Infusions
SUMMER 2023

Greetings from the Hemophilia and Thrombosis Team at UCSF Benioff Children's Hospital Oakland and San Francisco

Included in the picture: Shawn Norris, PT; Hattie Silliman, PNP; Jason Rahman; Beth Anne Martin; Erica Riray, Mary Lesh, PNP; Pattye Tobase, PT, Alison Matsunaga, MD; Shreya Agarwal, MD; Daisy Caburnay, RN; Susannah Lim, CRA; Theresa Garrety, RN, PHN; Madhav Vissa, MD; Carla Ruiz, OA; Katrina Unpingco, FNP; Zahara Jones, CRA; Judy Flores, OA; Michelle Wright, LCSW; Teresa Vazquez, MSW

Since 2000, it has been my privilege to be the HTC Medical Director at Children's Hospital Oakland. With the integration of UCSF Benioff Children's Hospitals in Oakland and San Francisco, I have now been appointed the HTC Medical Director on both campuses. I am so excited to join our Oakland and San Francisco Pediatric HTC's together into one comprehensive center to provide care for our patients and families with "bleeding and clotting" disorders throughout Northern California.

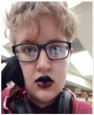
In addition to the wonderful team that you already know, I'd like to introduce some of our newest HTC members to include:

Dr. Shreya Agarwal, Theresa Garrety, RN, PHN. Daisy Caburnay, RN. Anthony Ong, PT

With gratitude,
Alison Matsunaga, MD
Medical Director
Hemophilia and Thrombosis Center (HTC)
UCSF Benioff Children's Hospitals Oakland/San Francisco

**Thank you Andrea Orozco, Executive Director, Hemophilia Foundation of Northern California, for coming to our Hemophilia & Thrombosis Center (HTC) in Oakland to meet some of our new team members!*

IN THIS ISSUE



What We Have In Common

by Mason Bobro

"Cisgender" (or "cis") is a phrase used to refer to people who identify with the gender associated with their sex assigned at birth; that is to say, not transgender. I want to preface by saying that critical and non-exclusionary discussions of gender are not possible without this term, and if you believe the term is a slur (as has been public discourse lately), I encourage you to reach out to discuss. This term will be used throughout the article.

When people ask me to share my experience as a trans man with a bleeding disorder, I'm never really sure what to say.

In truth, my experiences as a trans man directly overlap very little with my experiences as a person with factor X deficiency. Sure, I could talk about my horrific periods, my experiences with birth control, my chronic pain, my disappointing visits to doctors' offices and overall feeling like I'm out of place. But those experiences are not ones that are unique to a trans person. Indeed, I feel my experiences with these subjects is very similar to that of a cisgender woman's. As far as my bleeding disorder goes, my being trans has very little impact on it, and with the exception of an infusion prior to surgery, the reverse is also largely true.

That's why it sometimes feels disingenuous for me to talk about myself and my experiences. It's nothing new - while my being trans does come with extra difficulties, they aren't ones that any other disadvantaged group wouldn't also face (although they come with different contexts). What I continually see in my experiences with the bleeding disorders community is that while each individual story is unique - and that is certainly important, don't get me wrong - the *themes* of those stories are not. So instead of focusing on *me*, I prefer to focus on *us*, as a community. On *what we have in common*.

For example, any cisgender woman could tell a story about their pain being dismissed by a doctor because of their sex. If you have or were assumed to have a vagina by your medical office, I'm sure you have a story, too, even if you don't even realize that that was the case. Even perfectly healthy, straight, white, cisgender women have this issue.

Having a bleeding disorder - a set of disorders historically believed to be exclusive to people with XY chromosomes - compounds this. Not only are you not believed like your healthy counterparts, you are now rendered incompetent by *science*, as though the historical lack of cis women in research somehow had no impact on its result. Many of you with bleeding disorders won't even be diagnosed due to the inherent and unjust classification of women as

"exaggerators" or "just carriers" (and therefore somehow not worth listening to) that pervades even the sanctity of the HTC. I'm sure this is a familiar scenario to most of you reading this article.

I, as a white person, have no real experience being discriminated against for my race, but I do want to briefly point out here that this is a major factor as well. BIPOC have also been historically excluded or even abused in research, and the ways in which they are treated in medicine is appalling (and has been since the earliest days of the United States). Discriminatory misconceptions continue to exist today, making access to equitable, competent, and compassionate healthcare difficult.

continued on page 3

continued from page 2

Being trans adds another layer of complexity. I am seen as an attention-seeker, or people tiptoe around referring to me in conversation. Suddenly every medical or psychological appointment is no longer about what I came in for: it's a philosophical discussion of my autonomy and my gender identity. "Are you sure that's what you really want?" is so common a phrase that I have a physical reflex preventing me from grimacing when I hear it. And while you, dear reader, are likely not trans (though, if you are, hello!), I'm sure you've heard this phrase too.

I was asked this question about my birth control, about my testosterone, about my hysterectomy, and about my decision to not be on prophylaxis for my bleeding disorder. Two of these were "women's" issues, two were "transgender" issues, and three were "bleeder" issues (and I promise I did my math right), and yet, the same question applied to every single one. This is what I mean by *what we have in common*.

Like you, I have to worry that my medical care will become illegal or impossible to obtain. Like you, I had to beg and plead and cry for years to finally get a doctor to believe me. Like you, I had to convince a romantic partner that it wasn't about *them*. Like you, I had to convince an authority figure that I wasn't making it up and that I did actually have to see a doctor or get a test. Like you, I feel excluded when I enter a space that I fully deserve to have a place in. Like you, I have to face the reality of a medical world that was not tested for me, that is not ready for me.

Possibly *un*like you, I see these issues through the lens of being a transgender man. But there are other lenses: the lens of being assigned female at birth, of being BIPOC, of having your specific bleeding disorder, of being "too young" or "too old," of being a minority sexual orientation, of being neurodivergent, of having comorbidities, or of the countless other factors I haven't mentioned. Each lens is important and necessary to see all of the facets of the problem, and the problem cannot be fully solved without all of them. But each lens comes together to reveal one underlying theme. Respect. Consideration. Competence. Compassion. Inclusion. *Empathy*.

I want to point out now that *what we have in common* doesn't only include experiences of pain - the majority are actually experiences of joy. Of finding our community, finding our voice. Talking to someone who *gets* it, leaning on someone who cares. Celebrating every step forward. Holding each other up for every step back. Learning something new and passing it on, using the community experience to create new knowledge. Telling your own unique story and hearing that you matter. Showing respect, receiving respect. Learning that you're not alone. Pointing out one of the million issues above and saying "Hey, this is a problem," and being not only heard, but listened to. Making change - *real* change, change that you can see and feel. Celebrating that change together.

I'm sure that you have a memory you thought of as you read each of those examples.

