

The News Infusion

The Official Newsletter of Bleeding Disorders Association of South Carolina

VOLUME 12, ISSUE 2

SPRING 2023



STEP

for bleeding disorders

Featured Articles

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Raising Awareness: A Month of Advocacy, page 10

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About BDASC & The News Infusion

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A Chapter of the National Hemophilia Foundation
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BDASC MISSION: To raise awareness for and advocate on behalf of persons with bleeding disorders and their families; provide education and supportive services; and promote ongoing research to improve the quality of life for those affected. **BDASC VISION:** The Bleeding Disorder Association of South Carolina is to be recognized as a leading organization providing valued services; as ambassadors of public outreach to enlighten and foster an understanding of what matters most to those affected by hemophilia and bleeding disorders; and to be our community's first choice in partnership to achieve their highest potential through empowerment, connection to their community and being part of the solutions that affect them the most, until a cure is achieved.

Spring-Summer 2023 Calendar of Events

Looking Ahead: Save the Dates!

Community Engagements

June 9-10, 2023: 50th Annual Meeting and HELLO Conference

June 12-16, 2023: Camp Burnt Gin (Ages 7-18 yrs)

June 14, 2023: Chapter Day at Camp Burnt Gin

June 25-30: Camp Courage

June 27: Chapter Day at Camp Courage

June 25-29, 2023: Camp Victory Junction

July 23, 2023: Back to School Community Engagement, Greenville Drive

August 10-13, 2023: Teen Retreat, Camp Canaan, Rock Hill, SC

August 17-20, 2023: NHF's Bleeding Disorders Conference, Maryland

September 22, 2023: Par for the Clot Charity Golf Fundraiser, Greenville, SC

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About This Publication

The News Infusion's mission is to provide communication, connections, education and advocacy awareness. It is published quarterly by the Bleeding Disorder Association of South Carolina as an informational service to its members, friends, and affiliates of South Carolina's bleeding disorders community. *The News Infusion* does not endorse any provider, company or product, and further recommends that its readers always consult with their physicians and health care providers. *The News Infusion* is for educational and communication purposes only and makes no claim to its accuracy. *The News Infusion* is endorsed by the South Carolina Hemophilia Treatment Center and the National Hemophilia Foundation. We encourage your feedback and communications as a forum for exchange of information, ideas, and opinions. We welcome your letters, articles, questions and pictures. All articles may be published or distributed in print, electronic, online or in other forms. All submissions will be verified and subject to editing. Please send to the editor-in-chief at: sue.martin@bda-sc.org. Mail to: 25 Woods Lake Road, Ste 300, Greenville, SC 29607, Attention: Editor-in-Chief, The News Infusion. We look forward to hearing from you soon!

STEP For Bleeding Disorders 2023

May 6, 2023, Columbia, SC

On Saturday, May 6, we had a beautiful day to enjoy our 10th annual STEP for Bleeding Disorders Walk/5K Run fundraiser. Our volunteers arrived bright and early to get everything set up and ready for our participants. Our sponsors arrived shortly before our participants, and we knew it would be a fantastic day. In the end we had hundreds of people donate and join in the fun!

Participants enjoyed having fun with face painting and tattoos provided by Emerald Artistry, a photo booth, and our DJ Andre, provided by Big Time Entertainment. Olly the Otter, Benny the Blood Drop, and Cocky the USC Gamecock joined in on the dancing fun to get everyone warmed up and excited to take to the course. Before we headed out, we enjoyed a parade led by Olly, Benny and Cocky for those teams wishing to participate in the costume contest or to just walk in the parade. Our volunteer judges watched the parade as they decided which costumes would win the awards for the Most Creative Individual and Most Creative Team. This year, Team HEMariO Bros took both awards with Joey Krakowiak representing them as the Most Creative Individual Costume.

Once the parade completed, runners and walkers of all ages headed to the starting line. Participants were counted off by the DJ and the race began promptly at 10:00am. In a short 18 minutes, our first runner, Liam Robinson, returned to the starting line. He was quickly followed by his brother, Gregg Robinson, and Joey Krakowiak. Our top three runners were presented with medals to commemorate their achievement. Way to go!

As people began to complete their runs/walks, we were greeted by Marble Slab, who provided

ice cream and cookies! We are so thankful to Ryan Griffith of Marble Slab as he donated delicious ice cream and cookies for our walk again this year. Participants were also treated to a pizza lunch provided by Paragon and plenty of snacks and drinks were available at all times. We want to share with everyone our gratitude for those involved in this year's STEP for Bleeding Disorders. We are truly grateful for all the volunteers, participants, fundraisers, donors, and sponsors. With your help, we were able to raise \$51,293.70 — which was 85% of our goal. These funds you have helped us raise will help to aid in our mission to provide support, education, and advocacy throughout the South Carolina bleeding disorders community.

We are so grateful for everyone's continued support and commitment to raising funds to support our community. Congratulations to our award winners! Please view all our pictures on our Facebook page, and save the date of May 11, 2024, for our 11th Annual STEP for Bleeding Disorders Walk—same place, same time!

Most Creative and Original Costume: Joey Krakowiak- Super HEMariO Bros

Most Creative and Original Team Costumes: Super HEMariO Bros

Top Fundraising Individual: Joey Krakowiak — \$1,859.70

Runner-Up Individual Top Fundraiser: Mattie Watkins — \$670

Top Fundraising Team: Super HEMariO Bros — \$3,599

Runner-Up Top Fundraising Team: Team Logan — \$3,327.70

Largest Run/Walk Team: Tied at 24 each Team Limitless and Team Logan

Continued on page 4

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Runner-Up Top Run/Walk Team: Team Crispy Clotters

Oldest Participant: Chris Stokes at 71

Youngest Participant: Talton Baird — 9 months

Race Finishers:

1st Place: Liam Robinson

2nd Place: Greg Robinson

3rd Place: Joey Krakowiak

We are grateful to all our sponsors of the 10th Annual STEP for Bleeding Disorders



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With our Sincere Gratitude and Appreciation to our Past Board Presidents of 50 Years!

William Eichelberger

Betty Hammond

John Salter

Linda Robertson

George Dobbins

Pete Korn

Patty Korn

Tommy Williamson

Kim Wentzky

Darin Wentzky

Victor D. Fisher

Darin Wentzky

Rhonda Sumner

Frank Wentzky

Jim Hess

Mark Eichelberger

Lynn Warren

Phillip Lawson

Brandy Stewart

Gene Feather

Mark Eichelberger

Brandy Stewart

Victor D. Fisher

Vidalia McTeer

Suzanne (Sue) Martin

Lisa Bordelon

Mike Walden

Shelley Crisp

Aaron Smith (July 1, 2023)



HEMOPHILIA
of South Carolina
SERVING ALL BLEEDING DISORDERS



Executive Director's Welcome

By Sue Martin

"Never doubt that a small group of thoughtful committed individuals can change the world. In fact, it's the only thing that ever has."

— Margaret Mead

This June will be a time for reflection and an opportunity to honor the hundreds and hundreds of families and individuals who have worked relentlessly, and given tirelessly, and financially, throughout the past "50 years"! It is unbelievable that a small group of dedicated people can change the lives of those affected by bleeding disorders by doing the mission work of our organization. Starting out in 1973 as Hemophilia of South Carolina and now being known as Bleeding Disorders Association of South Carolina, the amazing work this organization has accomplished is something some may not understand or have not had the privilege to witness. For 20 years now, (hard to believe) I have witnessed first hand the transformation of HSC-BDASC, and I continue to admire so many individuals and be honored to serve as the executive director. There is not a day that goes by that I do not appreciate what others have done in the past, and currently do today, for this community.

Our [50th Anniversary Annual Meeting](#), being hosted on June 9-10 in Greenville, will be a time to honor and reflect on the past **50 years!** This includes our current members the organization has today, and those we have had over our 50 year history, those we have lost who were pivotal heroes to the bleeding disorders community and whom we miss dearly, and those who are yet to be born today. We will be sharing our stories, including providing a glimpse of the past 50 years of HSC-BDASC as we reflect on our advocacy successes and advancements in treatment care with a look

into our futures, and we will **celebrate!** This is a time to celebrate all of us, new members and all the past members, those still active, and those who have moved on. You all deserve our **DEEPEST GRATITUDE**, and for me personally, you have my deepest appreciation.

