

VHF GRATITUDE REPORT



Fiscal Year July 1, 2018 to June 30, 2019

LETTER FROM THE EXECUTIVE DIRECTOR

Dear valued donors, volunteers, partners, constituents, and friends,

What an amazing year it's been, thanks to all your contributions! This Annual Gratitude Report is a place where we get to thank you and honor all who make the work we do together at the Virginia Hemophilia Foundation (VHF) possible. Our organization truly would not thrive without your continued help, and we could not be more grateful!

This last fiscal year (July 1, 2018 - June 30, 2019) VHF focused on innovative programing to keep constituents up to date on changes in the medical landscape and new technologies - particularly by hosting our first ever Medical Symposium this past March during Bleeding Disorders Awareness Month. In addition to this event VHF recognized Bleeding Disorders Awareness Month with an annual giving campaign where you generously gave \$6,245 toward programs and services.

VHF also hosted our first Unite for Bleeding Disorders Walk in partnership with the National Hemophilia Foundation (NHF) - a fundraiser that brought together our whole community to raise an amazing \$47,112 towards the mission of VHF! Other highlights of the fiscal year included a brand-new women's retreat, another partnership with NHF for our first Red Tie Soiree, and our Annual Meeting in beautiful Natural Bridge, which focused on the importance of storytelling.

Your support of our advocacy efforts and a strong coalition with other healthcare nonprofits resulted in huge advocacy wins this past legislative session in the areas of accumulator adjusters and step therapy. In addition, the implementation of Medicaid expansion in Virginia this year meant that many community members were able to access affordable quality healthcare.

We look forward to working with you in the next fiscal year to expand our volunteer and donor networks so we can continue to bring strong education, community, and advocacy to those living with inherited bleeding disorders in Virginia. Enjoy the stories shared in this year's gratitude report and thank you for all you do to make this important work possible. It is a pleasure to work with each one of you.

Kelly Waters, LCSW, MSW

Executive Director | Virginia Hemophilia Foundation



BOARD OF DIRECTORS

Officers

President | Sarahbeth Spasojevich

Vice President | Kathy Mortimer

Treasurer | Jean Parnell

Secretary | Megan Arrington

Board Members

Kate Breitbeil

Monika Eiden

Murai Johnson

Michael Silva

Daniel Warren



Thank you VHF Board of Directors! Not only do 100% of the VHF Board of Directors contribute financially, but they also give their time in the form of speaking at events, attending and volunteering at fundraisers, and advocating on the state and federal level!

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.

EDUCATION

VHF is pleased to offer scholarships to attend national meetings which enable our community to come together and exchange information on a wide variety of topics, from the basics of diagnosis to the most relevant developments in treatment.

Meeting: National Hemophilia Foundation (NHF) Bleeding Disorders Conference, Orlando, FL | October 11 -13, 2018

"In October, I attended the NHF Annual Bleeding Disorder Conference in Orlando, FL. I had an amazing time and was able to take part in a variety of programs. The program track that I most enjoyed and benefited from was the rare bleeding disorders track. These sessions provided me with valuable information and resources to assist me in living with a rare bleeding disorder. There was a session that specifically discussed the basics of my bleeding disorder. This was great because I was finally able to understand my specific bleeding disorder, including the science behind it and the various ways it can affect me now and in the future. I also got to hear about the changes and progress being made for the rare bleeding disorders community. I talked to a hematologist who is working to bring factor products into the United States for my bleeding disorder, as currently there is no factor product available to me. It gave me hope to know that one day, myself and others could have access to this form of treatment. I also enjoyed connecting with others with rare bleeding disorders, sharing our experiences with each other, and learning from each other." **Patti Williford**, Recipient of VHF Scholarship for a National Meeting

Meeting: Hemophilia Federation of America (HFA) Annual Symposium, San Diego, CA | April 4-6, 2019

"I have two boys, ages 7 and 1, who have hemophilia B. We have been involved with VHF for about a year since moving from Florida. We have attended a few educational dinners, the walk, the Red Tie Soiree, and the event at Great Wolf Lodge.

