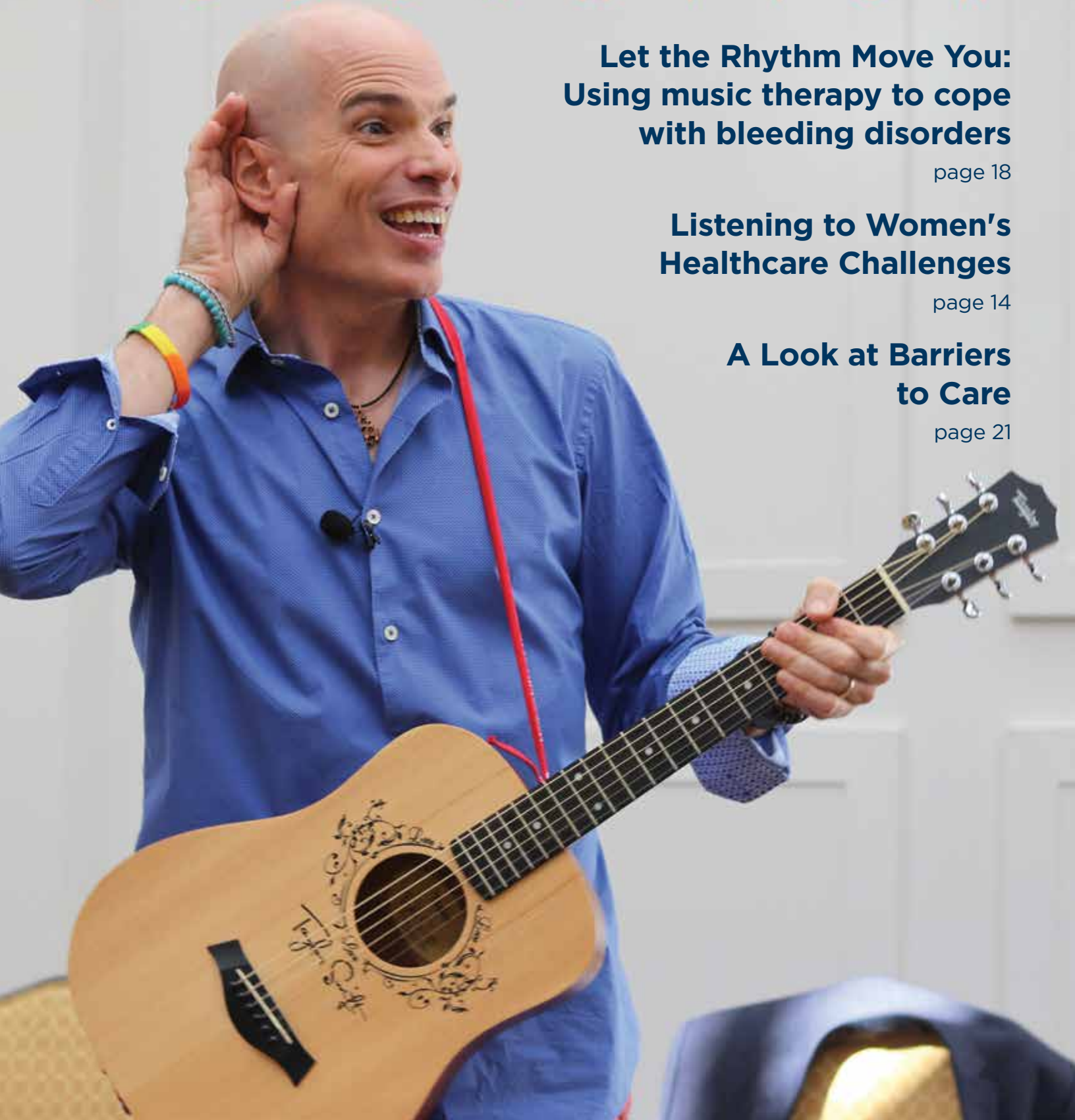
Volume 20 • Issue 4 • Winter 2019-2020

DATELINE FEDERATION



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EXECUTIVE CORNER

Dear Friends,

As another year begins we reflect on all that was accomplished in 2019 and the excitement 2020 holds for HFA and the bleeding disorder community.

What a busy year 2019 was for HFA! Celebrating its 25th anniversary at Symposium, we learned the submission to the Smithsonian was accepted. We are now working through the transition into a new CEO and much more.

I want to thank all who have attended Symposium and supported local member organizations—many of which utilized HFA's programming, worked to assist in HFA's advocacy efforts and supported our fundraising efforts, especially our Helping Hands program. All of these aspects have led to another successful year!

I would also like to point out some excellent collaboration and production discussions our HFA staff team has had with the staff at National Hemophilia Foundation to improve what both organizations offer the bleeding disorders community.

Finally, as many have heard through our social media or possibly from your member organization, the HFA board of directors has hired our next CEO, Sharon Meyers. The process of searching for the next CEO was a long one with input from many in our community. The board of directors sought feedback from board, member organizations and staff through surveys, as well as including representation from these groups in the interview process. We were very fortunate to have so many qualified candidates and ultimately selected Sharon to serve as our President and CEO. I know I am excited to see what the future holds for HFA through this change as well as all other opportunities to come in 2020.

Josh Hemann

Board Chair

Hemophilia Federation of America™

Assisting, educating, and advocating for the bleeding disorders community since 1994.

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Connect with us on social media for daily posts and updates about what's happening at HFA.

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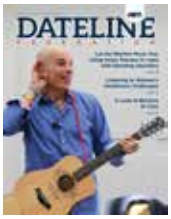
HFA's staff gathers in Washington, D.C., in the fall of 2019, during their bi-annual staff meeting. Meet our newest staff members on page 5.



ON THE COVER.
Tim Ringgold of California has made a career with his love of music and leads sessions for the bleeding disorders community on how to use music to cope with various aspects of bleeding disorders. Read his story of using music as a tribute to his daughter on page 18.

HFA Scholarship Winners Announced

Each year, Hemophilia Federation of America awards scholarships to promising students in the bleeding disorders community seeking post-secondary education at a college, university or trade school.

We are pleased to award scholarships to the following students:

Nicole Tooley

Attending University of Michigan in Ann Arbor, Mich.
Winner of HFA Educational Scholarship of $2,000

When I was 13, I had the opportunity to go to my local hemophilia chapter's summer camp. After being a camper, and now a counselor, it was there that I fell in love with working with kids and truly understood how impactful mentor relationships could be. This summer was my sixth, and it was an absolute blast. I'll be carrying that energy with me as I start my freshman year at the University of Michigan, where I plan on studying secondary education and English. A tremendous thank you to Hemophilia Federation of America for providing me with this scholarship—I am beyond honored. And an endless amount of love and gratitude to the bleeding disorders community for teaching me something new every day. May I take what I've learned from you all and continue to share it with the world.

Ryan Bernstein

Attending Stanford University in Stanford, Calif.
Winner of HFA Educational Scholarship of $2,000

Thank you for this very generous award. I am honored to have been selected for an HFA Education Scholarship. I will use this money to help pay my tuition at college where I plan to major in biology and psychology. I am interested in learning how the mind works, and my future goal is to become a doctor. The amazing medical professionals who have cared for me over the years inspired me to work to help others.