It has been an honor and a privilege to serve this South Carolina community in one way or another for the past 20 years and I thank you all for the support, your warm hearts, and your kindness. Things are changing in our bleeding disorders circles and will continue to change. Some may be concerning, and some may be for the better. One thing is always for sure, with time, things will always change. But if we walk together in unity side by side, we will always end up on top, and have success. One thing I believe will never change, and that is the strength of, and the love for, this South Carolina bleeding disorders family/community. I encourage you all to come to the annual meeting even if you have missed the deadline for our traveling guest rooms. I will need the final counts for food one week prior to the event, so there is still time. Call me, drive up for the day on Saturday, or Friday night, and let us celebrate together! Thank you Hemophilia of South Carolina — Bleeding Disorders Association of South Carolina for giving us hope and strength for **50 Years** and helping us build brighter futures for those impacted by bleeding disorders. Thanks for helping us dream for the day we will have a cure for all bleeding disorders! With my warmest regards and a grateful heart, thank you!

Love,
Sue

Thank you to my dear friend Rigoberto Garcia, Southern California Chapter, Executive Director for the translation that follows on the next page.

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Bienvenida de la Directora Ejecutiva

por Sue Martin

“Nunca dudes de que un pequeño grupo de personas reflexivas y comprometidas puede cambiar el mundo. De hecho, es lo único que lo ha hecho”.

— Margarita Mead

Este mes de junio, será un momento de reflexión, y una oportunidad para honrar a los cientos y cientos de familias y personas que han trabajado sin descanso, y han dado incansablemente, y financieramente, a lo largo de los últimos “50 años”! Es increíble que un pequeño grupo de personas dedicadas pueda cambiar la vida de los afectados por trastornos hemorrágicos realizando la misión de nuestra organización. Comenzando en 1973 como Hemophilia of Southern Carolina y ahora conocida como Bleeding Disorders Association of South Carolina, el increíble trabajo de esta organización ha logrado es algo que algunos no pueden entender, o no han tenido el privilegio de presenciar. Desde hace 20 años, (difícil de creer) he sido personalmente testigo de primera mano, la transformación de HSC-BDASC, y sigo admirando a tantas personas y tener el honor de servir como directora ejecutiva. No hay día que pase en que no aprecie lo que otros han hecho en el pasado, y hoy día, por esta comunidad. Nuestra reunión anual del 50 aniversario, que se celebrará el 9 y 10 de junio en Greenville, será un momento para honrar y reflexionar sobre los últimos 50 años. Esto incluye a nuestros miembros activos de la organización y a los que hemos tenido a lo largo de nuestros 50 años de historia; a los que hemos perdido, que fueron héroes fundamentales para la comunidad de trastornos hemorrágicos y a quienes extrañamos mucho, y a los que aún no han nacido. Compartiremos nuestras historias, y daremos

un vistazo a los últimos 50 años del HSC-BDASC mientras reflexionamos sobre nuestros éxitos en la defensa de la causa, los avances en los tratamientos y mirando hacia el futuro, ¡Y celebraremos! Este es un momento para celebrar a todos nosotros, los nuevos miembros y todos los miembros anteriores, los que siguen activos y los que se han ido. Todos ustedes merecen nuestro MÁS PROFUNDO AGRADECIMIENTO, y personalmente, tienen mi más profundo agradecimiento.

Ha sido un honor y un privilegio servir a esta comunidad de Carolina del Sur de una forma u otra durante los últimos 20 años y les agradezco a todos por el apoyo, sus corazones cálidos y su amabilidad. Las cosas están cambiando en nuestros círculos de trastornos hemorrágicos y seguirán cambiando. Algunos pueden ser preocupantes y otros pueden ser para mejor. Una cosa siempre es segura, con el tiempo, las cosas siempre cambiarán. Pero si caminamos juntos en unidad, uno al lado del otro, siempre terminaremos con éxito. Una cosa que creo nunca cambiará, y es la fuerza y el amor por esta comunidad familiar de trastornos hemorrágicos de Carolina del Sur. Los animo a todos a que vengan a la reunión anual, aunque haya pasado la fecha para nuestras habitaciones de huéspedes itinerantes. Necesitaré los recuentos finales de comida 1 semana antes del evento, así que todavía hay tiempo. Llámeme, vengan el sábado o el viernes por la noche y celebremos juntos. Gracias, Hemophilia of South Carolina - Bleeding Disorders Association of South Carolina por darnos esperanza y fortaleza durante 50 años y ayudarnos a construir un futuro mejor para las personas afectadas por trastornos hemorrágicos. ¡Gracias por ayudarnos a soñar con el día en que tendremos una cura para todos los trastornos hemorrágicos! Con mis más cordiales saludos y un corazón agradecido, ¡gracias!

Con amor,
Sue

Message From the President

Shelley Crisp, Board of Directors, President
Hello everyone!! Hope all is well with you. As many of you know we love coming together as a community to raise awareness and for educational purposes. With that being said, we need to make sure our funds are being used wisely. Unfortunately, with the cost of venues and food prices going up we are trying to make the most of what we have. We want to bring as much to our community as we can, so we need full participation and follow through. If you have registered for an event, please make sure you can come and if you need to cancel, please do it as soon as possible. We still have a lot of last-minute cancellations for our events, but trust us, we understand life happens. When this happens, we are still responsible for the agreed upon contracts and food costs with our venues, even if you do not show. We want to make sure we can continue to have local events brought to you, but if we continue to have last minute cancellations or no shows then we will not be able to do so in the future. We want to see you and share with you all we can. We love our

community and want nothing more than to have future events for us to come together. Thank you for your understanding.

Dedicated to Service

Please help us welcome our newest Board of Directors. They will begin their two-year term beginning on July 1. April Baird is not new to the board as she has served in the past. Cristal Day served a six-year term with a one-year break and is back to serve the organization again. We welcome back both April and Cristal and thank them for their commitment. We will officially welcome them at our Annual Meeting on June 9.

Volunteers Are a Welcome Gift!

Would you like to help support BDASC? Volunteering for events and committees is a fantastic way to help. In order to continue to support and engage with our community, BDASC requires some help at events — whether it is manning the registration booth, keeping an eye on the kids in childcare, or helping to plan our fundraiser, there is something for everyone! If you would like to volunteer, please contact Sue at the chapter office.



Community Engagements

Bleeding Disorders Awareness Month

Throughout the month of March, community members spread awareness for those with bleeding disorders. Bleeding Disorders Awareness (formerly Hemophilia Awareness Month) Month was first proclaimed by President Ronald Reagan in March of 1986. This proclamation was the first of many to come. Each year our community requests proclamations throughout the nation declaring March the official Bleeding Disorders Awareness Month. These proclamations are utilized to spread awareness for the bleeding disorders community. Each proclamation is read aloud during a council meeting and is often shared on social media. Proclamations provide a

microphone to ensure that more people learn about bleeding disorders and their effects on the community. We are very appreciative of all those community members who reached out to their local officials to declare March Bleeding Disorders Awareness Month.

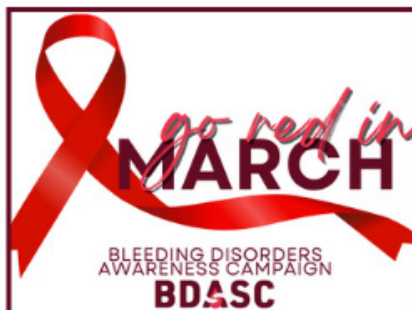
Thank you to the Keith family for securing a proclamation for the City of Irmo, SC. Thank you to the Martin family for securing a proclamation in Greenville County, the State of South Carolina, and the City of Greer. Thank you to the Javorka family for securing

a proclamation for the Town of Summerville. Thank you to the Smith family for securing a proclamation for the County of Richland. Thank you to the Day family for securing a proclamation for Anderson County. Throughout Bleeding Disorders Awareness Month — starting **February 28 with Rare Disease Day** and ending **April 17 with World Hemophilia Day** — community members came together to advocate for Bleeding Disorders. On February 28, our advocates participated in State Days Advocacy training to prepare for State Advocacy Days on March 1. Kicking off March with State Advocacy Days was an excellent way to start spreading awareness. Advocates shared their



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stories with members of the South Carolina House of Representatives as well as the South Carolina Senate. Continuing the advocacy efforts, eight advocacy coalition members attended NHF's annual Washington Days in Washington, D.C. This year marked a return to in-person Washington Day seeing almost 400 advocates gather. Each member has a unique story to share and were fortunate to be able to share their experiences with the legislative aides of our representatives.



