

HEMOPHILIA ACTION

A PUBLICATION OF THE HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

VOLUME 18 | ISSUE 1 | WINTER | 2022

13TH ANNUAL UNITE FOR BLEEDING DISORDERS WALK

HFSC Olympics: Let the Games Begin!

We were beyond excited to finally have had the opportunity to join together at this year's walk, where more than 300 attendees came out to the LA Coliseum on November 13, in support of those with bleeding disorders in Southern California. We are extremely grateful to everyone who donated, raised funds, volunteered, and promoted awareness for HFSC's Olympic-themed Walk.

We especially enjoyed the walkers' many costumes, representing various Olympic sports as well as famous Olympians! Participants had the opportunity to play a wide array of Olympic-themed games at the event, visit sponsor and activity booths, purchase tickets for a chance to win an arcade game loaded with 10,000 games, and enjoy the post-walk entertainment by Tiger Squadron, a precision formation flying and aircraft display team!

Although this year continued to present all of us with many challenges, HFSC's local community continues to be a constant source of support, raising nearly \$165,000 on behalf of advocacy and access to care, research, emergency financial assistance, scholarships, and Camp Blood Brothers & Sisters. *(Article continues on page 14)*



HEMOPHILIA FOUNDATION OF AMERICA SYMPOSIUM 2021

HFSC is honored to have received the "You Are Not An Island" Award, announced at HFA's Symposium, held from October 18 - 28, 2021. HFA Symposium 2022 will be held April 20 - 23 in San Antonio, Texas. To register, visit HemophiliaFed.org.

THANK YOU DONORS

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2022 CALENDAR

World Hemophilia Day
New Delhi Palace | San Bernardino, CA
April 16

emPOWERment Webinar Series
(Virtual)
April 20

HCC Future Leaders
April 19 and 26

Family Information Day
Ehlers Event Center | Buena Park, CA
April 30

Community Dinner
Santa Barbara, CA
May 11

HCC Virtual Legislative Day
May 18 and 20

Mujeres Enlazadas Dinner
Whittier, CA
May 25

Family Retreat Weekend
Pali Retreat Center | Running Springs, CA
June 3 - 5

Community Dinner
Santa Barbara, CA
June 14

emPOWERment Webinar Series
(Virtual)
June 15

Shaka Surf Fest & Beach Day
Santa Monica, CA
June 25

HEMOPHILIA ACTION

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In Honor

G. Beverly Bergmann, in honor of Erik E. Johnson
Harry and Juanita Boessler, in honor of Tyler, Abby and Michael
Marilyn Borowsky, in honor of Cole Warner
William and Judy Metscher, in honor of Sid Katz
Joseph Nazarian, in honor of Eric Hardeman
Erika Overland, in honor of Cole Fenton
Joan Parker, in honor of Perry and Corey Parker
Michele and Doug Warner, in honor of Cole Warner

In Memory

Frankel Zacharia CPA, in memory of Susan Stone
Kelly Green-Fice, in memory of Gerry Green
Terry Hays-Horner, in memory of Verne, Chris, Joe and Tom Hays
Sharon Hylton Filsinger, in memory of Mike Hylton
Hillarey and Peter Knabel, in memory of Susan Stone
Timothy and Judith Newsome, in memory of Gerry Green
Ohama Community Foundation/ The Scoular Foundation, in memory of Susan Stone
Margarete Schwall, in memory of Susan Stone
Mary Wallis, in memory of Michael L. Schmidt
Annette Williams, in memory of Susan Stone

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A LETTER FROM THE BOARD PRESIDENT

The past two years, we have all been put to the test, as we have navigated the COVID-19 pandemic. I am immensely proud of our community for their continued and unwavering support of one another and of the HFSC staff for constantly pivoting and innovating during this time, hosting events virtually to keep the community safe, while still providing the most relevant and effective resources and information for the community.