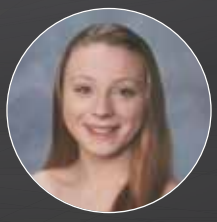
Savannah Reimann

Attending Arizona State University in Tempe, Ariz.
Winner of HFA Parent/Sibling/Child Educational Scholarship of $2,000

I am immensely grateful to have been chosen to receive the Hemophilia Federation of America parent/sibling/child scholarship. I will be attending Arizona State University and will be majoring in applied biological sciences. My goal of being a doctor started when I was young. I have always been interested in the human body, how it works, and how technology is constantly improving to allow us to heal and live longer. My interest in the human body has increased over the years as I continue to learn more about it. I have always dreamed of making a difference in this world. I believe that as a doctor, I would be able to achieve that goal. The medical staff I have been around have had such a positive impact on me. My family and my doctors are the heroes I look up to. This scholarship is a great honor. I am very blessed to have this financial help from the HFA to help me pursue my goal of becoming a doctor. I would like to thank the HFA for believing in me and for helping me succeed.

Rachel Wile

Attending University of California in Los Angeles, Calif.
Winner of HFA Medical/Health Services Educational Scholarship of $4,000



I am honored to be accepting this scholarship from the Hemophilia Federation of America. I am a senior at University of California, Los Angeles majoring in physiological science. My family's background, as well as my own experience with the hemophilia community, has inspired me to pursue a path of medicine. After I graduate, I hope to attend medical school and, eventually, specialize in hematology in order to help progress the knowledge of bleeding disorders and the treatments available for the community. This scholarship will help me achieve my educational goals, and I am very grateful to HFA for this award!

Getting to Know HFA's Newest Staff Members

We recently welcomed some new staff members to help us better serve the bleeding disorders community.

Kimberly Ramseur
Senior Manager for Policy and Advocacy

Kimberly serves as a liaison between our patient community and healthcare policymakers. This includes examining existing or proposed legislation to ensure our community is protected and has a voice in the policymaking process, drafting comments, giving presentations or writing policy papers. She holds a Bachelor of Arts in political science, a JD and MPH with concentration in epidemiology. Before joining HFA, she was a healthcare advocate. In her free time, she loves gardening, cooking and playing with her newly adopted dog, Bella.

DeBran Traver
Senior Research Analyst

DeBran analyzes and manages data for research, evaluates projects and the PEER Portal, prepares reports and disseminates results. She holds a Ph.D. and MPH in health education and promotion. Before joining HFA, she worked in public health program evaluation, community-based participatory research, HIV/AIDS and cancer education and prevention. She likes to travel, cook and try new eating establishments, and she ministers to kids with special needs at her church.

Allison Harrison
Helping Hands Program Manager

Allison manages HFA's Helping Hands emergency assistance program by working closely with the committee and processing applications. She's also working on a new program that will address the educational and financial barriers to sustaining employment for people with bleeding disorders. Allison has a master's degree in social work and certificate in nonprofit leadership. She has worked for nonprofits in program design and management, and outreach with special interest in illness, trauma and community engagement. She and her partner enjoy exploring the food and drink of D.C., their dog Wally, and listening to music. She is part of the D.C. chapter of Showing Up for Racial Justice and a published poet.

Yota Dermatis
Helping Hands Coordinator

Yota serves as a coordinator in HFA's Helping Hands program. She works closely with community members following a referral for emergency assistance, medical assistive items and inhibitor support. She holds a bachelor's degree in social work. Prior to working for HFA, she worked with adults with intellectual disabilities, first doing behavioral intervention and then case management. She enjoys drawing, baking and volunteering as a Best Buddy.

Alexander Butler
Data Coordinator

Alexander joined HFA this fall to manage data. Prior to joining HFA, he worked in data and contract management for a talent agency and multimedia company. He lives with his partner, Carl, and beagle-basset hound Fat Boy. He enjoys writing and performing poetry and music.

HAPPENING **HIGHLIGHTS**

HFA and NHF Collaborate on Patient Safety

In response to the recent unexpected number of recalls and other product safety issues, Hemophilia Federation of America and the National Hemophilia Foundation have responded to the community's needs and assembled a Safety Summit to be held in 2020. These events have highlighted the need to articulate communication standards that will serve the community well as it enters in to a new and uncharted era of gene therapy and other novel treatments. The issue of safety and properly communicating issues to the community is important to everyone. HFA and NHF have invited all representatives of the key stakeholder groups to join the Safety Summit.

Community leaders, patient organizations, industry partners and regulators will be in attendance. At this invitation-only summit, the goals are to identify gaps in knowledge and understandings of current drug safety standards, develop educational resources to address the identified gaps, create a Patient Bill of Rights and Responsibilities, and complete a patient/organization-authored white paper along with any other materials identified that could benefit the community. The organizations hope to share preliminary outcomes shortly after the Summit and expect the white paper will become public by the spring.

If there are issues/questions the community would like to be addressed at the summit, they are encouraged to submit them to **The Patient Voice**, an inbox created by HFA and NHF at http://bit.ly/PtVoiceSafety, to hear concerns. The organizations will work to ensure submitted issues or questions are discussed. The primary goal of the summit is to ensure safety is put front-and-center in the mind of every community member and that the organizations are equipped to ensure it remains a crucial piece as we move forward.

Visit http://bit.ly/PtVoiceSafety.

Blood Vibrations Drops New Album

The latest Blood Vibrations album has been released. The album debuted at the Blood Vibrations Listening Center as part of the Blood Work exhibition by FOLX (Justin Levesque) during the National Hemophilia Foundation Bleeding Disorders Conference in Anaheim. **Blood Vibrations: 8 (Blood Work Mixtape)** features sounds and visions from people in the bleeding disorders community. The latest release features an album cover by Kennet Kaare and music by various artists.

HFA's Learning Central Launches New Learning Opportunities

Hemophilia Federation of America is excited to offer several new learning opportunities for the bleeding disorders community in HFA's Learning Central at www.hfalearning.org. New courses include Joint Health, Employment Rights and Factor VII.

Current, New, and Emerging Therapies

With so many new treatment and therapy choices making their way to market, trying to learn about them all can be overwhelming. This course offers a refresher on what's out there now and the basics of what is in clinical trials.

Access this new course in Learning Central's University section.

Employment Rights

HFA's Helping Hands team interacts with more than 400 households each year — community members who say they face barriers to sustainable employment. Some are in physically unsustainable jobs while others are in low-wage jobs that do not cover monthly expenses.

The Employment Rights course offers information about the Americans with Disabilities Act and the Family and Medical Leave Act, specifically applicable to those living with bleeding disorders. It includes first-hand information from community members about their experiences and tips for self-advocacy in employment.

Access this new course in Learning Central's Planning Office section.

Bleeding Disorders Types – Factor VII

Among the other bleeding disorders types courses available, the most recent type added is Factor VII. Other types already available in Learning Central include an introduction to hemophilia, Factor VIII (hemophilia A), Factor IX (hemophilia B), and Factor XI (hemophilia C).