Outside of advocating for our community, members came together to kick-off our community fundraiser — the STEP for Bleeding Disorders Walk. March marks our campaign to gather as teams to raise money for our South Carolina bleeding disorders communi-

ty. On Friday, March 17, we hosted a Virtual Pizza Party where we played Kahoot! and learned more about the STEP for Bleeding Disorders Walk. We also celebrated our first Adult Men and Women's Retreat and Medical Symposium to round out the month of awareness.

Men And Woman's Adult Health Equity & Medical Symposium

March 31 - April 2, Greenville

To close out a great month of Bleeding Disorders awareness, we enjoyed a weekend away for adults who are impacted by bleeding disorders at the beautiful AC Mariotte Hotel in the heart of downtown Greenville. The weekend began on Friday night with a welcoming dinner presentation on Gene Therapy, (now available for the hemophilia B population) sponsored

by CSL Behring. Before the activities of the night got started, attendees got to know one another with a tasty M & M ice breaker activity moderated by BDASC. Equally exciting, following the dinner presentation was the discussion from Dan Korn who was joining us all the way from Australia. (He was visiting family

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Continued from page 11 in Greenville.) Dan shared his experience of having Gene Therapy from a clinical trial several years back and his insight on his experience and what it has meant to him and his family. Then it was off to do a little adult “Group Therapy,” well... we are really talking about where we threw axes and played wacky golf, curling, ping pong, and hung out and laughed. Oh, and yes, a little karaoke to close out the night for the women.

The following morning and afternoon on Saturday, we enjoyed an educational session for both men and women, and then we broke out for sessions geared mainly just for men, and just for women. It was nice to have some conversations alone among groups of the same sex. Our sessions included:

Supporting Health Equity, Women’s Health – Saving One Uterus at a Time, “Masculine Mental Health”, Women with Bleeding Disorders & Surgery, Tackling Transitions and Embracing Change, Mental Health & Wellness; Caregiver Stress, We don’t have to be a Superwoman, Wrap Sessions for Men, A Focus on Women’s Health – Sunrise Self-Reflection, Safe Movement & Empowerment, Lifeguards – What Keeps You Afloat, and a Group Advocating Activity; What Would You Do?

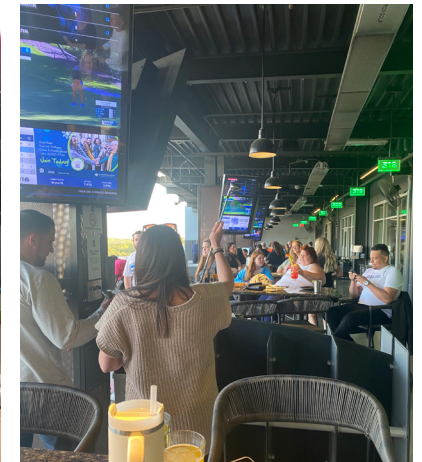
After some free time to enjoy exploring downtown Greenville, we were treated to a **Group Dinner Presentation; Pushing Through with Positivity**–presented by Pete Dyson,

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a Gettin' in the Game Athlete, and a Team Building Golf Competition. This was sponsored by CSL Behring at the [Top Golf of Greenville](#). It was exciting to see so many new "golfers" in the group as they hit and swung their clubs high off the third floor into the nets below. It was a great way to end a day of educational support among the community. On Sunday we began all over again until noon when we finished with a wrap

up session and headed home. The hotel and downtown Greenville did not disappoint, along with the speakers, sponsors, and of course our fellow members. Look out for next year, secure the babysitters, and we will do it all over again. We so appreciate all our sponsors and those who were able to spend the weekend with BDASC!





Celebrating World Hemophilia Day: One Family

On April 17, the global bleeding disorders community came together to celebrate World Hemophilia Day. Our BDASC families also came together to celebrate at the Westin Poinsett Hotel in downtown Greenville. The theme of this year’s celebration was “One Family”, and experiencing the power of protection with access to care and treatment.

The community enjoyed a wonderful dinner with hands-on activities that focus on four key themes: factor activity, pharmacokinetics, and why they matter, bleed protection and lifestyle, and telling your story as a form of self-advocacy. The overarching message of the night was the importance of community connection. It was a nice night of community engagement and we thank Sanofi for the opportunity to come together and celebrate!

with a fun evening of painting and community, followed up by a board and brush event in Summerville, and completed the sweep with a community dinner event in Greenville. It was so wonderful to come together to celebrate the women in our lives throughout the state.



Celebrating the Women in Our Lives During Mother’s Day Weekend Throughout the State

The chapter swept through all three regions to bring together our women in celebration of Mother’s Day weekend. We started in Columbia

Painting With a Twist

May 11 in Columbia, SC

On Thursday evening, May 11, our women came together for an evening of painting, dinner, and community. Our women were treated to a presentation on mindfulness and how to be aware and present in the moment. The presentation included the benefits of mindfulness such as reducing stress and managing pain. After the presentation, we spent the evening chatting and creating our works of art!



Nailed It! DIY Studio

May 12th in Summerville, SC

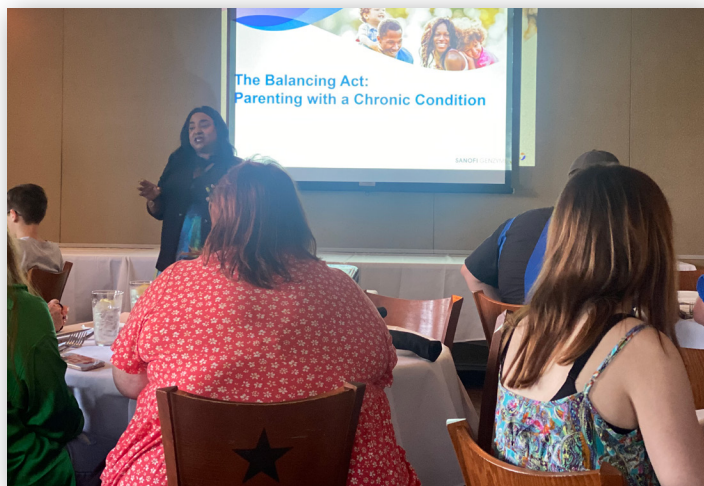
Next stop was Summerville for an evening of community and more artistry! Our women were treated to dinner and were able to choose a

wood sign design to create for their homes. Many women from the low country and beyond were in attendance and had a wonderful time.



CityRange Steakhouse – Community Connection Event May 16 in Greenville, SC

On our way back around the state, we stopped in Greenville for an entire community engagement event at CityRange Steakhouse. Participants were presented with a fantastic talk about parenting children with chronic conditions. Robust conversations and sharing provided insight from each family on how they handle situations with their children and what works for them. Dinner was enjoyed by all. Thank you to everyone who came out to our events throughout the regions. It was a busy three days, but it was so much fun!



Upcoming Engagement Opportunities

50th Anniversary and HELLO Conference Honoring Our 50 Years, Our Legacy

“Behind every mask lies a story” — The story of our community’s 50 years of strength and courage

On June 9-10 in Greenville, we will honor our 50th Anniversary celebration at our annual meeting and HELLO Conference. 2023 marks 50 years since the inception of Hemophilia of South Carolina (now known as the Bleeding Disorders Association of South Carolina).

In 1973, a group of parents of children with hemophilia came together to promote awareness, provide support, and assist other national hemophilia organizations. For 42 years the chapter existed as an all-volunteer organization providing education, support, and advocacy. In 2021, HSC became the Bleeding Disorders Association of South Carolina (BDASC), providing a more inclusive community focusing on all bleeding disorders.

