FALL 2026

Infusions

Navigating Care: A Family Summit

Saturday, 9/26 Santa Rosa

Back to School - Backpacks and supplies

What is HTC Comprehensive Care?

Northern California Bleeding Disorders Foundation

Scan the code, register for free!

IN THIS ISSUE

FAMILY SUMMIT

continued from page 1

INSPIRE · CONNECT · EMPOWER

Navigating Care: A Family Summit

Northern California Bleeding Disorders Foundation

Pfizer · sanofi · octapharma · InfuCare Rx · Bleeding Disorders Council · CVS Health · Optum · National Bleeding Disorders Foundation · Genentech · SOLEO Health · PROFUSION Specialty Pharmacy · HFHealthcare · Bayer · HEMA Biologics · UC Davis Health · Autism Social Communities

FEATURED SESSIONS

Back to School | Backpacks and Supplies

Planning ahead with school nurses, 504 plans, and care at school.

What is HTC Comprehensive Care?

Presented by the Bleeding Disorders Council of California.

Saturday, September 26 · 8:30 AM check in. Must be registered to attend.

Finley Center, Person Senior Wing, Santa Rosa

INCLUDED

Breakfast and lunch

Childcare, ages 0–4

Activities for ages 5–18 from UC Davis Child Life Art Therapy and Autism Social Communities

Space is limited, register early to reserve your spot

Register Free

scan to register

Traveling with hemophilia

To travel and discover new places is exciting and adventurous!

Having hemophilia or other clotting and bleeding disorder should not stop us from enjoying life. Being as best prepared and understanding our limits can make the trip even better.

I have mild hemophilia A, so only treat when needed. I've learned having my FACTOR VIII medicine, infusion and first aid items is the best first line of action. Knowing our body, the type of injury, and quick response in treating a bleed is super important. Also, when and where to go, whether to a Hemophilia Treatment Center (HTC), Urgent care or doctor's office for rapid assessment (may include ultrasound, x-rays, MRI) and medical treatment.

That said, let me take you on my most recent adventure, which was to Machu Picchu in Peru. The famous world heritage Inca site in South America. I had a 6am flight out of San Diego. Barely awake at 4am, I went down the stairs at home as Uber was waiting for me. I didn't turn on the light thinking the night light in the living room was enough to see. My bad! Thinking I had reached the bottom of the stairs I put my foot out to walk on the floor. Noop! I missed a step and fell. Looking, I knew I had sprained my ankle, but it didn't look bad. I knew I didn't break it as I was able to bear weight on my foot. This trip was so important to me, so I made a quick assessment and determined I could go, but needed to self-treat and attend to it ASAP.

To the airport, I took my FACTOR VIII and supplies (ace bandage wrap for compression, frozen packs to ice, 4 quart size zip lock bags to double bag when using ice, and Celebrex for inflammation). I used the frozen packs to ice in the Uber. Airport TSA security allows frozen liquid to pass, so continued to use the packs waiting for my flight.

I approached the gate agent, requested, and the airline confirmed via email, wheelchair assistance for all my flights, including connections.

Once on the plane, I kindly explained to the flight attendant my situation and need to use the bathroom to infusion my medicine. She was very compassionate, told me not to worry and take my time. The baby changing table in the bathroom was helpful as it gave a lot of room to lay out everything and infuse my FACTOR VIII. The flight attendant put ice in my zip lock bag so I could continue to ice on the flight, I took my Celebrex, and used the ace wrap.

Once in Lima, Peru I continued at my partner's home to use RICE (Rest, Ice, Compression, Elevate) for the next 6 days before the trip up to the Andes Mountains. I was able to infuse 2 more doses of FACTOR VIII, for a total of 3 as I did not bring enough. Again, my bad! A call to my HTC assured me that my 3 doses over 3 days, and RICE method should hold the bleed. And it did. I found a doctor in Lima who assessed my ankle. The x-rays confirmed a small bone fracture, and nothing broken. The ultrasound confirmed a torn ligament on the outer side of the ankle, and no active bleed as a clot had formed. Good enough news, that I decided to continue the trip.

