SUMMER 2026

Infusions

What Sustains Us: The Volunteers Behind Our Mission

Behind every program, every connection, and every moment of support is someone who chose to give their time. NorCalBDF thrives because people choose to invest their time, care, leadership, and partnership in the community. In this issue, we're highlighting three dedicated volunteers whose service reflects the many ways our community helps sustain the mission of the Northern California Bleeding Disorders Foundation.

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Northern California Bleeding Disorders Foundation

The Volunteer Experience at NorCalBDF... See on Page 3

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In nonprofit work, it is easy to focus on programs. We talk about events, services, education, outreach, and all the visible ways a mission comes to life. Those things matter deeply. They are how we serve our community. But programs do not exist on their own. They are carried forward by people.

Behind every support group, family event, educational program, and community gathering, there are individuals who choose to give something of themselves. They give time, energy, leadership, compassion, expertise, encouragement, and heart. They step in early to set up, stay late to clean up, answer questions, welcome new families, serve on boards and committees, offer professional partnership, and keep showing up year after year.

That is what truly sustains a nonprofit. Not only the structure of its programs, but the strength of the people who believe in its purpose.

At the Northern California Bleeding Disorders Foundation, we see that every day. Our mission is advanced not only by what we offer, but by who stands beside us to make it possible. Volunteers, board members, community partners, and supporters each play a role in building the sense of connection and care that our community depends on. Their service reminds us that impact is never created by one organization alone. It is created together.

> Volunteers make the mission possible, and the mission endures because people keep showing up.

This issue is a chance to honor that truth. We are proud to highlight several longtime volunteers whose generosity reflects the many ways people help keep our mission strong. When people invest in a community, they do more than support programs. They create belonging. They strengthen trust. They help ensure that families continue to feel informed, connected, and cared for.

Programs are important. But people are what make them meaningful. In the pages that follow, we are proud to share the voices of three dedicated volunteers whose service reflects the heart, commitment, and community behind our mission.

If you have an interested in getting involved, either on a program level or a leadership level, we have many opportunities. Check out the article **"Join Us in Strengthening Our Community"** on page 7.

SPOTLIGHT

The Faces of Service Behind Our Foundation

Board member volunteer Alan Wu

What led you to serve on the NorCalBDF board, and what has made that service meaningful to you?
I knew the current president of NCBDF and he asked if I would be interested in serving, and I applied because I would like to give back to the community and extend our work.

How do you see volunteer leadership strengthening the Foundation's mission and future?
Volunteer leadership strengthens the Foundation because everyone is interested in the long term mission and not get distracted by short term gains that sacrifice long term results.

What do board service and volunteerism have in common?
As I mentioned earlier, both are dedicated to the mission and have an input in changing things for the better.

Why is community involvement so important to the health and resilience of a nonprofit organization?
Community involvement is important because it is how we advocate the work that we do and increase the number of people we reach. Future leaders can also be identified from community outreach.

What are you most proud of when you look at what NorCalBDF has built together?
I have gotten a lot of useful information from our newsletter and met a lot of interesting people from all walks of life, where normally we might not otherwise cross paths.

What do you think makes this community so special?
This community is special to me because we all realize the different struggles that we have to go through.

What do you hope supporters, donors, and volunteers understand about what it takes to keep this work strong?
I hope that supporters, donors, and volunteers realize that we are all doing work to advocate for improving people's lives and connect people to ensure they are able to get support.

Looking ahead, what gives you confidence about the future of NorCalBDF?
Active participation in our events and people who are happy about the results that we are doing gives me confidence that the future will be even better for the Foundation.

How do volunteers, board members, donors, and partners each play a different but essential role in sustaining the Foundation?
We all have different roles that we can play. Volunteers can donate their time when they are available without as much time commitment. The board members can focus on the decision making, whereas donors and partners can support the mission by giving funding needed to run the Foundation.

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Volunteer Rodney Delbosque

Tell us about your role in the bleeding disorders space and how you came to support this community.