To commemorate BDASC’s achievements over the past 50 years, the HELLO Conference will evolve into a celebration of our past, present, and future. On Friday night, we will host a Masquerade Gala. This celebration will honor our 50-year legacy of providing support to our bleeding disorders community here in South Carolina. We will kick off the evening with dinner, our annual awards, and a night of dancing.



There will be opportunities to come together as a community and share what makes this bleeding disorders family unique.

The Gala will also be a time to recognize the members within our community with our Chapter Awards, announcement of new and retiring Board Members, and scholarship

winners. We are thrilled to be able to formally recognize members of the community.



Our day of educational sessions will begin with our Keynote Speaker, Dr. Duc “Bobby” Tran speaking about our past, present and the future of Bleeding Disorders Treatment and Care. Dr. Tran joins us from Emory University School of Medicine at the Comprehensive Bleeding Disorders Clinic. Dr. Tran will be joined by community members who will be sharing their experiences with their bleeding disorders over the past 50 years. Following his session will be an advocacy look at BDASC past, present, and future. Additional sessions include Shared Decision Making and the Shift to Person Centered Care, Women Who Bleed, Advocating in the ER, Learning the Science of Kinesiology Taping, VWD Education and Support, and an Infusion Class.

We didn’t forget to include our youngest members of the community. Our children will be able to participate in Wacky Olympics! The kids will create their own countries, flags, and uniforms, then participate in the wackiest Olympics events ever! On-Site childcare will be provided by Corporate Kids Events and supported by BDASC. Our tweens will also be treated to an educational session provided by Optum and our younger kids will have the opportunity to participate in an educational program provided by CVS Specialty. Our Teens will have their own programming as well. This year, GutMonkey is back! Teens will participate in the Leading-Edge program with GutMonkey. In this year’s program, participants will explore “Systems,” or the small ways in which we live our lives and what it says about who we are and our future goals. Our day will end with a wrap-up dinner outside on the hotel terrace.

Join us for “Back-To-School” with the Greenville Drive July 23, 2023 at 3pm

On July 23, the Greenville Drive will face off against the Asheville Tourists at Fluor Field in Greenville. Join us at this community engagement event sponsored by Takeda to celebrate the end of summer and the start of a new school year. An educational presentation

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will be enjoyed along with food and drinks. You can enjoy watching the game in our box seating suite which will provide comfort to you and your family with the opportunity for support and fellowship with members of BDASC. Registration

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will open in late June and will be on our website and provided in our email blasts, and for our iPad users, the icon will be available to register from your device.

Please note: Greenville Drive policy limits and restricts the size and type of bags that are permitted into the stadium during Drive games. Check out the [Greenville Drive website](#) for more information on their policy.



Summer Camps Programs and Assistance

Camp Burnt Gin & Camp Courage

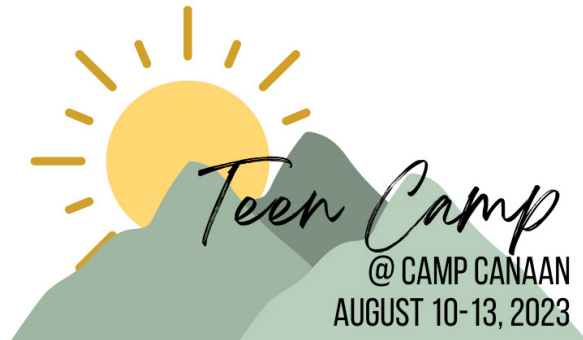
We are very excited to be able to support the children in our community. Summer Camps for our kids are back this year and we are excited to be attending both Camp Burnt Gin & Camp Courage with our famous Ice Cream Social! Look for our Executive Director, Sue Martin, at Camp Burnt Gin on June 14 and at Camp Courage on June 27! The ice cream for this event was generously provided by Marble Slab and our friend Ryan Griffith!



Teen Retreat

The “Carolina Crew” Teen Retreat will again be hosted by the Bleeding Disorders Association of South Carolina in partnership with the Bleeding Disorders Foundation of North Carolina. This retreat is available to community member teens

with bleeding disorders, between the ages of 13 and 18. This year, the Teen Retreat will be August 10-13 at Camp Canaan in Rock Hill, SC. If your teen has already started school by this date, please reach out to Sue at the Chapter Office to see if it can be arranged for your teen to attend Friday Night – Sunday. We understand that this week is not ideal now with the schools changing the starting days to earlier in August so we will



do our best to accommodate if we can. It is important to note that BDASC does provide travel grants for those community families who are traveling to take their child/children to summer camp. For more information and to find the application for BDASC Summer Camps Programs and Assistance, please visit our website at [bda-sc.org](#) under the “Members Services” section.

The Par for the Clot Returns to The Preserve at Verdae

September 22, 2023

The Bleeding Disorders Association of South Carolina is excited to host our annual charity golf fundraiser, “**Par for the Clot**” on September 22, 2023. Players will enjoy a wonderful day of golf, food, fun, and competition. Last year, we had 36 teams and 144 participants who competed for some great prizes and enjoyed a wonderful awards dinner reception banquet immediately following the tournament at the Embassy Hotel Terrace in Greenville.

Continued on page 22

FACTOR UP with ALTUVIIIIO™

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week

ALTUVIIIIO™
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*Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

†159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

‡Data based on treated bleeds.

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Your healthcare provider may give you ALTUVIIIIO when you have surgery.

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What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full [Prescribing Information](#).

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MAT-US-2301368-v1.0-03/2023

Voices of Our Community

Proclamations Received

Over the course of Bleeding Disorders Awareness Month, BDASC tasked our members to reach out to their local city, town, or county to procure proclamations declaring March Bleeding Disorders Awareness Month. A total of 7 proclamations were procured by various members throughout the state. Executive Director, Sue Martin and her family were able to secure Greer, Greenville, and Greenville County. Marilyn and Keith Ward were able to secure the city of Irmo. Samantha Javorka and her



family were able to secure the town of Summerville. The Smith family were able to secure the proclamation for Richland County. These proclamations are more than just a piece of paper. Each proclamation represents awareness being brought to the Bleeding Disorders Community. For those interested in securing a proclamation next year, it's simple. Visit our website to learn how to procure proclamations. It's as simple as sending an email and showing up at a council meeting.



Von Willebrand and Women Who Bleed Community News

To best serve our VWD and Women Who Bleed Communities, we are excited to share two opportunities during the HELLO Conference dedicated to meeting your needs.

The Women Who Bleed community will have a session dedicated to addressing carrier status. This session will empower women to know the meaning of their bleeding disorder carrier status and treatment options. The VWD Community will come together for a round-table discussion about the challenges of living with VWD. This session will be moderated by BDASC and our HTC staff. Discussions will center around the unique challenges the VWD Community faces and how to overcome these obstacles. We hope to see you there!

Study Suggests Significant Rates of Depression and Anxiety for Individuals with VWD

While it is well understood that individuals with von Willebrand disease (VWD) will experience a variety of bleeding episodes throughout their lifetime, the psychosocial impact of these symptoms has received relatively little inquiry. Greater knowledge of these impacts could help inform and support potential mental health screening efforts for VWD patients at U.S. hemophilia treatment centers (HTCs).

To help fill this gap a group of researchers from several HTCs across the country sought to estimate rates of symptomatic depression and anxiety among individuals with VWD. Investigators used specific validated measures to evaluate the sociodemographic and clinical characteristics associated with depression and anxiety. They employed two patient questionnaires—one focused on depression and another on generalized anxiety disorder—to collect data on VWD patients' sociodemographic information, joint problems,



and health-related quality of life (HRQoL).

Study participants were enrolled from HTCS located in seven states, including Georgia, Michigan,

Illinois, Missouri, New York, Washington, and California. Ultimately, 77 patients with VWD type 1, 2 (2A, 2B, 2M, 2N), or 3 VWD were included in the analysis, all of whom were 12 years of age or older.

The results, which were published in the journal *Haemophilia*, showed that a relatively high proportion of the participants met the criteria for both depression and anxiety, with rates at 63.6%, and 58.3% respectively. There was not a significant difference in depression rates between participants ages 12–17 years and adults 18 years of age and older (65% vs. 63.2%). The anxiety rate among age 12–17 years was 16.2% higher than among adults (70% vs. 53.8%), though deemed “not statistically significant,” by the authors.