(And if you don't yet, you will.) These are the experiences that make the true backbone of the bleeding disorders community - the reason that newcomers and old returnees alike are all welcomed with the same open arms and open hearts, year after year after year. The reason that we can find so much belonging in a community that, prior to diagnosis, most of us never knew about. The reason that, no matter who belongs to the community at a particular point in time, we can always come together and recognize *what we have in common.*

COMMUNITY SPOTLIGHT

My Experience as a Gene Therapy Clinical Trial Participant

by Cody Aronson

I'm currently a participant in a gene therapy clinical trial verbosely titled "Phase 3, Open-label, Single-Arm Study to Evaluate the Efficacy and Safety of PF-07055480 (Recombinant AAV2/6 Human Factor VIII Gene Therapy) in Adult Male Participants with Moderately Severe to Severe Hemophilia A (FVIII:C≤1%)". I was diagnosed with severe hemophilia as a one-year-old in the early 1990s and spent most of my life using factor VIII for treatment –first on-demand, then prophylactically, precociously self-infusing from age six until December 2020, when I received gene therapy. Since then, I have had a normal factor level without taking any factor VIII.

Participating in this study changed my life in big and small ways. Even the lead-in study helped me be more conscious of my health by making me log all my infusions (I had gotten sloppy and stopped logging decades before). I could see that I was indeed dosing every other day, or extra if I had an injury. After gene therapy, my relationship to hemophilia treatment completely changed, and it changed my life.

Every few years I'd hear that a cure for hemophilia was just 10 years away. A cure never seemed to materialize or seem any closer, but since prophylaxis with recombinant factor (a technological marvel itself) hadn't let me down, I wasn't phased. It is perhaps premature to use the word "cured" because this is a very new treatment, but right now I effectively don't have hemophilia. I'm told the gene therapy may last for a few years, maybe 10, maybe more. The aggregate of the experiences of study participants like me will tell.

For most of my childhood, I was treated at the UCSF Hemophilia Treatment Center by Dr. Koerper. I injected factor on-demand until I was about six years old, with lots of hospital visits, mostly for ankle bleeds. After starting prophylaxis around age six I largely avoided any serious bleed-related injuries by sticking rigorously to the schedule (and naturally having an aversion to contact sports) throughout childhood, high school, college, and most of my adult life.

I learned about the gene therapy study after I moved to Seattle for a new job. After moving, I connected with the local HTC with UCSF's help – at the time this was called Bloodworks Northwest, now named Washington Center for Bleeding Disorders. During one annual check-up, a research nurse asked me if I'd be interested in participating in hemophilia research. She gave me information about studies and arranged a meeting with Dr. Barbara Konkle, who was the principal investigator of the study I ultimately decided to participate in. Research wasn't completely new to me, the HTC encouraged patients to participate in research if they were comfortable. I had participated in some cool hemophilia studies before, testing the efficacy of using portable, take-home handheld ultrasound machines for diagnosing bleeds or the effects of Tai Chi practice on hemophilia patient outcomes, but I had never been involved in a clinical trial for a drug.

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continued from page 4

I spoke with with Dr. Konkle about the study process and her opinions about the likelihood of success. Previous studies testing the safety and dosing of this gene therapy showed harmful effects were unlikely and many patients had a positive response. I was compelled by the idea that at least for a while, for a few years or more, I wouldn't have to worry about things like stockpiling factor, or having a job that provides good enough health insurance to get factor in the first place. I could focus my energy on my passions instead of seeking stable, dull, jobs with good enough insurance in order to keep getting factor.

Before receiving gene therapy, the study had a lead-in phase where I logged all my infusions any any bleeds using an Android phone with a special app for about nine months. This information established a baseline to use as a control to compare against after I received the study drug. For similar reasons, my joints were x-rayed and I received a liver ultrasound to create a record of my pre-treatment health (the gene therapy is expected to mostly target liver cells).

I was also screened for having antibodies to the modified adeno-associated virus (AAV) vector used to deliver the gene therapy. If I had been previously exposed to the virus, which occurs in nature, and developed antibodies, I couldn't participate in the study because my immune system would attack the viruses and destroy the treatment. For the same reason, after I received this specific gene therapy, I wouldn't be able to receive it again because my body will have developed an immune response.

While safety was evaluated in previous studies, it wasn't guaranteed. I had ample time to consider whether to proceed to the infusion during the lead-in phase, or quit the study early (without any penalty). Due to the COVID-19 pandemic, the infusion was postponed several months, so by the time I was scheduled to actually undergo treatment, I was certain that I wanted to proceed.

Actually receiving the gene therapy was undramatic, and not uncomfortable nor difficult. The morning of the infusion I walked to the nearby University of Washington medical center and checked in to the translational medicine department. I got cozy in a hospital bed and ate breakfast while the researchers assembled an IV to infuse about a liter of liquid over the course of a few hours. The staff donned PPE while handling the virus-based study drug to avoid exposure while I read, used my laptop, and watched a movie. I spent the night in the hospital and had a mild fever, likely from an immune response to the viruses. Only during that fever did I begin to have some anxiety about whether I'd made the right decision, but as the fever faded my doubts also dissipated. Thirty-some hours later, in the early afternoon, I walked home from the hospital feeling tired, but okay.

The weeks immediately following the infusion were a blur of blood draws and check-ups as researchers closely monitored my factor levels, my viral load, and my liver's reaction to the gene therapy. After several months of less and less frequent blood draw, I now have only have one blood draw every three months and one clinic visit a year to contend with for the next several years.

As for efficacy, the gene therapy has been working well at keeping my factor levels between 50% and 70%, which is within the normal range. I naturally have a factor level under 1%, so these percentages are striking compared to my pre-treatment baseline. I haven't needed to infuse any factor VIII since my body started producing its own factor about a week after the treatment. Now two years have passed since I've had to infuse any factor at all.

After undergoing gene therapy I haven't worried about having access to factor or having to take it with me when I travel. I was away from home for much of summer last year, visiting friends, attending conferences, camping, and generally enjoying life. Recently, lived in Taiwan for six months to study Chinese. While in Taipei, I event had two gene therapy check-ups at NTU hospital, one of the study sites. I felt comfortable enough about my health that I left an underwhelming full-time job to focus on doing meaningful volunteer and lightly-compensated work while I search for a new career path more in line with my interests. I wouldn't have attempted these kinds of risky things doing before gene therapy. The freedom from worrying about how I'll get factor and the logistics of bringing it with me when I'm away from home has made me happier and knocked down walls in the way of pursuing my interests. It's not an exaggeration to say that the last two years of my life, in a large part due to participating in this study, have been some of the most exciting years so far.

ASK THE DOC

MARION KOERPER, M.D.

Q: WHAT IS GENE THERAPY?

A: Gene Therapy is a new form of treatment for individuals with hemophilia A and B. It may eliminate the need for factor concentrate for many years.

Q: HOW DOES GENE THERAPY WORK?

A: A virus called AdenoVirus (which causes the common cold) has its internal DNA removed. The DNA codIng for Factor VIII (Hemophilia A) or Factor IX (hemophilia B) is inserted into the empty virus capsule. The virus capsule is the envelope and the hemophilia gene is the letter. The filled viral capsule is administered via IV to the patient. A Factor VIII letter is delivered to a Hemophilia A patient, or a Factor IX letter to a Hemophilia B patient. The letter is delivered to the patient's liver, which uses the message to make factor.

Q: WHO IS ELIGIBLE FOR GENE THERAPY?

A: Patients that are 18 years old or older with severe Hemophilia A, with no inhibitor, or severe Hemophilia B with no inhibitor.

LinkedIn: hemophilia-foundation-of-northern-california

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

Youtube: HFNC1958

Where

can you find us?