After a long two years in a mostly virtual environment, I am looking forward to hope and recovery from the pandemic and to seeing all of you in person at HFSC's events this year. I am especially looking forward to the Family Retreat, which will be held June 3 - 5 in San Bernardino County at the Pali Retreat Center and Camp Blood Brothers and Sisters July 19 - 23 at the Painted Turtle in Lake Hughes, CA.

We plan to host live events as much as possible, though the health, well-being and safety of our community continues to remain a top priority for HFSC. To that end, the Board's approved policy for all upcoming live events remains in place - all attendees ages 12 and older need to present proof of COVID-19 vaccination or a negative COVID-19 test result within 72 hours prior to entry. In addition, all attendees must continue to wear masks at all times, regardless of vaccination status, unless eating or drinking. We will continue to follow public health guidance to prevent the spread of COVID-19 and reassess on a regular basis to ensure the safety of all.

Thank you for your diligence in continuing to help keep our community safe and healthy.

I look forward to seeing you soon! In the meantime, please feel free to reach out to me with any questions or if I can help in any way. - Rick Kelly, MBA

A LETTER FROM THE EXECUTIVE DIRECTOR

I may sound like a broken record, but I can't emphasize enough how much I miss seeing you all and especially the children. I feel like they have missed out on the much-needed peer support during this time and, as such, we will strive to do our best to meet in person in the safest way possible. If you are interested in camp, please apply as soon as possible, as spaces are limited, and reach out to us if you have any questions or need help with your application. If your child isn't ready, our HFSC Family Retreat, "Under the Sea," is a sure way for them to get a feel for camp. I'm also so happy to share that our men's group, BRO, has been actively meeting bimonthly. To register for any of our events, please visit www.hemosocal.org.

A few larger projects we are now tackling include publishing a Back-to-School manual in English and Spanish to provide you with needed resources for school as well as rehauling our look and feel with a new logo and website. Finally, we are launching a deep dive needs assessment, "Your Voice is Our Future," to help direct future strategic initiatives in Southern California. I urge you to participate! As always, if there is anything we can help you with, if you want to volunteer, or have any questions, please reach out to me at michelle@hemosocal.org or 626-765-6656. - Michelle Kim, Esq.





No actual patients depicted.

ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]
REAL LIFE. REAL BLEED PROTECTION.*

AdynovateRealLife.com

HEMOPHILIA A IS A PIECE OF YOU. NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.^{1,2}

*In clinical trials, ADYNOVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds²

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)²

- **Children Under 12 Years:** This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment²
 - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median[†] overall ABR[‡] of 2.0
 - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

[†]Median is defined as the middle number in a list of numbers arranged in numerical order.

[‡]ABR=annualized bleed rate, the number of bleeds that occur over a year.

[§]Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information

What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mice or hamster protein.
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)].

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

- **Adolescents and Adults 12 Years and Older:** This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups²
 - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
 - 0 bleeds in 40% (40 out of 101 per-protocol[§] patients) during 6 months on twice-weekly prophylaxis

What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADYNOVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache, diarrhea, rash, nausea, dizziness, and hives. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.adynovate.com.

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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Patient Important Facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

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

Do not attempt to do an infusion to yourself 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 infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

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ADYNOVATE is not used to treat von Willebrand disease.

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You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

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The common side effects of ADYNOVATE are headache, diarrhea, rash, nausea, dizziness, and hives. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-TAKEDA-7.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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COMMUNITY DINNER

Sponsored by Genentech
10.06.21

Our first live event in 17 months, over 50 HFSC community members met at a dinner at Canaletto's in Newport Beach to learn how to "Reframe Your Mindset." Thank you to Maria Perez for her very timely presentation and for sharing how we can change negative thinking patterns during times of change. We especially enjoyed the interactive role play!

Thank you to Genentech for your support!

ADVOCACY UPDATE

HFSC has been busy supporting several advocacy coalitions and initiatives.

On the federal front, HFSC signed on to the All Copays Count coalition letter commenting on a proposed rule issued by the Health and Human Services to ensure that insurers and Pharmacy Benefit Managers (PBMs) count all copayments made by or on behalf of an enrollee toward the enrollee's annual deductible and out-of-pocket limit.