Several variables were strongly associated with depression in adults, including most prominently, joint problems. Being single, divorced, widowed, or separated were also linked to depression in adult participants, prompting the authors to emphasize the value of a strong support network for individuals with VWD. In addition, participants aged 12–17 were more likely to have anxiety. The authors describe this as a time when adolescents with VWD begin a slow transition to adulthood, wherein they gradually take greater ownership of their own care. Coinciding with puberty, this is a process that will naturally prompt some stressful situations even under the best of circumstances.

The authors posit that findings such as these should be impetus for enhanced mental health screening with VWD patients at HTCs.

Continued on page 23

Did You Know?

Substance Use & Mental Health Access Coalition

As a founding member of the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC), the New England Hemophilia Association (NEHA) is leading the

way to ensure that all individuals with bleeding disorders have access to appropriate substance use and mental health treatment facilities.

Coalition Origins

In late 2021, a 20-year-old individual from New England with a bleeding disorder asked their hemophilia treatment center (HTC) for help in finding a residential treatment facility for their substance use disorder (SUD). Although the HTC nurse called many local residential SUD treatment facilities, none of them would take a patient with bleeding disorder who required intravenous (IV) infusion medications during their stay. Without access to appropriate treatment, the patient overdosed and died. After her patient's death, the HTC nurse contacted NEHA to help ensure that no one else



BD SUMHAC

Bleeding Disorders Substance Use & Mental Health Access Coalition

would be denied access to necessary SUD treatment because of their bleeding disorder. Chaired by a board member, NEHA brought together the Hemophilia Federation of

America, the National Hemophilia Foundation, HTC providers, other chapters, and bleeding disorder community members to establish the BD SUMHAC. The mission of the coalition is to advocate for access to appropriate substance use and mental health treatment facilities for all individuals with bleeding disorders.

This coalition features members from across the country and a variety of bleeding disorder related groups and chapters, who all unite on one thing: getting community members the mental health/substance use disorder treatment they so desperately need, when they need it most. Learn more about BD SUMHAC at <https://hemaware.org/life/behavioral-care-mental-health-crisis> or <https://www.newenglandhemophilia.org/sumhac/>.

Continued from page 18

Tax deductible sponsorship packages are available on the website. We hope you will join us in this business-friendly charity golf

tournament. Registration for this event is now open. Visit our website at <http://www.tinyurl.com/2023ParForTheClot>.



Guilt in Mothers of Children with Hemophilia Focus of New Study

Researchers from the Children's Healthcare of Atlanta and Emory University recently published the results of a small study investigating the subject of guilt in mothers of children with hemophilia (CWH).

Anonymous electronic surveys were distributed to 291 mothers of CWH from May to October 2021, which measured feelings of guilt along with potential contributing factors, subsequent coping strategies, and perception of their child's life satisfaction.

In all, 87 mothers completed the survey. The mean of respondents were 41.6 years and their CWH were a mean age of 13.3 years. While mothers indicated perceptions of their child's life satisfaction that didn't vary appreciably from the general population, 40% did indicate increased guilt. The most commonly cited reasons associated with this guilt were passing on the X chromosome associated with their condition and putting their child through painful

infusions. The most common coping strategies were accessing social support, self-education, and connecting with other mothers of CWH in the inherited bleeding disorders community.

The authors emphasized the need for healthcare providers to "tactfully" provide anticipatory guidance and counseling for these mothers. They also suggested some positive takeaways.

"Community immersion was beneficial, as other mothers in the community served as a source of social and educational support. Most mothers did not report guilt, illustrating the adaptability and resilience of the haemophilia community," concluded the authors.

The study, "The Emotional Experience of Mothers of Children with Haemophilia: Maternal Guilt, Effective Coping Strategies and Resilience within the Haemophilia Community," was published online in the journal *Haemophilia*.

Source: Hematology Advisor, February 21, 2023

Continued from page 21

"In conclusion, our study revealed higher rates of major depression and anxiety in this VWD sample than in the general US population. Depression or anxiety had a significant negative impact on HRQoL in individuals living with VWD. Mental health screening is critical, especially for patients who lack social support, have joint problems, have worse health or those in their adolescent years," explained the authors. "This study underscores the need for a multidisciplinary approach and adequate funding for the comprehensive care of VWD

patients and should compel VWD providers to offer regular mental health assessments in conjunction with bleeding symptom evaluation." Read the **paper published by *Haemophilia*** for more about the validated measures utilized in this study, along with more information on survey administration, data gathering, study limitations, and additional findings. Visit <https://onlinelibrary.wiley.com/doi/10.1111/hae.14725> to read more.

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Advocacy Action

Advocacy Updates

By Jim Romano, Legislative Coordinator

Since the beginning of the year, the Bleeding Disorders Association of South Carolina (BDASC) has had a series of advocacy events and successes. The year started with BDASC taking the lead in creating the Palmetto Health Collective (PHC). The Palmetto Health Collective was formed to bring together patient advocacy organizations in South Carolina to share and collaborate on the work and missions of organizations, including our success and the barriers we face in South Carolina serving our members. This is a coalition to advance patient priorities in South Carolina and provide a platform for important state health issues. BDASC has been instrumental in the introduction and advocacy for H. 3618, the Copayment Accumulator legislation in South Carolina. State Representative Patricia Henegan (D-54th) introduced the legislation for rare disease and chronic illness patients in South Carolina. Advancing the legislation has been the focus of BDASC. The chapter has collected the majority of the cosponsors for the legislation through meetings, action alerts and a push to receive a hearing for the bill in the legislature. BDASC has also worked to identify a Senate sponsor for the bill and will pursue that in 2024.

The BDASC kicked off 2023 hosting its inaugural Legislative Breakfast at the Capitol. Over 50 Members of the South Carolina House of Representatives and Senate came to breakfast with the Bleeding Disorders Community. This event allows the community to have in-depth conversations in a relaxed atmosphere with legislators and the support staff. The chapter has scheduled a legislative breakfast for January 2024. BDASC needs the community to join the chapter leadership at this event. The legislative breakfast is the kickoff of our yearly advocacy efforts.

The annual Bleeding Disorders Advocacy Day

at the Capitol was held on Wednesday, March 1, 2023. The evening before, the chapter hosted the annual training meeting where we hosted two legislators—Representative Henegan and Representative John King (D-49) who discussed the legislative process and the copayment accumulator legislation (H. 3618). The next day, approximately 40 Community members met with legislators. BDASC was recognized in both the South Carolina House of Representatives by Representative Jason Elliott (R-22) and in the South Carolina Senate by Senator Larry Grooms (R-37). This year was the first year the chapter was recognized in the SC Senate. The Community met with South Carolina Lieutenant Governor, Pamela Sue Evette, where the Lieutenant Governor read the proclamation of Governor McMaster for recognizing March as Bleeding Disorders Awareness Month. The Community met many members of the legislature, approximately 60, and tripled the number of cosponsors for H. 3618 including obtaining the first Republican cosponsor. A week after the Bleeding Disorders Advocacy Day, the National Hemophilia Foundation hosted Washington Days. BDASC sent a serious advocacy delegation to Washington Days representing 5 out of the 7 Congressional districts. The focus of Washington Days was H.R. 830, the HELP Copays Act introduced by Congressman Buddy Carter (R-GA). The delegation met with Senator Tim Scott (R-SC) and Congressman Joe Wilson (R-SC) as well as Congressman Carter (R-GA). The delegation was part of over 400 advocates from across the nation.

Since Advocacy Day at the Capitol in Columbia, BDASC Chapter leadership has met with legislative offices asking for co-sponsorship of H. 3618. Sue Martin and Jim Romano have spent two days a month in March and in April to meet with legislative offices. The goal is advancing

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the legislation, focusing on obtaining a hearing in the House Labor, Commerce, and Industry Committee. The leadership met with majority staff of the committee to discuss advancing the legislation and obtaining a hearing.

The Bleeding Disorders Association of South Carolina has had a successful beginning for 2023. We are going to work with the community to continue the success in the second half of the year by championing the passage of H. 3618 and through our leadership in the Palmetto Health Collective.