Twitter: HemoFoundation

Instagram: @hemo_norcal

Facebook: HemoFoundation

WALK
10/1/2023

CAMP HEMOTION NEEDS FUNDING!

Camp Hemotion will cost $500 per camper unless we can raise funds this year!
***Actual cost per camper - $1650**

YOU can HELP by following the EASY steps below

STEP 1
RECORD VIDEO - WHAT DOES CAMP HEMOTION MEAN TO YOU/YOUR CAMPER - LOAD VIDEO HERE

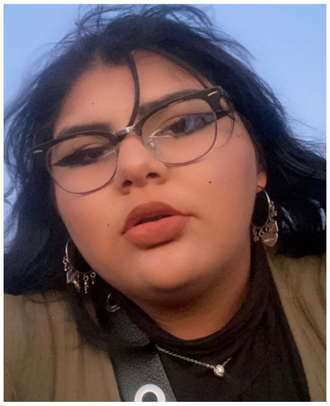
STEP 2
START YOUR WALK TEAM & FUNDRAISE - GO HERE

STEP 3
COME TO THE WALK ON 10/1 IN WALNUT CREEK - YOU/YOUR CAMPER SHARE ON MICROPHONE WHAT CAMP HEMOTION MEANS TO YOU

Kurt Pollard

Memorial scholarship

Winner



RAMONA JALOMO

Congratulations

I am truly honored to have been chosen for the Kurt Pollard Memorial Scholarship for the Fall 2023 semester at California State University, Monterey Bay.

With this opportunity, I will further expand my horizons within the psychology and sociology field, so I can become one step closer to a lifelong dream of mine to give back to the community that has helped me become the individual I am today! Being a college student away from home is no easy feat, but with the love and support from my family and communities like this, I can say that the journey of discovery is much more reassuring and stabilized. Once again, I would like to give my thanks for being chosen for this scholarship! It will forever impact my educational journey, and become a stepping stone that will guide me closer to my own success story.

Sincerely,

Ramona Jalomo, Class of 2026.

Sue Anderson/Susan Kuhn

Memorial scholarship

Winner

KAYLA GREGORY

Congratulations

Thank you so much!! I'm honored to receive an award honoring two incredible women. Growing up with a rare disorder can be isolating, but the community I've found through von Willebrands has provided me with such a special support system. I'm so excited to share those connections I've built with other individuals through my future work in the medical field.

HCC Future Leaders Program 2023: A Retrospective

This year, the Hemophilia Council of California brought our Future Leaders Program back to fully in-person. We had fourteen teens and three mentors- Rigo Manzo, Stephanie Dansker, and Ryan Faden- join us in Sacramento on March 19 – 21st. Teen program facilitators Tom Hamm and Pat Torrey from Gut Monkey led the teen activities, with HCC Executive Director providing interactive sessions on the legislature and legislative process. This year's program took place at the Sheraton Grand Hotel, the California Endowment's Center for Healthy Communities, and a special Alumni reception at Cafeteria 15L.

On the evening before Legislative Day, our teen program participants were joined by Future Leader Alumni for the evening reception. At this reception, the teens and the alumni of the program could mingle, share experiences during and after their time as Future Leaders, provide advice, and more.

The experience was capped by legislative office meetings on Legislative Day, where the teens were joined by the community at large to tell their stories and request support for GHPP, CCS and the copay accumulator ban AB 874.

What makes the Future Leaders Program so special to the teens who participate?

The most frequent reply we received from our Future Leaders when asked what they liked about the program was, "making some new friends within the community" and "meeting individuals who had my condition". Often, these teens do not know very many kids their age who share a bleeding disorder. The Future Leaders Program is a rare opportunity to meet other teens, not just from their region but from the entire state, who are part of the same community. At Future Leaders, even the time between activities and training is a chance to connect with the other teens. One Future Leader mentioned that during free time "I got to learn new things about other participants who came to this Future Leaders."

What is the purpose of Future Leaders Program games and activities?

Building friendships with other teens from across the state does not end once training starts, however. Even after the official Program began, our Gut Monkey facilitators Pat and Tom excelled at incorporating "teamwork activities [that were great for] building bonds" into Future Leaders. They used these games to form connections between the teens. Part of building connections is also

continued on page 12

continued from page 11

creating a safe space for nervous or shy teens to open up. One of the Future Leaders noted this by saying the games were "really fun and relieved tension." Another explained she liked "activities to help us be more confident and braver". An additional benefit of increasing the teens' self-confidence was that it made telling their story and advocating easier.

Learning how to tell your story was a huge part of preparing for Legislative Day. Games that develop storytelling skills in a fun way can make a big difference in helping teens feel prepared. One Future Leader was very grateful for the preparation, saying "I really appreciated all [Gut Monkey] have done to prepare us for Legislative Day". Of course, never underestimate the additional value of just having fun: As one Future Leader phrased it, "We learned a lot while having fun the whole time."

How does the Future Leaders Program teach teens advocacy?

Bringing together fourteen teenagers from across the state can lead to great advocacy.

How does meeting other teens help a Future Leader develop their advocacy? and Why is advocacy training so much more effective when done in a group setting vs. in isolation? One of our teens said it best when he explained, "Meeting other people who have had experiences similar to mine was helpful to understanding how good I really have it." By sharing their experiences, the teens started to understand the bleeding disorders community as a whole instead of just looking at their disorder from their own point of view. Another teen realized "I learned to be more comfortable with my hemophilia" after participating in the program. The group dynamic can lead to a change in perspective. And this new perspective can fuel their advocacy on behalf of the whole community.

As teens in Future Leaders grow more comfortable telling their own stories, they also learn how to tell them effectively to advocate. One participant mentioned "I learned more on how to speak up using concise language" while another said "This program taught me a lot about advocating for my disorder". Once the teenagers felt comfortable with their stories and confident in their skills to tell them, they began to feel the power of advocacy. And what is that power? The power to impact the community in a positive way for change.

Future Leader mentor Rigo Manzo said it best- "It was amazing to see the Future Leaders use what they learned and apply it when speaking to legislators and their staff." Or in the words of a teen in the program, the experience "benefitted my knowledge and impacted the community." By speaking to legislators on behalf of CCS, GHPP, and AB 874, these teens were certainly impacting their community for the better this March 2023.

How does the Future Leaders Program benefit teens?

Oftentimes, teens will come away from Future Leaders with a newfound confidence. "It has helped me to come more out of my shell than I thought I ever could," said one young man after finishing the program. Such personal growth does not end at year one for many program attendees, either. Teens can return for multiple years until they graduate high school. A recent graduate reflected, "I've done this for three years now, and it has helped me connect to others like me and allow myself to advocate for others like me." Future Leaders can indeed help teens grow immensely over their time in the program. According to Future Leader Mentor Stephanie Dansker, "The transformation I witnessed in each of [the teens] through the course of the weekend was inspiring. They gained self-confidence, found their voices, learned to work together and developed new skills that will be useful beyond their advocacy efforts on behalf of the bleeding disorders community." If Stephanie saw all of that in just three days, imagine the impact of several years as a Future Leader!

Final Thoughts

Transformational, indeed. One teen called the Future Leaders Program "eye-opening". It introduces teens to the power of telling your story and raising your voice to your representatives. Teens grow in confidence and skill as they learn and practice advocacy. And as has been mentioned before, it is fun! How do we know?

