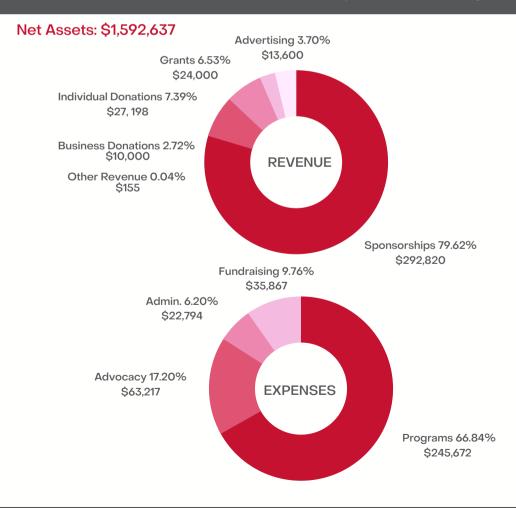
VHF continued to build community and offer support through programs, such as: an e-newsletter sent to over 1,000 people each month with chapter updates and timely resources on topics like financial assistance, emerging therapies, and mental health. Over 30 education sessions during this past fiscal year, July 1, 2021 – June 30, 2022 (both in-person and virtual) that included popular programs such as Pop-up Day Camp, Virtual Craft Nights, Advocacy Chats, Women's Day Out, and more!

This fiscal year VHF has been able to offer over \$2,400 in financial assistance to benefit individuals and/or families in covering prescription copays, transportation to clinic, gas cards, rent, utility bills, and medical bills.

For additional financial details visit: https://vahemophilia.org/about/annual-reports-strategic-documents/

REVENUE AND EXPENSE DETAILS

From Audited Financial Statements July 1, 2021 through June 30, 2022

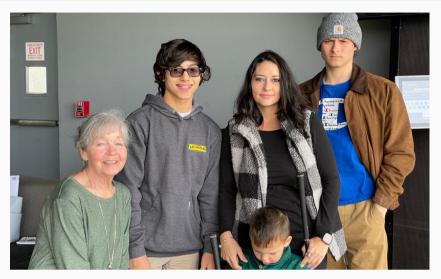


During Fiscal Year 2021 - 2022, 84 cents of every dollar went to serving the inherited bleeding disorders community!



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 <u>Legacy Society</u> 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 <u>kelly@vahemophilia.org</u>.

HOPE SOCIETY

Make a monthly gift to be part of our <u>Hope Society</u> – 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 2021-2022: **Therese Ihrig, Jeff and Christine Krecek, Donald and Beth Smith, Steve and Sarahbeth Spasojevich, Kelly Waters, Sarah Waniewski, and Barbara Wheatley.**

CHC: CREATING HEALTHIER COMMUNITIES'

VHF is a member of CHC: Creating Healthier Communities' workplace giving campaign in Virginia. Thank you to the 2021 Combined Federal Campaign (CFC) donors **Taryn Marie Denham and Kamala Lannetti.** We would also like to thank **Mandy Baker, Michael Baker, Marty & Natalie Kaszubowski, and Charles White** for their workplace giving in the 2021/22 United Way South Hampton Roads (SHR) Corporate Workplace Giving Campaign.

To donate to VHF with the state employee campaign (Local Government and Schools United Way), direct your donation to #06043.

Unite For Bleeding Disorders Walk

The VHF community came together on October 17th, 2021, in support of our Virtual Unite for Bleeding Disorders Walk. Thank you to everyone who contributed to the success of this event! Whether you fundraised, sponsored, donated, or shared your story with your friends and family, your hard work paid off and made a BIG impact. Together with sponsorship and matching gifts, you raised an amazing \$33,243 – we are so grateful!

