

VIRGINIA
HEMOPHILIA
FOUNDATION
for all bleeding disorders

GRATITUDE REPORT
2019-2020

EXECUTIVE DIRECTOR STATEMENT

Kelly Waters, LCSW, MSW

Dear Friends of VHF,

Each year we present to you, our valued community members, supporters, and advocates, our "Gratitude Report". This report is a summation of a fiscal year's worth of programs, activities, and organizational milestones, all in deep gratitude to everyone who makes it all possible. In many ways, the Fiscal Year (FY) 2019-2020 issue will be no different than in the past. You will see recognition of individual and organization donors as well as features on programs and services connected to our mission of serving those living with an inherited bleeding disorder through education, advocacy and community.

However, this past year is unlike any other year that we have experienced. As VHF entered the fiscal year in July of 2019, much was as it had been in the past. Camp Youngblood at Camp Holiday Trails was just about to begin (you can see from the photos on the cover that we were off to a great start)! We were beginning a robust revamping of our Volunteer Management Program, starting with our first ever award for Volunteer of the Year announced later that year in December 2019.



We also enjoyed a lot of splashing around in the puddles at our rain-filled second annual Unite for Bleeding Disorders Walk, and our first Men's Retreat in Charlottesville brought our community members closer together.

As we entered 2020 and the second half of our Fiscal Year, things were, well, different. The tradition of "Richmond Days," VHF's legislative day at the Virginia State Capitol was disrupted when Governor Northam declared a state of emergency, due to potential civil unrest at the Virginia State Capital, at the same time as our traditional day of advocacy on Martin Luther King, Jr. Day. Our second annual Medical Symposium was held in March and was the last time we saw you face-to-face as the country soon closed for safety during the worst global pandemic since the 1918 flu.

Since that time, the word of the day, week, month and year has been "pivot." VHF staff, along with our respected industry and community partners, adapted many of our programs to virtual and strived to bring you, our amazing community, together through the world of Zoom - by offering advocacy chats, a support group for new parents, educational meetings, and our statewide annual meeting. The summer was filled with turmoil and change with the pandemic and the global movement toward racial equity and equality. Although we ended the fiscal year on June 30th in a much different place and space than we could have ever imagined, we remain committed to serving the inherited bleeding disorders community.

We are hopeful, and we hope you are too, for what 2021 will bring to VHF and to our community. We will continue to fight alongside you for access to affordable health care. Your resilience, creativity, and commitment to the bleeding disorders community through the past few months has been inspiring to see and we are grateful to have been a part of it. We are so grateful for the continued service of our wonderful volunteers, the donations that keep us a strong, and the continued love of community that we see from each person who attends an event, participates in a webinar or walks in unity with VHF at the Unite Walk. We care and are here for you every step of this journey. With a new year comes new possibilities and opportunities. And we couldn't be more grateful. Thank you!

BOARD OF DIRECTORS

July 1, 2019 - June 30, 2020

President Sarahbeth Spasojevich

Vice President Kathy Mortimer

Treasurer Jean Parnell

Secretary Daniel Warren

Directors

Kate Breitbeil

Monika Eiden

Tory Gilliam

Murai Johnson



Thank you VHF Board of Directors for donating your time and talents! 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.

MISSION

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

VISION

Become the recognized voice and go-to resource for those impacted by a bleeding disorder.

Thank you volunteers!

The VHF Volunteer Program improves the lives of those living with bleeding disorders through supporting development efforts, spreading community awareness, championing advocacy efforts and assisting with programs.

To learn more about volunteering, contact Megan Schowengerdt at megan@vahemophilia.org.



PROGRAM HIGHLIGHTS

From July 1, 2019 to June 30, 2020, VHF served approximately 200 households and offered 20 events both in-person and virtual - here are some of the highlights!