Once at Machu Picchu, my first day went okay. I hiked up and down Inca ruins on stone for about 1 hour. Otherwise, I was adhering to the RICE method in the little hotel. The second day I did more hiking at Machu Picchu for about 2 hours. It was more strenuous on my joints and ankle, especially hiking down. **I MADE IT! YAY!!** Can you see my ankle in ace bandage wrap in the photo? It kept me from re-spraining it.

continued on page 4

TRAVELING *continued from page 3*

However, the next morning my ankle was in a lot of pain and swollen. I was worried I had caused a re-bleed. It was important to cut short the remaining portion of the trip, yet I had a BIG smile knowing I made it to Machu Picchu. I returned to Lima early and continued the RICE method along with Celebrex. It worked! The pain and swelling mostly subsided. The flight back to San Diego was long, and when I arrived my ankle was again swollen and in pain. I had pre-arranged a visit my HTC at UC San Diego Center for Bleeding and Clotting Disorders (CBCD), so got in the day after my return. My Nurse Practitioner and Physical Therapist were excellent in assessing my condition with ultrasound, x-rays, Rx of more Factor VIII, fitted me with a boot to protect and "lock down" the ankle, care instructions, and follow-up. In short, I am getting better. According to them, hemophiliacs heal slower than general population. Expect 4 to 6 months with torn ligaments. I'm determined to do whatever it takes to heal it faster so I can get back outdoors, have fun and enjoy life.

Ever since I was a kid, I loved to explore anything outdoors. So can you! Look around, there is something to explore: a garden, field, creek, canyon, water fall or lake, bay or ocean beach, hill or mountain, and park or zoo. The fresh air of the outdoors does something good for us. It makes us feel more alive and connected to the world. Getting out and physically moving also helps our joints, muscles, and cardio. So, it's a motivator. Doing some pre-planning that fits our budget and physical limits helps. Don't say I can't do anything. Find what works best for what you want to do. For example, taking a car, bus, train, plane, go with a family member or friend, ride with someone, or ride-share. The outdoors can be as simple as a walk, bicycle, go sightseeing, a hike, swimming, fishing, rowing a boat along a lakeshore, to recreational outdoor sports whether watching a baseball game or playing golf, depending on what you feel comfortable with doing. Go for it! Your mind and body will love you for it.

UPCOMING EVENTS

Welcome to FALL

Check out these upcoming events happening across Northern California this fall - dinners, education programs, family gatherings, and our biggest fundraising walk of the year. Everyone in the bleeding disorders community is welcome.

SEPTEMBER

4–6 FRI–SUN

Familia De Sangre 2026

Hilton Anaheim

ESPAÑOL Décima conferencia anual en español para personas con trastornos sanguíneos, presentada junto a CCBDF, HASDC y HFSC.

17 THU

Sanofi Live Stream Dinner Event — San Leandro

5:30 PM PT | Location TBA, San Leandro

ENGLISH Join us for a nationally broadcast live stream dinner event connecting foundations coast to coast. For Hemophilia A and B families. Dinner is free, courtesy of Sanofi.

26 SAT

Navigating Care: A Family Summit

9:00 AM – 2:00 PM | Finley Center, Santa Rosa

ENGLISH FLAGSHIP EVENT A day focused on whole-family health: workshops for all ages, teen/youth sessions, childcare for ages 0–4, and prize drawings for all attendees.

OCTOBER

8 THU

Dinner & Education with CSL Behring — Fresno

6:00 PM | Location TBA, Fresno

ENGLISH Join us for dinner as CSL Behring shares education about gene therapy for hemophilia B. All are welcome. Registration required.

11 SUN

Dinner & Community with Juan Pablo — Bayer

12:00 PM | Ruth's Chris Steakhouse, Fresno

ENGLISH Join us for lunch and conversation with Juan Pablo, who lives with hemophilia and uses Jivi. Free event, bilingual English/Spanish. Registration required, seating limited.

NOVEMBER

7 SAT

Unite for Bleeding Disorders Walk 2026

Check-in 8 AM, walk starts 9 AM | Heather Farm Park, Walnut Creek

ENGLISH FLAGSHIP EVENT Our biggest event of the year! Walk to fund camp, advocacy, education, and support for local families. This year we're walking Parrothead style!

7 SAT

Lunch and Education: Walnut Creek

12:00 – 2:00 PM | Location announced soon

ENGLISH Sponsored by HEMA Biologics — an afternoon of lunch and education, connect and learn together.

15 SUN

The Female Factor Meets — Paint & Connect

11:00 AM – 1:00 PM | The Hot Spot Studios, Union City

ENGLISH Join women 18+ from The Female Factor community for an afternoon of pottery painting, education, and connection. Lunch included. Registration required, new attendees get priority.