BDASC State Advocacy Days

March 1, 2023 in Columbia, SC



On Wednesday February 28, our advocates from across the state came together to train for our State Advocacy days in Columbia, SC. Each member of our advocacy coalition was treated to an evening of education and conversation to prepare for their meetings with Representatives and Senators from their district. On Thursday, March 1st, our advocates kicked off bleeding disorders awareness month by meeting with their legislators.



Each group of advocates met with their district representatives to share their stories. The topics of conversation centered around House Bill

3816, the Copay Accumulator Adjustor Bill and a continuation of the HAP (Hemophilia Action Program). Each advocate was armed with information on both the House Bill and HAP. Advocates shared their stories and tried to get representatives to sign H.3816. One of our young members, Danny Shelton, was instrumental in securing one of the new signers. Our advocacy coalition held meetings throughout the day and received much positive feedback.



Along for the ride was Omni Productions. Jason and his team were able to follow BDASC advocates around the Capitol building. Omni productions had been tasked with creating a video to showcase our advocacy efforts throughout the state. Jason compiled videos and photos from our State Advocacy Days, as well



as interviews with coalition members to present our story. We invite you to view the final videos

which are available on our website and our YouTube Channel.

We are grateful to our Advocacy Days Sponsors for helping to make this important event possible!

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NHF's Washington Days

March 8-10, 2023 in Washington, D.C.



This year, nearly 400 advocates from all over the country (representing 45 states and Puerto Rico) gathered together in our Nation's Capital for the first time since March 2020. Eight Coalition Members from South Carolina were in

attendance to represent the Bleeding Disorders Association of South Carolina.

Our advocates participated in an introductory webinar prior to Washington Days to prepare them for one day on the Hill. Advocates then traveled to Washington D.C. and received training to attend meetings on Capitol Hill. Advocates were informed of the federal bill H.R.830 – HELP Copays Act and the federal programs that fund hemophilia treatment centers and the CDC hemophilia surveillance programs.

Once everyone was prepared for the day, the advocates received a schedule of meetings to attend throughout the day. Advocates were assigned meetings based on the district that they live in. Divided into state teams, each state decided which meetings each member was to attend.



Early Thursday morning advocates gathered for breakfast and last-minute preparations for their meetings. NHF brought Representative Buddy Carter, from Georgia, to speak on the HELP Copays Act (Copoly Accumulator Adjustor Bill). Representative Carter presented the bill to



the House of Representatives this session. Rep. Carter is hopeful to pass this bill with the help of patient voices. Patients are particularly important to him as he was a pharmacist for 20+ years

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National News



The South Carolina Hemophilia and Bleeding Disorders Advocacy Coalition

The Coalition's Mission: To Empower the Hemophilia and Bleeding Disorders Community in South Carolina to speak to public and private decision-makers about improving Access to Quality and Affordable Health Care and Treatment.

On May 23, BDASC hosted a webinar on the South Carolina Medicaid unwinding. BDASC, along with SC Medicaid experts provided important information to help South Carolinians stay eligible, along with sharing what you can do if you have now become ineligible. Following the webinar, SCHBDAC advocates provided a recap to the barriers to treatment and the issues that will need to be addressed in 2024. Did you miss the webinar? Read on to learn more about the Medicaid unwinding that is currently happening now.

Medicaid & CHIP Unwinding

Do you or a family member currently have health coverage through Medicaid or the Children's Health Insurance Program (CHIP)? If so, you may soon need to take steps to find out if you can continue your coverage. States have resumed Medicaid and CHIP eligibility reviews. This means some people with Medicaid or CHIP could be disenrolled from those programs. However, they may be eligible to buy a health plan through the Health Insurance Marketplace®, and get help paying for it.

Here are some things you can do to prepare:

- Make sure your address is up to date

- Make sure your state has your current mailing address, phone number, email, or other contact information. This way, they'll be able to contact you about your Medicaid or CHIP coverage.

- Check your mail

Your state will mail you a letter about your Medicaid or CHIP coverage. This letter will also let you know if you need to complete a renewal form to see if you still qualify for Medicaid or CHIP. If you get a renewal form, fill it out and return it to your state right away. This may help you avoid a gap in your coverage.

What if you don't qualify for Medicaid or CHIP?

If you or a family member no longer qualify for Medicaid or CHIP, you may be able to buy a health plan through the Health Insurance Marketplace®. Marketplace plans are:

- Affordable. 4 out of 5 enrollees can find plans that cost less than \$10 a month.
- Comprehensive. Most plans cover things like prescription drugs, doctor visits, urgent care, hospital visits, and more.

Find Marketplace plans and see if you might save on premiums. When you apply, don't forget to include current information about your household, income, and your state's recent decision about your Medicaid or CHIP coverage. For more information visit: <https://apply.scdhhs.gov/CitizenPortal/application.do> or call 888-549-0820

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before becoming a member of the House. Advocates from South Carolina took seven meetings throughout the day. Aaron Smith and his two young sons shared what it is like to live with Hemophilia and the important role the HTC's have played in their journey. Samantha Javorka and Taylor Upton shared what it is like living with a copay accumulator and the struggles they face to be able to afford their expensive medications.

Shelly Crisp shared the experiences she has had being a caretaker to a child with severe hemophilia. Sue Martin explained the need to continue the funding for the HTC's and the negative affects the Accumulator Adjusters in our insurance Market Place plans have on the citizens of South Carolina with rare and chronic diseases, and asked for their support to sign on the bill as a cosponsor.



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Hemophilia Federation of America's Symposium 2023

April 13-16, Orlando, Florida

BDASC's executive director, Sue Martin, attended the 2023 Symposium in Florida and spent most of the time in the Chapter Leadership Sessions, gaining insight and knowledge into several key areas of interest to the chapter. Sessions included knowledge on Overcoming Insurance Barriers and Access Issues, Insights on advocacy, and policymaking, Evolving Treatment Options for Mild Patients, and diagnosis and treatment of

Von Willebrand Disease to name just a few. The Symposium bring experts in bleeding disorders together in one place, while providing education to individuals and families throughout the nation. It is also an event to network with others. The final night celebration was provided by Novo Nordisk and included dinner and a visit to Sea World.

NHF's Bleeding Disorders Conference — NHF Celebrates 75 years!

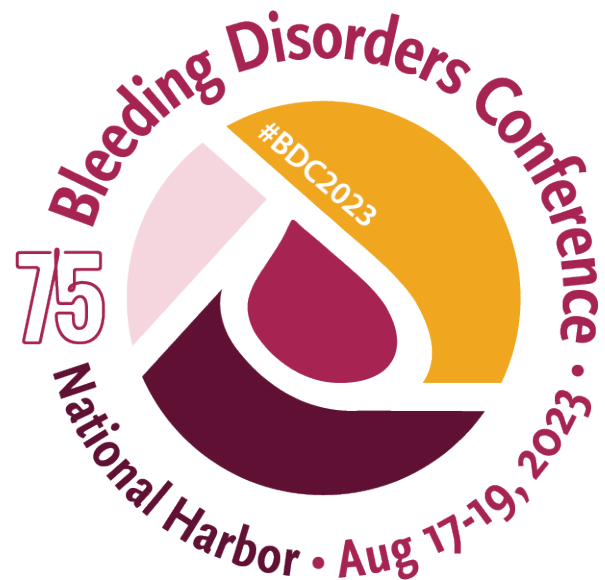
August 17-19, National Harbor, Maryland

The National Hemophilia Foundation was founded in 1948 and has been one of the nation's leading communities dedicated to serving the bleeding disorders community. In celebration of this milestone, NHF is hosting a variety of events, content, and programming throughout the year. Their theme is "The Red Thread," signifying the tie that holds the organizations history and achievements together.

On the NHF website, they are hosting a 75-year timeline of important information relating to bleeding disorders—from the creation of NHF through the rebranding of NHF—which is happening August 31, 2023 to be more inclusive of all bleeding disorders. Discover the story of NHF alongside major medical advances throughout the seven and a half decades. Learn more about the organization's origins starting in 1948, to its modern-day legacy.