I became involved in the bleeding disorders community through a desire to build stronger connections with individuals and families navigating rare diseases. Over time, I found myself drawn to opportunities where I could offer support, share resources, and help people feel seen and understood throughout their care journey. What started as an interest in advocacy quickly became a genuine passion centered on trust, education, and community. I value being a reliable presence for others, whether that means helping connect families to resources, supporting awareness efforts, or simply listening and learning from the experiences of those within the bleeding disorders space. The resilience and strength of this community continue to inspire my commitment to serving and supporting others.

What first drew you to volunteer with NorCalBDF beyond your professional role?

What drew me to volunteer was the sense of community and genuine human connection. Beyond my professional responsibilities, I wanted to show up simply as someone who cares and is willing to listen, support, and learn. NCBDF creates spaces where patients and families can feel seen and empowered, and I wanted to contribute to that mission in a meaningful way.

How has volunteering helped you better understand the experiences of patients and families living with bleeding disorders?

Volunteering has given me the opportunity to hear stories and perspectives that go far beyond clinical conversations. It has helped me better understand the day-to-day realities families face the emotional challenges, the resilience, the advocacy, and the importance of having a strong support system. Those experiences continue to shape how I approach my work and remind me to always lead with empathy.

Why is it important for industry professionals to show up as volunteers in community spaces?

I believe it's important because trust is built through relationships and consistency. When industry professionals show up in community spaces as volunteers, it demonstrates that we are invested not only in treatment outcomes, but also in the people behind them. Being present, listening, and engaging outside of a professional setting helps create stronger partnerships and more authentic support for the communit

What have you learned from families, patients, or caregivers through your volunteer experiences?

I've learned the true meaning of resilience and advocacy. Families and caregivers often carry an incredible amount of responsibility while still finding ways to support and encourage others in the community. I've also learned how valuable it is to simply listen. Sometimes the most meaningful support comes from being present and understanding someone's experience without trying to immediately fix it.

Can you share a moment when volunteering reminds you why this work matters?

One of the most meaningful moments for me has been seeing families who may have initially felt isolated leave an event feeling connected, supported, and hopeful. Watching patients and caregivers realize they are not alone and seeing the confidence that comes from community is a powerful reminder of why this work matters so much.

How do partnership and volunteerism work together to strengthen nonprofit organizations like NorCalBDF?

Partnership and volunteerism strengthen organizations by creating collaboration built on shared purposes. Volunteers bring time, perspective, and heart, while partnerships help expand resources and reach. When those things work together, organizations like NCBDF can create a greater impact for the community and continue building programs that truly meet patients' needs.

What keeps you coming back year after year?

The people. The relationships, the conversations, and the opportunity to make even a small difference in someone's experience keep me coming back. Every interaction reinforces how strong and supportive this community is, and I feel fortunate to continue learning from and growing alongside it.

What gives you hope for the future of the bleeding disorders community?

What gives me hope is the continued progress in treatment, education, and advocacy, but even more than that, it's the strength of the community itself. I see patients, families, providers, and organizations working together in ways that are creating greater awareness,

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Volunteer Patrick Wagner

Tell us about your role in the bleeding disorders space and how you came to support this community.
I am currently a community educator for Takeda. I have a career in hematology sales and patient education and began working in northern California area in 2022.

What first drew you to volunteer with NorCalBDF beyond your professional role?
I believe in giving back to the bleeding disorders community and my company fully supports my volunteer work with patients and caregivers. I have a history of working with bleeding disorders organizations in other states and it was a very natural fit for me to volunteer with NCBDF.

How has volunteering helped you better understand the experiences of patients and families living with bleeding disorders?
I believe that volunteering within this community allows me to listen and learn when patients and caregivers open up about what challenges and needs they have. There is a trust level that people give when you show that you are willing to work hard and engage with them. I am very focused on making the community a better place and we need to be able to focus our efforts around where the greatest needs are.

Why is it important for industry professionals to show up as volunteers in community spaces?
Bleeding disorder organizations need volunteers to be able to facilitate programs and services to their communities. Most chapters do not have adequate staff or resources to execute programs and events at the level needed in most cases. Paying for content speakers and work groups to help with events would be a significant spend of the non-profit annual budget.