Access this new course in Learning Central's The Knowledge Park under Bleeding Disorders Types.

Joint Health

Safe physical activity offers many benefits, including diminishing joint bleeds and supporting a faster recovery from joint bleeds. These courses tell what joints are, how they work, and what really happens when a bleed occurs. The courses also provide advice on choosing ideal physical activities, keeping physical activities safe, and modifying physical activities to accommodate a body's current needs.

Access this new course in Learning Central's Health and Wellness Center section.

Register Now For HFA's Annual Symposium!

April 23–26, 2020
Baltimore, Maryland

What's waiting in Baltimore?

- 1,000+ community members to connect with
- Three days of educational programming and workshops
- 50+ exhibitor booths

Symposium registration and hotel room block is now open.

Learn more and start planning your experience at our annual meeting.

CHARTING OUR Future

HFA

www.hemophiliafed.org/symposium

Helping Hands Announces Changes in 2020

Each year, Hemophilia Federation of America's Helping Hands programs helps hundreds of families in their time of need. The Helping Hands Team announces some changes to the program in 2020. These changes are intended to help HFA focus resources on the most pressing and unmet needs of the bleeding disorders community.

Fitness Support

Fitness support, such as gym memberships and fitness items, will no longer be part of the Items program, but will be covered for people with an active inhibitor (a measurable titer and/or shortened half-life) as part of the Inhibitor Support program. Items assistance with items such as protective gear, mobility supports, braces, medical IDs and heating/cooling items continues.

Other Inhibitor Support Changes

Assistance for educational travel will no longer be covered under the Inhibitor Support program. We are concentrating on filling gaps in services for inhibitor families who need educational support for students, medical travel assistance and fitness support. Most conferences with inhibitor education have scholarship programs to reduce the financial burden of educational travel for inhibitor families.

Inhibitor families who are interested in HFA's Symposium 2020 Inhibitor Track, but are in need of assistance, can apply for a hotel scholarship within the Symposium 2020 Registration.

*There are currently no changes for the **Emergency Assistance** program.*

Visit www.hemophiliafed.org/helpinghands for more information!

We are grateful for our community.

In this season, we give thanks to our community,
and wish you a happy and healthy holiday season.

Connect with us @HemophiliaCoRes

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Standing Up

Young adults from around the U.S. learn to advocate for themselves in Washington

BY SARAH SHINKMAN, HFA STAFF

Hemophilia Federation of America's third annual Young Adult Advocacy Summit took place in Washington, D.C., this fall. The four-day event brought together 17 young adults with bleeding disorders from around the U.S. and focused on developing advocacy and leadership skills through interactive training with experts in policy, advocacy and communications.

Attendees spent a day on Capitol Hill talking with legislators and their staff, as well as dropping off information packets at 20 offices in between meetings. Other highlights included an improv for advocacy workshop, takeover of HFA's social media accounts, evening tour of the D.C. monuments, health literacy presentation, and networking with other young adults with bleeding disorders about the challenges they face every day.

Top left: Jonathan of Florida shares his story during Capitol Hill visits; top right: Gage of Ohio and Jonathan of Florida talk during the Improv for Advocacy workshop; middle left: Tameelah of South Carolina created a social media video during her time on Capitol Hill; middle center: Hector of California listens intently on during the summit; middle, right: Sebastian of Puerto Rico, Frances and Jonathan, both of Florida, pose outside the capitol. Bottom: Participants of the Young Adult Summit and HFA staff members pose outside the Capitol.

ADVOCACY **PROFILE**

Interim President and CEO Chosen to Lead the Charge

Hemophilia Federation of America's board of directors has selected Sharon Meyers, M.S., CFRE, to serve as the next president and chief executive officer.

> "After reviewing more than 143 applicants, and a selection process that incorporated many different voices from key stakeholders throughout the community, I am thrilled to share that the board has extended an offer to Sharon Meyers," said Josh Hemann, chairman of the board of directors. "With a passionate and experienced staff, a dedicated board of directors and a community with unparalleled engagement, our ability to serve the bleeding disorders community is stronger with Sharon at the helm."

Meyers has been part of HFA's leadership team for more than four years and has 15 years of healthcare and university nonprofit leadership experience. Prior to joining HFA, she was president and chief development officer of the St. Anthony North Health Foundation in Denver, vice president of the Penrose-St. Francis Health Foundation in Colorado Springs, foundation executive director and director of advancement of the St. Michael's Catholic Academy in Austin, and associate executive director of the University of Southern Mississippi Foundation.

Meyers is a Certified Fund Raising Executive (CFRE) and holds a Nonprofit Management Executive Certificate from Georgetown University in Washington, D.C. She is currently working on a doctorate in education at the University of Southern California in Organizational Change and Leadership. Earlier in her career, she was a public servant working on an ambulance as a nationally-certified EMT-I and answering 911 calls. She has volunteered and served as a board member for various nonprofits serving the poor and those in need.

New HFA President and CEO Sharon Meyers, center, visits with community members Trevor Ekema of Texas, right, and Juan Sedano of Texas at a congressional reception.

The search was conducted in partnership with Aspen Leadership Group, an executive search firm specializing in career placement in philanthropy. Meyers has been interim president and CEO since September after Kimberly Haugstad resigned to accept a position at Global Genes, a California-based nonprofit advocating for rare diseases.

You are part of the community.

It's time to become an *official* member of HFA.

Annual Membership Is Open

Membership with Hemophilia Federation of American means belonging to an inspiring family who cares about people living with bleeding disorders. Membership allows HFA to continue to advocate, educate and assist the community and gives members an active role in shaping the organization.

Your membership has a profound impact and comes with a number of benefits:

- Full access to our programs and services.
- Regular communication on topics and resources important to the community through our email newsletters, magazine and other updates.

Membership Dues: Paid in a one-time, non-recurring payment of $35 for an individual or $50 for a family.

Sign up today at www.hemophiliafed.org/membership!

Business, specialty pharmacy and HTC memberships are also available.

Uniting Voices for Change

Listening to the healthcare challenges women with bleeding disorders face

BY JANET CHUPKA, STAFF WRITER

Hemophilia Federation of America (HFA) has been working to better understand barriers and potential gaps in care for women with diagnosed bleeding disorders. As part of this effort HFA invited women, aged 18 and older, with a diagnosed bleeding disorder, who are members of its Blood Sisterhood and/or Moms in Action programs, to participate in discussion sessions. These discussion sessions occurred at HFA's 2019 Symposium in San Diego, California. The purpose of these discussion sessions was to better understand participants' experiences with their symptoms, diagnosis, treatment and overall care for their bleeding disorder.

Twenty-three women attended one of three discussion sessions. In the discussion sessions the women were asked a series of prepared questions designed to engage participants in sharing their experiences. The questions and conversation were guided by a trained facilitator. Each session lasted 90 minutes and was recorded with permission from each attendee. There was also a professional notetaker in the room, taking notes of the discussion, and an HFA staff person providing oversight of the group discussion and available to provide support to the women. All persons in the room were female. From the compilation of these discussions, we identified a number of themes that were shared among participants' experiences.