July 7th – 12th We started the fiscal year with almost 60 campers, ages 7 - 17, attending a week of summer camp at Camp Youngblood at Camp Holiday Trails in Charlottesville, thanks to VHF and in partnership with the Hemophilia Association of the Capital Area (HACA). (See front cover for photos)

August 9th 15 teens from throughout the state enjoyed a fun and educational Teen Retreat Weekend in Virginia Beach, in partnership with HACA. (Photo top right)

September 14th Over 80 community members gathered in Norfolk for an Industry Symposium and an exclusive screening of Bombardier Blood at Nauticus Museum. This film chronicled Chris Bombardier and his mission to become the first person with severe hemophilia to climb the Seven Summits, the highest mountain on each continent. (See back page for photos)

October 20th It was a rainy fall day, but we gathered and celebrated success together despite the weather and had a fantastic time at our second annual Unite for Bleeding Disorders Walk in Richmond. Overall, individual donors raised over \$17,000 - this is a 23% increase in fundraising from 2018's walk! You exceeded our goal of \$16,000 from participants and we are so very grateful. (Photo top middle right)

November 9th New this year, in partnership with HACA, we offered a Men's Retreat at Wintergreen Resort! Participants enjoyed education and time with other men who encounter similar challenges. All who attended agreed this retreat will now be something for our members to look forward to! (Photo bottom middle right)

December 7th VHF Winter Gatherings were held at Dave & Busters in both Richmond & Virginia Beach. Members celebrated the holiday season with education, games and plenty of time to connect with family and friends! (photo bottom right)



February 8th Our rejuvenating Women's Retreat weekend in Williamsburg was filled with female focused educational programming, and time for community building for women whose lives are impacted by a bleeding disorder. (photo top right)

February 26th - 28th National Hemophilia Foundation (NHF) Washington Days was an opportunity for VHF constituents to travel to DC for a chance to meet with the offices of our Virginia Senators and House of Representatives, and share their stories and advocate in support of federal issues important to the bleeding disorders community. (photo middle top right)

March 7th The second annual Medical Symposium in Richmond provided consumers with the knowledge needed to discuss new and current treatment options, plus have conversations around product safety and how to make tough decisions about medical care. This program also recognized March as Bleeding Disorders Awareness Month. (photo middle bottom right)

March 8th VHF's last in-person community event was held at Top Golf in Richmond. Members had the opportunity to spend time with an on-site golf pro, learning tips on how to warm up and how to safely practice their golf swing. Golf is a great sport and is recommended for those with bleeding disorders as a good physical activity that the whole family can enjoy! (photo bottom right)

May 21st In partnership with our Virginia Hemophilia Treatment Centers (HTC) Social Workers, VHF designed our first virtual First Step support group. We are so grateful to the many mentor families that came together to volunteer their time to this program, and showed their support of families of infants and young children with hemophilia and other inherited bleeding disorders with community connection and education.

June 4th - 20th This year's Annual Education Meeting went virtual! We were able to take one of our largest events of the year and spread it over the course of the month of June. VHF staff, with the help of our supportive industry partners, offered a high level of virtual education, bringing experts from around the state and country on such topics as: Maintaining Joint Health Through Exercise, Beyond Trough Levels: Taking A Closer Look at How to Evaluate Hemophilia B, Wonderful Women of Bleeding, Mental Health 101, and a session just for teens - The Power of Empowerment. We ended it all with an enjoyable community event - a virtual "camp fire" with our friends from Camp Holiday Trails!



WHERE THE MONEY GOES

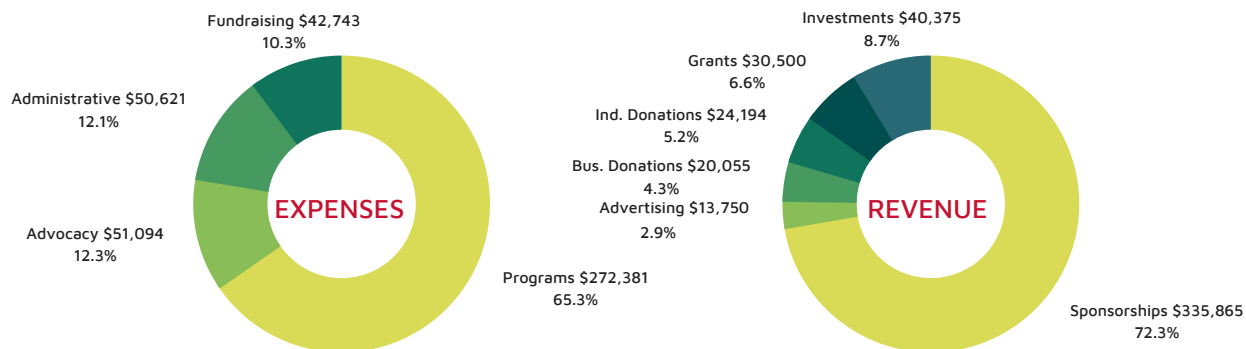
From Audited Financial Statements Year Ended June 30, 2020

IN FISCAL YEAR 2019 - 2020, 78 CENTS OF EVERY DOLLAR WENT TO SERVING THE INHERITED BLEEDING DISORDERS COMMUNITY!