What have you learned from families, patients, or caregivers through your volunteer experiences?
I have learned so much through my years of volunteer experiences through the years. What I have learned is that each family has unique and different needs. Some need education, some need financial, some just need the support of a strong, family-like community.

Can you share a moment when volunteering reminds you why this work matters?
I would say the moments that come to mind most often are at family camps or kids camps when we near the end of the event. As the families or kids prepare to leave the connections and bonds that they have made during that week or weekend really show as they say goodbye and truly feel that they have made a life-long friend or connection with someone. There is often sadness but also gratitude and love with knowing they now have a relationship with someone that they can share their bleeding disorder world with.

How do partnership and volunteerism work together to strengthen nonprofit organizations like NorCalBDF?
Financial partnership and volunteerism are the two main components that groups like NCBDF need the most. Non profit groups need to maximize their education and event offerings to meet their community's needs. This can only be done with funds and hands.

What keeps you coming back year after year?
I strongly believe that giving back to this community is one of the most important things I can do with my skill sets. Seeing successful education and family events keep the motivation there to do more. And the best kept secret is that we have almost always have fun when we are all together and that is an added bonus to the work we do.

What gives you hope for the future of the bleeding disorders community?
The biggest motivator I see is the community members that want to see the organizations continue on into the future. The needs of the bleeding disorders community are changing and the organizations need to change with them. New and existing members are giving feedback on what matters to them and the organizations are listening and evolving to meet the patients where they are.

List of Ongoing Volunteers from 2024-2026

Eugene Ahn
Jose Amador Caro
Jesse Amador Caro
Gisela Azonos
Anita Bawa
Abel Beltran
Niyati Bondale
Kerri Borgese
Michael Bradley
Daisy Caburnay
Emir Calderon (Esquivel)
Carolyn Callander
Paul Castro
Randall Curtis
Benjamin Davis
Nic DeFalco
Dylan DeFalco
Rachel DeFalco
Rodney Del Bosque
Ava Dillon
Michelle Douglas
Edna Espinoza
Ava Felix
Leslie Ferber
Tyla Fowlkes
Janice Gau
Julie Gatty
Suzanne Goldman
Justin Gray
Camille Harris
Mark Helm
Hugo Helm
Areli Hernandez
Shelley Jajeh
Tim Jeung
Madeleine Jeung
Elaine Lai
Judith Lea
Yueqing (Bella) Li
Arthur Long
Alejandra Lopez
Denise Lowery
Angela Mamangun
Cathy Marquez-Velasco
John Martinez
Tony Materna
Alex Mateos
Piper Morgan
Jacob Nole
Huong Nguyen
John Orr
Christine Orr
Lupe Ozeda Torres
Aiyana Parham
Dan Peterson
Darcy Phelan
Scarlett Peepe
Dawn Pollard
Shannon Powell
Doris Quon
Latha Rao
Lisandro Rios
Ernesto Rios
Julian Ross
Ryan Santos
Thalia Santiago
Derek Sim
Shaharah Simmons-Crick
Cassidy Thorpe
Patricia Tobase
Robert Toledo
Melissa Towers
Ruetima Titapiwatanakun
Cassidy Thorpe
William Thorpe
Katrina Unpingco
Janet Vang
Teresa Vazquez
Patrick Wagner
Mosi Williams
Alan Wu
Anthony Yazurlo
Curtis Yee
Jeanmarie Zoland
ADD YOUR NAME HERE!

Join Us in Strengthening Our Community

At the Northern California Bleeding Disorders Foundation, our work is made possible by people who care enough to step forward. Whether you have time to volunteer occasionally, want to share your professional skills, or are looking for a deeper leadership role, there are many ways to make a meaningful difference. Together, we serve more than 3,000 individuals and families across 20 Northern California counties through education, advocacy, outreach, and support.

1. Join a committee
Our standing committees help guide and strengthen the Foundation throughout the year. Opportunities include the Community Engagement Committee, Education & Program Development Committee, Finance Committee, Donor Engagement & Events Committee, and Governance & Nominating Committee. These groups offer meaningful ways to contribute your skills in outreach, education, financial stewardship, event planning, donor engagement, and organizational leadership.