Identifying their symptoms, obtaining a diagnosis, and receiving adequate care remains a challenge.

Overall, participants believed the most significant barrier to identifying, diagnosing, and treating women's bleeding disorders is a generalized lack of awareness and information regarding these types of conditions in females, among both health care providers and the general public. Participants talked about their challenges in obtaining a diagnosis and receiving adequate treatment, related to providers. Many participants felt this was due to the absence of established guidelines for diagnosis and treatment for women, along with healthcare providers' lack of empathy or interest

Word cloud summarizing feelings currently experienced by discussion group participants.

in listening to their concerns. Participants specifically mentioned that they felt women are being treated with protocols developed based on data collected from men and the male experience, which may not be applicable to women. During the discussion, participants identified a persistent and generalized belief within the medical community that women are not affected by bleeding disorders and that doctors do not have enough information or show an interest in listening to their female patients. Participants believe this lack of diagnosis and acceptance by the general provider community is a direct result of:

- an absence of adequate testing criteria for diagnosing women (or lack of criteria developed based on data collected from females)
- the absence of a standardized protocol that is sensitive and inclusive of women's needs

- the lack of communication between different medical specialty providers

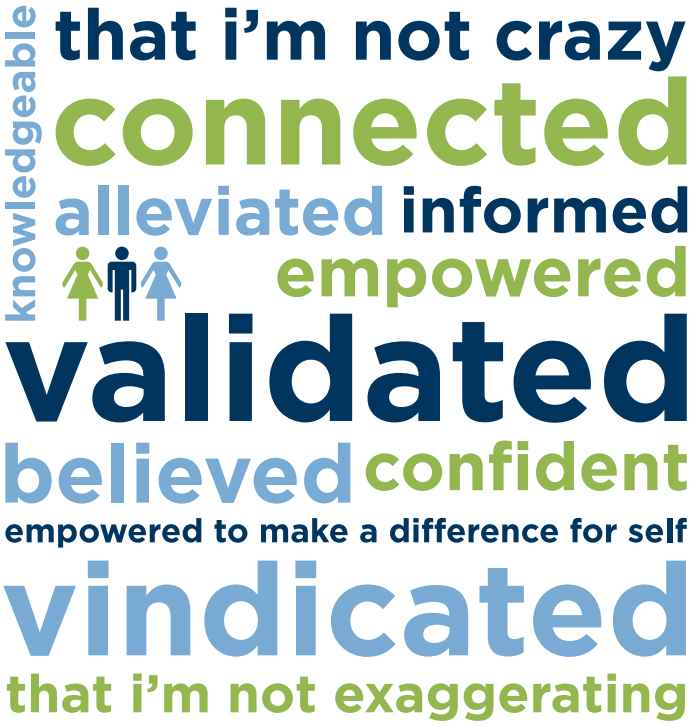
Participants also discussed the lack of knowledge and awareness among the general public about bleeding disorders in women and the corresponding signs and symptoms among women, that contributes to a strong challenge in obtaining a diagnosis. Participants felt this lack of awareness and information delays or prevents women from seeking medical attention and/or sharing their concerns with the right specialists, thinking what they were experiencing was normal or not serious enough for a medical consultation.

Once obtained, a diagnosis seems to have a positive impact on the quality of life of female patients.

From a physical standpoint, a diagnosis and corresponding treatment help women control or better manage their pain and bleeding episodes. From an emotional standpoint, a diagnosis provides women with validation and empowers them to take control over their treatment. We created a word cloud that summarized the feelings experienced by the participants of these discussion sessions about the impact of receiving a diagnosis. Twelve unique responses were provided by the participants. The larger, bolder words are those that were shared by multiple participants. In other words, those feelings were more common among the participants.

Yet, living with a bleeding disorder takes a significant emotional toll on female patients.

Most participants indicated they continue to deal with anxiety about knowing what to do if they experience a bleeding episode and what steps to take to deal with the symptoms and stop the bleed. Additionally, participants felt they live with the stigma of having a bleeding disorder, which limits their ability to perform daily activities and responsibilities. Some of the challenges included missing school or work because of heavy periods and not being able to take care of their children because of pain and weakness. Other challenges were related to their social interactions, such as missing out on social events when on their periods, staying home to avoid having people question them about their bruises, and limiting their participation in physical activities and/or playing with their children because of fear of having a bleeding episode and getting injured. Another word cloud was created that summarizes the emotions that women with a bleeding disorder experience in relationship to their diagnosis. Fifteen unique responses were provided by the participants. The larger, bolder words are those that were shared by multiple participants. In other words, those feelings were more common among the participants.



Word cloud summarizing feelings experienced by discussion group participants after being diagnosed.

Support provides benefits for women

Based on both their positive and negative experiences in the identification, diagnosis and treatment of their bleeding disorders, the general consensus among women who participated in the discussion groups was that they could have benefited from a variety of things: being better educated themselves; having their health care providers be more empathetic, compassionate, and open to the idea of women being affected by hemophilia and other bleeding disorders; having access to support groups or connecting with other affected women. These things could have helped the participants receive earlier diagnoses, earlier treatment, and more importantly, prevented them from experiencing a traumatic experience.

> **"I wish (the disorder) had been recognized sooner, that doctors (had been) more willing to speak about it... I just thought bleeding was normal, having grown up in a household with it. But you know, quicker recognition, more conversation with the providers, and with other women, groups like this (discussion group) ... we learn more from each other than we do from providers."**

The following summarizes what participants believed could be done to improve the experiences of undiagnosed and diagnosed women:

- **Information is empowering.** Participants felt that had they and their parents/families been better informed about the possibility of women in the family being affected by a bleeding disorder, they would have been better prepared to recognize the symptoms and advocate for diagnosis or treatment. More education and awareness among the general public about bleeding disorders, the signs and symptoms of abnormal bleeding, and incidence rates could help identify women and girls affected sooner and at a younger age prior to issues related to uncontrolled bleeding.

"It was a nurse (the one who suggested) a test. The doctor didn't. It was her. She said, 'you have a history of hemophilia in your family — have you been tested?' I (knew) I (was) a carrier. I didn't even know that we need to be tested."

- **Health care providers acknowledging that women are also affected.** The consensus among discussion group participants was that the medical community still operates under the assumption that only men are affected by hemophilia and other bleeding disorders.

"I was fortunate to have a provider that understood and… didn't have the mentality that women aren't affected."

- **Health care providers truly listening to them.** What made the difference for these women in getting diagnosed or accessing adequate treatment was that their doctors paid attention to their symptoms, instead of simply basing their decision on current diagnostic criteria.

"That might be the standard of care. The standardized care may be for them to understand that they have to look at us individually."

"He (the provider) wasn't certain what it was, but he felt like historically, that he knew. I had an educated provider, an open-minded and educated provider."

- **Raising awareness among providers that women are not just carriers but can have a bleeding disorder themselves.** While all of the women found doctors who listened to them and received a diagnosis, many of these women had past experiences with doctors who were dismissive of their symptoms and not open to being "educated" by the patients.