19 THU

Dinner & Education with CSL Behring

6:00 PM | Location to be announced

ENGLISH Join us for an evening of dinner, education, and connection. Topic and location to be announced. Presented in English. Registration required.

Looking Back on Our Latino Outreach Program

This year, our Latino Outreach Program brought me to four dinners across Northern California, and each one reminded me why this program is so important. These evenings have given us a chance to sit down together, share a meal, reconnect with familiar faces, welcome new families, and have honest conversations about the needs of our Latino bleeding disorders community.

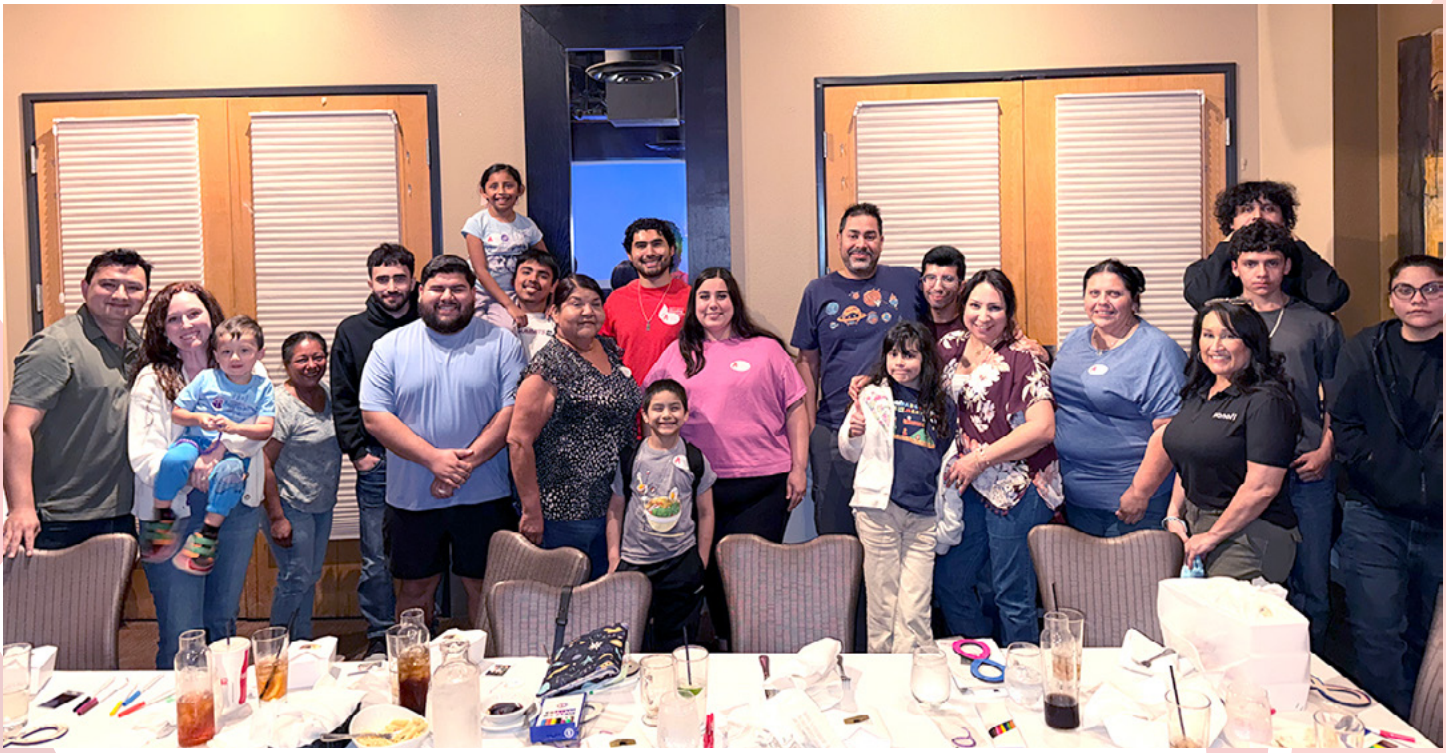
We started the year on January 15 in Poplar, where community member Thalia Santiago helped us organize and lead an incredible evening. Thalia brought so much heart to the event and helped us create a space that truly felt welcoming and connected to the community. We were also grateful to have Virginia and Destiny from InfuCare Rx sponsor the dinner, provide great education, and bring a fun activity that gave our families another way to learn and connect.