When you make a donation to VHF, you are supporting a myriad of programs and services throughout the year that directly impact individuals living with bleeding disorders and their immediate family members. Educational opportunities include an annual education meeting and annual medical symposium, as well as relevant and timely information delivered via our e-newsletter and social media. VHF also participates in national and federal advocacy initiatives, such as Advocacy Training and Richmond Days and the National Hemophilia Foundation's (NHF) Washington Days.

VHF builds community by strengthening relationships and offering support including our valuable financial assistance program, scholarships and Camp Youngblood, a week-long summer camp for kids and teens. Additional financial details can be found at connectva.org/groups/virginia-hemophilia-foundation/financials.

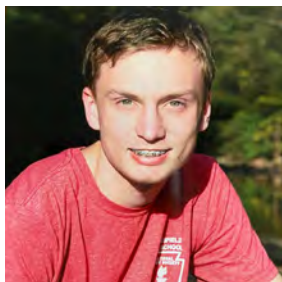
VHF Net Assets - \$1,383,659



LYMAN FISHER SCHOLARSHIP

Congratulations to 2020 recipients: Noah Boucher and Emma Kaiser!

The VHF Lyman Fisher Scholarship was established to honor Dr. Lyman Fisher: a teacher, researcher, and clinician in hemostasis who for many years directed the adult hemophilia program in Virginia. This scholarship provides a one-year award in the amount of \$2,000 for a full academic year.



Noah Boucher "I hope to graduate from Tidewater Community College (TCC) in two years with an Associate's Degree in General Engineering. This scholarship will allow me to graduate with low or zero cost out of pocket. In addition to all the great work you've done for my family and the hemophilia community, I am so honored that I was selected to receive this scholarship. I will work hard at TCC to honor your choice to select me as the recipient of this scholarship."



Emma Kaiser "I am an upcoming junior at George Mason University studying Criminology with a concentration in Law and Society. My college education is very important to me and will allow me to go to law school after receiving my bachelor's degree. Receiving the Lyman Fisher scholarship will help me further my education without as much financial worry. The scholarship will also help ensure that I can further my education and receive my degree. I am very thankful to be able to receive this scholarship."

ADVOCACY REPORT

Becky Bowers-Lanier, VHF/HACA
Advocacy Consultant

Finding and keeping our voice with our health care providers and policymakers is a responsibility that belongs to all of us.

We each have a role to play to make sure that members of our community have access to the full range of products that keep them healthy and living meaningful, productive lives. While the responsibility falls to all of us, we are blessed to have community members who step up to the plate regularly in advocating for all of us. Thanks especially go to our VHF staff, to our advocacy committee headed by Ann Kendall and Krista Davidson, and to the support we receive from Hemophilia Foundation America (HFA) and National Hemophilia Foundation (NHF) policy staff!

For the past several months, we've had to re-evaluate how we advocate, moving into the virtual space for just about all of our work. That means we're becoming experts (or quasi-experts) on Zoom and similar platforms, remembering to "unmute" ourselves and "turn on our cameras" on a regular basis.

Before these changes, in November 2019 we held our inherited bleeding disorders stakeholder meeting, highlighted by presentations from Marvin Figueroa, Deputy Secretary of Virginia Health and Human Resources; Jan Kuhn, Coordinator of the

Virginia Bleeding Disorders Program; Nathan Schaefer, VP of Public Policy at NHF; and Miriam Goldstein, Director of Policy at HFA.