2. Explore board service
For those who have already been active through committee work, program volunteering, or strong mission support, board service may be a natural next step. Board members help provide strategic direction, support fundraising and advocacy, strengthen governance, and ensure the long-term health of the organization. Board service also includes participation on at least one standing committee, making it a meaningful opportunity for those who want to deepen their impact.

3. Volunteer at programs and events
There are many hands-on ways to support NCBDF programs throughout Northern California. Volunteers help with events and educational opportunities such as Camp Hemotion, the Unite for Bleeding Disorders Walk, Family Camp, Family Education Day, Men's Meetup, Female Factor quarterly programs, advocacy outreach, and so much more. Whether helping welcome families, support logistics, assist with activities, or lend a hand behind the scenes, volunteers help create the connection and care that define our community.

Share your skills where they are needed most

We welcome volunteers with a wide range of experience, including finance, healthcare, education, communications, outreach, governance, project management, advocacy, and relationship-building. Some people serve year-round, while others help with one event or project at a time.

You don't need to have a bleeding disorder to volunteer for NorCalBDF. We appreciate you all as every contribution matters, and there is a place for every kind of volunteer. If you are interested in joining a committee, learning more about future board service, or helping with programs and events, we would love to hear from you. Your time, talents, and commitment can help strengthen our mission and support families across Northern California.

To start the conversation, please contact April Steger, Executive Director at director@NorCalBDF.org or (510) 658-3324.
You can also check out our volunteer sign up page at https://www.norcalbdf.org/. Select "Get Involved".

We look forward to working alongside you to advance the mission of the Foundation.

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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

Family Camp Experience 2026

My name is Breanna, I was asked by Pedro to write about mine and my family's experience at this year's family camp. We've been to camp one other time YEARS ago back when I was a teen and for myself wasn't an enjoyable experience. It was before I knew about factor for my VWD and I was having my menstrual at the time. I was only taking Amicar at the time and didn't help very much as I would've wanted. Fast forward now I really loved my experience at family camp. This year for family camp it was myself, my mom Maria (Madi), my sister Kayla, my cousin Lisa, and my daughter Amiah. This year was my daughters very first family camp, and needless to say the second we pulled up to camp she was so excited seeing so many new and different things. When it came time to get into groups Amiah was anxious about being away from me because she's always close to my side. Amiah has separation anxieties, and autism. When split into the groups she met another young boy named Jackson. Jackson helped her really be able to enjoy her time and they became best friends.

I honestly loved all the information and all the different people we had met while at camp. Creating those memories, bonds, and experiences together. Pedro did a really great job and so grateful we were able to attend and be a part of it all. Now Amiah has a bestie she can still see and hang out with and I got support and information for how to help myself and my daughter through all our bleeding needs.


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HYMPAVZI™
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For routine prophylaxis in patients 12 years and older with hemophilia A or B without inhibitors

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Introducing HYMPAVZI—**a once-weekly subcutaneous** prophylactic treatment that comes in a **fixed-dose,* prefilled pen**

*Your first dose (loading dose) of HYMPAVZI is 300 mg (two 150 mg injections). Then you will inject a weekly (maintenance) dose consisting of 1 or 2 injections as prescribed by your healthcare provider. If more than one injection is required to deliver a complete dose, administer each injection at a different injection site.

What is HYMPAVZI?
HYMPAVZI is a prescription medicine used to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A without factor VIII inhibitors or hemophilia B without factor IX inhibitors.

It is not known if HYMPAVZI is safe and effective in children younger than 12 years old.

IMPORTANT SAFETY INFORMATION

Important: Before you start using HYMPAVZI, it is very important to talk to your healthcare provider about using factor VIII and factor IX products (products that help blood clot but work in a different way than HYMPAVZI). You may need to use factor VIII or factor IX medicines to treat episodes of breakthrough bleeding during treatment with HYMPAVZI. Carefully follow your healthcare provider's instructions regarding when to use factor VIII or factor IX medicines and the prescribed dose during your treatment with HYMPAVZI.