In CA, HFSC joined a coalition of rare disease nonprofits to support a Rare Disease Council in CA to give a voice to those living with rare disease in CA.

COMMUNITY SPOTLIGHT: THE KIM FAMILY



The Kim family was in Korea for 5 years and currently lives in San Gabriel. Their son, Dohyung, has severe hemophilia A. When he was about 7 months old, he started crawling and his chest started to bruise. After treatment at a nearby pediatrician's office, he was transferred to the hospital and diagnosed. He had regular injections at the hospital until he was three years old, and his mother has been giving them herself since then.

Our family's motto is "公勤寬信 : 공정하고 부지런하고 너그럽고 믿음직한 삶을 살자." If this is translated in English, "Live a life of fairness, hard work, generosity and trustworthiness."

Our family enjoys camping. And our son enjoys swimming, badminton and basketball.

When we were living in Korea, we were able to interact with other family members through the Korea Hemophilia Foundation. We got to know HSFC through a community member and were able to participate. Our son's favorite event is the family camp event held every May. We look forward to seeing you at the family camp soon.

HSFC is a center where we can have a voice. By working together and sharing information, we can be empowered. We always thank HFSC for accessing new information through communication and improving the quality of life and helping hemophilia patients.

SNOWFLAKE FESTIVAL 2021

In December 2021, HFSC served over 300 community members by hosting nine Snowflake events to celebrate the end of the year. We were thrilled to see so many!



Coco Palms | Pomona, CA
12.01.21

What a fun-filled night to finally see the community together on Wednesday, December 1 at the beautiful Coco Palms in Pomona, California! With over 60 attendees, families enjoyed seeing each other and sharing what they were grateful for. Thank you to Albert Maffei and Sanofi Genzyme for sponsoring this great event, and thank you Brothers Healthcare for your continued support to the community!



Mama Tosca's | Bakersfield, CA
12.02.21

On December 2, 2021, families met at Mama Tosca's in Bakersfield for a community holiday dinner and educational presentation on "Your Time to Thrive: Harness the Power of Joy." Thank you to sponsor, Genentech, and to speaker, Maria Perez. Special thank you to Rose Cardenas, our community liaison in Bakersfield, for hosting the event. It was so great to see all of you there!



Capital Grille | Costa Mesa, CA
12.02.21

Over 35 attendees enjoyed a wonderful evening at the Capital Grille in Costa Mesa, filled with celebration, great company, and an informative presentation by Dr. Soto Velez, "Talking About Hemophilia - How It Can Help." Thank you to Novo Nordisk for hosting a special evening and all who joined us and shared their stories. It was so wonderful to be with all of you!

SNOWFLAKE FESTIVAL 2021 *(continued)*



Embassy Suites | Downey, CA
12.07.21

On December 7, HFSC hosted 22 families at the Snowflake Dinner at Embassy Suites in Downey. Attendees participated in an interesting discussion "Post-Pandemic Conversation" presented by Silvia Vega from Bayer. After a delicious dinner, everyone participated in an exciting white elephant game. Thank you to Bayer for sponsoring this dinner, and to Fidelis Specialty Pharmacy for providing a craft for the children in attendance.



Aloha Steakhouse | Ventura, CA
12.08.21

On December 8, HFSC hosted 40 community members at the Snowflake Dinner at Aloha Steakhouse in Ventura. Attendees enjoyed playing a mobile escape room game "Unlock the Science of Investigational Gene Therapy Research for Hemophilia" presented by Guillermo Campillo from Spark Therapeutics. Following a delicious dinner, everyone participated in a fun white elephant game. Thank you to Spark Therapeutics for sponsoring this dinner, and to Soleo Health for bringing a craft for the children and providing each family with a gingerbread house to take home.