The various reflections of state and national policy trends and initiatives helped to inform our advocacy work going into the 2020 General Assembly (GA) session and the ongoing work of Congress. At the beginning of the GA session on Martin Luther King, Jr. Day (MLK Day), we typically hold our Advocacy Training and Richmond Days in partnership with HACA, where we visit with our state legislators. MLK Day is usually the largest lobbying day at the GA with many interest groups coming to Richmond. This year, we cancelled for the first time in over a decade! The reason for the cancellation was a larger-than-expected gathering of Second Amendment advocates and a subsequent State of Emergency called by the Governor of Virginia. Little did we know that future advocacy days would soon be changing due to COVID-19.

During the 2020 GA session, VHF worked in two coalitions - the Healthy Market Virginia Coalition and the Healthcare for All Virginians Coalition. Through our efforts, the Governor vetoed three insurance bills potentially detrimental to pre-existing conditions, and the GA voted to provide Medicaid adult dental benefits. The benefits were confirmed by the GA in its special session from August-November.

Stay tuned for the 2021 GA session beginning January 13, 2021. It will be held virtually, which means a new experience for all!



CONTRIBUTIONS

Below are individuals who have made a financial contribution in FY 2019-2020. VHF is so grateful to you all. If we inadvertently omitted or misspelled your name, please accept our apologies.

Patron Friend | \$1,000+

Jeff & Christine Krecek
John Parron

Sustaining Friend | \$500-\$999

Marty & Natalie Kaszubowski
Kevin & Dorothy O'Connor
Steven & Sarahbeth Spasojevich
Michael & Barbara Wheatley

Supporting Friend | \$250-\$499

Lamont Banks
Wesley & Debbie Baugher
Laura Boyd
Colin & Krista Davidson
TJ & Monika Eiden
Tory Gilliam
Frederick & Carlene Harmeling
Bethany Hunter
Marquita Reinhardt &
Brandon Taggart
Dianne Rust
Tom & Candy Spasojevich
Michael Fatsi & Polly Stephens
David & Mary Valentino

Contributing Friend | \$100-\$249

Casey Benson
Stephanie Binger
Zack & LeAnn Bordone
Flula Borg
Paul & Frances Brayshaw
Kate Breitbeil
Jim & Fran Brooks
Matt Campbell
Alison Conley
Charles & Susan Cowell
Deborah Davis
Mari Droney & Sue Lahet
Thomas Eiden
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Randy & Kathy Mortimer
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Jonathan & Betty Passick
Bryan & Lisa Pearson
Nichole Phillips
Kelli Plusch
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Richard Rath
Carol Rose
Mike Scantlin
Donald & Beth Smith
Fred Smith
Edwin & Teresa Smith
Barbara Smith
Samuel & Bonnie Spasojevich
David & Theresa Stone
George & Cyndi Stone
Sue Tucker
Lisa Vance
Deeann Wagner
Eric & Amy Walker
Reginald & Luicianne Warren
Jennifer Watts
Megan Whiteaker
Davida & Wesley Wickline
Allen & Barbara Young

Friend of VHF | \$5-\$99

Alex Adams
Katrina Addison
Tara Alexander
Ava Allen
Ranesha Allen
Gary & Linda Anderson
Judy Bagato
Michelle Banton
Victoria Barnhill
Suman Bhatia
Bryan Blackwell
Carla Boucher
Shea Bradley
Walter & Susan Branam
James Breitbeil
Kevin & Tanya Brennan
Kenneth & Heather Brinkley
Edmund & Amanda Brooks
Aaron & Eileen Bunn
Rachel Bunn
Robyn Cathcart
Leesa Christian
Heather Conner

Alison Conners
Katie Cooper
Steve & Sarah Covert
Michael Craciunoiu
Kevin Crider
Holle Cuje
Jackie D'Alton
Melissa Dart
James Davis
Stanley Davis
Louise Denkins
Dustin Derrick
Andrea Dharamsi
Paula Diefenderfer
Jacqueline Dietz
Bev Doud
Becky Dubois
Lauren Dunn
Jeanette Dupree
Wendy Eubank
Shelly Evans
Sarah Fey
Brad & Kendall Fitzpatrick
Michael Gardner
Dwight & Kathleen George
Dana Gifford
Jessica Graham
Scott & Shannon Gravitt
Thomas Gray
Dennis & Lisa Hancock
Justin Hardy
Tami Harlan
Frances Herring
Tyechia Hogan
David Hubbert
John Hudnall
Karen Jackman
Sarah Jarandeh
Sasha Jean-Noel
Tara Jenkins
Matthew Johnson
DJ Jones
Rhonda Jones
Jessica Jones
Aaron Jordan
Demet Karail
Soykan Karail
Roxane Kays
Barbara Kearney
Vance Kerry

CONTRIBUTIONS

Below are individuals who have made a financial contribution in FY 2019-2020. VHF is so grateful to you all. If we inadvertently omitted or misspelled your name, please accept our apologies.