My family was recently granted a travel scholarship via VHF to be able to attend our first HFA conference in San Diego. My family had an amazing time and we were excited to meet families and new lifelong friends. There was a class that was very helpful for our family about sending a child to camp since this will be the first year my son will attend. We learned a lot of tips and got real-live experiences from past campers that will help us deal with sending him to camp. Overall, the HFA conference was beneficial to our family and I am happy we were able to attend. Our family will forever be grateful for the opportunity that was granted to us by VHF!" **Temesha Pollock**, Recipient of VHF Scholarship for a National Meeting



WHERE THE MONEY GOES

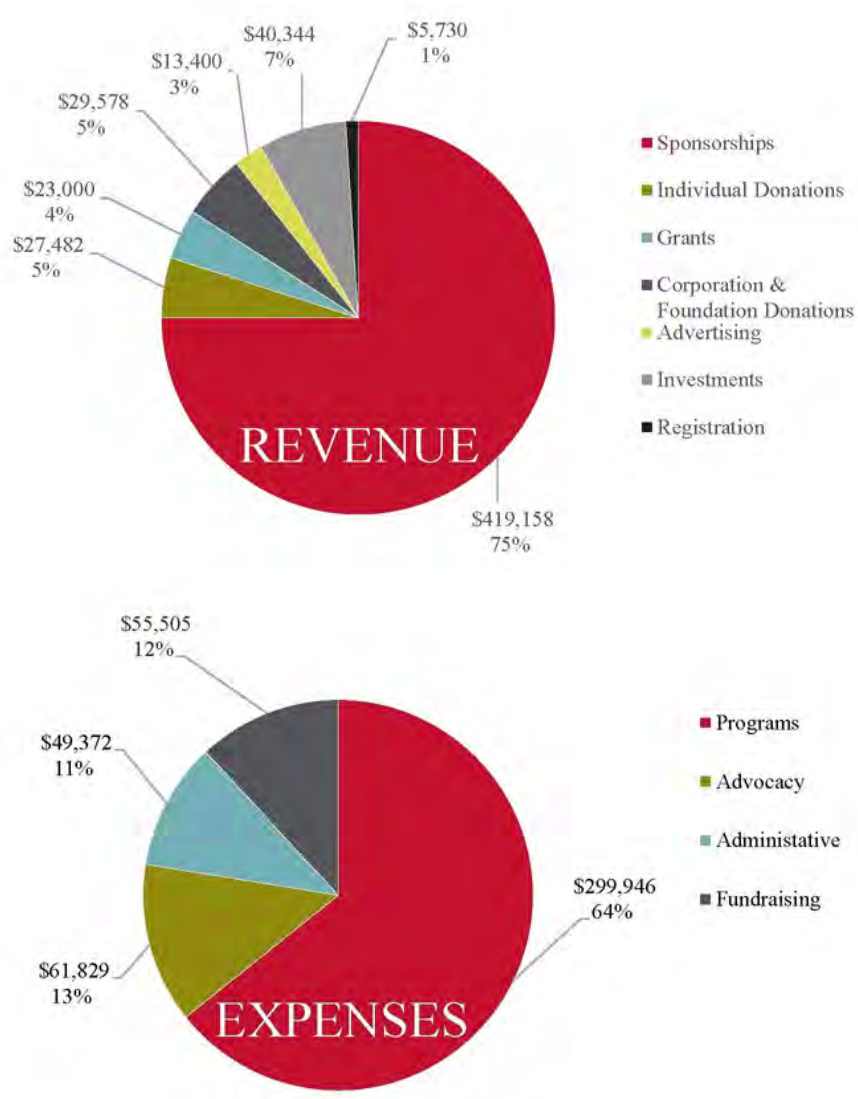
When you make a donation to VHF, you are supporting a myriad of programs and services throughout the year that directly impact individuals living with bleeding disorders and their immediate family members.