Thompson Brewing Company | Riverside, CA
12.08.21

Over 40 community members enjoyed celebrating the holidays on December 8 at the Thompson Brewing Company in Riverside, while learning more about "Exercise and Your Joints." Thank you, Martina Willis-McCullough, BSN, RN for your informative presentation, and Octapharma for your generous support! Thank you also to Profusion Specialty Pharmacy for your donation and volunteers Karla Reynado Arce and Mauricio Reynado for your help! It was so wonderful seeing everyone!





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The most comprehensive hemophilia program for children and adults in Southern California.

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**Orthopaedic
Institute for Children**
 Hemophilia Treatment Center
IN ALLIANCE WITH **UCLA** Health

ortho-institute.org/hemophilia

SNOWFLAKE FESTIVAL 2021 *(continued)*



La Cañada Country Club | La Cañada, CA
12.08.21

Over 70 community members joined the LA County dinner on December 8 at the La Cañada Country Club. BioMarin led the program with an exciting and competitive "Gene Therapy Jeopardy." Children made holiday crafts and decorated cookies thanks to support from Accredo, and each family brought home a gingerbread house thanks to support from Guided Alliance. The night ended with the longest ever white elephant game, with everyone taking home a nice extra surprise in addition to gift cards for the children. HFSC thanks its volunteers: NCL Glendale, Vicky Michua, Rosie Villalpando, Maria Gerrero, Nate McFadden, Erika Clement, Connie Inglis, Charlie Inglis, Linda Clement, Mathew Casas and BioMarin again for its sponsorship of this event!



Double Tree Hotel | San Bernardino, CA
12.14.21

With over 45 attendees on a rainy Southern California day, families gathered on Tuesday, December 14, 2021 at the Double Tree Hotel in San Bernardino, CA. Jesse Stacks shared his experience growing up with a bleeding disorder. Both adults and youth had many questions for him! The message taken from this gathering was to not let a bleeding disorder get in the way of your dreams! Thank you CSL Behring and Specialty Care Rx for your support!



BRO Snowflake Lunch | Los Angeles, CA
12.19.21

Bleeders Reaching Out (BRO) had an amazing Sunday lunch on December 19 in Los Angeles, CA. From playing the White Elephant game, to sharing stories and planning for future gatherings, all in attendance were happy to end the year celebrating with their blood brothers. Thank you to Rigo Manzo and Fray Forde for helping organize this fun and lively event!

Aging Against All Odds: USC Social Work Professor Investigates Forgotten HIV Population

December 17, 2021 / by Michele Carroll

The first generation of people with hemophilia to live past 50 are aging in a world that doesn't know what to do with them.

"I wasn't expecting to be alive past 12, then 15, then 35-ish, and now I'm a fluffy 50 and having to deal with a system that's not ready for me," said Bobby Wiseman, who has severe hemophilia and is HIV-positive. "We weren't supposed to get old."

In the 1980s nearly 90% of people with severe hemophilia, a genetic disorder that prevents blood from clotting properly and typically results in death in young adulthood, contracted HIV from tainted blood products used to treat their disease and half of the people with hemophilia in America died. Today, that story has receded into largely forgotten history, but many of those who did survive have now become the first cohort of people with hemophilia in history to live past 50, thanks to advances in treating both hemophilia and HIV.

"Navigating Time and Space: Experiences of Aging with Hemophilia" is the first research study to address this groundbreaking cohort. Sara Schwartz, clinical associate professor at the USC Suzanne Dworak-Peck School of Social Work and National AIDS Memorial Board Member co-led the study of this little-known chapter of the HIV/AIDS crisis and its implications for today's aging hemophilia survivors with Tam E. Perry, associate professor at the Wayne State University School of Social Work.

"As someone who has been active in the HIV and AIDS community for many years, it blew my mind and shamed me that I didn't know this history," Schwartz said. "This is such a powerful story of resilience. It has completely pivoted my work. They are the first cohort to age and it's important to document their stories and collect information from them while we can."

