



# JULY 1, 2020 - JUNE 30, 2021 **GRATITUDE REPORT**



# Mission

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

## Table of Contents

3	Executive Director Statement
4	Revenue and Expense Details
5	Board of Directors
6	VHF Staff
7	Education
8	Advocacy
9	Contributions
10	Contributions & Supporting Orgs.
11	Ways to Give
12	Community Member Spotlight
13	Community Partner Spotlight
14	Volunteer of the Year 2020
15	2022 VHF Calendar

## EXECUTIVE DIRECTOR STATEMENT

Kelly Waters, LCSW, MSW

**“Resilience or hardiness is the ability to adapt to new circumstances when life presents the unpredictable.”**

– Salvatore R. Maddi



As we wrap up another fiscal year, I am reflecting on how much we have all gone through since March of 2020. When we finished our last strategic planning process in 2018, we knew that the needs of the community were changing. New therapies were on the market that would impact quality of life, gene therapy was the hot topic of the moment, and community members were living longer than ever before. We knew at that time we would need to be resilient, flexible, and responsive to the needs of our members in this changing landscape. What we did not have any way of predicting is the global pandemic that has affected all our lives and changed everything we have done as an organization—in ways that have been challenging and at times positive.

In fiscal year 2020–2021, VHF has worked hard to continue to provide quality, tailored educational programs, robust year-round advocacy efforts, and opportunities for our community to come together, despite meeting virtually. We streamlined some of our internal infrastructure to be better stewards to our donors and decided to close our physical

office location and have our employees work remotely.

As we move forward into program planning for next year, we have some exciting new developments that should allow us to come together in meaningful ways. We look forward to continuing to maintain our creativity, flexibility, and access to a virtual meeting space, but we are also very much looking forward to hopefully seeing you in person this spring or summer!

What will come our way in 2022 is unclear, but VHF is ready to explore the opportunities and see what is possible. We plan to address future challenges head-on and begin a new strategic planning process with a sense of hope and optimism. The path is uncertain—but we have amazing community members, donors, supporters, and volunteers leading the way, and that is what will allow us to continue to succeed in serving the bleeding disorder community.

Thank you for all that you do!



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.

Despite the pandemic, VHF continued to build community and offer support through programs, such as: a monthly electronic newsletter with chapter updates and timely resources on topics like COVID-19 and bleeding disorders, financial assistance and mental health and 40 virtual education sessions that included popular programs such as Camp Youngblood, Community Game Nights, Rap Sessions for Men and New Families, Craft Nights, Advocacy Chats, a Medical Symposium, and more!

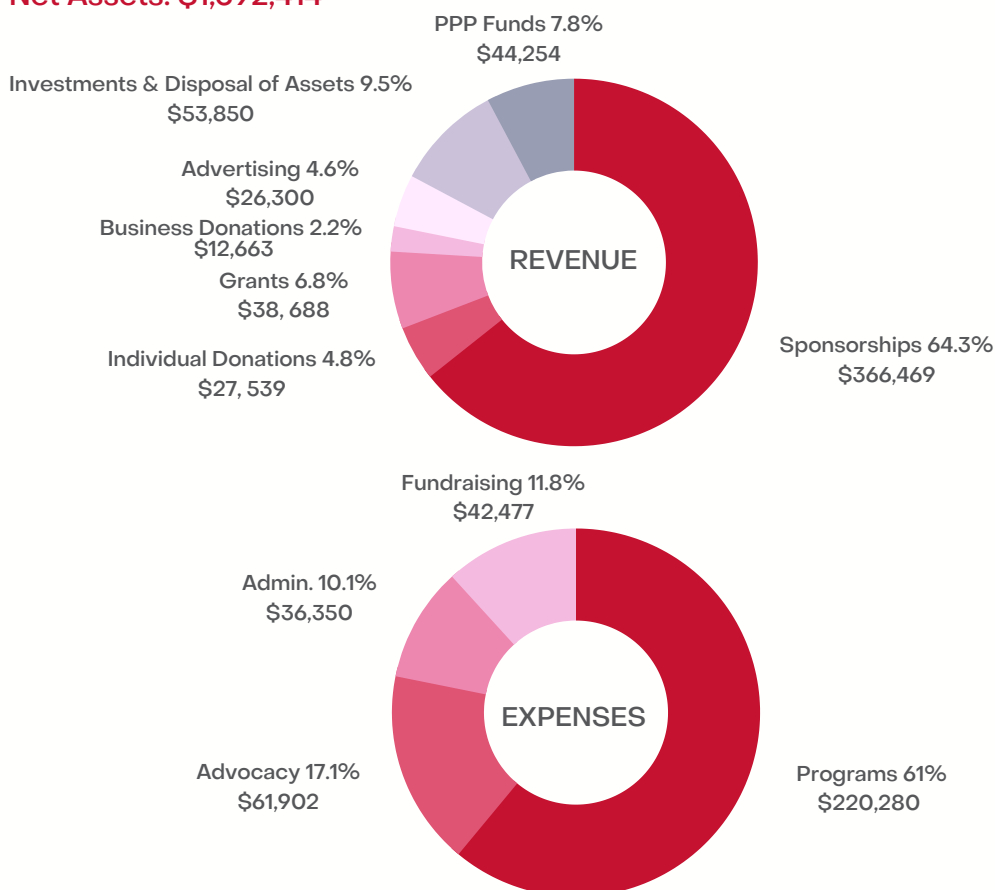
Thanks to the Colburn-Keenan Foundation Inc.'s COVID-19 Community Relief Grant Program, we were able to partner with Virginia's Hemophilia Treatment Centers (HTC's) to offer over \$2,500 in grocery gift cards to benefit individuals and/or families.