To celebrate 75 years of hope, history, and progress, the organization is reflecting upon major milestones and accomplishments, and also looking towards the future. Follow NHF on social media to participate in anniversary-related trivia and subscribe to HemAware to read monthly historical articles. BHF's Bleeding

Disorders Conference (BDC) will also provide an opportunity to look back at NHF's history and the impact that they have made on the bleeding disorders community, as well as looking to our future. BDC will also include a special presentation on the unveiling of NHF's upcoming rebranding.



The Annual Bleeding Disorders Conference will take place from August 17 to 19, 2023, in National Harbor, Maryland (DC Area), at the beautiful Gaylord National Resort & Convention

Center. Join the national bleeding disorders community for three full days of educational sessions, networking opportunities, and access to our exhibit hall. Your registration includes entrance to the Opening Session, Awards Luncheon, and the exciting Final Night Event. Educational Kids Programs will be available for children 12 years old and younger. BDC provides community members the

opportunity to follow several “tracks” based on their needs. These tracks include general interest, inhibitor, intersections, men, mental health, parents/caregivers, spouses/partners, teens/young adults, ultra-rare bleeding disorders, VWD and women and people with the potential to menstruate.

For registration and information, visit the website. <https://nhfbdc.vfairs.com/>

Own Your Path: A Resource App for Patients with Hemophilia A and B

NHF’s Own Your Path program has officially launched! If you are a young adult male with severe Hemophilia A or B, and are on a prophylaxis regimen, you may qualify to join this free program! We know that maintaining adherence to a prophylaxis regimen can have short and long-term health benefits. This program focuses on helping participants be successful by focusing on education, health coaching, skill building, and relationship building, all within an app-based environment that includes participation incentives. Additional program benefits include:

- Free App Based Program
- A Go at Your Own Pace Experience
- Program Participation Prizes
- Improve Skills to Manage Hemophilia
- Exercise and Mindfulness Activities
- Improve Sleep and Manage Stress
- Coaching to Help You Crush Your Health Goals



OWN YOUR PATH

- Virtual Meetups with Peers

For more information about this program, email ownyourpath@hemophilia.org, or complete this screening survey to see if you qualify: <https://www.surveymonkey.com/r/TG532PH>

Research & Development

My Life Our Future – Genotyping Project Informed Inhibitor Risk

Between 2013-2017, the “My Life Our Future” (MLOF) project offered eligible individuals with hemophilia free genotyping, which is historically hard to access, expensive, and not covered by insurance. Conducted through the laboratory analysis of a single blood sample, genotyping can reveal the specific genetic mutation responsible for a patient’s disease such as those located in the factor VIII and factor IX genes in the case of hemophilia A (HA) and hemophilia B (HB) respectively.

MLOF was a partnership between the National Hemophilia Foundation (NHF), American Thrombosis and Hemostasis Network (ATHN), Bloodworks Northwest, and Bioverativ/Sanofi (formerly Biogen). Individuals who participated in the program could also opt – via informed consent – to have a blood sample with their de-identified genome sequence data deposited into the MLOF Research Repository. Investigators could apply for access to the database to support their research, with acceptance contingent upon their ability to demonstrate both scientific merit and ultimate benefit to patients.

Ultimately, samples from more than 6,000 individuals were included in the repository to help advance the scientific understanding of the disorder. MLOF was a boon to researchers, particularly to those looking to better understand the genetic differences that affect bleeding severity and reactions to certain therapies. One such example is a new paper “Race, Ethnicity, F8 Variants, and Inhibitor Risk: Analysis of the ‘My Life Our Future’ Hemophilia A Database,” published in the *Journal of Thrombosis and Haemostasis*.

Armed with ample collection of samples generated by MLOF, the authors of the paper sought to investigate some existing hypotheses related to inhibitor risk amongst individuals with HA.

A total of 4169 subjects were included in the primary analysis, 2,443 with severe HA and 1726 with mild or moderate HA – this analysis examined several key variables including demographic, clinical, factor VIII gene (F8) sequence data. Investigators found inhibitor incidences of 30.3% in those with severe HA and

7.9% in the mild/moderate group. In the severe group, 1075 (44%) had an intron-22 inversion mutation of the F8 gene, and of those, 388 (36.1%) developed an inhibitor.

The result of a crossing over between two linked gene pairs of the same chromosome, intron 22 inversions account for nearly 50% of severe hemophilia A cases. Investigators sought to determine whether inhibitor risk associated with these type mutations are similar to those associated with other large structural changes in the F8 gene. They ultimately found no difference in inhibitor risk amongst those severe HA participants with an intron-22 inversion vs other large structural changes in the F8 gene.

The authors also looked at another hypothesis informed by earlier research which suggested that increased inhibitor risk could be caused by specific mutations known as non-HA causing, non-synonymous single nucleotide polymorphisms (nsSNPs). Often associated with disease, nsSNPs are caused by a change to the amino acid sequence of a genetically encoded protein. In fact, the analysis showed that nonpathogenic ns-SNPs in the F8 were not associated with inhibitor development.

The analysis also confirmed earlier studies suggesting an increased risk for FVIII inhibitor development in both Black/African American and Hispanic HA patients, relative to White non-Hispanic individuals with HA in the U.S.

Investigators signaled the potential implications of this study, and future research, in helping to inform therapeutic plans that better anticipate inhibitor risk.

“It is hoped that future studies, e.g., whole-genome sequence analyses to detect genetic variations contributing to inhibitor risk, will identify specific, clinically actionable genetic correlates indicating increased susceptibility to, or protection from, hemophilic inhibitor development and possibly suggesting novel therapeutic interventions to promote immune tolerance to FVIII,” concluded the authors.

Visit the *Journal of Thrombosis and Haemostasis* to [view the abstract](#).

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Continued from page 24

Sanofi — Marathon Sponsor Sherlene Maloy

Specialty Care RX- Mile Sponsor Stacey Aiken

Stanley Clinkscale

Steve and Jeanette Bloss

Sue and Ric Martin

Sue Martin

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Takeda — Quarter Mile Sponsor Trey Causey

Valarie Rankin

William Metz

Thank you for walking with us, your registrations make a difference in the lives of our community!