With support from medical sociologist Charles Kaplan, former associate dean of social work at USC, and Dana Francis, a social worker at the University of California San Francisco, the research team evaluated participants in four key gerontological areas: self-care, social networks, the meaning of home/aging in place and productive aging contributions. Their investigation focused on strategies to optimize functioning, shifting the perceptions of time and ways to better address the needs of this underserved population.

"With this study, NHF's Innovative Investigator Research Award is going to a social worker for the first time ever," said Len Valentino, president and chief executive officer of the National Hemophilia Foundation. "Social workers are part of the critical foundation, along with research and advocacy, to ensure that people and families impacted by inheritable blood disorders may thrive."

Uncharted territory for aging

For people with hemophilia, a relatively minor injury can turn into a life-threatening bleed if not appropriately treated, so the things that many of us take for granted as we age — colonoscopies, heart care, long-term residential care — are uncharted territory for this group and their medical professionals. Having survived so far beyond their own and everyone else's expectations, they are having to advocate for themselves and create a new path forward for the patients with bleeding disorders who will follow them.

"This research definitely highlights the medical needs in my not-so-distant future and beyond," said Patrick Lynch, a 36-year-old filmmaker and health advocate with severe hemophilia. "I'm going to be the beneficiary of this, but only if I'm paying attention."

This cohort of persons surviving with hemophilia also faces a host of unforeseen issues associated with aging. Eighty-eight percent of study participants reported being profoundly affected by their unexpected longevity. With the expectation of a short lifespan, most did not plan for the future — the practicalities of careers, 401ks or savings accounts. Many did not marry or have children, either because their HIV or hemophilia status isolated them socially or because they did not think they would be around long enough.

"It was not on the concept to say invest in this because it was like, 'to hell with it, I'm going to be dead,'" Wiseman said. "And now it's this whole thing that I might be here until I'm 85."

Decades of chronic physical pain, isolation from peers and the disorienting feeling of facing a future they never expected to have, as well as survivor's guilt, have also created complex psycho-emotional needs. Across the board, study participants called for great mental health support tailored to their population, which often includes intersectionality with HIV status, sexual orientation, age and race.

"It was a medical holocaust," said Francis, who has focused on the hemophilia community since 1988 and literally seen many of the survivors in the study grow up from children and teenagers, even as many more of their cohort passed. "The younger generation doesn't know what they don't know. I want this information to be there when they get to 50."

The study also explores how the perception of a time horizon often influences our actions, emotions and goals. Using Socioemotional Selectivity Theory to understand what it means when nearness to death expands rather than contracts, many of these findings may have application in use with long-term HIV survivors and, as life expectancy grows longer for typical Americans, broader implications and insights for aging overall.

"It is so important to realize that the stigma and discrimination of marginalized communities has such a corrosive impact on society and that it also directly impacts others," said John Cunningham, chief executive officer of the National AIDS Memorial. "In the case of AIDS, the hemophilia community was devastated, losing half of all people with hemophilia in a short ten years. It is important to remember injustice upon one is injustice upon all."

Beyond the fallacy of a "men-only" disease

Schwartz plans to expand on her research to include a focus on women with bleeding disorders. Until recently, it was falsely perceived that men primarily developed hemophilia and women were only the carriers. Now it is being discovered that women can also suffer from the disease, but because the symptoms are often milder or it expresses itself through longer periods of menstrual bleeding, it has often been discounted by doctors. As more women are correctly diagnosed, other serious health complications are being discovered from years of iron deficiency.

"I discovered the hemophilia community and what they're going through today and I just couldn't look away," said Schwartz. "This is a very traumatized and wounded community. They have been overlooked and stigmatized and ostracized. I want to share their story and that's what I will continue to do."

Citation: Carroll, Michele. Aging Against All Odds: USC Social Work Professor Investigates Forgotten HIV Population. University of Southern California, Dec. 17, 2021, <https://dworakpeck.usc.edu/news/aging-against-all-odds-usc-social-work-professor-investigates-forgotten-hiv-population>.