For additional financial details visit: [connectva.org/groups/virginia-hemophilia-foundation/financials/](https://connectva.org/groups/virginia-hemophilia-foundation/financials/).

## REVENUE AND EXPENSE DETAILS

From Audited Financial Statements July 1, 2020 through June 30, 2021

**Net Assets: \$1,592,414**



During Fiscal Year 2020 - 2021, 78 cents of every dollar went to serving the inherited bleeding disorders community!



## BOARD OF DIRECTORS

Thank you 2020-2021 Board of Directors for donating your time and talents!

**President** Sarahbeth Spasojevich

**Vice President** Kathy Mortimer

**Treasurer** Donald G. Smith

**Secretary** Tory Gilliam

### Directors

Debbie Baugher

Kate Breitbeil

Monika Eiden

Murai Johnson

Ann Kendall

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](mailto:kelly@vahemophilia.org).



The [National Hemophilia Foundation Chapter \(NHF\)](#) of Excellence Award is given to chapters that demonstrate excellence in achievement of standards and best practices evaluated through a rigorous chapter review process. **VHF is one of only three chapters** to obtain the six-star status. We have demonstrated diligent efforts in the following areas: Volunteer Management, Fundraising and Development, Governance and Board Leadership, Advocacy and Public Policy, Programs and Services, and Partnership in shared initiatives with NHF.



VHF is honored to meet the [Better Business Bureau \(BBB\)](#) 20 Standards for Charity Accountability. A BBB Wise Giving Alliance evaluation of our organization found that we met all 20 of the BBB Standards for Charity Accountability which address charity governance, finances, effectiveness reporting, appeal accuracy, website disclosures and donor privacy. Charities that meet all these standards are called Accredited Charities. These standards also go beyond the requirements of local, state, and federal laws.

## MEET THE VHF TEAM!

### **Kelly Waters** Executive Director

*"I have had the honor of serving as VHF's executive director since May 2006. I can't believe how fast the time has gone. It has been wonderful seeing the kids grow-up, hearing about your lives, and learning from you. I feel so fortunate to be part of the Virginia bleeding disorders community. This year has been one of creativity and flexibility! I am most proud that VHF has been able to shift our programs to a virtual format and continue to provide advocacy, education, and a sense of community during this time. One of the things I have particularly enjoyed doing recently is cooking. I like the challenge of purchasing what is on sale at the grocery store and then choosing recipes from there. We have had quite the variety with very few recipes made twice."*

### **Heather Conner** Program & Communication Director

*"Since February of 2011 I have had the privilege of serving the bleeding disorders community. I had no idea when I started that I would be here for ten years – what an amazing decade of growth and change it has been! When people ask what I do at VHF I often joke that I send emails for a living and now I have had to change my answer to say that I Zoom for a living! I am so proud of our team and the way we have transitioned to virtual and I am so proud of the many community members that have joined us for the many virtual programs, committee meetings, advocacy check-ins, and so much more."*

### **Megan Schowengerdt** Development Director

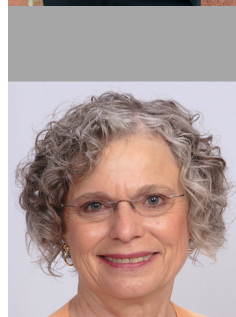
*"I have served with VHF as the Development Director since November of 2017 and I have truly enjoyed getting to know the community and seeing our culture of philanthropy change and grow. I love working with our Unite Walk Team Captains and helping them see the power in sharing their stories while giving back to the inherited bleeding disorders community! Shifting to virtual has really challenged our community to think creatively about fundraising and that is exciting to see! From Facebook birthday fundraisers to utilizing the Unite Walk app, we have come a long way from e-mail only fundraising and candy sales. I hope we continue to see growth in these areas as we move back into in-person in 2022."*