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 and Camp Youngblood, a weeklong summer camp for kids and teens.

In fiscal year 2018 - 2019, VHF served approximately 185 households and offered 27 events. Events ranged in size from intimate retreats with 10 people all the way up to a family weekend with over 200 attendees!



From Audited Financial Statements Year Ended June 30, 2019



Make a monthly gift and 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 2018 - 2019 members:
Jeff & Christine Krecek, Michael & Barbara Wheatley, Steve & Sarahbeth Spasojevich

ADVOCACY

VHF has had an active year in advocacy, and we are grateful for our advocacy committee in partnership with the Hemophilia Association of the Capital Area (HACA). **Here are the top advocacy highlights from this past Fiscal Year:**

Advocacy Training, “Richmond Days” and NHF Washington Days: In partnership with HACA, approximately 55 attendees participated in Advocacy Training and Richmond Days and 40 attendees joined us at NHF Washington Days!

"I really enjoyed feeling like I was able to make a difference for the bleeding disorders community by going around and talking to the representatives and their staff. I felt like I was able to show them an example of some of the people affected by these very influential bills and acts that are getting passed, and hopefully teach them a bit about hemophilia too." **Jack Spasojevich**

"Overall, talking to our representatives about bleeding disorders was a cool experience. I felt comfortable talking about hemophilia and would like to help other people share their stories." **Cody Davidson**

Coalition Building: VHF collaborated with the Healthcare for All Virginians (HAV) in opposition to the Virginia Medicaid agency's (DMAS) submission of an 1115 waiver to institute work requirements for able-bodied Medicaid recipients as well as the Fair Health VA coalition to promote fair co-payments and to constrain the use of step therapy.

Constituent Storytelling: In partnership with Hemophilia Federation of America (HFA), VHF was able to record videos of 21 constituents at the 2019 Annual Meeting.

HACA/VHF Advocacy Ambassadors: This program was created with the goal of having volunteers host and lead local initiatives and events as well as educate fellow constituents on statewide issues throughout the year.

2019 General Assembly: We achieved success with the passage of HB 2126, which puts constraints on the use of step therapy for insurance plans regulated by the Commonwealth. This was a culmination of four years of advocacy work. VHF also worked with coalition partners to advocate for the passage of HB 2515 and SB 1596, bills eliminating the accumulator adjusters on plans regulated by Virginia's Bureau of Insurance, which were the first bills of its kind to pass in the US!

NHF Chapters of Excellence Awards: For the second time VHF was a recipient of the Advocacy and Public Policy Award. We also received NHF's State Based Advocacy Coalition Grant.



CONTRIBUTIONS

Listed below are individuals who have made a financial contribution from July 1, 2018– June 30, 2019. VHF is so grateful to you all. If we inadvertently omitted or misspelled your name, please accept our apologies.

Patron Friend | \$1,000+

TJ & Monika Eiden
Frederick & Carlene Harmeling
Marty & Natalie Kaszubowski
Jeff & Christine Krecek
Sean & Kim McGarry
Kevin & Dorothy O'Connor
John Parron
Tom & Candy Spasojevich

Sustaining Friend | \$500-\$999

Kristin & Bernard Arnoldi
Brad & Kendall Fitzpatrick
Eric & Jeanne Mann
Mike & Ashley Silva
Steve & Sarahbeth Spasojevich
David & Mary Valentino
Michael & Barbara Wheatley

Supporting Friend | \$250-\$499

Robyn Arrington
Lamont Banks
Debbie Baugher
Laura Boyd
Catherine Breitbeil
Travis Campbell
Christopher & Kate Dolan
Bryan Gibson
Kristen Hudacek
Robert & Theresa Kitts
Rick & Julie LeFevre
Lucky Lippa
James & Virginia McCauley
Randy & Kathy Mortimer
Jane Newman
Kelli Plusch
Temesha & Josh Pollock
Douglas & Donna Puryear
Elizabeth Ravn
Marquita Reinhardt & Brandon Taggart
Beth and Chuck Robertson
David Smalley
Thomas Sprouse
Sue Tucker