THE BLEEDING DISORDERS COMMUNITY MOURNS THE PASSING OF VAL BIAS



by Brett Spitale, VP of Advancement
Dec. 31, 2021 – New York, NY

NHF is deeply saddened to announce that former NHF CEO and community member, Val Bias, passed away suddenly on Thursday, Dec. 30.

NHF will forever honor Val's legacy and all that he accomplished for the inheritable blood disorders community in the United States and internationally. Most remarkably, Val was a uniquely skilled community builder, building bridges, coalitions and cultivating champions for our community. Prior to his tenure as CEO of NHF, Val served as Chairman of The Board of Directors of NHF from Jan 1992 - Jan 1994. He also served in multiple capacities on the global stage working closely with the World Federation of Hemophilia, including advancing the International Twinning Program.

Val transformed the NHF chapter network unifying and strengthening our voice and impact from the statehouse to the halls of Congress. His many notable contributions included establishing the first NHF Washington Days and championing the National AIDS Memorial's Hemophilia Circle. As CEO he led NHF into a new era of growth and service, he stabilized NHF funding and built programs to serve those who had been left behind. His lifelong commitment to families and youth was no more evident than through his commitment as a summer camp counselor and innovative summer camp programming in his service as Camp Founder and Staff Director of Camp Hemotion: Camp for Children with Bleeding Disorders. He began his career with NHF in Washington championing the passage and funding of the Rick Ray Act and working to transform the regulatory framework to ensure the tragedy of HIV/AIDS would not repeat. His impact and the effect of his forceful advocacy will long be felt, from the halls of power at the U.S. Capitol Building, to the arts and crafts room at local summer camps. "The reason NHF and the inheritable blood disorders community has come so far is because of what Val was able to accomplish," said NHF President and CEO Len Valentino. "I had the honor to walk alongside Val both professionally and personally and can say with certainty that what he has done throughout his life inspired change. His legacy will live on forever, and he will be greatly missed."

Mother of Ryan White, Jeanne-White Ginder said in tribute "I am most grateful to Val for including me in the hemophilia community and widening the circle to make sure everyone's voice was heard. He made sure our losses were not forgotten, especially through his efforts to include the hemophilia community in the National AIDS Memorial Grove. Val knew the hemophilia community because he lived hemophilia alongside all of us. In spite of his own health battles and personal losses, he carried on with courage and strength that inspired us all, making him not only an accomplished leader but a role model that will never be forgotten."

NHF and the community are heartbroken over this sudden loss. Val served as NHF's CEO for over a decade and carved the path for the organization's continued growth and sustainability. NHF extends sincere condolences to Val's beloved son Langston, his loving wife of twenty years, Robin, and his entire family.

NHF looks to respect the Bias family's privacy at this time and will provide further information to the community at an appropriate time. All condolences and communications may be sent to communications@hemophilia.org.



**WE'RE IN THIS
TOGETHER.**

Sunday 2:16 pm

Jogging in the park
with his girlfriend

Ben, living with
hemophilia A

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

bleedingdisorders.com



13th Annual Unite for Bleeding Disorders Walk (continued from cover)

A special thank you to Langston Brown, Lindsey Adey, Corey Parker, Perry Parker, Rigo Manzo, Manny Forde, Mathew Casas, Mia Castaneda, Heidi Agama, The Painted Turtle, and HFSC's Board for presenting at this event! And much gratitude to Amelie Iavicoli for singing the National Anthem, Karlyn Brown for serving as Chair for the walk, and to all of our community Olympians for their participation! A shout out also goes to NCL Glendale and all of the volunteers who helped make this event possible!