### **Becky Bowers-Lanier** Advocacy Consultant

*"Since 2008, I've had the pleasure of working with VHF as your advocacy consultant. I don't feel almost 14 years older, but my pictures indicate that that is the case! One fun fact: since COVID has come into my life, I've discovered two jigsaw puzzle apps, and I've become addicted to them! I have three devices with both apps loaded onto each, so at any one time, I have six puzzles going. I'm in puzzle heaven. VHF asked me to relay how COVID has changed the work we do. From the advocacy perspective, while we have reduced our face-to-face involvement with policymakers, we've increased our ability to meet with them virtually—from anywhere at almost any time, and that is a good thing!"*

### **Sarah Covert** Accountant

*"After 18 fabulous, fun, (and at times) challenging years as a stay-at-home mom of three sons, I was thrilled to join Warren Whitney, a local management consulting firm, for an opportunity to delve back into my accounting career. In March 2017, I visited my first client VHF. From the start, I could see that everyone involved with VHF works together seamlessly to achieve the meaningful mission of the organization. I felt fortunate to partner with the VHF team and contribute to their efforts through my collaboration and accounting support. More recently, I have had a behind-the-scenes glimpse at the tireless work and extensive effort expended to quickly and effectively pivot from in-person to virtual events. During the past months of changes and challenges, I am grateful to work with such talented and dedicated individuals who are professional, knowledgeable, and innovative. It is an absolute privilege and delight to be a part of the VHF team."*





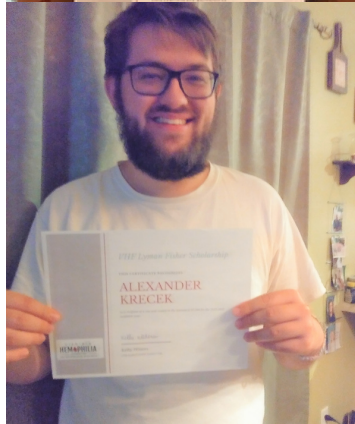
## EDUCATION

### Congratulations to our Lyman Fisher Scholarship Winners!



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 for Virginia. He will be remembered for his steadfast commitment to his patients and students, his respect for those who served under him, his community service, and his affection for his family.

During the 2021 March Bleeding Disorders Awareness Month Campaign you helped us raise \$6,367 (our goal was \$2,500!) which allowed us to increase our Lyman Fisher Scholarship awards from two recipients to four!



#### **Nick Cleghorn**

*"I really appreciate being selected for the VHF Lyman Fisher scholarship. Living with Hemophilia has always had its challenges, but the support of the Hemophilia community and learning from others has been of great support to me. In the fall, I will be attending Chowan University and majoring in business management while also playing baseball. This scholarship, along with the support of my family and the community, will help me achieve my goal of being a student athlete in college. Thanks for believing in me and granting me this opportunity."*



#### **Alexander Krecek**

*"This scholarship means a lot to me because it will help me continue my studies at a school that actually allows me to major in something that I am truly passionate about. Every little bit helps relieve some of the stress that the rising costs of going to college brings with it."*

#### **Eden Laubscher**

*"This scholarship will help pursue my dreams of going to college to become a teacher. It will help me pay for my tuition at James Madison University, where I will study elementary education. I am so thankful for this opportunity that will help me further my education."*



#### **Josiah Walker**

*"Thank you so much for this offer. I am excited to accept this scholarship not because it will help me afford school, but also because it is from a community that has played such a vital role in my life. I am thankful for this award, the Hemophilia community and looking forward to attending college."*

## ADVOCACY

### George Stone, Advocacy Committee Member & Volunteer

As a [VHF volunteer](#), I serve on both the Development, and Program committees and as VHF's [Hemophilia Federation of America \(HFA\)](#) representative. I also serve on the VHF Advocacy Committee in partnership with the [Hemophilia Association of the Capital Area \(HACA\)](#).

I want to extend my appreciation to our VHF leadership, professional staff, legislative advocates and Advocacy committee chair Ann Kendall for their work during another challenging year. Like most community members, I spent much of my time wearing a mask, washing my hands, and participating in Zoom meetings given COVID risks. COVID didn't slow me or VHF's advocacy activities.

I gathered virtually with other VHF volunteers at The [NHF's "Washington Days"](#) where we told our stories to legislators and staff in support of essential appropriations to fund HTC's, government-sponsored research, and community data collection and analysis.

VHF's advocacy chats introduced us to Delegate Kathleen Murphy (34th District, Virginia House of Delegates) so we could learn more about the passage of HB 1995 that created the Rare Disease Advisory Council and its proposed scope of work. And the Virtual Advocacy Stakeholder and Education Meeting had great talks from Delegate Dawn Adams (68th District, Virginia House of Delegates) and other advocacy leaders to ensure we were up to date on state and federal issues.