- **Education and comfort of self-treating at home.** The discussion group participants valued the information and services available to them at hemophilia treatment centers (HTCs) and being able to treat at home which provides more freedom and flexibility, although they recognize it is not always easy to self-treat. However, more education and guidance on treating at home, how to do it, and when to do it would help self-treatment at home become a more comfortable practice and reduce women's stress.

"I was afraid to infuse myself. Is that not the craziest thing? I was scared… I was crying, and I said, 'what is the matter with me?' Like, I got my diagnosis, I have my factor, and now I'm afraid to do it."

- **Support from a community.** The support and information provided through support groups has been extremely helpful for discussion group respondents and helps prevent them from feeling isolated and alone.

"Fifteen years (after my diagnosis), we have these meetings, and for the first time in my life, I'm in a group of women that are also in the same boat as me… and we're not talking about our kids, we're talking about our symptoms!"

The information collected in these discussion groups provides HFA with a better understanding of the experiences of the women who participated in them. The experiences shared in our discussion groups are not meant to be reflective of the experiences of all women with bleeding disorders, or even the diagnosed adult women participating in HFA's Blood Sisterhood and Moms in Action programs. However, the themes identified provide HFA with a better understanding about barriers and potential gaps in care for women with diagnosed bleeding disorders. HFA plans to continue these conversations with women, so that it can develop programs and activities to better address the needs of women with bleeding disorders more directly and ultimately improve their quality of life.

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Hitting the Right Note

California man finds inspiration to bring music therapy to patients

BY MICHAEL DEGRANDPRE, STAFF WRITER

Anyone who has tapped the steering wheel or sung along with the radio in the car has already proved Tim Ringgold's theory correct—everyone is musical. If you haven't done either of these things, try reciting your phone number or Social Security number, and notice the cadence with which you speak. That's rhythm, and that's what Tim is all about.

Based in Orange County, Calif., Tim, a licensed, board-certified professional music therapist has sought to promote music therapy services for the last 11 years. When his daughter, Bella, was born in 2009 with an extremely rare skin disease called epidermolysis bullosa, or EB, Tim and his wife Angelique were thrust into a new world of medical terminology, challenges, pain, hope and finally inspiration they didn't see coming.

With EB, patients like their daughter are born without the gene responsible for making the "anchors" that adhere her skin to her body, including inside her mouth and her entire gastrointestinal tract. According to a blog the Ringgolds kept during their experience, "any friction, rubbing or bumping caused blisters to form, or it caused her skin to shear clean off."

Not realizing the condition was present at birth, doctors pulled Bella out during delivery and their grip on her legs caused instant and irreversible damage, landing her in the NICU immediately, wrapped in specialized bandages to prevent further havoc. With no family history and no clue about the condition, Tim and his wife took their cue from Bella, who "remained bright and cheerful" as they navigated the process of working through this unexpected diagnosis.

After complications from a transplant procedure, Bella passed away on Oct. 11, 2010, just shy of 17 months old. Even at such a young age, she inspired a lasting impact with Tim, Angelique and their other daughter, Bella's older sister.

Before his daughter's death, Tim had completed NICU music therapy training and found Bella was his first patient. Every time they changed her bandages, music was involved. Both for Bella and her inexperienced parents, music provided an auditory support to help make it through this new and unexpected experience.

Music has always been in Tim's life. At the age of 4, Tim found himself singing his first solo. Later catapulted to performing a solo for the pope in St. Peter's Square, he found himself bounding down a professional musical path,

which included several years working in Los Angeles as a recording artist, playing places like the famed Troubadour nightclub in West Hollywood. Emotionally and physically worn, and realizing, with then-girlfriend Angelique's support that the rock 'n' roll culture wasn't a healthy long-term option, Tim had to make a decision about his future, and let the beat guide him. Capitalizing on his strengths and interests, he found a university degree program that spoke to those strengths and began to pursue music therapy.

"I knew that if I stuck with it, it would be awesome, and without my wife's support, I would have quit several times," he acknowledged. "It has been totally worth it."

Now entertaining and educating across the country for many different groups and causes, including bleeding disorders, one thing remains the same for Tim: the heartbeat of purpose. Whether with adolescents or the elderly; people improving their mental health or in treatment; children with developmental or intellectual challenges, the universal language of music always shines through clearly to every audience—which is the point of his message.

Especially for families who can be subjected to unexpected stress, such as those with a bleeding disorder, learning how to utilize music as a coping mechanism can be life changing. For Angelique and Tim, music was a non-intrusive, positive support tool they could use as a family when they went through the often painful, even traumatic, process of changing their daughter's bandages. The soothing sounds of sonic mediation helped keep the mood of the room relaxed and calm during an otherwise upsetting experience.

One part of Tim's message is that families with bleeding disorders might consider using music they enjoy as a soundtrack while they infuse or work through a time when there might be an emotional disturbance. He has found music works for both the patient and the caretaker(s) as it helps soothe both parties while they work.

As Tim reflected, "Music can help calm you down quickly. If you're suffering from stress, there's nothing that works faster than music which can help." His recommendation is to create a playlist ahead of time with your three favorite songs, (heavy metal is admittedly not recommended). If you are able, take a quick walk while listening to something you know, with an upbeat, inspiring, warm and personal meaning, can make all the difference.

"The gold-standard is to interact with the music in some way. Hum, tap, sing, dance, etc.," he recommends. "Music resets the stress response in the nervous system faster than any oral medication."

"All of us are musical, and our bodies naturally run on rhythm," Tim declared. "There is a myth that music and talent are generic, but that's not true. You just need to connect with the music in the right way."

As we carry on in this hustled world, often impatient and desperately seeking solace, we might consider turning up the music and tapping or singing along. You probably won't win a Grammy for your performance, but you'll find yourself rewarded with a new kind of inner peace that can help carry you through the moment.

As Tim looks forward, Bella's legacy is actualized through every note and harmony brought to life in his work. As a national speaker and through his company, Sonic Divinity, Tim leads a team that brings music therapy to life, and provides an alternative, non-medical treatment for everyone.

Visit **www.timringgold.com** to learn more about Tim.
Visit **www.sonicrecovery.com** for information, updates, email newsletter and more related to stress management through music.

The hemophilia treatments of today were once the dreams of yesterday. Proof that when

SCIENCE AND THE COMMUNITY

come together, great things happen.

Los tratamientos para la hemofilia de hoy fueron alguna vez los sueños de ayer. Eso prueba que cuando

LA CIENCIA Y LA COMUNIDAD

se juntan, ocurren grandes cosas.

Let's put science to work

GenentechHemophilia.com

Pongamos la ciencia a trabajar

GenentechInscripcion.com

Genentech
A Member of the Roche Group

Hemophilia A
Hemofilia A

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Managing Gaps in Care

A look at potential barriers to care, from aging out of pediatric care to language barriers

BY ANDY ANDERSON, STAFF WRITER

In an oral history interview collected by Hemophilia Federation of America, Paul Clement, a father of a man with hemophilia, puts the situation succinctly:

...Once you transitioned into the adult side, they had no hematologists with bleeding disorders experience. They were all basically oncologists. So, hopefully you're up to speed on how to care for yourself by then. Because if you're not, you're going to get in trouble... Some families don't question, at all, what the doctor says. They do whatever the doctor says, and they don't know what product they're on, or why they're taking this product, or how much they're taking...