Some final thoughts from this year's teen participants:

"This has been a great experience for me and would do it again in a heartbeat!" and
"[I] will greatly cherish these memories for years to come and cannot wait for the experience again next year."

MEMBER SPOTLIGHT

Washington Days 2023

As Experienced by Pamela Lauer

Snow began to fall harder and the winding road to town was just barely safe enough to sneak out for the day. My 13 year old son and I began the adventure of traveling from the Lost Coast to "Washington Days" to represent the Northern California Chapter of the Hemophilia Foundation. We flew out of the Arcata Airport on a tiny plane and said goodbye to the ocean for a few days. Travel is always hard on me, the elevation and hours of sitting are terrible on my back and my arthritic knees but besides the pain, TSA is always the worst part about flying. From always taking apart my meds bag (those ice packs sure look suspect!) to usually deciding my cane is likely a weapon, it is extra cumbersome to have a bleeding disorder and travel by flight. TSA also thinks my braided hair is threatening and sometimes make me take my braid out! I honestly always say "never again!" every single time I fly.

This time, though, I couldn't say no. Being requested to attend a conference in Washington D.C. was such an honor. The opportunity to learn how to advocate for our bleeding disorders community and then immediately put that education to work on Capitol Hill was worth it! I love spontaneous adventures and instant gratification...this trip would be all that and so much more!

I am getting ahead of myself. So, we traveled all day. We arrive at the hotel finally around midnight, D.C. time. The Hyatt Regency on Capitol Hill was a sight for sore eyes, and we slept well, albeit with no idea what the city out our window was like until morning. Upon waking we had time to explore a bit and were amazed at how incredibly close we were to the Capitol building!

That afternoon we checked in at the conference and walked into a giant room filled with large round tables. Upon each one was a tall label with a state's name. There were a few tables for some of the more populous states. I was surprised to find that my son and I represented all of Northern California and it kept him serious in his attention to the details of our next day's assignment on Capital Hill.

All the meals were wonderful throughout the stay. While we enjoyed the meal we gave our attention to the front of the room where a small stage was set up. The staff of NHF had worked hard to prepare us ahead of time but wanted to review all the details one more time. Their talk was full of useful reminders and they had even organized a cute skit to remind us what not to do.

The following morning came early and the same room of tables with fifty states labeled was a buzz with well groomed and well prepared bleeding disorder patients and their families. We were honored to get to listen to the representative Earl L. "Buddy" Carter (R-GA), that we were there to discuss. It was refreshing to hear that he understood what low income, chronically injured folks are going through. It was also interesting to learn that he had previously been a pharmacist and that is why he knew so much about the health care industry and billing.

Armed with the knowledge that some representatives are already on our side my son and I followed Lynne Kriste, to The Hill. I was really thrilled that Lynne, someone who used to work on Capitol Hill for a living, was willing to guide us that day. She knew exactly where to go and stopped often to take our picture near the Capital Building and other key spots that would look good in print. We were in good hands. I felt confident that all would go well at our 10:30 appointment with Jared Huffman's Chief of Staff, Jennifer Godeke. All my son and I were expected to do was explain what it is like to live with a bleeding disorder. Lynne would come in with the hard hitting facts and we could take a breath.

continued on page 14

continued from page 13

Everything did go mostly as planned. We entered the room to meet with Jennifer and a co-team member and shook hands. As I sat down I leaned my cane on the couch. It immediately fell to the floor with a loud bang. Jennifer laughed and said, "This room is haunted."

"Well Ghost, I don't really like my cane either!" It was a great seg-way into why a 42 year old woman needs a cane and with that we dove into why we had come.

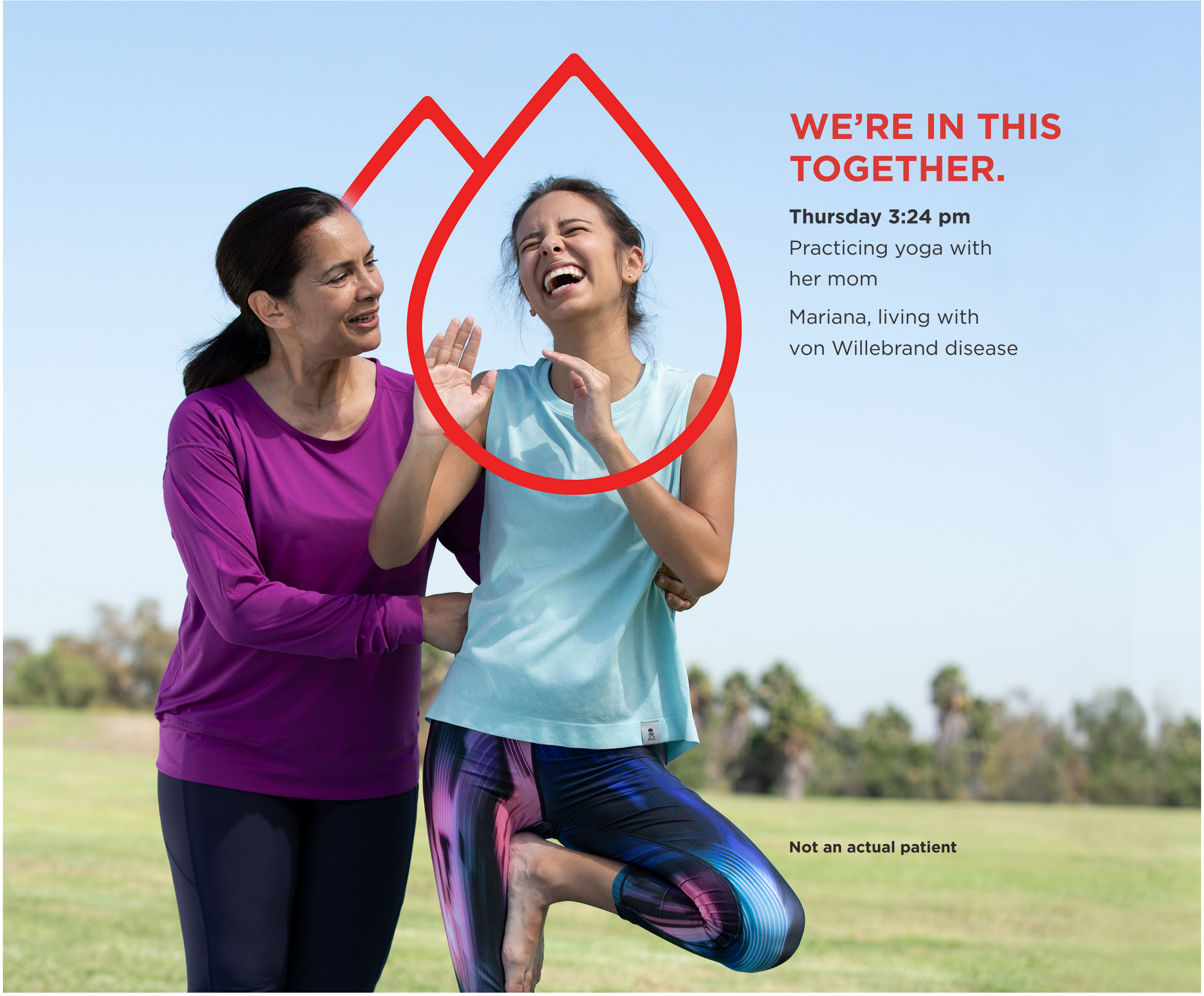
I spoke first, explaining that living in Humboldt County has its health care challenges. The beauty of our county can sometimes be overshadowed by how far I have to drive to get medical care. I explained that I was not diagnosed as a hemophiliac until I was 38 and have not yet figured out how to place a vein alone. That means driving 45 minutes to the Emergency Department in a nearby town. I told Jennifer and her staffer how my husband has learned to help and how it has affected our marriage to always rely on him. My son then talked about how he never really considered his life to be affected by my disorder but that often he will ask me to take him somewhere and I have to tell him no due to how my body feels that day.