The [General Assembly weekly updates](#) kept me informed on VHF's continued advocacy for health insurance that does not negatively impact individuals with pre-existing conditions and opposed plans that do. For example, VHF has actively opposed association health plans (AHPs) because they do not provide adequate coverage for bleeding disorders. Fortunately, support for AHP legislation diminished in 2021. In addition, I learned about Virginia establishing a reinsurance program aimed at decreasing the overall cost of health insurance plans sold on the state marketplace. VHF also didn't forget the hot topic of COVID Vaccines and invited NHF President and CEO Leonard Valentino, M.D. to join the virtual medical conference where he discussed such things as COVID's impact to the bleeding disorders community and advocated for vaccinations.

Although VHF was virtual this year, I still had the opportunity to learn more about the advocacy issues that affect those with bleeding disorders and was able to be actively engaged. I hope you will consider joining me this year as we continue our advocacy efforts.





## CONTRIBUTIONS

Over the next two pages are individuals who have made a financial contribution in FY 2020-2021. 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  
Marty & Natalie Kaszubowski  
George & Cyndi Stone

### Sustaining Friend | \$250-\$999

Kristin & Bernie Arnoldi  
Lamont Banks  
Matthew Berg  
Robert & Donna Bordone  
Zack & LeAnn Bordone  
Becky Bowers-Lanier  
Travis & Mei-Ling Campbell  
Shantih Charlton  
Todd & Becky Christensen  
TJ & Monika Eiden  
Brad & Kendall Fitzpatrick  
Bethany Hunter  
Vivek & Marian Kshetrapal  
Rick & Julia LeFevre  
Kevin & Dorothy O'Connor  
Jean Parnell  
Marquita Reinhardt & Brandon Taggart  
Mike & Ashley Silva  
Donald & Beth Smith  
Steven & Sarahbeth Spasojevich  
Tom & Candy Spasojevich  
Michael Fatsi & Polly Stephens  
Randy Stone  
Sarah Waniewski  
Kelly Waters  
Barbara Wheatley

### Contributing Friend | \$100-\$249

Brian & Stephanie Bartko  
Debbie & Wesley Baugher  
Shalu Bhambhani  
Suman Bhatia  
Christopher & Carla Boucher  
Paul & Frances Brayshaw  
Kate Breitbeil  
Edmund & Amanda Brooks  
Jim & Fran Brooks  
John Burnett  
Matt Campbell  
Virginia Chandler  
Kenneth Cooke  
Steve & Sarah Covert  
Colin & Krista Davidson  
Cory Dunn  
Thomas Eiden  
Patricia Falls  
Joe Fink  
Kathy Gause  
Marc Gilgannon  
Tory Gilliam  
Pam Gleason  
Guy Grundman  
William Horton  
Roberta Hylton  
Diane Interdonato  
Erik Jaynes  
James & Murai Johnson  
Mike Johnson  
Aaron Jordan

Jon & Carol Joyce  
David & Ann Kendall  
Robert & Theresa Kitts  
Michael Lee  
Boyd Lewis  
Deborah Lohmeier  
Gita Massey  
David & MaryAnn McCrum  
John & Patricia McFadden  
Linda Mills  
Randy & Kathy Mortimer  
Judie Mullins  
Luke Olenick  
Aaron Parks  
Sharie Parks  
Linda Price  
Betsy Rhodes  
Megan Rodman  
Dianne Rust  
Mike Scantlin  
Mike Scholfeld  
Megan Scholz  
Fred Smith  
Barbara Smith  
Edwin & Teresa Smith  
Vicky Hawk & Shelby Smoak  
Michael Therrien  
Joseph Tieger  
Kim Trentham  
Laura Unruh  
Suzanne Vaughan  
Tara Wagner  
DeeAnn Wagner  
Eric & Amy Walker  
Alison Wolfe  
Allen & Barbara Young  
Peter Ziehl

### Friend of VHF | \$5 - \$99

Jennifer Adriany  
Andrea Annas  
Linda Ardrey  
Megan Arrington  
Tony Atlas  
Judy Bagato  
Sara Bailey  
Ryan Ball  
Susan Ballesteros  
Michelle Banton  
Jennifer Barnes  
Kathy Bartko  
Karen Bartko  
Linn Barton  
Erl Beano  
Jessica Bell  
Sreepad Bhagwat  
Brenda Bitikofer  
Dan Blakeslee  
Nachar Boutin  
Pamela Bowman  
James Breitbeil  
Kenneth & Heather Brinkley  
Marilyn Brister  
Amber Brister