From there, we traveled to Fresno on April 17 for a special dinner in recognition of World Hemophilia Day. Sponsored by Eva Felix with Sanofi, the evening brought together families from throughout the Fresno area for a night centered on education, conversation, and community.

In May, we brought the program to Oakland for our third dinner of the year. Sponsored by Zuiho with Pfizer, the evening also welcomed guest speaker Claudia, who joined our families for an amazing night of education, conversation, and connection along the water.

continued on page 7

UPDATE *continued from page 6*



Most recently, on August 20, we returned to the Fresno region for our fourth dinner. Cathy Marquez with Novo Nordisk sponsored the evening, with Destiny and Virginia from InfuCare Rx joining us once again as co-sponsors. What stood out to me most were the conversations around the everyday realities of living with a bleeding disorder. Families talked openly about navigating school, accessing quality healthcare, and the challenges they continue to face. Those conversations are exactly why we continue doing this work.

Four dinners in four different communities, but the same thing stood out at every one: families showing up for one another.

That is the heart of our Latino Outreach Program and what we hope to accomplish through Dinner & Dialogue. We want our families to have a place where they can learn, ask questions, share their experiences, and connect with people who understand what they are going through. We want to provide culturally appropriate resources, improve access to healthcare and support, increase understanding of treatment options through multilingual education, and help families become stronger advocates for themselves and their loved ones.

More than anything, we want every family who joins us to leave knowing they are part of a community that is here for them.

I am grateful to every family, community member, sponsor, and partner who helped make these evenings possible this year. I am proud of what we have built together, and I look forward to seeing where this program takes us next.

-Pedro P.

FOR PATIENTS WITH HEMOPHILIA B

ACHIEVE NEW HEIGHTS

with proven, long-lasting bleed protection

IDELVION®
Coagulation Factor IX (Recombinant), Albumin Fusion Protein

ONLY IDELVION DELIVERS

7 and 14 DAY DOSING† FLEXIBILITY
FDA-APPROVED FOR ADOLESCENTS AND ADULTS

+ **20%** STEADY-STATE **TROUGH LEVELS**
WITH 7-DAY PROPHYLACTIC USE‡

+ **0** SPONTANEOUS **BLEEDS**§

LEARN MORE >

* Hemophilia FIX Market Assessment. Third-Party Market Research.

† Once well-controlled (1 month without spontaneous bleeding or requiring dose adjustments on a weekly dose of ≤40 IU/kg), people 12 years and older can be transitioned to 14-day dosing.

‡ The average dose for adolescents and adults receiving prophylaxis every 7 days was 37 IU/kg.

§ The median AsBR for people who started on 7- or 14-day prophylaxis was 0. For people who switched to prophylaxis from on-demand, the median AsBR was 0.7. AsBR=annualized spontaneous bleed rate.

IMPORTANT SAFETY INFORMATION

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in children and adults with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. IDELVION can reduce the number of bleeding episodes when used regularly as prophylaxis.

IDELVION is administered by intravenous injection into the bloodstream and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

The most common side effects of IDELVION are headache and dizziness. These are not the only side effects possible. Tell your healthcare provider about any side effect that you experience, and contact provider immediately if bleeding does not stop after taking IDELVION.

Please see full prescribing information for IDELVION, including patient product information.

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**.

You can also report side effects to CSL Behring's Pharmacovigilance Department at **1-866-915-6958**.

CSL Behring

NEWS

Bleeding Disorders Conference

We had a very productive Bleeding Disorders Conference in Orlando. In addition to presenting some data to the medical track, I moderated a panel on Hemophilia Treatment Center (HTC) care for consumers. The panel included our very own Pedro Preciado, Walnut Creek and Lisandro Rios from Fresno.

The room was full and we got rave reviews!

The NorCalBDF team was very busy meeting with our business partners to outline support for our new and existing programs.

I was able to attend the Medical and Scientific Advisory Committee (MASAC) meeting, where clinicians create guidelines for the care of bleeding disorders for the whole country.

A new Marion Koerper Innovation Fund has been created by Dr. K's family to support MASAC and research in her name.

Most of the material was clinical, but one important item was the return of Stimate by the end of the year.

Nationally, there is a continuing effort to remove people from the Medicaid rolls. This is not affecting Californians currently, but people receiving Supplemental Security Income from the Social Security administration are receiving notifications for "redetermination" or something like that. It looks like a regular statement, but you need to take this letter to your doctor and be re-evaluated. Otherwise, you may be removed from the rolls
Bottom-line – READ YOUR MAIL.