Just then there was a knock on the door and another mother and son entered. They were from Southern California and their staff member meeting had been canceled last minute. They decided to find and join us and I am so glad they did!

In their household it wasn't the mother but the son who was affected. It was an interesting role reversal to hear how infusing and now injecting have become a part of his morning routine before school. He explained that he was okay with taking his meds on his own but upset that even with his medicines there are some sports he can't play. Then mom chimed in and explained how much it actually costs for one dose of factor. It really was jaw dropping to think about how much money a family spends on medication. This mom, (I am so sorry I forgot her name, she was so kind and her son was such a sweet heart!) did an amazing job explaining how inappropriate it is that co-pay donations from grants do not count towards what co-pays patients have to dish out. She hashed out the math of how much it costs a month just to keep her son from bleeding.

Lynne spoke next and finalized the request we had for Jared Huffman to sign and possibly even champion the bill. She knew all the lingo and I was relieved my part was over. We had one more surprise before we left though. Jennifer explained that usually she doesn't make time for meetings like this, Chief of Staff is a big job and she usually just can't find time. Today, however, she heard we were coming to discuss bleeding disorders and she had been close friends with a boy when she was young that was also affected. His memory had always stuck with her. It was a heart warming moment realizing that she did know a little about what we live with.

As we stepped into the hall to take a few pictures near the signage at the door I had to smile realizing that our words had made a difference and the difficulty of the travel had been worth the half hour meeting. We were heard and promised that Jennifer and her co-staff would encourage Representative Huffman to consider the bill as it is very important to people in the rural county of Humboldt, California.


WE'RE IN THIS TOGETHER.
Thursday 3:24 pm
Practicing yoga with her mom
Mariana, living with von Willebrand disease
Not an actual patient

NHF's WGPPM Summit 2023 Atlanta Georgia

By Ashley Gregory

When I arrived at the Atlanta WGPPM (Women, girls and those who have or have had the potential to menstruate) Summit by NHF I knew this was different. There were no event wraps on the elevator doors, no specially marked hotel key with the logo of the event and most notably, no industry partner booths. I was intrigued to learn the agenda and who else was there. I had been invited as a representative of Hemophilia Foundation of Northern California to share two things: What HFNC has been doing for WGPPM and my personal story as a woman with a bleeding disorder. It proved to be the most groundbreaking experience I have ever been a part of and it truly was different from any other event I have attended.

Let me offer a bit of hindsight. The bleeding disorders community has been working to educate and empower WGPPM for at least 30 years about their bleeding symptoms and how to access care. More recently, within the last 10 years, national and local programs have been focusing on WGPPM and ensuring they are aware of what symptoms are and how to keep track of them in order to report them to our providers and access the care we need. It is at these educational events that there are industry partners with booths, educators, fun activities and lots of sessions aimed at empowering and educating our community. There was a 5000 participant genetic study of hemophilia A patients and their female relatives called My Life/Our Future that identified the many genetic variants of hemophilia A (genotype) and has allowed researchers to study them and discover differences in phenotype (bleeding presentations, frequency and severity of events). Based on this education and armed with knowledge, many WGPPM's went to Hemophilia Treatment Centers (HTC's) to seek care for their symptoms. Some were offered care, some were not daunted by a refusal of care and countered with written documentation of their genetic variant and symptoms and requested to be reconsidered and many simply gave up seeking any relief from the devastating consequences of living with an untreated bleeding disorder.

In response to this, many organizations and individuals began championing the cause; WGPPM coalitions popped up and specialty pharmacies specialized in servicing WGPPM as well as men and boys. Local organizations hosted WGPPM educational events and they filled up with waiting lists. Industry partners implemented educational models and brought in experts to educate and empower WGPPM to obtain their diagnosis and treatment. Once again, WGPPM went to HTC's to seek care for their symptoms. Some chose to engage in medical tourism. There are some HTC's that understand and treat WGPPM and are willing to provide care to those able to access this resource, even from another state. Some were offered care at their local HTC's, some were not daunted by a refusal of care and countered with written documentation and current research of their genetic variant and symptoms and requested to be reconsidered and many simply gave up seeking any relief from the devastating consequences of living with an untreated bleeding disorder.

continued on page 17

continued from page 16

Which brings us to 2022 when the conversation had been going on for so long that I personally would talk to anyone that would listen as I professionally fielded calls, texts, emails and personal requests for help in accessing care for WGPPM that were suffering without treatment for their bleeding disorder. I attended conferences as part of my role at HFNC as Education and Advocacy Director and wondered what could be done to overcome what seemed to be an insurmountable hurdle; to see the coming together of the new science of WGPPM and bleeding disorders and the old practice of treating bleeding disorders. It was at one of these conferences that a blood brother approached me and said let's work on this together using tactics we as men used in the 80's to obtain the care we needed for the Hiv/AIDS we were infected with from factor product that was bad due to improper cleaning prior to distribution. I said yes, let's do this! FAIR Time for Women national coalition was incubated by HNC until a 3rd party fiduciary agent was located and has just completed the first year of goals: a website where anyone can go to obtain all the information about bleeding disorders that is available (ftfw.org), a list of 1000 treaters we plan to ask to sign on to MASAC #264 (Medical and Scientific Advisory Committee; #264 addresses WGPPM with genetic bleeding disorders and their diagnosis, care and treatment), an algorithm created by experts to assist in diagnosing, caring for and treating WGPPM and a toolkit created by experts to be used to access care.

So when I was invited to NHF's WGPPM Summit in May 2023 in Atlanta to speak, I knew, based on my career that I had a decade of stories and data to share and wondered who else would do the same. I was incredibly surprised to see a representative of every stakeholder in the room; medical experts, organizational leaders, WGPPM patients including transmales and patients of color, industry partners and treaters were all there to hunker down and come out with a plan; a plan to finally address the gaps in care for WGPPM with bleeding disorders! I was enthralled as I listened to the Lived Experience Experts (LEE's) share their nightmare stories of misdiagnosis, unnecessary surgeries and procedures, prolonged bleeding, multiple miscarriages, enduring medical sexism, delayed diagnosis, and lack of treatment while many of their male counterparts have expert medical care for their bleeding disorder. As we listened and learned the entire room became steeled to one goal: The time has come for WGPPM and bleeding disorders to be treated equitably.