Peggy Britton  
Aaron & Eileen Bunn  
Rachel Bunn  
Adriana Campos  
Victor Canacci  
Ian Cassell  
Shannon Colby  
Lain Conley  
Heather Conner  
Bernard Cooley  
Mindy Cooper  
Luis Coppa  
Chris Coster  
Kelsie Cotman  
Matt Cox  
Melissa Dart  
Alison Davidson  
Arch Davis  
James Davis  
Charlie Dawson  
Shawn Decker  
Penny DeFilippi  
Donna Deicken  
Bunty & Andrea Dharamsi  
Paula Diefenderfer  
Jacqueline Dietz  
Chris Dolan  
William Donatelli  
Marianne Drone  
Jenifer Duck  
Lauren Dunn  
Mari Dyer  
Kat Edwards  
James Eiden  
Kevin Ellis  
Jen Erator  
Mark & Deborah Estienne  
Shelly Evans  
Keira Feagley  
Chasidy Felton  
Keith Forsythe  
Gene Friedman  
Morris Gadsden  
John Gallahorn  
Tammy Gaudet  
Natasha Gealey  
Dwight & Kathleen George  
Janet Gibson  
Gina Gilbert  
James Golder  
Michael Goodrow  
Will Gordon  
Lisa Graf  
Jessica Graham  
Scott Grieser  
Erin Hackett  
Tami Harlan  
Frederick & Carlene Harmeling  
Tawheed Haroon  
Sara Haroon  
Kerry Hartman  
Debra Hedgecock  
Gwen Heekin  
Krystn Helen

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

Ginelle Heller  
 Jeff Herring  
 Terry Hodge  
 Mary Hodges  
 Sharon Hoover  
 Liza Hopper  
 Cathie Howard  
 Holly Hudgins  
 David Hudson  
 Jeff Hunt  
 Bernie Hyde  
 Cat Jackson  
 Rebecca Jacobs  
 Dan Jacobson  
 Garrett Johnson  
 Nanette Johnson  
 Charles & Mary Johnson  
 Eric Jones  
 Margot Kaminsky  
 Ted Karch  
 Marcus Katabian  
 Tom Killian  
 Melissa Kirby  
 Christina Kminek  
 Larra Koiner  
 Girish Kolantra  
 Victoria Kuhn  
 Janice Kuhn  
 Carol Kuykendall  
 Kate Kvaternik  
 Lesa Lank  
 Jane Larson  
 Michael Larson  
 Lynne Layton  
 Jerrad Lee  
 Axel Lee  
 Kristie Legg  
 Estle Lewis-McBride  
 Jen Lillehei  
 Leasha Litif  
 Margaret Llitas  
 Mike Loslo  
 Karen Lucas  
 Lorraine Lupini  
 Wayne Lutz  
 Andrea Marbet

Chasity Marie  
 Lyd Marie  
 Peter Maris  
 Virginia Marsh  
 Pedro Martinez  
 Karen Mask  
 Courtney Mason  
 David & MaryAnn McCrum  
 Tony Merendino  
 Predrag Mikov  
 Donald Miller  
 Tim Miller  
 Amy Moses  
 Manon Moynihan  
 Wayne Muhlstein  
 William Neill  
 Angela Nichols  
 Jessica Nizamoff  
 Abbie Olenick  
 Lyn Owens  
 Chris Oxford  
 Becky Palik  
 Debbie Parsons  
 Melanie Paschal  
 Jennifer Paules  
 Kathy Pedrick  
 Zane Pion  
 Melissa Poff  
 Phyllis Prado  
 Nancy Price  
 Dean Price  
 Deborah Reading  
 Tanya Reagan  
 Gretchen Reid  
 Leigh Renkar  
 Dennis Rice  
 Andy Rich  
 Linda Rickman  
 Jessica Ridlen  
 Jennifer Rinker  
 Monica Rogers  
 Annie Roman  
 John Roman  
 Justin Roman  
 Carol Rose  
 Kelly Ruotolo  
 Tabatha Sanders

Ila Santimauro  
 Jean Satterwhite  
 Kathryn Schowengerdt  
 Megan Schowengerdt  
 Loren Setlow  
 Katherine Shaver  
 William & Rachel Shifflett  
 Lennie Showalter  
 Sonya Shrewsberry  
 Leslie Sim  
 Simons Family  
 Edward Smietana  
 Gina Smiley  
 Rosalie Smith  
 Alicia Smith  
 Dave Snyder  
 Laura Stewart  
 Pat Stone  
 Mary Suman  
 Bonnie Sutton  
 Deborah Taggart  
 Conley & Elizabeth Taylor  
 Jessica Teran  
 Sarah Touchet  
 Mary Trautner  
 Jordan Tucker  
 AnnMarie Tussey  
 Jason Valentino  
 Nicole Valentino  
 Allison Vaughan  
 Kiki Venable  
 Visuvabharathy Visuvalingam  
 Dennis & Anne Walker  
 Michael Waniewski  
 Cary Washburn  
 Debora Watson  
 Kiersten Whitaker  
 Megan Whiteaker  
 Elaine Whiteaker  
 Christy Whiteside  
 Rachel Williams  
 Dominic Wing  
 Connie Wright  
 Katie Young  
 Keith Young

## SUPPORTING ORGANIZATIONS

Below are organizations which have made a financial contribution in FY 2020-2021. If we inadvertently omitted or misspelled your name, please accept our most sincere apologies.