STEP for Bleeding Disorders Participants

Aaron Smith

Adam Driggers

Addi Hayden

Adonis Rabb

Alyssa Prest

Alyssa Cogdill

Amanda Vinluan

Amelia Powers

Anthony Rabb

April Baird

Asher Powers

Bo Martin

Bob Turnmire

Brandon Pittman

Brantley Smith

Brett Parsons

Bri Small

Bryan Pierce

Bryce Martin

Bryson Cusimano

Carlton Freeman

Carson Cusimano

Carter Gmitter

Cathy Crisp

Catie Ellisor

Charlie Parsons

Chris Stokes

Corbin Martin

Coree Snider

Cristal Day

Cynthia Randolph

Dan Shelton

Daniel Clark

Danny Shelton

Daphne Javorka

DJ Kincaid

Drake Martin

Edna Rabb

Elianna Shelton

Elizabeth Gossett

Emma Martin

Equilia Kershaw

Faye Gough

Felicia Davenport

Finley Huggins

Finnegan Javorka

Grady Smith

Grayson Smith

Gregory Robinson

Griffin McNeely

Holly Penfield-Neith

Hunter Prest

Hunter Day

Jakavius Watkins

James Zieche

Jax Martin

Jeaneane Tam

Jennifer Zachry

Joanne Boggs

Joey Krakowiak

Joey Segars

Jonathan Garrett

Jonathan Smith

Jonathon Cusimano

Jordan Martin

Josh Mcmillan

Justen Martin

Kannon Smith

Kathryn Friedrichs

Katie Freeman

Katie Parsons

Kenneth Dabney

Kerrie Barnes

Kevin Maloy

Kevin Robinson

Kim Rapp

Kristen Smith

Kristin Shelton

Lacey Mcneely

Larry Rabb

Lauren Monk

Leighanne Pierce

Leslie Martin

Liam Robinson

Lilyan Shelton

Lincoln Smith

Lindsay Amburn

Lindsey Pittman

Logan Smith

Logan Lofland

Lucas Crisp

Mac Martin

Mackenzie Yekich

Maddix Maloy

Maddix Smith

Maggie Pittman

Margaret Zieche

Marilyn Keith

Mark Crisp

Mark Javorka

Martha Hanks

Martha Aultman

Martha Breitwieser

Mattie Watkins

Mazia Jenkins

Michelle Krakowiak

Mike Maloy

Miles Phifer

Miles Martin

Mimi Martin

Parker McNeely

Parker Pierce

Parker Lofland

Patricia Tucker

Paula Guillette

Pierson Lofland

Preston Maloy

Preston Javorka

Raegan Prest

Rebecca Bonig

Ric Martin

Richard Barrett

Rick Massimo

rick massimo

Robert Neith

Robin Simuel

Rory McNeely

Rylee Copeland

Sadie Garrett

Samantha Javorka

Samuel Krakowiak

Shannon Maloy

Shelley Crisp

Sherlene Maloy

Sherry Segars

Skyllar Neith

Sue Martin

Tammy Lofland

Tarra Elkins

Taylor Upton

Thomas Parsons

Thomas Krakowiak

Timothy Freeman II

Toler Maloy

Valerie Jamison

Vanessa Martin

Wendy LeGrand

Zoe Yekich

Zoey Shelton

Stay Connected with BDASC

BDASC is always looking for ways to keep you informed and up-to-date with all the resources available to the South Carolina bleeding disorders community. We want to ensure that everyone in our community is aware of upcoming events. Check out up-to-date information on our social media pages, website, and do not forget to look for our E-Newsletter Blasts in your email inbox. Not seeing the e-news? Check your spam! If you are not seeing our social media content in your news feed, we can help you with that. The way Facebook and Instagram work is that they try to predict what you want to see based on what you comment, like and share. Sometimes it works great, and you see everything you want to, but other times it doesn't work out so well.

To help ensure that you are seeing our content, you can do a few things. First thing is to ensure that you are a follower of our pages. Once you are following our pages, like, comment on, and share our content. Over a short period of time, Facebook and Instagram will catch up and start showing you our content in your news feed. We share tons of information on our social media pages! Anything from upcoming events (with registration links) to informational tidbits. After events, we share photos that we take (or, with their permission, photos from others). We would love for you to share photos, quotes, thoughts, etc. with us to share on our social media pages. After all, the community is about raising your voices and sharing your story!

Resources & Contact Information

Medical Facilities

The Hemophilia Treatment Center of South Carolina
Children's Cancer & Blood Disorders Clinic at Prisma Health Children's Hospital-Midlands
7 Richland Medical Park Rd., Suite 7215
Columbia, SC 29203-6872
Phone: 803-434-3533

For all new and previously scheduled appointments, factor refills, school needs, general questions or general concerns: Contact Robin Jones, MSN, MHA, RN, CPN, CPHON Children's Cancer and Blood Disorders Nurse Navigator/ SC Hemophilia Treatment Center Nurse Coordinator at 803-434-1028 or email @ schemophilia@prismahealth.org. You may leave a message and your call will be returned as soon as possible. Robin may be away from her desk or with a patient in the clinic.

Prisma Health's Upstate Children's Hospital
MAIN CAMPUS:
BI-LO Charities Children's Cancer Center Serving Hematology/Oncology Patients
900 W. Faris Road
Greenville, SC 29605
Phone: 864-455-8898
Fax: 864-455-5164

Hours: Mon, Wed., Thurs. 8:00-4:30;
Tues & Fri. 8:00-12:00

SATELLITE OFFICE:
Spartanburg- Children's Hospital Outpatient Specialties
1700 Skylyn Drive, Suite 200
Spartanburg, SC 29307
Phone: 864-716-6490
Fax: 864-596-5164

Hours: Wednesday - alternating mornings and afternoons

SATELLITE OFFICE:
Anderson - Pediatric Specialties of the Upstate
2000 E. Greenville Street, Suite 3500
Anderson, SC 29621
Phone: 864-716-6490
Fax: 864-716-6492

Medical University of South Carolina
Shawn Jenkins Children's Hospital
10 McClennan Banks Dr.
Charleston, South Carolina 29425
Shayla Bergmann, MD, Assistant Professor
Director, Pediatric Hemophilia Clinic
Phone: 843-876-1980
Mobile: 843-812-5682
Fax: 843-792-7562

Local and National Orgs

Bleeding Disorders of South Carolina
Green Gate Office Park
25 Woods Lake Road, Ste 300
Greenville, SC 29607
Phone: 864.236.8663
Fax: 864.236.8663
Email: info@bda-sc.org
Web site: www.bda-sc.org

National Hemophilia Foundation
7 Penn Plaza, Suite 1204
New York, NY 10001
Phone: 212-328-3700
Fax: 212-328-3777
Phone: 800- 42-HANDI (4-2634)
Fax: 212- 328-3799
Email: handi@hemophilia.org
Website: <http://www.hemophilia.org/>

Hemophilia Federation of America
999 North Capitol Street, NE, Suite 201
Washington, DC 20002
Phone: 800-230-9797
Email: info@hemophiliafed.org
Website: www.hemophiliafed.org

World Federation of Hemophilia
1425, boul. René-Lévesque O.
Bureau 1010
Montréal, Québec
H3G 1T7 Canada
Phone: +1 (514) 875-7944
Fax: +1 (514) 875-8916
Email: wfh@wfh.org
Website: www.wfh.org

Resource Information

SC Dept. of Health & Environmental Control (DHEC)
Children with Special Health Care Needs Hemophilia Program
2100 Bull Street
Columbia, SC 29201
Phone: 803-898-0784
Website: <https://www.scdhec.gov/health/child-teen-health/services-children-special-health-care-needs/hemophilia-assistance-plan>

American Pain Foundation (APF)
Phone: 1-888-615-PAIN (7246)
Hemophilia Chronic Pain Support Group
Website:
<http://painaid.painfoundation.org>

American Society of Pediatric Hematology/Oncology
Phone: 847-275-4716
Website: www.aspho.org

The Coalition for Hemophilia B, Inc.
Phone: 212-520-8272
E-Mail: hemob@ix.netcom.com
Website: www.hemob.org

Bleeding Disorders Legal Hotline
Phone: 800-520-6154

Centers for Disease Control & Prevention
Phone: 1-800-311-3435
Website: www.cdc.gov

Committee of Ten Thousand (COTT)
Phone: 800-488-2688
Website: www.cott1.org

LA Kelley Communications, Inc.
Phone: 978-352-7657
Website: www.kelleycom.com

Patient Access Network Foundation
805 15th Street, NW, Suite 500
Washington, DC 20005
Phone: 202-347-9272
Website: <https://panfoundation.org/index.php/en/>

Helps underinsured people with life-threatening, chronic and rare diseases get the medications and treatments they need by assisting with their out-of-pocket costs and advocating for improved access and affordability.

Patient Notification System
The Patient Notification System is a free, confidential, 24-hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.
Phone: 888-UPDATE U (873-2838)
Website:
www.patientnotificationsystem.org

Accessia Health
Provides financial assistance to people who are diagnosed with chronic medical conditions.
P.O. Box 5930
Midlothian, VA 23112
<https://accessiahealth.org/>
1-800-366-7741

Medic Alert Foundation
2323 Colorado Avenue
Turlock, CA 95382
Phone: 800-432-5378
Website: www.medicalert.org

South Carolina Healthcare Market Place
Call 800-318-2596
Website: www.HealthCare.gov

The South Carolina Rare Disease Advisory Council
Website: <http://rarediseasesc.org/>

Upcoming BDASC Community Events

Mark Your Calendar!

Looking Ahead: Major Community Engagement Opportunity – Save the Dates!

June 9-10, 2023: 50th Annual Meeting and HELLO Conference

August 10-13, 2023: Teen Retreat

September 22, 2023: Par for the Clot Charity Golf Fundraiser

December 9, 2023: Winterfest State-Wide Gathering

Additional ways to support BDASC



Go to www.bda-sc.org and click “Make a Donation” to learn more about how you can support BDASC!



Donate through United Way! Go to <http://www.unitedway.org/>



Shop, sell, and donate for a good cause! Go to www.charity.ebay.com



Bleeding Disorders Association
of South Carolina
Green Gate Office Park
25 Woods Lake Road, Ste 300
Greenville, SC 29607
www.bda-sc.org



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FOR THE CLOT

September 22, 2023