Contributing Friend | \$100-\$249

Megan Arrington
Mary Blanchard

Robert & Donna Bordone
Robert Breitbeil
Virginia Chandler
Rebecca & Todd Christensen
Susan Davies
Frank Garcia
Melvis Garcia
Victor Gardner
Frances Herring
Bethany Hunter
Diane Interdonato
Cedron Kirby
Vivek and Marian Kshetrapal
Michael Larson
Michael Lee
Fred Marks
Gita Massey
Joann Mathews
John Mathews
Freda McIver
Kristina Montuori
Gary & Crystal Morris
Charles Oshields
Jean Parnell
Gary Phillips
Barbara Pollock
Schuyler and Kauai Porche
Steve & Debbie Schofield
Tim & Susan Shomaker
Ralph Silva
Edwin & Terry Smith
Barbara Smith
George Stone
David & Theresa Stone
Jamison Taggart
Larry Taylor
Albert & Marijane Valentino
Allison Vaughan
Deeann Wagner
Tyrone Walker
Troy Wallace
Reginald & Lucianne Warren
Kelly Waters
Jennifer Watts
Jerry & Michele West
Mary Wiggs

Friend of VHF | \$5-\$99

Guzin Akan

Ava Allen
Edwin & Madeline Andera
Kianna Arnold
Jillian Avey
Kelly Ball
Candy Baynard
Bob Benton
Morgan Bethany
Jennifer Blackwell
Alyssa Bouchard
Walter & Susan Branam
Paul & Frances Brayshaw
Christie Breitbeil
Tanya Brennan
Christian Brock
Aaron & Eileen Bunn
Karly Burns
Kimberly Burton
Miranda Butler
Carol Byrd
Christy Cable
Jennifer Coachman
Heather Conner
Alexander Cooper
Katie Cooper
Sarah Covert
Lawrence & Nancy Cowan
Norman & Ann Marie Crawford
Stephanie Creekmore
Holle Cuje
Colin & Krista Davidson
Chris Davis
Shebony Davis
Dorothea Davis
Stanley Davis
Jared Dean
Nyingha Dempsey
Deanna Dick
Jacqueline Dietz
Bev Doud
Becky Dubois
Robert Dunigan
Lauren Dunn
Jeanette Dupree
Kelly Durham
Donna Esposito
Cicely Evans
Patricia Falls
Beth Falwell

COMMUNITY

My son Matthew was diagnosed at only three days old with Severe Hemophilia Factor 8 deficiency. When he was 14 months old, we found out he had developed an inhibitor. I was later diagnosed as a spontaneous carrier for the gene and could finally answer some of my own puzzling health concerns. We had no other family history of bleeding disorders. Having an inhibitor actually is inhibiting. It inhibits normal clotting factor from working and it inhibits our lives in many ways. I wish people who aren't familiar with bleeding disorders knew how hard it is. Some families struggle every day emotionally, physically, and financially. We are in a better place with our medical care than previous generations, but we still have far to go through research and finding better treatment. We must continue to fight for ourselves and for our children, through advocacy and education.

Our Unite for Bleeding Disorders Walk Team, Star City Bleeders, was inspired to be successful because we know first-hand how important this funding is and how a little bit can go a long way. Our team is based out of Roanoke, Southwest VA. There is only a few of us affected with bleeding disorders, but yet we are large in voice and advocacy. Here, we are a small minority who usually has to travel out of town for medical appointments regularly. The Unite Walk allows us the opportunity to spread awareness about bleeding disorders.

Our goal was to spread awareness about bleeding disorders and to raise funds to support the needs of our community members. In a small town, hemophilia is rare and it is strange, so every person we can reach with our campaign becomes aware of the issues our community faces, and the need to support them.