Though this sounds like a story from a forgotten chapter of our community history, Clement was recounting his experience during the mid-2000s when his son started college and transitioned from pediatric hematology care to a treatment center for adults. Though treatment for bleeding disorders has made huge strides over the past half a century, some members of our community still struggle with access to quality care.

In addition to the often-bumpy transition from pediatric to adult healthcare, there are other common barriers to care for significant segments of the bleeding disorders community:

Gender

People diagnosed outside of early childhood, especially girls and women, may lag behind their earlier-diagnosed peers in the terms of quality of life. Women and girls with von Willebrand disease face an average delay of 16 years from the first symptom of a bleeding disorder to diagnosis. By the time a reliable plan of care is in place, patients may have suffered irreversible damage to the body or experienced significant financial and psychosocial challenges.

Communication

Language barriers can make it difficult to adequately address the complex and varied needs of a person with a bleeding disorder. Despite the fact that an estimated 13 percent of Americans speak Spanish as their primary language, the United States health care system is "largely geared toward serving English speakers."

A 2010 study found that language barriers in healthcare settings were associated with increased risk of adverse outcomes and decreased access to care. Interpreter-translator services provided by hospitals can help to decrease these risks and improve the quality of care received by patients who do not speak English as a primary language. In addition to utilizing these services when offered, patients

and their families can advocate for themselves by asking questions during visits with healthcare providers and keeping detailed records about their own health.

Self-Advocacy

Unfortunately, medical visits can often feel rushed and the time allotted inadequate to address all the medical and psycho-social issues related to having a bleeding disorder.

Patients may feel intimidated and believe they lack the medical literacy required to have a fruitful conversation with their physicians. Adding to the problem is the fact that many patients have a mistrust of providers and may tend to avoid healthcare in general because of the consistent dismissal of their symptoms. Given these powerful and often overlapping circumstances, self-advocacy can seem an overwhelming challenge.

To help you make sure you're getting the most out of your time with your doctors, we've put together the following tips.

- Keep detailed records of symptoms, even those that may not seem to be related to your bleeding, and all medications used. Consider using a smartphone app to log this information and then share with your providers quickly and easily.
- Remember you are the expert on your body. If a healthcare provider refuses to run diagnostic tests, is unable to recommend treatment, or is unable to make a conclusive diagnosis, ask them to make sure that this is clearly stated in your medical records.
- Don't be afraid to seek a second opinion.
- Find your peers! Talking with others in the community can be enlightening and empowering when considering your quality of life and what improvements might be possible.

Ask your doctor...

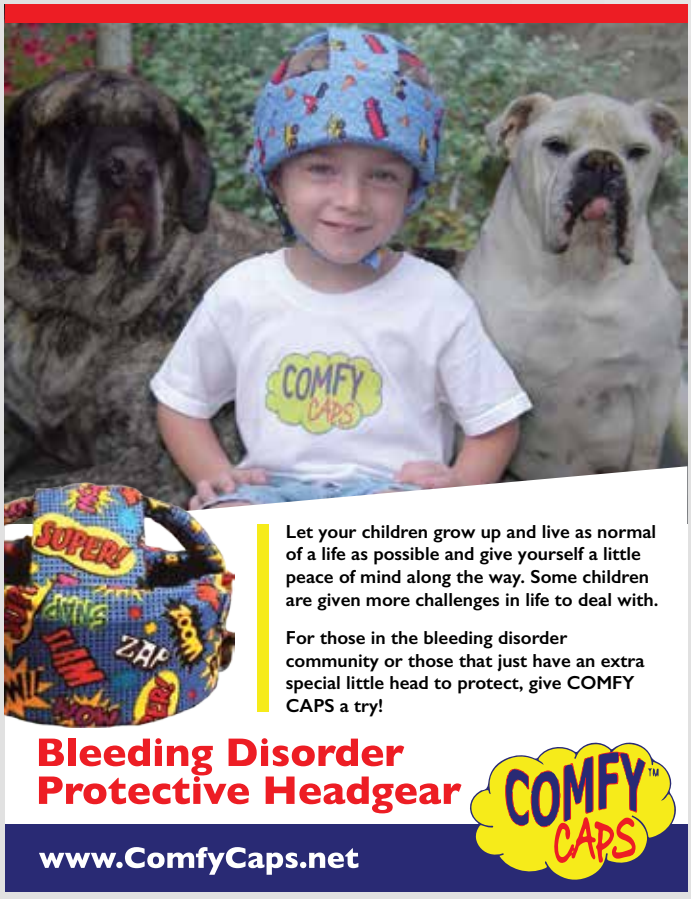
- If my test results come back as inconclusive, what are the next steps?
- Is there anything I should avoid or consider modifying in my daily routine?
- How can I manage my symptoms?
- I don't feel like my quality of life is where it could be. Can you work with me toward some positive changes?

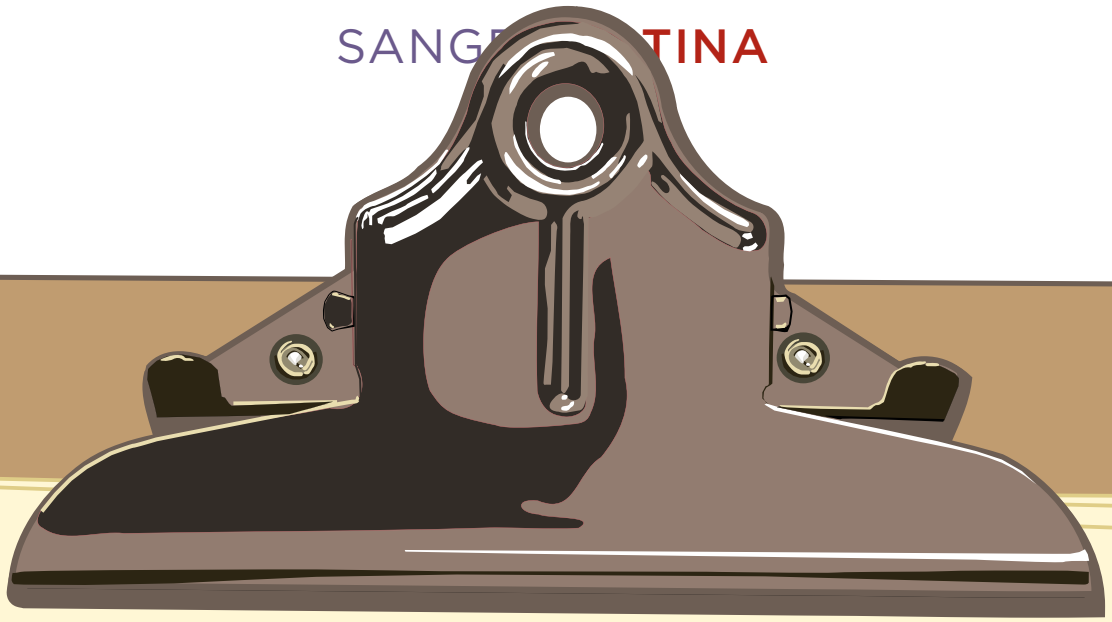
Sources:

Kirtava et al. 2004: Trends in clinical management of women with von Willebrand disease: a survey of 75 women enrolled in haemophilia treatment centres in the United States.