Before using HYMPAVZI, tell your healthcare provider about all of your medical conditions, including if you:
- have a planned surgery. Your healthcare provider may stop treatment with HYMPAVZI before your surgery. Talk to your healthcare provider about when to stop using HYMPAVZI and when to start it again if you have a planned surgery.
- have a severe short-term (acute) illness such as an infection or injury.
- are pregnant or plan to become pregnant. HYMPAVZI may harm your unborn baby.

  Females who are able to become pregnant:
  - Your healthcare provider will do a pregnancy test before you start your treatment with HYMPAVZI.
  - You should use effective birth control (contraception) during treatment with HYMPAVZI and for at least 2 months after the last dose of HYMPAVZI.
  - Tell your healthcare provider right away if you become pregnant or think that you may be pregnant during treatment with HYMPAVZI.
- are breastfeeding or plan to breastfeed. It is not known if HYMPAVZI passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements.

What are the possible side effects of HYMPAVZI?
HYMPAVZI may cause serious side effects, including:
- **blood clots (thromboembolic events).** HYMPAVZI may increase the risk for your blood to clot. Blood clots may form in blood vessels in your arm, leg, lung, or head and can be life-threatening. Get medical help right away if you develop any of these signs or symptoms of blood clots: swelling or pain in arms or legs; redness or discoloration in your arms or legs; shortness of breath; pain in chest or upper back; fast heart rate; cough up blood; feel faint; headache; numbness in your face; eye pain or swelling; trouble seeing
- **allergic reactions.** Allergic reactions, including rash and itching have happened in people treated with HYMPAVZI. Stop using HYMPAVZI and get medical help right away if you develop any of the following symptoms of a severe allergic reaction: swelling of your face, lips, mouth, or tongue; trouble breathing; wheezing; dizziness or fainting; fast heartbeat or pounding in your chest; sweating

The most common side effects of HYMPAVZI are injection site reactions, headache, and itching.

These are not all the possible side effects of HYMPAVZI. Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

Please see Important Facts about HYMPAVZI on the next page or at www.HYMPAVZI.com

Pfizer

IMPORTANT FACTS

HYMPAVZI™
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Important information: Before you start using HYMPAVZI, it is very important to talk to your healthcare provider about using factor VIII and factor IX products (products that help blood clot but work in a different way than HYMPAVZI). You may need to use factor VIII or factor IX medicines to treat episodes of breakthrough bleeding during treatment with HYMPAVZI. Carefully follow your healthcare provider's instructions regarding when to use factor VIII or factor IX medicines and the prescribed dose during your treatment with HYMPAVZI.

What is HYMPAVZI used for?

HYMPAVZI is a prescription medicine used to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A without factor VIII inhibitors or hemophilia B without factor IX inhibitors.

It is not known if HYMPAVZI is safe and effective in children younger than 12 years old.

What should I tell my healthcare provider before using HYMPAVZI?

Tell your healthcare provider about all your medical conditions, including if you:

- have a planned surgery. Talk to your healthcare provider about when to stop using HYMPAVZI and when to start it again if you have a planned surgery.
- have a severe short-term (acute) illness such as an infection or injury.
- are pregnant or plan to become pregnant. HYMPAVZI may harm your unborn baby.
  - **Females who are able to become pregnant:**
    - Your healthcare provider will do a pregnancy test before you start your treatment with HYMPAVZI.
    - You should use effective birth control (contraception) during treatment with HYMPAVZI and for 2 months after the last dose of HYMPAVZI.
    - Tell your healthcare provider right away if you become pregnant or think that you may be pregnant during treatment with HYMPAVZI.
- are breastfeeding or plan to breastfeed. It is not known if HYMPAVZI passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements.

How should I use HYMPAVZI?

See the detailed "Instructions for Use" that comes with your HYMPAVZI for information on how to inject a dose of HYMPAVZI, and how to properly throw away (dispose of) used HYMPAVZI prefilled syringe or HYMPAVZI prefilled pen.

- Use HYMPAVZI exactly as prescribed by your healthcare provider.
- Your healthcare provider will provide information on the treatment of breakthrough bleeding during your treatment with HYMPAVZI. **Do not** use HYMPAVZI to treat breakthrough bleeding.