Accredo  
 AmazonSmile  
 AMF Bakery Systems  
 Bayer Pharmaceutical  
 BioMarin  
 BioMatrix  
 Colburn-Keenan Foundation, Inc.  
 ComForCare Home Care  
 CSL Behring  
 CVS Pharmacy  
 DrugCo Health  
 Genentech  
 Grifols

HEMA Biologics, LLC  
 Hemophilia Alliance Foundation  
 Hemophilia Federation of America  
 Home Depot  
 Hoos at Home  
 Jacobs  
 Kroger Cares  
 Markel Corporation  
 Medexus  
 National Hemophilia Foundation  
 Network for Good (Facebook)  
 Novo Nordisk, Inc.  
 Octapharma USA, Inc.

Optum  
 PayPal GivingFund  
 Pfizer  
 PhRMA  
 Responsive Technology Partners  
 Sanofi  
 Soleo Health  
 Spark Therapeutics, Inc.  
 State Farm  
 Superior Biologics, Inc.  
 Takeda  
 Virginia Commonwealth University  
 West Charitable Trust

## 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](mailto: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](http://vahemophilia.org).

**Hope Society Donors 2020–2021:** 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 following individuals who pledged support through the 2020 statewide CHC Campaign:** Heather Brinkley, Taryn Marie Denham, Shelly Evans, and Kamala Lannetti. We would also like to thank Mandy Baker, Michael Baker and Charles White for their workplace giving in 2020 through United Way of South Hampton Roads.

VHF has been approved to participate in the 2021 Commonwealth of Virginia Campaign, running through January 15, 2022. 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 10th, 2020, in support of our first-ever 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 \$32,262 – we are so grateful!

**Special thanks go out to our Top 3 Teams in 2020:** Star City Bleeders, Team Lukasz, and Marian's All Stars

**Top Individual Walkers:** Colin Davidson, Monika Eiden, and Vivek Kshetrapal.





## COMMUNITY MEMBERS

VHF community members were a big part of our transition from in-person to virtual - thank you all for showing up and learning with us!

### David Wickline

"Wade and I live in Hardy, VA near beautiful Smith Mountain Lake. Our first VHF event was First Step Program for New Families at Maymont in Richmond, when Wade was still in a stroller. We met a man named Terry Lamb that day who became a resource for our son with Severe Hemophilia A. Terry gave me hope that everything would be ok, and Wade would live a long life, unlike my father who passed away from complications of hemophilia when I was 2.5 years old. Wade is 17 years old now and he is currently a senior who enjoys mountain biking, rock climbing and is also taking welding classes at Central Virginia Community College in Lynchburg, VA.

"As a parent I appreciate all the advice, helpful hints, friendship and love the VHF Family has given us throughout the years. **Recently with the Covid-19 Pandemic, I have greatly missed seeing our VHF folks in person, but the virtual events have let us interact with others and continue to help one another through this strange new world we live in.** I especially enjoy the Virtual Paint Night events. It's wonderful to see how everyone brings out their creative sides! Wade always sneaks in the video, even if he's not participating. We are so grateful for each and every member of VHF."

### Regina Winner

"We are Jason, Regina and Evan Winner. Evan was discovered to have hemophilia after a bad knee sprain landing him in the hospital at the age of 3 (fun fact, we knew that hemophilia runs in my family but the pediatrician refused to get him tested at birth, even going so far to pull out a genogram to tell us it was impossible for him to have it!) That was about four years ago and since then we have become connected with the VHF community. **Although we tried to attend events and be involved, I think going virtual really helped us in our busy lives be connected even more.** We love the virtual programs especially the fun atmosphere of game night and can't wait to see what else may be in store for the future!"

### Kelsie Gail

"We are the Gail family. Our son, King (7) has Hemophilia B Severe. We have been a member of VHF since he was diagnosed at six months of age. As a family, we look forward to the holidays and hosting our annual pajama game night. We enjoy attending VHF events. We are so thankful we were able to continue virtually over the last 18 months. **Attending virtually has allowed us to still feel connected to members, engage in fun activities, and learn about resources that are available.** Our most favorite event was the holiday event last year, building gingerbread houses, meeting Santa, and playing trivia games. We look forward to this year's event!"