The impact of language barriers on the health care of latinos in the united states: a review of the literature and guidelines for practice, Caraway l. Timmins cnm, msn

Language spoken at home by ability to speak english for the population 5 years and over (hispanic or latino), Universe: Hispanic or Latino population 5 years and over, 2017 American Community Survey 1-Year Estimates





Cuidando su bienestar mental en estas fiestas

POR MARTHA BORIA NEGRÓN- PERSONAL DE HFA

Ya se acercan las fiestas. Los días festivos para muchos pueden ser época de alegría, algarabías y de mucha felicidad. La música y las recetas de la abuela son los principales invitados en nuestras casas. Es la temporada de avivar nuestras relaciones familiares y de hablar y compartir con amigos. Nos preparamos con días de anticipación, nos ponemos nuestros mejores atuendos, preparamos las recetas de la familia, decoramos las casas y bailamos y cantamos las tradicionales canciones.

Para otros pueden ser días obscuros y difíciles. Hay personas que solo sobrellevan celebrando las tradiciones con otros. A muchos les invade la nostalgia, la tristeza y la ansiedad por haber perdido a un ser querido, el no estar cerca de familiares, la perdida de trabajo, la situación económica, una enfermedad crónica como los trastornos de sangrados, entre otras cosas. Lo antes expuesto pueden desencadenar depresión, ansiedad y síntomas físicos. Es importante recordar cuidarse durante este tiempo. Una caminata corta, comer una comida nutritiva, reírse con un amigo y recordar descansar puede ser suficiente para pasar un día difícil. No es señal de debilidad, sino de fortaleza, pedir ayuda si se siente abrumado.

ALGUNOS CONSEJOS:

1. Administre bien tu tiempo- Comience semanas antes con las compras, decoración, planificación de la comida y más. Hay mucho que hacer y dejarlo todo para el último minuto aumentará su estrés.

2. Vigile su billetera- No siempre el comprar regalos caros hace más feliz a nuestros familiares, amigos e hijos. Haga un presupuesto para no afectar su billetera.

3. Tome tiempo para usted- Busque tiempo para meditar, tomarse una taza de café, leer un libro y relajarse. Las fiestas y sus preparativos pueden ser abrumadoras.

4. Pida ayuda- Recuerde que no todo debe recaer sobre usted y que otros también tienen talento y habilidades para hacer que las cosas queden bien. También, no importa que las cosas no queden perfectas. Valora el tiempo y las festividades y crea nuevos recuerdos.

¡Lo importante es la estabilidad emocional de todos y que la alegría llegue a cada casa y a cada familia en estas fiestas!

Mis factores de estrés (Enumere los cinco principales)	**Como los puedo eliminar**
(ejemplo) No tengo tiempo para las compras	Planificaré y hare una lista de cosas más importantes por hacer
1.	
2.	
3.	
4.	
5.	

EL REEMPLAZO DE FACTOR REFLEJA LA PROTECCIÓN INTERIOR

Para gente con hemofilia, el tratamiento de Factor reemplaza temporariamente lo que falta.[1-2] Con un largo historial de resultados probados, el tratamiento de Factor trabaja con el proceso de coagulación natural de tu cuerpo para formar un coágulo adecuado.[2-6]

Takeda lo hace posible con su dedicación a la búsqueda de avances en hemofilia por más de 70 años.[7]

Las posibilidades te mantienen fuerte.

Referencias: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet.* 2016;388:187-197. **2.** Canadian Hemophilia Society. Factor replacement therapy. http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-treatment-of-hemophilia/factor-replacement-therapy/. Consultado el 18 de mayo de 2018. **3.** Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost.* 2014;40:571-576. **4.** Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost.* 2007;5:2408-2414. **5.** Antovic A, Mikovic D, Elezovic I, Zabczyk M, Hutenby K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in haemophilia A patients treated on demand. *Thromb Haemost.* 2014;111(4):656-661. **6.** Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry.* 5th ed. New York, NY: WH Freeman; 2002. https://www.ncbi.nlm.nih.gov/books/NBK22589/. Consultado el 18 de mayo de 2018. **7.** Shire. Shire's 70+ year commitment to the hemophilia community. https://www.shire.com/en/newsroom/2018/january/7sossj. Consultado el 6 de junio de 2018.

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S50142 07/19

Takeda

Mi Diario de Bienestar

Fecha:

Pensamiento positivo del día

¿Qué hacer hoy?

Solo para mí

Mi presupuesto y en que voy a gastar

Voy a pedirle ayuda a:

1.
2.
3.

Instrucciones para usar **Mi plan diario** para que pueda mejorar su estrés.

Pensamiento del día—Escriba tres diferentes pensamientos todos los días.

Solo para mí—Haga algo diferente para usted todos los días. Tomarse un café, salir con amigos, ir al cine.

Mi presupuesto y como voy a gastar—Mantener sus finanzas en orden y no gastar de más, puede ayudarle a no tener estrés.

Voy a pedir ayuda a—Enumere tres personas a las que puede pedirle ayuda con lo que tenga usted que hacer.

HFA Partners with CDC to Promote Men's Joint Health

BY ANN LEWALK, HFA STAFF

This fall Hemophilia Federation of America kicked off **Your Journey the Healthier Joints** with six member organizations fielding teams of up to 10 men with bleeding disorders to participate in an eight-week activity challenge.

The challenge is part of HFA's cooperative agreement with the Centers for Disease Control and Prevention to promote joint health in men with bleeding disorders. Throughout the challenge, the participants worked as a team to motivate each other to reach the team goal of achieving the highest step count by late December.

Teams representing Asociación Puertorriqueña de Hemofilia (Puerto Rico), Hemophilia Association of New York, Hemophilia Foundation of Michigan, Hemophilia Foundation of Oregon, Northern Ohio Hemophilia Foundation, and Oklahoma Hemophilia Foundation, worked to improve their joint health, while competing to represent their member organization and present the secrets of their success at HFA Symposium in Baltimore in April.

Throughout the eight-week challenge, participants wore Garmin Vivofit 4 activity trackers to log their daily steps and activities. While the winning team was determined by most steps logged, the competition platform had the capacity to convert their other physical activities to steps. This proved successful, as many of the participants had their own fitness routines coming into the challenge.

Some teams put forth champions to share their experience along with their alternative ways of staying active. Kevin Finkle, HFO Bleeders of the Great Northwest shared a video of his unique form of exercise. Finkle is a member of a Marimba band, who uses his practice time as a workout, something most people may not think of as a way to keep active! His teammate, Matthew Taché, had his own way of staying active and fit. He lifted weights for four or five years and credits his workouts with strengthening his muscles and reducing target joint bleeds.