What warnings should I know about HYMPAVZI?

HYMPAVZI may cause serious side effects, including:

- **blood clots (thromboembolic events).** HYMPAVZI may increase the risk for your blood to clot in blood vessels in your arm, leg, lung, or head and can be life-threatening. Get medical help right away if you develop any of these signs or symptoms of blood clots:
  - swelling or pain in arms or legs
  - redness or discoloration in your arms or legs
  - shortness of breath
  - pain in chest or upper back
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing
- **allergic reactions.** Allergic reactions, including rash and itching have happened in people treated with HYMPAVZI. Stop using HYMPAVZI and get medical help right away if you develop any of the following symptoms of a severe allergic reaction:
  - swelling of your face, lips, mouth, or tongue
  - trouble breathing
  - wheezing
  - dizziness or fainting
  - fast heartbeat or pounding in your chest
  - sweating

The most common side effects of HYMPAVZI are injection site reactions, including:

- itching
- swelling
- hardening
- redness
- bruising
- pain

Headache and itching were also common side effects. A serious side effect of swelling in the legs happened in one patient in the clinical trial.

These are not all of the possible side effects of HYMPAVZI. Call your doctor for medical advice about side effects. For more information, ask your doctor.

This information is not comprehensive. How to get more information:

- Talk to your health care provider or pharmacist
- Visit www.HYMPAVZI.com to obtain the FDA-approved product labeling
- Call 1-888-HYMPAV-Z

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.

Pfizer

Pfizer Inc., 66 Hudson Blvd East, New York, NY 10001

ADVISOR'S GUIDE FOR PLANNED GIVING

Gifts from Wills and Trusts

When making a charitable gift to a nonprofit organization, it is vital the legal name of the charity, city, and other identifying details be used. To name the Northern California Bleeding Disorders Foundation (NorCalBDF) in your will or trust, please use the following suggested language:

Residual Bequest Language

A residual bequest comes to us after your estate expenses and specific bequests are paid.

I give and devise to the Northern California Bleeding Disorders Foundation; Tax ID #: 94-1638703, located in Morgan Hill, CA, all (or state a percentage) of the rest, residue and remainder of my estate, both real and personal, to be used for its general support (or for the support of a specific fund or program).

Specific Bequest Language

Naming NorCalBDF as a beneficiary of a specific amount from your estate is easy.

I give and devise to the Northern California Bleeding Disorders Foundation; Tax ID#: 94-1638703 located in Morgan Hill, CA, the sum of $ [amount] (or [asset]) to be used for its general support (or for the support of a specific fund or program).

Contingent Bequest Language

NorCalBDF can be named as a contingent beneficiary in your will or personal trust if one or more of your specific bequests cannot be fulfilled.

If [name] is not living at the time of my demise, I give and devise to the Northern California Bleeding Disorders Foundation Tax ID #:94-1638703, located in Morgan Hill, CA, the sum of $ [amount] (or all or a percentage of the residue of my estate) to be used for its general support (or for the support of a specific fund or program).

Gifts of Appreciated Securities

Please contact us directly for a stock transfer form at contact@norcalbdf.org

New Research Sheds Light on Platelet Dysfunction in Ehlers-Danlos Syndrome

A growing body of research is helping clinicians better understand why many people with Ehlers-Danlos syndrome (EDS) experience frequent bruising, bleeding, and prolonged recovery after injury or surgery. A recent research initiative highlighted by the National Bleeding Disorders Foundation (NBDF) is adding important new insight into the role platelets may play in these bleeding complications.

The project, Platelet Dysfunction in Ehlers-Danlos Patients with Bleeding Phenotype, focuses on investigating how platelet abnormalities may contribute to bleeding symptoms in individuals with EDS. The work is being led by Dr. Mariia Kumskova at the University of Iowa under the mentorship of experts in platelet biology and bleeding disorders.