### Patricia DeRatto

"My family and I have been members of VHF for many years. My sons Daniel and Matthew are both severe VIII and my daughter, Rose and I are carriers. We are a family of animal lovers and between 3 households we have 14 cats and a few other assorted pets.

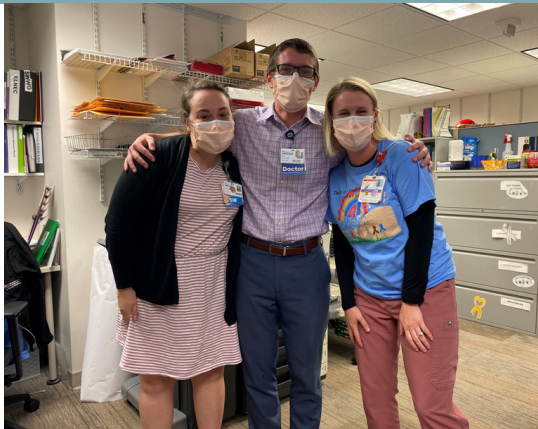
"This past 18 months have been challenging for all of us and we here are still trying to get used to the new normal. **The virtual activities that the Chapter has been able to sponsor have been wonderful. Between Christmas parties, Paint Night and Camera On to name a few, this staff has been busy.** I would have to say that I really enjoyed the Camera On night the best since I love to take pictures. It is nice to know that I am not the only one that grabs the camera to take pictures of seemingly random things. I am looking forward to the many new events in 2022 and for that day when the invitation can read, 'This is an in person event.' Going forward maybe the in person events can be attended virtually for those that cannot get to the event in person."





## COMMUNITY PARTNER SPOTLIGHT

Meet the Virginia Hemophilia Treatment Centers (HTCs) staff!



### Children's Hospital of The King's Daughters (CHKD) Pediatric Program

*"Despite the crazy yearish, we have been pretty productive adding some new members to our team, another nurse and another doctor! Like the rest of the world, we were doing some telehealth appointments, back in clinic, still doing some telehealth appointments. Seeing our patients back in-person has been reinvigorating. There is lots of laughing, singing, eating, and planning for the future of our bleeding disorder team. We can't wait to be able to see our patients out at VHF events soon!!!"*

- Megan Songer, MSW, LSW, Social Worker



### University of Virginia (UVA) Pediatric Program

*"We did our first remote clinic in Bristol Virginia recently and saw 10 of our bleeding disorders patients from SW Virginia. We plan to do one remote visit per year and one in person visit with us traveling to them to save the patients the long drives to UVA. We are very excited to have this clinic now up and running!"*

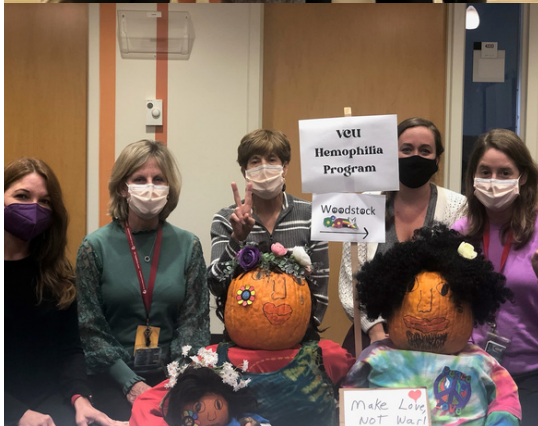
- Margy Sennett, RN BS CPNP CPON Peds Hem/Onc Senior Nurse Practitioner



### University of Virginia (UVA) Adult Program

*"UVA Health established an adult Hemophilia Treatment Center in May 2020 to complement services already provided by the pediatric HTC. UVA Hematologist Dr. Louise Man who leads the team became interested in offering comprehensive services to patients with bleeding disorders to provide improved comprehensive care and prevention services. We are grateful that Marc Gilgannon, our physical therapist, and Lindsay Comstock, our research nurse coordinator, have been able to join us on HTC days from the pediatric team, so patients transitioning from pediatrics to the adult clinic can see some familiar faces! Julie Armatas is our clinic nurse practitioner and enjoys getting to know our patients and their families. Starting a new clinic during a pandemic is a challenge, but we are grateful to see our patients in person again!"*

- Adonice D'Atre, MSW, LCSW, Clinical Social Worker



### Virginia Commonwealth University (VCU) Adult and Pediatric Program

*"While VCU returned to in person clinical care last year, many of our team members continue to work hybrid schedules. We've become experts at conducting team meetings via Zoom and this has extended to our collaboration with VHF as well. Participating in virtual "First Steps" new family meetings has provided flexibility and broader access to both the community and HTC staff. HTC social workers have also met quarterly with the VHF team to discuss patient support and programming needs. Finally, the continued support through the VHF patient assistance program has been an invaluable resource during the uncertainty of the past 18 months."*

- Lauren Dunn, Social Worker

## VOLUNTEER OF THE YEAR PROGRAM

Join us in congratulating the 2020 VHF Volunteer of the Year: Tory Gilliam!