We then broke into working groups for the rest of the time and got down to the business of having those hard conversations; what is lacking, where can we provide improvement, what needs to change? We all worked so hard that when it was time to end for the day, we realized we were exhausted but hopeful for this first of its kind meeting of the experts. The second day we were shown the memorialization of the sum total of our work which will become a white paper in 3-6 months. White papers inform policy and government on a certain topic or issue. I am humbled to have been part of this experience as HFNC's Education & Advocacy Director and FAIR Time for Women's Director and encouraged that real change is on the horizon for WGPPM, finally after almost 30 years. It is noteworthy that our independent facilitators which were brought in for this summit shared how incredibly moved they were by our stories and our collective trauma. Having it reflected back to us by them was enlightening and allowed us a moment to be present with the gravity of our endeavor.

continued on page 18

continued from page 16

I want to thank every WGPPM that has ever been brave enough to share their story; blood brothers that witness every day the needless suffering of the WGPPM in their lives and experience guilt, anger and frustration at the inequity of it all; the organizations that have constantly been providing education and resources in this monumental undertaking and the educators that despite knowing they may face backlash from their more conservative colleagues push through and stay true to the science. WGPPM have bleeding disorders and soon the entire nation will be made aware of how to treat us based on NHF's WGPPM Summit 2023 in Atlanta and the work done there by so many caring experts. Below is a summary of outcomes to be expected based on the work and my notes. Please refer to NHF's upcoming white paper publication for actual results as they may differ from mine.

Address access areas such as:

- Provider bias
- Genotype vs phenotype
- Clinical trials and WGPPM
- Standards and guidelines across all HTC's
- Health equity including socioeconomic, cultural, gender, race
- Development of testing standards and specific recommendations

Improve patient education:

- Identifying and reporting symptom
- Identifying WGPPM relatives of males with bleeding disorders (where appropriate

Improve Health care delivery

* Build trust with provider
* Build workforce sustainability for provider
* Ongoing provider education for all disciplines
* Shared decision makin
* Fill data gaps in WGPPM researc
* Cultural competence and humility training for health care provider
* HTC collaboration for best outcome for WGPPM
* Rating system for HTC's

Western States Regional Hemophilia Network

by Randy Curtis

The Western States Regional Hemophilia Network comprises most of what used to be called Federal Region IX: California, Nevada, Hawaii and Guam. This is an annual opportunity for clinicians to gather and share information about the latest treatment options for persons with bleeding disorders. Breakout sessions are available for physicians, nurses, physical therapists, data managers and social workers. The focus of this year's meeting was women.

Women in entertainment was the title for the first night's reception, with Alex Borstein as the guest speaker. Alex stars as Susie Myerson in the Marvelous Mrs. Maisel and is the voice of Lois in Family Guy. She is also a woman with hemophilia and is hilarious in person.

In addition to sessions on Women of child-bearing age and pregnancy, Toddlers and School-age Children, Gender-Affirming Medicine and Impacts on Coagulation Disorders, and Post-menopausal women, there was also a presentation on Sexism and its Impacts in Academia and Bleeding Disorders.

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

4/28/2023

Alex Borstein, comedian and two time Emmy award winning actress for *The Marvelous Mrs. Maisel* and *Family Guy*, has hemophilia and was keynote speaker at Western States Hemophilia Regional Network Conference in Irvine, California.

Northern California's Leadership with Alex Borstein
Left to Right: Stephanie Hill of CCHF, Lynne Kinst of HCC, Alex Borstein, Rigo Garcia of HFSC, Nooshin Kosar of HASDC, Andrea Orozco of HFNC

continued on page 20

continued from page 19

Andrea and I attended the breakout session for Consumer, Chapter Leaders & Community-Based Organizations. This is a once a year opportunity for chapter leaders to meet with the Hemophilia Council and talk about what's working and what isn't. The overall feeling is that attendance is down compared with pre-COVID levels and the community may not need the same type of programming in this new world of long-acting prophylaxis.

One potential scenario would be to have fewer, bigger events, focused on the strengths of the different organizations. San Diego has a great teen camp and SoCal has Familia de Sangre. NorCal could be the center for Women's Retreats and Men's Retreats. We need to reexamine what is working in other parts of the country and bring the best ideas back to California.

My favorite part of the meeting is always the Pharmaceutical Panel, where each company gets up and presents what they are working on. I also like the update from the Centers for Disease Control and Prevention as well as the American Thrombosis and Hemostasis Network (ATHN) and their National Hemophilia Program Coordinating Center (NHPCC). This is a great overview of what is going on at the national level.

One Woman’s Journey Living with Hemophilia

By Pamela Lauer

My diagnosis change from carrier to mild hemophiliac at the age of 34 was a real eye opener to me. It explained so much about my health but it was still somehow surprising to me! When I was in fifth grade my social studies teacher, Mr. Bennett, told me he had noticed the major amounts of bruising I always had. I was worried he would think I was being abused at home. I told him my father was a hemophiliac and I was a carrier, it was normal. When Mr. Bennett called my home out of concern, he got an earful from my father. Next it was my turn. I was told never to discuss my father’s health with anyone ever again.

Back then, at the age of ten, I just thought my dad didn’t like being talked about. I know better now. The stigma about hemophiliacs was real back then and I can never really know what my father went through. I won’t ever forget though, that my dad told that teacher that he must be an idiot since everyone knows women can’t have hemophilia. Now we all know better, well, most of us.

I have been told at two of the four hemophilia conferences I have recently attended (usually by a man with hemophilia) that I can’t possibly be a hemophiliac. Granted, they are usually an elderly person who has been told their whole lives that this is true. I have also been told that I shouldn’t be taking hemlibra because I am taking that precious drug away from others who need it more! Worse, last week I was on the phone with an HTC I shall not name, getting a second opinion and the nurse on the phone told me she was surprised that I had been diagnosed a mild hemo as women don’t usually have that. The nurse at an HTC!!! LAST WEEK!!!

Okay, enough with the all caps, sorry. I didn’t mean to yell, but, come on! Right? This isn’t a women’s lib issue, its science! Science is always changing and nothing in science is permanent. If the medical world never updated its thinking we would all be using leeches to get rid of headaches! I came across a great quote about this recently,

“Science gathers knowledge faster than society gathers wisdom.” - Isaac Asimov

Issac Asimov was a science fiction writer but I think he understood more than just the fiction in science. I find his quote so true. It was heart breaking to meet young women at a bleeding disorders conference telling me that its so nice to be believed! It is because of this that I have made it my goal to remind society that science embraces change. Change is the only constant in life and it sure is spontaneous!

So, next time someone tells you something is impossible, its been proven by science, please, remind them that it may not be true… yet! You never know what’s next and you never know who you will offend when you say things that you haven’t proven to be true yourself! Most of all though, for goodness sake, if someone is willing to open up to you and explain their life’s challenges, don’t tell them it can’t be true. If you do, they may just spontaneously step on your foot when they turn on their heels to leave you in the dust of the past.

Dr Marion Koerper is awarded a LIFETIME ACHIEVEMENT AWARD

Spring 2022 Dr Marion Koerper is awarded a LIFETIME ACHIEVEMENT AWARD by Hemophilia Foundation of Northern California. She is unable to attend and does not receive her award but is notified.

Summer 2023 Dr Marion Koerper is presented her award by Randall Curtis, HFNC Board President and dear friend of Dr. K's, as she is affectionately known by her former UCSF Hemophilia Treatment Center patients for which she was the Medical Director for many years prior to retiring.

She is currently retired and spends her time with her husband and grandchildren.