Understanding EDS and Bleeding

Ehlers-Danlos syndrome is a group of inherited connective tissue disorders that affect collagen and other structural components throughout the body. Common symptoms include joint hypermobility, fragile skin, chronic pain, and tissue fragility. Many individuals with EDS also report significant bleeding symptoms such as:

- Easy bruising
- Frequent nosebleeds
- Heavy menstrual bleeding
- Prolonged bleeding after procedures
- Gum bleeding
- Delayed wound healing

Historically, these symptoms were largely attributed to fragile blood vessels and weakened connective tissue. However, researchers have increasingly suspected that platelet dysfunction may also contribute to the bleeding tendency seen in some patients.

What Are Platelets?

Platelets are tiny blood cells that play a critical role in clotting. When a blood vessel is injured, platelets quickly gather at the site to form a plug and help stop bleeding. If platelets do not function properly, clot formation can be delayed or impaired, leading to excessive bleeding.

Previous studies have suggested that platelet abnormalities may be common in EDS, but the exact mechanisms have remained unclear.

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Key Findings from Recent Research

Recent studies connected to this research project have identified several important platelet-related abnormalities in individuals with EDS. Researchers found that platelets in some EDS patients showed:

- Reduced platelet activation
- Impaired platelet aggregation and spreading
- Decreased expression of important platelet receptors, including GPVI and PAR1
- Defects in integrin αIIbβ3 activation, which is necessary for stable clot formation

These abnormalities may make platelets less effective at responding to injury and forming clots.

Researchers also studied a mouse model of EDS and found similar platelet signaling defects, along with increased bleeding times. These findings strengthen the evidence that platelet dysfunction is likely an important contributor to hemorrhagic complications in EDS.

Why This Research Matters

This research represents an important step toward improving care for people with EDS who experience bleeding symptoms. Better understanding the biological mechanisms behind bleeding can help clinicians:

- Identify patients at higher risk for bleeding complications
- Improve pre-surgical planning and bleeding management
- Develop more targeted therapies
- Expand awareness that bleeding in EDS is not solely due to fragile connective tissue

Investigators have suggested that platelet function testing may eventually become an important tool for evaluating certain EDS patients, especially those preparing for surgery or invasive procedures.

Looking Ahead

Although additional studies are still needed, this work is helping move the field toward more personalized and evidence-based care for individuals living with EDS.

For patients and families affected by EDS, the findings also provide validation that bleeding symptoms are real, measurable, and biologically complex.

As researchers continue exploring the relationship between connective tissue disorders and platelet function, there is growing hope that these discoveries will lead to improved diagnostics, treatment strategies, and quality of life for individuals living with Ehlers-Danlos syndrome.

Sources

- National Bleeding Disorders Foundation (NBDF)
- University of Iowa Hematology Research
- *Blood* Journal: "Platelet defects in patients and mice with Ehlers-Danlos syndrome"
- Journal of Thrombosis and Haemostasis research on hemostatic abnormalities in EDS

Finding Community at SpringFest

by Ramona Jalomo

As a college student living away from home, one of the biggest challenges of managing a bleeding disorder has been learning how to advocate for myself. For most of my life, my mom has been my biggest supporter and advocate, helping me navigate appointments, treatments, and the many unknowns that come with having a bleeding disorder. Being away from her while attending college has been both difficult and, at times, scary.

There were moments when I experienced injuries or struggled through difficult menstrual cycles and felt overwhelmed trying to manage everything on my own.

Without health insurance, accessing the care and medications I needed often felt out of reach, and I wasn't always sure where to turn for help.

That is why SpringFest meant so much to me.

What I found was more than educational sessions and resources—I found a community. Through the conversations I had, the people I met, and the support offered by the Northern California Bleeding Disorders Foundation, I realized I wasn't navigating these challenges alone. Hearing the experiences of others helped me feel understood, while the information shared throughout the conference gave me hope and direction.