Our team was dedicated to reaching our goal and showing support for our local chapter through the Unite Walk. It is important for moms and dads to have a platform and an event to meet other parents who they can relate to and for older adults to learn about aging with hemophilia and new treatments. It is important for young people affected to learn how to infuse themselves, and VHF does all of that through their educational meetings and events. The funding we raise is crucial to supporting those efforts and ensuring we get the best education we can for our community members.

Marquita L Reinhardt

Top Team Captain

2018 Unite for Bleeding Disorders Walk



CONTRIBUTIONS

Listed below are individuals who have made a financial contribution from July 1, 2018– June 30, 2019. 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'd.

Amanda Farnham
Jenifer Feagins
Lucy Fick
Tina Fitchet
Kelly Fitzgerald
Cristy Fossum
Deonta Gail
Jessy Garcia
Shelika Garcia
Patricia Gary
Chris & Joyce George
Janet Gibson
Wendy Gill
Bob Gilliam
Joylynn Givens
Lynnita Glass
Crystal Godwin
Cara Graves
Sharon Hall
Melinda Harden
Debra Herrington
Jane Higdon
Tyechia Hogan
Cathie Howard
Theresa Ihrig
Evelyn James
Brett Jameson
Sasha Jean-Noel
Jean Jirovec
Murai & James Johnson
Keonna Johnson
Brenda Kelly
David & Ann Kendall
Bobby & Margaret King
Kimberlee Koerner
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Susan Leonard
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Sarafina Maggio
Kelly Matthews
David & MaryAnn McCrum
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Judd & Sara Mendelson
Lawrence & Judith Meyer
Brian & Joy Milligan
Linda Mills
Karen Minkoff
Barbara Mitchell
Thelma Mitchell
Claire Moore
Brandy Mosley
Gayle Mustoe
Sidney Newton
Lara Nichols
Mindy Nolte
Aine Norris
Arvena Nowell
Judy Okain
Stephanie Owen
Melissa Park
Nick Parnell
Regina Pannell
Melanie Paschal
Laura Patton
Kirby & Barbara Perkins
Lindsey Plessinger
Jennifer Pollock
Lovice Pollock
Whitfield Pollock
Moveda Porath
Lisa Prado
Shan Pratt
Jason Priest
Wes Pruitt
Shereen Ramos
Dean Rasmussen
Gina Raymond
Christine Regan
Dennis Regan
Kathleen Rehnberg
Kathy Ridenour
Torrence Robinson
Megan Rodman
Amy Rohrbaugh
Tina Rollins
Tameka Rollins
Kenneth & Jessica Rose
Victoria Rytter
Lisa Saba
John & Diana Sanny
Ila Santimauro

Mike Scantlin
Jack Schoch
Mike Scholfield
Megan Schowengerdt
Ryan Schwan
Anita Schwartz
Jeanette Seagraves
William & Rachel Shifflett
Lennie Showalter
Joan Silva
Lindsay Silva
Sherene Silverberg
Brenda Simmons
Rajah Smith
John Smith
Jazmine Smith
Bruce Steeley
Scott Steen & Sharon Moore-Steen
Polly Stephens
Vonitta Stuart
Marie Summers
Deborah Taggart
Conley & Elizabeth Taylor
Sarah Tepe
Scott Tinkel
Khiem Tran
Brandy Traver
Walter & Jacqueline Tucker
Andrea Turner
Rebecca Underhill
Tameeka Vance
Robert & Karen Visser
Joe & Jackie Wadle
Kim Walker
Dennis & Anne Walker
Amy Walker
Sarah Waniewski
Daniel & Lydia Warren
Danny Weibling
Michael Welshonce
Eric Werner
Pamela White
Jasmin White
Patricia White
Donald & Rosalyn Wiggins
Faith Winstead
Allen & Barbara Young
Neil Zaccari

SUPPORTING ORGANIZATIONS

Listed below are organizations which have made a financial contribution from July 1, 2018 – June 30, 2019. If we inadvertently omitted or misspelled your name, please accept our most sincere apologies.