Friend of VHF | \$5-\$99 cont...

Amy Key
Karen Kirsch
Andrea Kish
Sarah Knight
Amanda Knoepp
Betsy Knop
Weston & Kimberlee Koerner
Vivek & Marian Kshetrapal
Janice Kuhn
Kristen Lahocki
Amy Lambert
Michael Larson
Robin Laubscher
Noah Laurence
Dana Beers & Elizabeth Leftwich
Paul Lerner
Kristen Lewandoski
Jennifer Lillehei
Padee Ly
Christina Major
Hallie Mason
Gita Massey
Virginia Mathurin
Susan Mays
James & Virginia McCauley
Renee McCurry
Trenton McDorman
Kenneth McElderry
John & Patricia McFadden
Cynthia Michener
Linda Mills
Andrea Mims
Robert & Barbara Morton
Anthony & Kimberly Moyers
Allison Mullens
Pamela Mullins

John & Vicki Nachman
Heather Nassaur
Lara Nichols
Stacey Noble
Melinda Nolte
Amanda Norman
Arvena Nowell
Carole O'Keefe
Charles Oshields
Stephanie Owen
LaToya Pace
Becky Palik
Melissa Park
Jean Parnell
Melanie Paschal
Rosie Pinkerton
Beth Plummer
Josh & Temesha Pollock
Barbara Pollock
Lisa Prado
Lisa Ransone
Tanya Reagan
Leigh Renkar
Lauren Ricci
Kathy Ridenour
Richard & Brenda Robertson
Justina Rollins
Megan Ruedas
Lisa Saba
Ila Santimauro
Jean Satterwhite
Donald Saxer
Teresa Scantlin
Rachel Schoultis
Megan Schowengerdt
Anita Schwartz
Dan & Susan Seftick

Margaret Shelton
William & Rachel Shifflett
Sonya Shrewsberry
Elizabeth Skaggs
Vicky Hawk & Shelby Smoak
William & Karen Steiner
Marie Summers
Tim & Jill Swinger
Jamison Taggart
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Michael Therrien
Pat & Jane Thiegs
Joe Towner
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Leslie Traylor
AnnMarie Tussey
Tamara Tyler
Albert & Marijane Valentino
Tameeka Vance
Allison Vaughan
Shannon Wagner
Dennis & Anne Walker
Troy Wallace
Sarah Waniewski
Daniel & Lydia Warren
Cary Washburn
Kelly Waters
Jerry & Michele West
Elaine Whiteaker
Adam Wilkie
Kristin Williams
Larry & Deborah Williford
Betty Winter
Kathryn Young
Linda Yuan



VHF LEGACY SOCIETY

You can be a part of VHF's Legacy Society by remembering VHF in your estate plan or will and 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 info@vahemophilia.org.

SUPPORTING ORGANIZATIONS

Below are organizations which have made a financial contribution in FY 2019-2020. If we inadvertently omitted or misspelled your name, please accept our most sincere apologies.

Accredo
AmazonSmile
AMF Bakery Systems
Bayer Pharmaceutical
BioMarin
BioMatrix
Capital One Services LLC
Colburn-Keenan Foundation Inc.
CSL Behring
CVS Caremark
CVS Pharmacy
Diplomat
Dominion Energy
DrugCo Health/DDP Pharmacy, Inc.
East Hanover Women's Church -
Softball League
Genentech

Grifols
Hemophilia Alliance Foundation
Hemophilia Fed. of America (HFA)
Home Depot
Hoos at Home (UVA)
Kroger Cares
Markel Corporation
Marriott
Matrix Health
Medexus
National Hemophilia Fnd. (NHF)
Novo Nordisk, Inc.
Octapharma USA, Inc.
PayPal GivingFund
Pfizer
Prime Education LLC
Queen of Virginia Skill & Ent. LLC

Sanofi
Sanofi US Services, Inc.
Spark Therapeutics Inc.
Superior Biologics, Inc.
Takeda
West Charitable Trust



FACEBOOK DONORS AND FUNDRAISERS

VHF would like to sincerely thank each of our generous Facebook donors and fundraisers who used the platform in the last fiscal year. We have limited data available from that platform, so please forgive us if your name is not included in our list of donors. Together, you helped raise over \$2,500 for the mission of VHF!