Respectfully submitted,

Randy Curtis, President

JOIN HERE!

Join a committee – Make an Impact!

NorCalBDF Standing Committee Opportunities

At the Northern California Bleeding Disorders Foundation, our committees are the heart of everything we do. Made up of dedicated community members, volunteers, and advocates, our committees drive the programs, events, and initiatives that directly support people with bleeding disorders and their families across Northern California. Whether you have a few hours to spare or are looking for a deeper, ongoing commitment, serving on a committee is a meaningful way to make a difference — and to connect with others who share your passion for our community. We welcome people of all backgrounds and experience levels. Explore the committees below and find the right fit for you.

Community Engagement Committee

Traits: Strong interpersonal skills, relationship-building, public speaking, storytelling social media, and marketing experience.

Role: Spreading awareness, engaging the community, developing campaigns, building partnerships.

Education & Program Development Committee

Traits: Youth (18-25), subject matter expertise, curriculum design, facilitation skills.

Role: Informing and equipping the community, Designing and delivering educational materials, workshops, webinars, and resource guides.

Finance Committee

Traits: Accounting, budgeting, compliance, risk management, detail oriented.

Role: Reviewing budgets, monitoring financial health, overseeing audits, and ensuring fiduciary responsibility.

Donor Engagement & Events Committee

Traits: Storytelling, Networking, persuasive communication, donor cultivation, event planning.

Role: Building donor relationships and ensuring consistent follow up, planning fundraising campaigns/events, donor pipeline development, grant prospecting, and stewardship. Serve as a "donor perspective" voice for the board, bringing insights into how events and cultivation are received by the community.

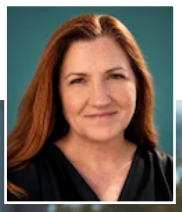
Governance & Nominating Committee

Traits: Familiarity with nonprofit bylaws, governance best practices, nominating and succession planning, policy writing, organizational strategy.

Role: Reviewing bylaws, policies, board effectiveness, compliance with nonprofit laws and ethical standards.

NEWS

A New Resource That Has Been Around for a Long Time



by Ashley Gregory

DEPARTMENT of REHABILITATION

Employment, Independence & Equality

I recently was able to access an incredible resource, the Department of Rehabilitation, or DOR. This is a federal program with state and local offices. Their goal is to return disabled folks to work. My disabilities are hidden; those others cannot see or determine unless I share that information with them. But I qualified because my college and medical records indicated my disabilities that qualified me for this service. I completed the application, received an intake evaluation over the phone with a very nice worker, and began my journey. I was able to seek the exact type of education I wanted and found it at a university that offers online education. I am considered a Lifelong Learner and am a distance learner. The certificate they offer will allow me to further my career. While I was taking classes and working, it became apparent to me that my current desk setup was lovingly hobbled together and although it was enabling me to accomplish my work and schooling, it was also injuring me. I had been working like this for seven years without an ergonomic assessment or adaptable equipment that would keep me safe from injury. I let my DOR case-worker know I was experiencing pain (I had been to physical therapy for the past year due to this concern) and asked if there was an ergonomic assessment available so I could obtain the proper equipment. I was put in touch with a contractor company that called me, asked some question had me send a photo of my current desk setup and asked some questions about my preferences of desk color, footrest type, was I a mac or windows user, etc. In about one month's time, the contractor let me know it was time for my installation. I was set up with a height adjustable desk (stand up/sit down), a monitor riser that enabled me to have the monitor screen at the correct height, a footrest with roller for sore feet, a chair that fit my small frame body with lumbar cushion, a light that backlights the wall behind my desk to reduce eye fatigue, a headset with microphone for those meetings where ambient sound from my surroundings may be a distraction. Once all installed, the contractor helped me carry the old 'desk' to the curb where someone is now lovingly using it for their purposes.

The difference between my old setup and new setup is night and day. The old setup hurt my eyes, arms, neck, back, and knees. The new setup offers support in the appropriate places, provides the proper lighting to reduce fatigue and the proper tools to provide excellent service to our community.

Not everyone will qualify for DOR services and to be honest, because the offerings are so great, you really must push them each step of the way. They want you to drive the entire process because they need to know you are motivated before they will pay for the supplies, education, etc.

continued on page 12

 continued from page 11

At the end of this, I will have a certificate in Nonprofit Management, taught by some of the most talented Bay Area nonprofit managers in our area. I am so lucky to have access to this resource and I am hoping that if you also see yourself as someone that could benefit from this service, that you will take a look at the website, and if this resource may be for you, complete the application and see what happens!