Our top teams this year were: Team Lukasz Marian's All Stars Spazvengers

Amazing job to all our Factor Club recipients, who each individually raised over \$500 for the walk:
Zack Bordone
Monika Eiden

Fred Harmeling Vivek Kshetrapal Sarahbeth Spasojevich George Stone



EDUCATION

Congratulations to our Lyman Fisher Scholarship Winners



The <u>Lyman Fisher Scholarship</u> 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.

During the 2022 March Bleeding Disorders Awareness Month Campaign, you helped us raise over \$2,800 (our goal was \$2,000!). The success of this campaign was one of the reasons that the VHF Lyman Fisher scholarship committee voted to extend the scholarship award from two to six!

Seth Boucher will be entering his sophomore year at Old Dominion University with the plan of graduating with a Master's in Humanities and Bachelor of Science in Philosophy. He volunteers at school and in his community. Seth is an active leader in Boy Scouts and even earned the Eagle rank in three years.

Paxton Calder is a member of numerous honor societies, an active volunteer with many organizations, and has received awards and recognition in science and English. She will be attending the University of Richmond. She plans to study biology and communication/language with the hopes of working towards a doctorate in some form of scientific research, using her passion for STEM and exploration to make a difference in the world.

Olivia Laubscher is entering her Junior year at University of South Florida with a degree in Architecture, which she is passionate about and can see herself doing in the future. She enjoys spending time with kids, volunteering at her church, reading, painting, and spending time with her family. Most recently she has joined a sorority, which has been allowed her to meet some great friends and expand her opportunities for philanthropy and volunteer work.

Jackson Spasojevich enjoys coding, collecting rare Star Wars toys, biking, and drumming, and hopes to join the drumline in college. He has been an active volunteer with Meals on Wheels and the Science Museum, as well as with VHF by helping with setup and take-down for events and has gone to the Capitol on multiple occasions to advocate for legislation that is important to the bleeding disorders community. He will be attending James Madison University and plans to double-major in French and Integrated Science and Technology.

Levi Walker is passionate about robotics, computer programming, and music. He serves as the robotics team captain and control systems team lead for his FIRST Robotics Team and has earned the Presidential Volunteer Service Award with his work teaching others about engineering and robotics. He leads vocal worship at Peninsula Community Chapel Student Ministries. He plans to pursue a degree in Computational Modeling and Data Analytics at Virginia Tech.

Wade Wickline graduated from Staunton River High School. He is continuing to take Welding classes at Central Virginia Community College in Lynchburg. Wade will also be attending Virginia Western Community College in Roanoke in the Mechatronics Program with a focus in design. He enjoys working part time at a local auto shop and helping others with anything mechanical or welding related. And has enjoyed volunteering at a local Humane Society.

ADVOCACY

Join your bleeding disorders community - your voice matters!

VHF continues to advocate on the 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 2021 - 2022 -

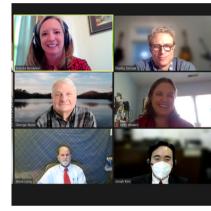
We strengthened our longstanding advocacy education partnership with HACA by offering virtual and in-person advocacy educational opportunities throughout the year, weekly check-ins during the General Assembly session, and an annual education and advocacy stakeholders meeting in the fall.

We continued our membership in the Fair Health Virginia Coalition and Health Care for All Virginians Coalition (HAV) and worked closely with HTC's, NHF, HFA, other health organizations, and legislators to address health access issues.

We attended NHF's virtual Washington Days, Insurance Reimbursement Conference, and most recently the Advanced Advocacy Training in Washington DC, where topics focused on health access and insurance trends and barriers to care, Medicaid updates and the importance of regulatory advocacy.

And we remained strong advocates to ensure all <u>All CoPays Count</u> and that the <u>Commonwealth Health Reinsurance Program (CHRP)</u> is established.

File



NATIONAL MEETINGS

A chance to share ideas and learn something new

Seven VHF constituents headed to Washington, DC on April 8th - 9th for the NHF Building the National Research Blueprint (NRB) - SME Workshop. VHF attendees included women who had participated in the NHF State of the Science Research Summit, as well as board members. It was a great opportunity to learn more about NHF's work on developing a research blueprint to move research forward into the next decade and how to engage community members in those discussions.