Accredo
AmazonSmile
AMF Bakery Systems
Aptevo Biotherapeutics
Bank of America Charitable Foundation
Bayer Pharmaceutical
Belle Isle Craft Spirits, Inc.
BioMarin
BioMatrix
Colburn-Keenan Foundation Inc.
Colonial Farm Credit Union
CSL Behring
CVS Caremark Specialty Pharmacy
Diplomat
Dominion Energy
DrugCo Health
East Hanover Womens Church Softball League
EMS Management & Consultants, Inc.
Factor One Source Pharmacy
Genentech
Grifols
Hemophilia Federation of America (HFA)
Hoos at Home
Houston-Holicky-Sitter Group

James & Vickie Scantlin Trust
King William High School
Kroger Cares
Markel Corporation
Marriott
National Hemophilia Foundation (NHF)
Novo Nordisk, Inc.
Octapharma USA, Inc.
PayPal Giving Fund
Pfizer
PhRMA
Prim Family Charitable Fund
Progressive Insurance Foundation
Sanofi Genzyme
Soleo Health
Spark Therapeutics, Inc.
Strategy Cafe
SunTrust Banks
Superior Biologics, Inc.
Takeda
The Hemophilia Alliance Foundation
Towne Bank
West Charitable Trust

COMMUNITY HEALTH CHARITIES

VHF is a member of Community Health Charities (CHC) workplace giving campaigns in Virginia. VHF has been approved to participate in the 2019 Commonwealth of Virginia Campaign, running through January 3, 2020. **To donate to VHF with the state employee campaign (Local Government and Schools United Way) direct your donation to #06043.**

Thank you to the following individuals who pledged support through the 2018 statewide CHC Campaign: Heather Brinkley, Shelly Evans, and Michael Gardner.

We'd also like to thank Mandy Baker, Michael Baker, and Charles White for their workplace giving in 2018 through United Way of South Hampton Roads.



Join our **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 last forever.

For more information call 804-740-8643 or email info@vahemophilia.org.

VHF CALENDAR 2020

January

19th – VHF/HACA Advocacy Training (Richmond)

20th – VHF/HACA Richmond Days (Richmond)

February

8th – Women's Retreat (Williamsburg)

9th – Women's Community Event (Williamsburg)

26th -28th – NHF Washington Days (Washington D.C.)

March **Bleeding Disorders Awareness Month**

7th – Medical Symposium Meeting (Richmond)

8th – Community Event (Richmond)

April

19th – Red Tie Soiree at the Dewey Gottwald Center (Richmond)

23rd – 25th – HFA Symposium (Baltimore, MD)

May

2nd – Educational Lunch and Community Event (Roanoke)

16th – First Step Program (TBD)

June

19th – Community Dinner (Virginia Beach)

20th – Annual Education Meeting (Virginia Beach)

21st – Community Event (Virginia Beach)

July

5th-10th – VHF/HACA Camp Youngblood at Camp Holiday Trails (Charlottesville)

August

6th – 8th – NHF Annual Meeting (Atlanta, GA)

21st – 23rd – VHF/HACA Teen Retreat (Charlottesville)

September

26th – Community Retreat at Great Wolf Lodge (Williamsburg)

October

25th – Unite for Bleeding Disorders Walk at the Stony Point Fashion Park (Richmond)

November

7th – Men's Retreat (Richmond)

8th – Men's Community Event (Richmond)

December

5th – Winter Gatherings (Virginia Beach and Richmond)

Please note that this is not a complete calendar. Dates and details are subject to change. Visit our website at www.vahemophilia.org or call 804-740-8643 for more information.

*Thank you for all your support in Fiscal Year
2018 - 2019. We can't wait to see you in 2020!*



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