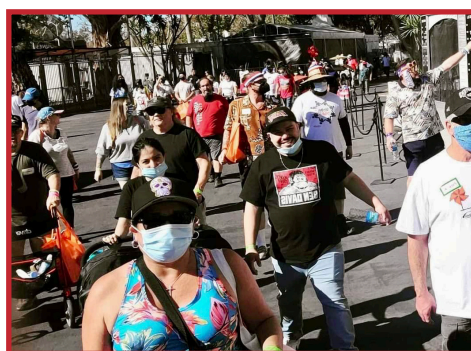
Congratulations to our Top 10 Teams: Team Kim Family, Perry Parker's Team, Amelie's GT Striders, Cole Train, Team Avila, Team Kacen, Langston's Gold Medal Walkers, Ortho Walkers, Ninja Stars, and Bonded By Blood

Congratulations to our Top 10 Individuals: Michelle Kim, Perry Parker, Michele Warner, Ashley Karnes, Amelie Iavicoli, Jesus and Paul Avila, Karlyn Johnson Brown, Richard Metz, Doris Quon, and Milo Burke

Congratulations to Best T-Shirt Award: Langston Brown, and to Best Costume Award: Amelia Tapia!

Thank you to our Local Sponsors! Silver: Center for Inherited Blood Disorders, CSL Behring, Fidelis, Genentech, Hema Biologics, Infucare Rx, Medexus, Novo Nordisk, Octapharma, Soleo Health, Specialty Care Rx, and Tremeau Pharmaceuticals. Bronze: Bayer, Profusion Specialty Pharmacy, Tito's Handmade Vodka, Walmart, and Westmount

Thank you to our National Sponsors! National Presenting Sponsors: Takeda and Hemophilia Alliance. National Community Partners: Biomarin, Sanofi Genzyme, and Pfizer. National Partners: Ascella Health, Bayer, Grifols, and Optum Infusion Pharmacy



Registration is now open for our 2022 Halloween-themed walk, which will take place on October 29 at the LA Coliseum! Sign up by visiting www.uniteforbleedingdisorders.org/event/socal today!



VOLUNTEER SPOTLIGHT: KATIE KLOPP

Katie Klopp, from Marina del Rey, started volunteering with HFSC in early 2020, right when the pandemic hit. As someone with vWD, she wanted to get connected with the local bleeding disorders community. "HFSC offers great educational events to keep up to date on bleeding disorder news. In addition, the community has been a great resource to guide me in living a life with a chronic disease." She has since volunteered virtually at the 2020 and 2021 Ignite Women's Retreats and Industry Forum and was able to volunteer in-person at our 2021 Unite Walk.

Katie, who is a graphic designer and freelance photographer, also designed the BRO (Bleeders Reaching Out) logo which has been used countless times! When asked what she wished other people knew about HFSC, she said, "HFSC has inspiring leadership and is so much fun to work with! Volunteering can be a great way to get to know the people behind the scenes, working tirelessly to put together this amazing organization."

Thank you, Katie, for all you do!

If you are interested in becoming a volunteer (virtually or in-person) for HFSC, please contact Laura Desai (laura@hemosocal.org).

DIA DE LOS MUERTOS SPONSORED BY TAKEDA

11.02.21

¡El 2 de noviembre de 2021, el grupo Mujeres Enlazadas por Sangre se reunió por primera vez después de casi dos años!

Fue un placer ver a todas las mamás, abuelas y cuidadores. Tuvimos la oportunidad de aprender a manejar situaciones estresantes en tiempos de COVID-19. Susana Escojido hizo una excelente presentación.

¡Gracias a Takeda por su apoyo a esta cena educativa!





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If you would like a copy of this newsletter in Spanish, please contact the HFSC office at 626-765-6656 or info@hemosocal.org, and we would be happy to send one to you!

¡Si desea una copia de este boletín de noticias en español, por favor póngase en contacto con la oficina de HFSC al 626-765-6656 o info@hemosocal.org!



Family Information Day

Saturday, April 30, 2022

8:30am-1:30pm
Ehler's Event Center
Buena Park, CA

Register:
<https://hfscfamilyinfoday2022.eventbrite.com>



Apply Now!

CAMP BLOOD BROTHERS AND SISTERS

July 19-23, 2022

Held at



Must be fully vaccinated

Spots are limited!

Siblings must apply for Sibling Camp (August 12-16)

<http://thepaintedturtle.org/campers-families/families/application/>