VHF is pleased to offer <u>travel grants to attend national meetings</u> and this past fiscal year we were able to assist Debbie Baugher with her airline fare to the HFA Symposium in San Antonio, TX April 20–23, 2022. <u>Go here to read more about her experience.</u>





COMMUNITY

So many things to celebrate in the bleeding disorders community

NURSE OF THE YEAR On August 28th, 2021 deserving members of the bleeding disorders community were honored and celebrated during the NHF 2021 Bleeding Disorders Conference (BDC) Awards Ceremony! The Nurse of the Year, chosen by the NHF Nursing Working Group, was our very own Margaret Sennett, PNP, University of Virginia (UVA) Division of Pediatric Hematology & Oncology, Senior Nurse Practitioner and Coordinator of Pediatric Bleeding/Clotting Disorders Program! Congratulations Margy!

TEEN IMPACT AWARD WINNERS The Teen Impact Awards are produced by Believe Limited and recognizes teens in the bleeding disorders community who are making a positive impact. Hosted by community advocate Patrick James Lynch and Save One Life CEO and world class mountaineer Chris Bombardier, the Awards are held annually on the opening night of the NHF BDC. The 2021 virtual event honored teens from across the nation and two of those teens honored were from Virginia! We are so proud of these two inspirational teens – **congratulations Anthony and Elsa!**

TEAM IMPACT PROGRAM VHF community member Brandon Nowlan signed a national letter of intent with Old Dominion University (ODU) Athletics men's basketball, joining the squad for the 2021–2022 season. The ODU Monarchs learned that Brandon has hemophilia through assistant Kieran Donohue, who is familiar with **Team Impact**, an organization that links children battling illness with sports teams in order to make a positive difference in their lives. Such a great way to spread awareness of bleeding disorders – **so proud of you Brandon!**

NEW DOCTOR CHKD-HTC was excited to announce that their long-awaited addition to the Bleeding Disorder team has arrived! He comes with a passion for all things bleeding, clotting, and Hampton Roads. **Dr. Kevin Todd** did his residency at CHKD and just completed his Pediatric Hematology/Oncology fellowship at Cincinnati Children's Hospital. His fellowship training focused on bleeding and clotting disorders and they are very excited to have him on their team!

MEMBER AWARD Congratulations to VHF member and HFA Board Member, George Stone, for receiving the "It Takes A Village Award" at the 2022 HFA Symposium! The Virginia bleeding disorders community is lucky to have you as a volunteer and advocate!

TERRY LAMB ENRICHMENT SCHOLARSHIP The VHF Terry Lamb

Enrichment Scholarship was awarded to Soren Johnson in Spring of 2022 to help assist on a college trip to NYC in conjunction with his college major. Gohere to read about his inspirational trip!















VOLUNTEER OF THE YEAR PROGRAM

Join us in congratulating the 2021 VHF Volunteer(s) of the Year: George Stone and Monika Eiden!

Each year, VHF recognizes at least three volunteers for their outstanding commitment to the mission of VHF. These individuals are nominated for the Volunteer of the Year Award, reviewed by our Board of Directors' Executive Committee, and the winner is recognized in December of that calendar year. VHF is proud to announce our 2021 Volunteer of the Year is George Stone. In a new category, we are also recognizing our 2021 Unite Walk Volunteer of the Year, Monika Eiden. Both George and Monika have demonstrated outstanding commitment to the mission of VHF this year, going above and beyond in their volunteer commitments and contributing in meaningful ways. Congratulations to both of you for an amazing year!

Below, check out all of our 2021 nominees and help us celebrate their contributions! Thank you so much to all of our volunteers for their time, their talent, and their dedication to the mission of VHF. Please note the this program was put on pause in 2022 but we hope to bring it back in some capacity in 2023.