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. Below, check out our 2020 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.

### Marquita Reinhardt

Marquita has been a constituent of VHF since her son Matthew, now 13, was diagnosed with Severe Hemophilia Factor 8 deficiency with an inhibitor. She has been an active volunteer for all three years of the Unite Walk program and a committee member for the last two years. Marquita says, *"I volunteer with VHF, because it is one way in which I can give back to my community. The VHF and its participants are my community. It is a community of blood brothers and sisters."*

### Krista Davidson

Krista has been an active constituent since 2015. She is the co-chair of the VHF/HACA Advocacy Committee, has volunteered her time creating and facilitating numerous advocacy education sessions, was elected to HFA's inaugural Advocacy Leadership Council, and is involved in fundraising for the VHF Unite for Bleeding Disorders Walk on the top team Star City Bleeders. Her team has made a huge impact on the walk program and she has organized a paint night and community yard sale to raise funds for the team. At the VHF/HACA Virtual Advocacy Chat in April 2020, Krista shared her personal story of working in a hospital setting during this time of COVID-19: *"It's not known when we're going to end up on the other side of this and despite the grim picture, I am hopeful too. As much negativity as we see, there is a plethora of positivity to help counteract it. The human connection is inspiring."*

### Tory Gilliam

Tory Gilliam serves as VHF Board Secretary and is serving his third year on the Board of Directors. Tory works as Senior Event Producer at MOSAIC Catering for his professional job. He also is a member of three VHF committees: Scholarship, Governance and the Red Tie Fundraiser and makes many valuable contributions in those roles. *"Giving back through non-profit work is something that I've always been passionate about. Throughout my career in the event world, I've worked with a variety of non-profit organizations. With VHF, I've been able to see firsthand, the impact of fundraisers, advocacy activities and volunteer efforts."*

### Monika Eiden

Monika Eiden is a community member and active volunteer with the Chapter as a member of the Board of Directors. Monika has been involved with VHF in a leadership role for 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. She led a Board "challenge" last fall to inspire others to give back to the organization by organizing their own walk teams and served on the Unite Walk Committee in 2020. *"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."*





## 2022 CALENDAR

Changes to the calendar are possible, contact VHF to confirm event details.

### January

17th – Virtual Advocacy Education Meeting  
18th & 25th – General Assembly Weekly Check-in  
27th – Virtual Education “Keeping and Maintaining Health Insurance During Uncertain Times”

### February

1st, 8th, 15th & 22nd – General Assembly Weekly Check-in  
10th – Virtual Community Event “Valentine's Day Crafts”  
20th – Virtual Education + Connection “Spark Your Curiosity – Escape Room”

### March BLEEDING DISORDERS AWARENESS MONTH (BDAM)

1st – 2nd – NHF Washington Days (Virtual)  
1st, 8th, & 15th – General Assembly Weekly Check-in  
(TBD) Virtual New Family Education & Support  
27th – Community Event “BDAM Celebration” TopGolf (Richmond)

### April

20th – 22nd – HFA Symposium: San Antonio, TX  
28th – Education + Connection “World Hemophilia Day Event” (TBD)

### May

8th – 11th – WFH World Congress: Montreal, Canada  
14th – Women’s Retreat (TBD)

### June

25th – Annual Education Meeting (TBD)  
26th – Community Event & Unite Walk Kick-Off (TBD)

### July

15th–17th – Family Camp at Camp Holiday Trails (Charlottesville)

### August

25th – 27th – NHF Bleeding Disorders Conference: Houston, TX

### September

(TBD) Virtual Advocacy Chat

### October

15th – Medical Symposium at Great Wolf Lodge (Williamsburg)  
16th – Unite for Bleeding Disorders Walk at Great Wolf Lodge (Williamsburg)

### November

5th – 6th – Men’s Retreat (TBD)  
(TBD) Advocacy Stakeholder & Education Meeting (Virtual)

### December

10th – Winter Gatherings (TBD)

**ADDRESS** 9702 Gayton Rd., Suite 277, Richmond, VA 23238

**PHONE** 804-740-8643 **EMAIL** [info@vahemophilia.org](mailto:info@vahemophilia.org)

**WEBSITE** [vahemophilia.org](http://vahemophilia.org)