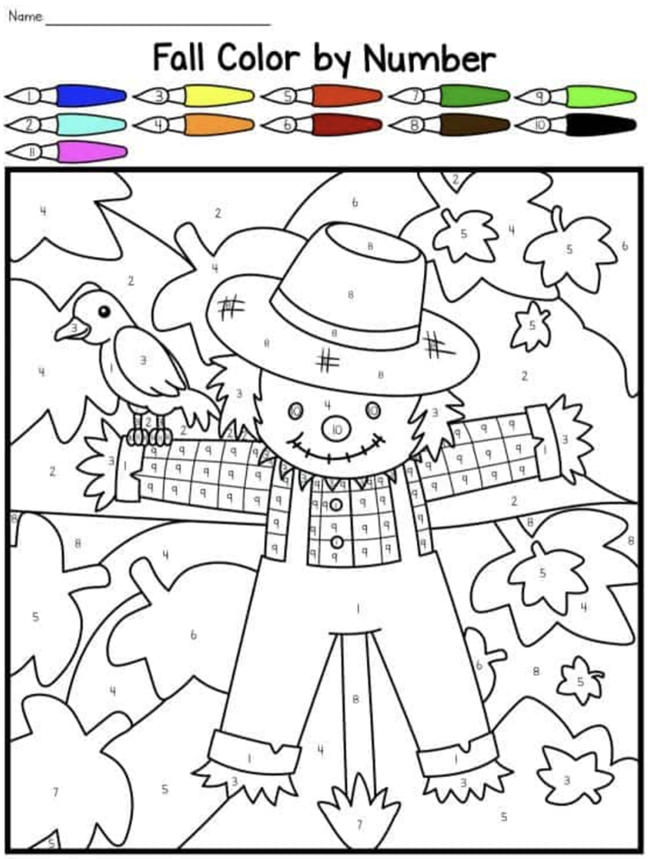
Kid's Page

Name: ______________________ Date: ______________

Autumn Days
Crossword

Across
3. Also known as corn.
4. October 31st.
5. The eleventh month of the year.
6. Used to keep birds off of crops.
9. Jack-o-lantern gourd.
11. The tenth month of the year.
12. The season that follows summer.
14. Might be patchwork.
16. Fun activity on a farm.
17. They fall from trees.
19. Leaf gathering yard tool.
21. Seat at a square dance (two words).
23. What squirrels often gather.
24. The fourth Thursday in November.

Down
1. Drink made from apples.
2. Halloween decoration made by a spider.
4. The gathering of crops.
6. The ninth month of the year.
7. A bit cold.
8. Popular autumn sport.
10. Decorative squash.
13. They're roasted on an open fire.
15. Semi-frozen rain.
18. Another word for the fall season.
20. Honeycrisp
22. Oak tree's fruit.



Name: ______________

Fall Color by Number

HOMEMADEHEATHER.COM

Autumn Riddles

Q:Why did the scarecrow win a Nobel Prize?

A:He was outstanding in his field!

Q: What month are trees afraid of?

A: Sep-timber!

Q: What is a scarecrow's favorite fruit?

A: Straw-berries!

Q: What falls but doesn't break, what breaks but doesn't fall?

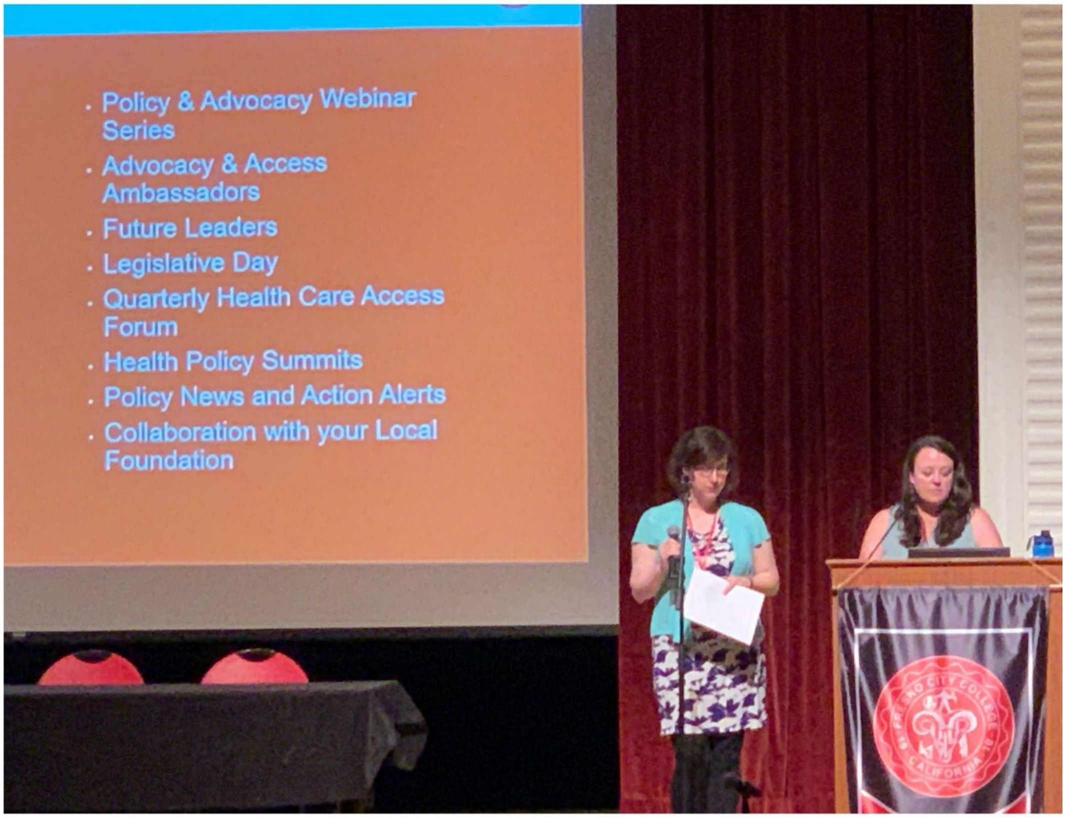
A: Night and Day.

SPRINGFEST

Fresno
4/22/2023

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

Hemophilia Council of California shared how they support the bleeding disorders community