DOR (Department of Rehabilitation) assists individuals with disabilities to build viable careers and live independently in their community. In FY 2016 - 2017, vocational rehabilitation counselors provided employment services to 100,442 eligible job-seeking adults and youth. DOR's Vocational Rehabilitation Program provides a variety of services including career guidance and counseling, job search and interview skills training, independent living skills, on the job training, employment preparation, assistive technology, and other services.

If you are eligible for DOR services, your counselor will work with you to help figure out your employment goals and what services you will need to reach these goals.

Services can include:

- Career counseling
- Career assessment
- College or career training
- Work-readiness training
- Assistive technology
- Job placement
- Job coaching
- Other support services

DOR staff will help you figure out your options and the pros and cons of each option to help you make decisions about how best to reach your goals.

Application: https://www.dor.ca.gov/Home/ContactUs

To be eligible for services, an individual must:

- have a physical or mental impairment that substantially impedes his / her ability to secure employment, and vocational rehabilitation services are required to prepare for, secure, retain, or regain employment consistent with the applicant's unique strengths, resources, priorities, concerns, abilities, interests, and informed choice;
- be able to benefit from the DOR's services in terms of an employment outcome in an integrated setting.

If your disability is so severe that you might not be able to benefit from DOR services, the DOR can arrange a trial work experience. This is an opportunity to work in a realistic work setting to demonstrate if you can benefit from DOR services.

If you are receiving Social Security Administration benefits or if you have a valid "Ticket to Work," you are presumed eligible for DOR services.

When the department does not have available resources to serve all applicants who are deemed eligible for our services, the federal government requires that we use an order of selection (OOS) process. DOR must serve people with the most significant disabilities first. Placing eligible applicants in a priority category provides a fair way to serve all applicants in the correct order.

All those in the "most significantly disabled" category will be served first, followed by everyone in the "significantly disabled" category and then the "disabled category."

Within each category, we serve people according to the date of application. The person who applies first is served first; the person who applies second is served next, and so on, until everyone in that category has been served.

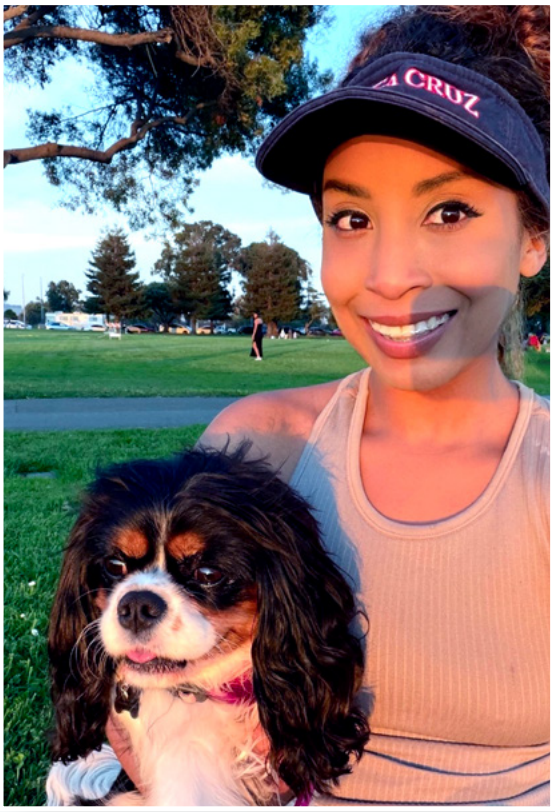
Waiting List

If the DOR does not have available resources to serve your category, you will be placed on a waiting list until your turn comes. If you are on the waiting list, we will send you a letter every 3 months to tell you which category we are currently serving. As soon as we can serve your category, we will let you know. You will then be served according to the date you submitted to your application.

INTRODUCING NEW STAFF PERSON

Charlette Viney

Partnerships and Grants Manager



Meet Charlette Viney, Manager of Partnerships and Grants! Charlette is new to our staff, please join us in welcoming her!

Charlette Viney is an institutional fundraising professional who believes that the right resources in the right hands can truly change lives. She comes to NorCalBDF with nearly a decade of experience working alongside health and social impact organizations, building institutional partnerships and funding relationships that allow communities to access the care and support they need. What drives Charlette is simple: she wants the organizations doing the most important work to have the funding and partnerships they need to keep doing it.