Monika Eiden

Monika is a community member and active volunteer with the Chapter who has been involved with VHF in a leadership role for over eight years and constantly finds new ways to contribute to the success of the organization with a strong focus on the needs of the community. Monika has led a strong fundraising effort for the Unite for Bleeding Disorders Walk in honor of her brother Lukasz and is consistently in the top teams for fundraising and serves on the Unite Walk Committee. "My involvement with Virginia Hemophilia Foundation began in 2012 almost exactly 4 years after my brother Lukasz, who had severe Hemophilia A, died from a brain bleed (third in his lifetime). He was 23 years old. His death shattered my world and left a big hole in my heart. Once I went through all stages of grief, I wanted to do something meaningful to honor Lukasz's memory and carry on his legacy."

Ann Kendall

Ann has worked closely with VHF as the Advocacy Committee Chair – successfully helping to prepare numerous advocacy grants, planning virtual advocacy chats, serving as a speaker and facilitator during advocacy presentations, and ensuring grant and advocacy strategic goals are met. She consistently attends VHF events to lend support and reviews advocacy requests for local and federal organizations to ensure they match VHF's mission.

Don Smith

Don, Treasurer on the Board of Directors, currently serves on the Executive, Governance, Finance and Development Committees. He says of volunteering – "I volunteer for VHF to help enhance the lives of others living with bleeding disorders. VHF is an organization that truly takes to heart their mission to improve the lives of those in the bleeding disorders community. The wonderful staff achieve amazing results with the help of dedicated volunteers. Everyone I've met who is involved with or touched by VHF are kind, passionate, and fun people to be around! I am blessed to be associated with them."

George Stone

George has been an active constituent with VHF for years, but since joining our Volunteer Program he has truly given back in generous and consistent ways—showing an aptitude for many facets of nonprofit volunteer leadership. He has been willing to show up and give back on several different committees and bring both his depth of experience as a community member and as a retired professional to these roles. He and his wife Cyndi have also been generous active donors to the organization.









VHF 2023 CALENDAR

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

January

17th - General Assembly Weekly Check-in (VIRTUAL)

19th - Education Dinner (Virginia Beach)

24th - Advocacy Education Meeting (VIRTUAL)

31st - General Assembly Weekly Check-in (VIRTUAL)

February

7th - General Assembly Weekly Check-in (VIRTUAL)

11th - Women's Day Out (Williamsburg)

14th - General Assembly Weekly Check-in (VIRTUAL)

21st - General Assembly Weekly Check-in (VIRTUAL)

March BLEEDING DISORDERS AWARENESS MONTH

4th - Community Education - BD Month Kick-off (Topgolf)

5th – Community Education – BD Month Kick-off (Topgolf)

8th - 10th - NHF Washington Days (Washington DC)

<u> 10th – Lyman Fisher Scholarship Application Deadline</u>

16th - Education Dinner (Roanoke)

23rd - Education Dinner (TBD)

30th - Education Dinner (Richmond)

April

13th - 16th - HFA Symposium (Orlando, FL)

17th - World Hemophilia Day

May

6th - Annual Education Meeting (Norfolk)

7th - Bleeding Disorders Awareness Education & Celebration (Norfolk)

20th - New Family Support & Education (Richmond)

June

4th - Community Event (West)

24th - Community Event (Virginia Beach)

July

16th – 21st - Camp Youngblood at Camp Holiday Trails (Charlottesville)

29th - Community Event (Richmond)

August

17th -19th - NHF Bleeding Disorders Conference (Washington DC)

September

TBD - Education Dinner (TBD)

30th - Medical Symposium at Great Wolf Lodge (Williamsburg)

October

TBD - Education Dinner (TBD)

November

4th - 5th - Adult Retreat (Staunton)

9th - HACA/VHF Advocacy Stakeholder & Education Meeting (VIRTUAL)

December

9th - Winter Gatherings (TBD)