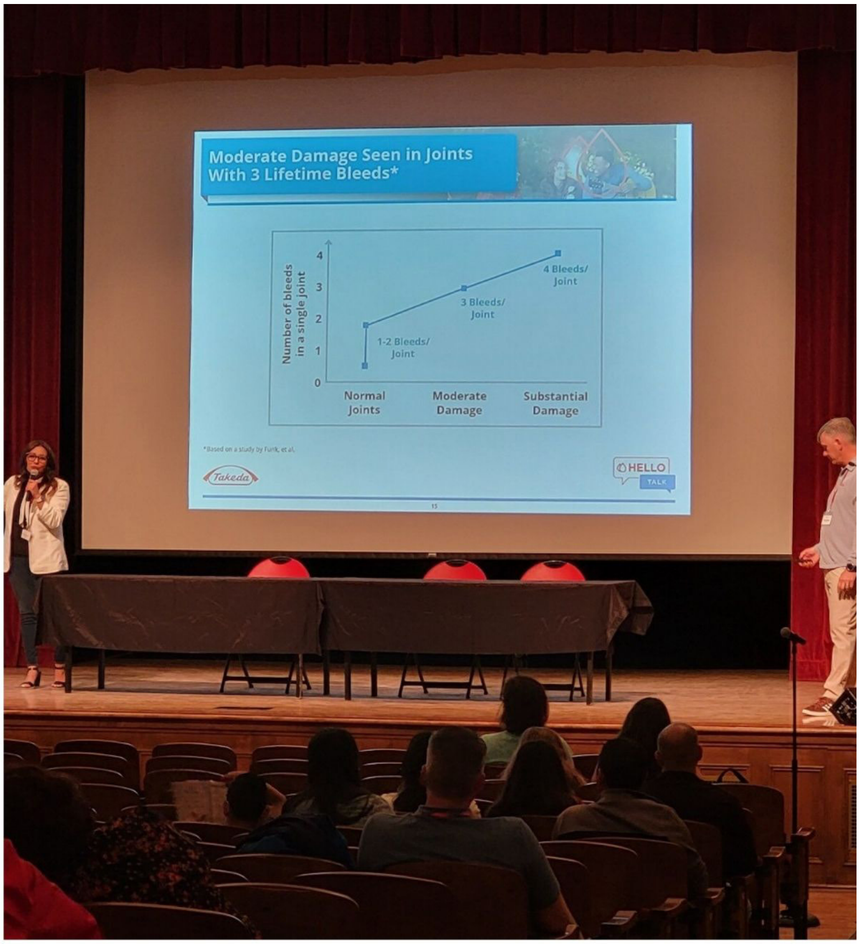
- Policy & Advocacy Webinar Series
- Advocacy & Access Ambassadors
- Future Leaders
- Legislative Day
- Quarterly Health Care Access Forum
- Health Policy Summits
- Policy News and Action Alerts
- Collaboration with your Local Foundation

Registration with Pedro Preciado
&
Community Members

Takeda Presents

How to Recognize and
Respond to a Bleed

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS


Moderate Damage Seen in Joints With 3 Lifetime Bleeds*

*Based on a study by Funk, et al.

Dual language presentation from Takeda in English & Spanish by Annabelle Garcia and Patrick Wagner

Infusion & Subcutaneous Administration of clotting agents demonstration

by Hugo Helm and Jess Hull

Fresno City College was a good venue for this event and we thank our volunteers for helping us secure the location

Alliance of Therapy Dogs
Thank you
handler
Connie Dennis
and
James
for
providing joy and comfort

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

Booths and Community

Thank you sponsors that make this event possible and bring education about products and resources

Takeda

THANK YOU TO OUR SPONSORS

SPRINGFEST 2023

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InfuCare Rx
HEMA Biologics
HFHEALTHCARE Infusing Health Right to Your Home
Pfizer
Brothers HEALTHCARE
Genentech
SOLEO HEALTH Innovators in Specialty Infusion

The National Hemophilia Foundation Has a New Name

The National Hemophilia Foundation is now the National Bleeding Disorders Foundation.

In 1948, the foundation got its start as simply “The Hemophilia Foundation” – then in 1956, the foundation formally incorporated into what is known today as – the National Hemophilia Foundation. Even then, it was important to capture the organization’s expanding footprint across the U.S.

Link to YOUTUBE VIDEO

Because of our longstanding name, the National Hemophilia Foundation is best known for helping people with hemophilia and also for serving the individuals and professionals who care for that community.

However, in the foundation’s many decades, we have also long served those facing other blood and bleeding disorders such as von Willebrand disease, rare factor deficiencies, platelet disorders, and more. Over the past 75 years, our powerful combination of research, education, and advocacy has improved the lives of people and families with a range of conditions – yet our name and image has not reflected that.

Now, as the National Bleeding Disorders Foundation (NBDF), we can be more inclusive of *everyone* we serve. Although hemophilia remains a major focus, our name ensures that all people with VWD and rare and ultra-rare deficiencies know that they can find a home within NBDF.

Although we’re adopting a new name and a new look, our work will not change in the short term. We remain dedicated to supporting our network of over 50 chapters across the country and channeling funds into blood and bleeding disorders research. And we will continue to educate and support families with these disorders as we work tirelessly to protect access to health care on the state and local level.

Over the long term, our new name will challenge us to explore how we can harness our resources and networks to help people facing other blood and bleeding disorders – because after all, bleeding disorders *are* blood disorders. In the same way that the National Hemophilia Foundation evolved to help people facing blood and bleeding disorders beside hemophilia, we can evolve once again to assist more families in need. Many rare blood and bleeding disorders don’t have a national support and advocacy network like ours — and together, we have a historic opportunity to change that.

As the National Bleeding Disorders Foundation, we will use our longtime legacy to inspire a future where even more people have access to the treatments and support they need to thrive. We will remain true to our core vision while raising awareness, expanding reach, and continuing to build upon 75 years of history, hope, and progress.

NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF

National Bleeding Disorders Foundation New Logo

CALENDAR

SEPTEMBER

9/4/23	Labor Day	Holiday HFNC closed
9/8/23-9/10/23	Familia de Sangre	Anaheim

OCTOBER

10/1/23	Unite for Bleeding Disorders Walk	Heather Farm Park Walnut Creek CA
10/6/23-10/8/23	CSL Behring's Gettin' in the Game	Henderson, NV
10/21/23	Board Meeting	In Person, TBD

NOVEMBER

11/4/23	Emerging Therapies	OakStop, Oakland CA
11/14/23	Board Meeting	Virtual
11/16/23-11/18/23	NBDF Chapter Leadership	Seattle
11/23/23-11/24/23	Thanksgiving Holiday	Holiday HFNC closed
11/28/23	Giving Tuesday	Campaign
11/30/23	WinterFest	Maggiano's San Jose

DECEMBER

12/1/23	World AIDS Day	AIDS Memorial Golden Gate Park San Francisco, CA
12/10/23	WinterFest	Fresno Breakfast House
12/24/23	Christmas Eve	Holiday HFNC closed
12/25/23	Christmas Day	Holiday HFNC closed
12/24/23-12/31/23	HFNC Office Closed	Holiday HFNC closed

JANUARY 2024

1/1/24	New Year's Day	Holiday HFNC closed
1/3/24	HFNC reopens	Virtual

HFNC	Hemophilia Foundation of Northern California https://www.hemofoundation.org/

AFFILIATED ORGANIZATIONS

HCC	Hemophilia Council of California https://www.hemophiliaca.org/
HFA	Hemophilia Federation of America http://www.hemophiliafed.org/
NBDF	National Bleeding Disorders Foundation https://www.hemophilia.org/ *NHF Chapters (See full list at NHF):*
WFH	World Federation of Hemophilia https://www.wfh.org/

HEMOPHILIA TREATMENT CENTERS HTC's

Stanford University Medical Center
https://www.stanfordchildrens.org/en/service/hematology
UCSF Benioff Children's Hospital Oakland
https://www.childrenshospitaloakland.org
University of California at Davis
https://www.ucdmc.ucdavis.edu/hemophilia/
University of California San Francisco
https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/
Valley Children's Hospital
https://www.valleychildrens.org/

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISORDERS

Hemophilia Foundation of Northern California is a 501(c)(3) non-profit. Donations are tax-deductible, much needed and appreciated.

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Visit our website at www.hemofoundation.org for important information.
If you would like to advertise in the next issue, please contact the foundation.

Infusions

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510-658-3324
www.hemofoundation/support/volunteer

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