In her spare time, she enjoys mentoring girls through Girls Inc., fitness and wellness, spending time with friends and family, and adventures with her pup, Bela. **She can't wait to meet you!**

DOLLY PARTON'S LEGACY

Do you and your family qualify?

Available in 42 counties in CA; click the link to see if your county qualifies. Find Dolly Parton's Imagination Library Local Program Partners In The USA.

Use the following map or menu to find **Dolly Parton's Imagination Library Local Program Partners** in your area.

Please Note: If the program isn't currently available in your area, enter your postcode below and provide your contact information to receive notification when the program does become available. Also, if you are interested in becoming a Champion in your community, visit our Start A Program page to learn more.

Dolly Parton's IMAGINATION LIBRARY

Parrothead & Tie-Dye Edition

UNITE FOR BLEEDING DISORDERS

SATURDAY, NOV 7, 2026 | Heather Farm Park, Walnut Creek

$0
NO SIGN-UP FEE

$75
PER T-SHIRT

Passports & Prizes
THE DAY OF THE EVENT

Food: plan ahead this year

No food served this year. Sign up for our post event lunch hosted by **Hema Biologics**, or secure your own spot at the park — picnic benches and bbq pits — and make it a day!

Post-event lunch
Hosted by Hema Biologics. Sign up ahead of walk day.

Sign up for lunch

Make a day of it
Claim a picnic bench or bbq pit at Heather Farm Park and stay a while.

Why we fundraise

Fundraise to ensure programs like **Family Camp**, **The Female Factor Retreat** and **Camp Hemotion** are here for the next generations of families.

Sign up at the QR code

uniteforbleedingdisorders.org/event/norcal-unite

Funds raised stay local with the Northern California Bleeding Disorders Foundation. Questions? **ashley.gregory@norcalbdf.org**

Northern California Bleeding Disorders Foundation

ALTUVIIIO®
Antihemophilic Factor (Recombinant), Fc-VWF-XTEN Fusion Protein-ehtl

Connect with an ALTUVIIIO® Peer Mentor

ALTUVIIIO Peer Mentors are real patients or caregivers who have had similar experiences to yours.

You'll have the opportunity to:

- Ask questions
- Hear firsthand experiences
- Learn helpful tips
- Get to know others in the community

"Maybe it's because I've always had such great support, but **engaging with others** is the best way for me to stay happy."

—AJ

AJ | ALTUVIIIO patient

AJ is a promotional speaker compensated by Sanofi.

Click here to sign up to meet a Peer today!

sanofi

MAT-US-2406913-v1.0-07/2024

PATIENT SURVEY

To better support our community, we're asking patients and caregivers to share their experiences.

Your input will help guide our efforts to improve access, strengthen care networks, and advocate for policies that support comprehensive treatment.

Access to comprehensive, coordinated care is essential for individuals living with bleeding disorders. From accurate diagnosis and specialized treatment to mental health support and care coordination, the comprehensive care model of the Hemophilia Treatment Center Network is proven to improve outcomes and quality of life.

According to the National Bleeding Disorder Foundation's Medical and Scientific Advisory Committee (MASAC), "Comprehensive or integrated care treats the whole person and the family, through continuous supervision of all the medical and psychosocial aspects of bleeding disorders. Comprehensive care is total care because every facet of the person is addressed, including their physical, emotional, psychological, educational, financial and vocational factors. The development of comprehensive care over the past 30 years has greatly improved the quality of life for people with bleeding disorders, helping them to be more independent and productive."

Despite progress, many patients still face barriers—whether due to geography, insurance coverage, or limited access to specialized providers. Understanding these challenges is critical to ensuring that care systems evolve to meet real patient needs. We know that both Medi-Cal Managed Care and Kaiser, in particular, can create barriers that prevent patients from receiving the comprehensive care they deserve.

To better support our community, we're asking patients and caregivers to share their experiences. Your input will help guide our efforts to improve access, strengthen care networks, and advocate for policies that support comprehensive treatment. Your story can help you and others access the care you need. Please take a few minutes to complete our short survey. Please only complete the survey once per patient in your family unless you have a new access issue to report. Your voice plays an important role in shaping the future of bleeding disorder care.

Please take a few minutes to complete our short survey. Please only complete the survey once per patient in your family unless you have a new access issue to report.