VHF is a member of CHC: Creating Healthier Communities' workplace giving campaigns in Virginia. Thank you to the following individuals who pledged support through the 2019 statewide CHC Campaign:

Heather Brinkley, Kelly Cartwright, and Kamala Lannetti. We'd also like to thank Mandy Baker, Michael Baker, and Charles White for their workplace giving in 2019 through United Way of South Hampton Roads.

VHF has been approved to participate in the 2020 Commonwealth of Virginia Campaign, running through January 15, 2021. To donate to VHF with the state employee campaign (Local Government and Schools United Way) direct your donation to #06043.



Make a monthly gift to be part of our Hope Society - a special group of people who are committed to VHF's future by giving hope to those living with bleeding disorders. Your support will make a big impact with our families! Sign up for a monthly gift today and find out other ways to give at vahemophilia.org.

Thank you to our 2019 - 2020 members: Wesley & Debbie Baugher, Jeff & Christine Krecek, Donald & Beth Smith, Steve & Sarahbeth Spasojevich, Sarah Waniewski, and Michael & Barbara Wheatley

VOLUNTEER OF THE YEAR PROGRAM

Join us in congratulating the 2019 VHF Volunteer of the Year: Amy Walker!

Volunteers are the "lifeblood" of any non-profit organization – VHF included. Volunteers are the people who step forward to work at events, sit on committees, and volunteer to serve on our board of directors. VHF began a focus in earnest in FY 19-20 to enhance and improve our Volunteer Program - beginning with the creation of our Volunteer of the Year Awards Program. Four volunteers are recognized in a calendar year for their outstanding commitment to the mission of VHF and are nominated for the Volunteer of the Year Award. Our Executive Committee of the Board of Directors considers each nomination and then the award is given in December of that calendar year. Below, please check out our first nominees for this annual program. We are so grateful for all of our volunteers for the time, talent and dedication they give to the organization. The impact on our community is immeasurable!

Debbie Baugher Debbie has served on the VHF scholarship committee since 2018 and is a familiar face as a day-of event volunteer at several major events throughout the year. Her youngest grandson, Ray, has severe Factor VIII deficiency.

"I'm so grateful to the VA chapter for the support they have provided to our family. From soft sided helmets for an active little guy learning to crawl and walk to all of the educational dinners and meetings for families living with bleeding disorders here in Virginia. I feel it's my privilege to give back to the Community that gives so much to us."

Temesha Pollock Temesha served on the Unite for Bleeding Disorders Walk Committee in 2019 and was recognized as our top individual walker, raising \$1,573 before walk day. Her team set a goal of raising \$1,000 in 2019 and ended up raising \$1,935!

"Since my oldest was diagnosed six years ago, I have been fundraising for our local chapter through the walk. My inspirations for my walk team, The Pollock Boys, are my kids. I want them to know that although they have hemophilia, they have the biggest team of supporters!"

Steve Spasojevich Steve serves as Chair of the Finance Committee, which provides oversight and guidance for the fiscal administration of VHF. He also is a consistent top fundraiser for the Unite for Bleeding Disorders Walk.

"VHF is very important to my family. We have benefited greatly from the educational programs, family events, and through connections to other families within the hemophilia community. I volunteer and fundraise as my way of showing gratitude for all they've done for my family."

Amy Walker Amy is the Program Committee Chairperson, new family mentor and go-to nurse and infusion support educator at Camp Youngblood, Teen Retreat and First Step Programs. She also fills in as the VHF representative at educational dinners in the Hampton Roads area. You will see her and her family participating in numerous VHF events throughout the year – especially Richmond and Washington Days - the Walker family has a passion for advocacy and sharing their stories!

"I volunteer with VHF because the community has become our family. My joy is to see kids and families with more education, independence, and confidence in caring for their bleeding disorder. I am excited to support new families and help them see they are not alone." **Congratulations Amy!**





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