John Faria with Oklahoma Hemophilia Foundation and Tim Wicks with Hemophilia Foundation of Michigan worked hard to meet the daily goal of 6,000 steps. As they faced some physical obstacles in the midst of the challenge, both men found alternative activities and exercises they could do to keep active through injuries and still add steps for their teams. They also credited HFA Learning Central Joint Health modules (www.hfalearnin.org) with providing options for seated and adaptive exercises to be used while experiencing a bleed.

Other participants, like Eduardo Rodriguez of the team representing Puerto Rico, found participation in the challenge to be an opportunity to control weight and improve overall health. While his teammate, Orlando Vives, came to a surprising realization by wearing his activity tracker, of how much exercise he gets through his daily walks from his apartment to his college campus and back.

HFA and the CDC are hopeful that engagement in *Your Journey to Healthier Joints*, an increased knowledge of the importance of joint health and a focus on health, wellness, and the adoption of healthy behaviors, will reduce or prevent complications among persons living with hemophilia and other bleeding disorders.

This work is supported by Cooperative Agreement Number, NU27DD001151-05, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

Tim Wicks with Hemophilia Foundation of Michigan worked hard to meet the daily goal of 6,000 steps

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John Faria with Oklahoma Hemophilia Foundation used alternative exercises to meet his daily step goal.

Matthew Taché lifted weights for four or five years and credits his workouts with strengthening his muscles and reducing target joint bleeds.

Read participants' stories at www.hemophiliafed.org/bestofyoujointhealthchallenge
For more information about joint health and physical activity, visit HFA Learning Central — Health and Wellness Center to complete the informative, interactive joint health modules. www.hfalearning.org

BEST OF YOU
YOUR JOURNEY TO HEALTHIER JOINTS
Hemophilia Federation of America & Member Organization Joint Health Challenge

Team Challenge

Goal: 6,000 steps per day per participant

Final Order of Results

WINNER **

Hemophilia Foundation of Oregon – Bleeders of the Great Northwest

Oklahoma Hemophilia Foundation

Hemophilia Association of New York

Hemophilia Foundation of Michigan

Asociación Puertorriqueña de Hemofilia

Northern Ohio Hemophilia Foundation

**As winners of the challenge, Bleeders of the Great Northwest and their executive director will present their strategies for success at a Joint Health session at Symposium in Baltimore April 23-26, 2020.

Joint Health Challenge by the Numbers:

227 pounds lost

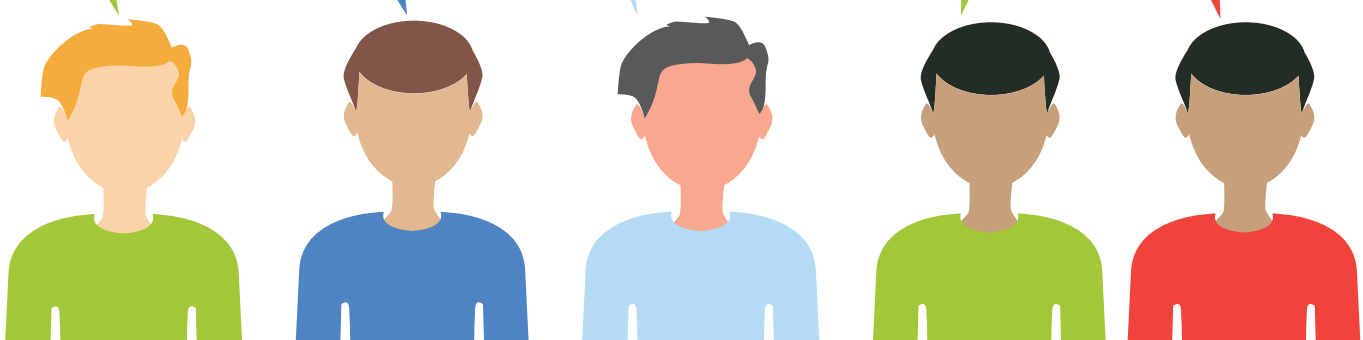
759,390 calories burned

6,680 average steps per day

49 participants (in six teams)

17,675,336 total steps walked

Equivalent to THREE trips across North America



TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®

IN HEMOPHILIA B

Rebinyn® elevates factor levels above your normal levels[a]

+94% Factor IX (FIX) levels achieved after an infusion[b]

83-hr (3.5 day) average half-life in adults[a]

With a single dose of Rebinyn® 40 IU/kg in adults with ≤2% FIX levels[a]

Clayton, 34 years old, is a pilot and enjoys hiking and camping in his spare time. Clayton lives with hemophilia B.

Achieve higher factor levels for longer

Compared with Alprolix®[c], Rebinyn® provides

4x greater factor coverage

6x higher factor levels at 7 days

Image of hemophilia patient shown is for illustrative purposes only.

[a]In a phase 3 study of adults, single dose pharmacokinetics were tested during the first Rebinyn® 40 IU/kg dose in 6 adults.

[b]Based upon a 2.34% increase in factor levels per IU/kg infused in adults.

[c]Based upon a phase 1 study comparing a single 50 IU/kg dose of Rebinyn® to a single 50 IU/kg dose of extended half-life rFIXFc in 15 adults. To allow for direct comparison between products, all patients received the Alprolix standard 50 IU/kg dose.

INDICATIONS AND USAGE

What is Rebinyn® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for routine prophylaxis or for immune tolerance therapy.

IMPORTANT SAFETY INFORMATION

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

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.** Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

Who should not use Rebinyn®?

Do not use Rebinyn® if you:

- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
- are allergic to hamster proteins.

What should I tell my health care provider before using Rebinyn®?

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.
- **Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.**
- Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

- **Common side effects include** swelling, pain, rash or redness at the location of the infusion, and itching.
- **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- **Tell your healthcare provider about any side effect that bothers you or that does not go away.**
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

Please see Brief Summary of Prescribing Information on the following page.

Rebinyn® is a prescription medication.

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.

Learn more at rebinyn.com and connect with your local HCL

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rebinyn®

Coagulation Factor IX (Recombinant), GlycoPEGylated

rebinyn®

Coagulation Factor IX (Recombinant), GlycoPEGylated

Brief Summary Information about:
REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/REBINYN.pdf to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

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

Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing REBINYN® so that your treatment will work best for you.

What is REBINYN®?

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat and control bleeding in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

REBINYN® is not used for routine prophylaxis or for immune tolerance therapy.

Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

What should I tell my healthcare provider before I use REBINYN®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

How should I use REBINYN®?

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® 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 hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

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

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

Use in children

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using REBINYN®

Do not stop using REBINYN® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much REBINYN®?

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of REBINYN®?

Common Side Effects Include:

- swelling, pain, rash or redness at the location of infusion
- itching

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor IX products. **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

Animals given repeat doses of REBINYN® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

These are not all of the possible side effects from REBINYN®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the REBINYN® dosage strengths?

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store REBINYN®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about REBINYN® and hemophilia B?

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

More detailed information is available upon request.

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: http://novonordisk-us.com/patients/products/product-patents.html

Manufactured by:
Novo Nordisk A/S
Novo Allé, DK-2880 Bagsværd, Denmark

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