Your voice plays an important role in shaping the future of bleeding disorder care.

TAKE THE SURVEY

RESPONDA LA ENCUESTA

BLEEDING DISORDERS COUNCIL OF CALIFORNIA

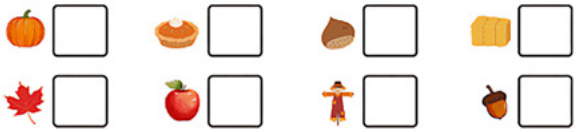
Kid's Page

...and playful adults!

COLOR ME!

autumn

I SPY



WORD SEARCH

FIND AND CIRCLE EACH WORD!

P	C	P	A	T	C	H	C	P
U	O	O	F	B	A	T	A	U
N	H	R	S	A	N	A	N	M
B	T	N	A	T	L	D	D	P
L	R	W	O	N	U	L	Y	K
O	E	N	W	O	G	M	D	I
H	A	L	L	O	W	E	E	N
K	T	R	I	C	K	S	C	N
O	C	T	O	B	E	R	K	E

Orange, Bat, Pumpkin, Patch, Fall, October, Treat, Costume, Halloween, Owl, Candy, Trick

HALLOWEEN MAZE

Find your way through the maze to reach the pumpkin in the center.

Happy Halloween!

START HERE

CALENDAR

SEPTEMBER 2026

9/4/26-9/6/26	Familia de Sangre	Anaheim
9/17/26	Sanofi Live Stream and Dinner	San Leandro
9/26/26	Navigating Care; A Family Summit	Santa Rosa

OCTOBER 2026

10/8/26	Education & Dinner with CSL Behring	Fresno
10/11/26	Education & Lunch with Bayer	Fresno

NOVEMBER 2026

11/7/26	Unite for Bleeding Disorders Walk	Walnut Creek
11/7/26	Education & Lunch with Hema Biologics	Walnut Creek
11/15/26	The Female Factor Meets	Union City
11/19/26	Education & Dinner with CSL Behring	Walnut Creek

DECEMBER 2026

12/5/26	WinterFest	San Jose
12/6/26	WinterFest	Fresno

NorCalBDF Northern California Bleeding Disorders Foundation
https://www.NorCalBDF.org/

AFFILIATED ORGANIZATIONS

BDCC Bleeding Disorders Council of California
https://www.bdcouncilca.org

HFA Hemophilia Federation of America
http://www.hemophiliafed.org/

NBDF National Bleeding Disorders Foundation
https://www.bleeding.org/
NBDF Chapters (See full list at NBDF)

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/

Kaiser Oakland Pediatric Hematology/Oncology
https://Kaiser Oakland Pediatric Hematology/Oncology

Northern California Bleeding Disorders Foundation

Northern California Bleeding Disorders Foundation (NCBDF) does not endorse any particular pharmaceutical manufacturer or home care company.

PLEASE NOTE: The companies whose advertisements are listed herein have purchased this space, and are NEVER provided with members' names, addresses or any other personal details. Paid advertisements and paid inserts should not be interpreted as a recommendation from NCBDF, nor do we accept responsibility for the accuracy of any claims made by paid advertisements or paid inserts.

Since we do not engage in the practice of medicine, we always recommend that you consult a physician before pursuing any course of treatment.

Information and opinions expressed in this publication are not necessarily, those of the Northern California Bleeding Disorders Foundation, or those of the editorial staff.

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

CONTACT INFORMATION
305 Vineyard Town Center #132
Morgan Hill, CA 95037

Office hours: Mon-Fri, 9am-5pm

www.norcalbdf.org
contact@norcalbdf.org

(510) 658-3324 phone
(510) 658-3384 fax

Infusions

Published four times per year by
Northern California Bleeding Disorders Foundation

Editor
Ashley Gregory, *Associate Director, Education & Advocacy*

Medical Editor
Tiffany Lucas MD, *Medical Director*

Contributors
April Steger, *Executive Director,*
Pedro Preciado, *Outreach & Engagement Coordinator Bilingual*

DONATE DIRECT

2026 PUBLICATION SCHEDULE

ONLINE
MARCH 1 · JUNE 1 · SEPTEMBER 1

ONLINE AND PRINT VERSION MAILED
DECEMBER 1

HOW TO:

UPDATE YOUR CONTACT INFORMATION

BECOME A CONTRIBUTOR TO INFUSIONS

ADVERTISE IN INFUSIONS

VISIT OUR WEBSITE