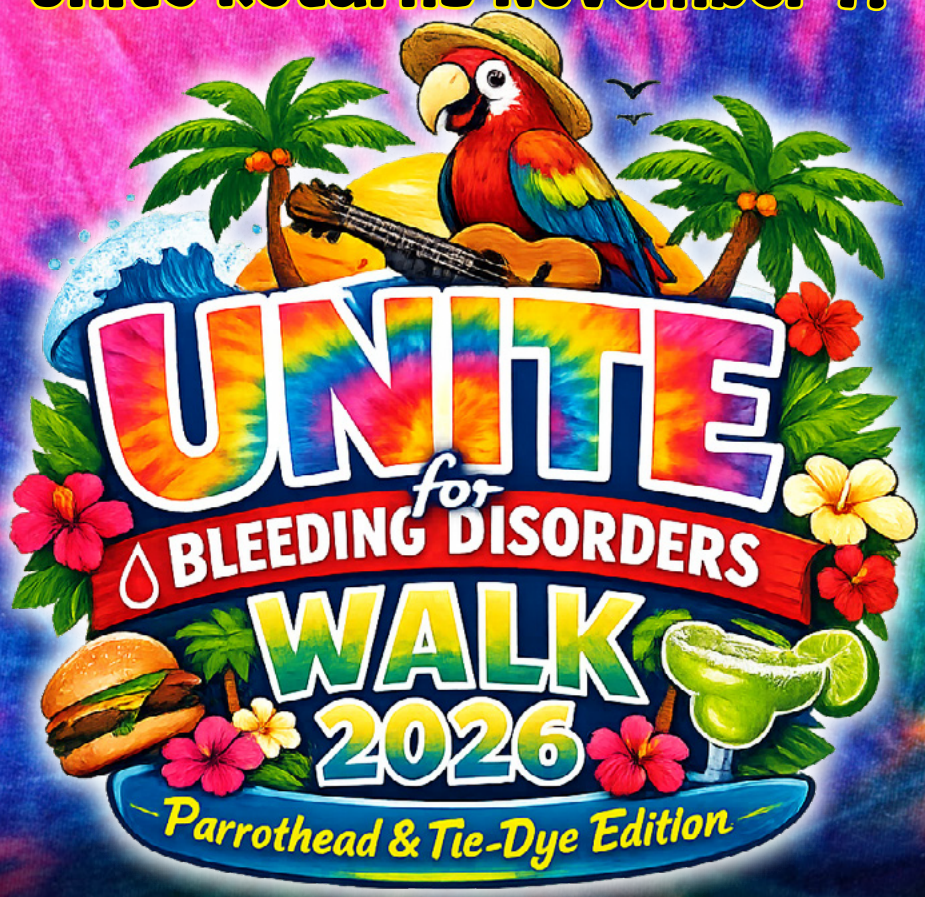
Most importantly, the connections I made through SpringFest helped me begin the process of obtaining health insurance so I can access the care I need and focus on taking care of my health. What once felt overwhelming suddenly felt possible because there were people willing to guide and support me along the way.

I am incredibly grateful to the Northern California Bleeding Disorders Foundation for creating opportunities like SpringFest. The Foundation's commitment to education, advocacy, and community support truly changes lives. As I continue navigating my own health journey, I do so with more confidence, more knowledge, and the reassurance that

I am part of a community that cares.

SpringFest reminded me that while living with a bleeding disorder can sometimes feel isolating, there is strength in connection, and there is always support available when we reach out for it.

Get Ready to Unite: NorCal Unite Returns November 7!



Mark your calendars and dust off your brightest tie-dye NorCal Unite is back and bringing the ultimate Parrothead party to Walnut Creek!

Join us on November 7 at Heather Farm Park, where the day kicks off with registration opening at 8:00 AM. This year's theme is all about laid-back island vibes with a colorful twist: **Tie-Dye Parrothead**. Think sunshine, music, and a whole lot of fun for a great cause.

We're turning up the energy with live music from **Garratt Wilkin & the Parrotheads Trio**, setting the perfect soundtrack for a day of community and celebration. And what's a Parrothead party without great food and drinks?

Enjoy crowd favorites like Cheeseburgers in Paradise, refreshing (virgin) margaritas, and plenty of other tasty treats.

Whether you're coming for the cause, the music, or the margaritas, NorCal Unite is a day you won't want to miss.

Register now and join the fun

Grab your friends, wear your brightest tie-dye, and get ready to unite for an unforgettable day!

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

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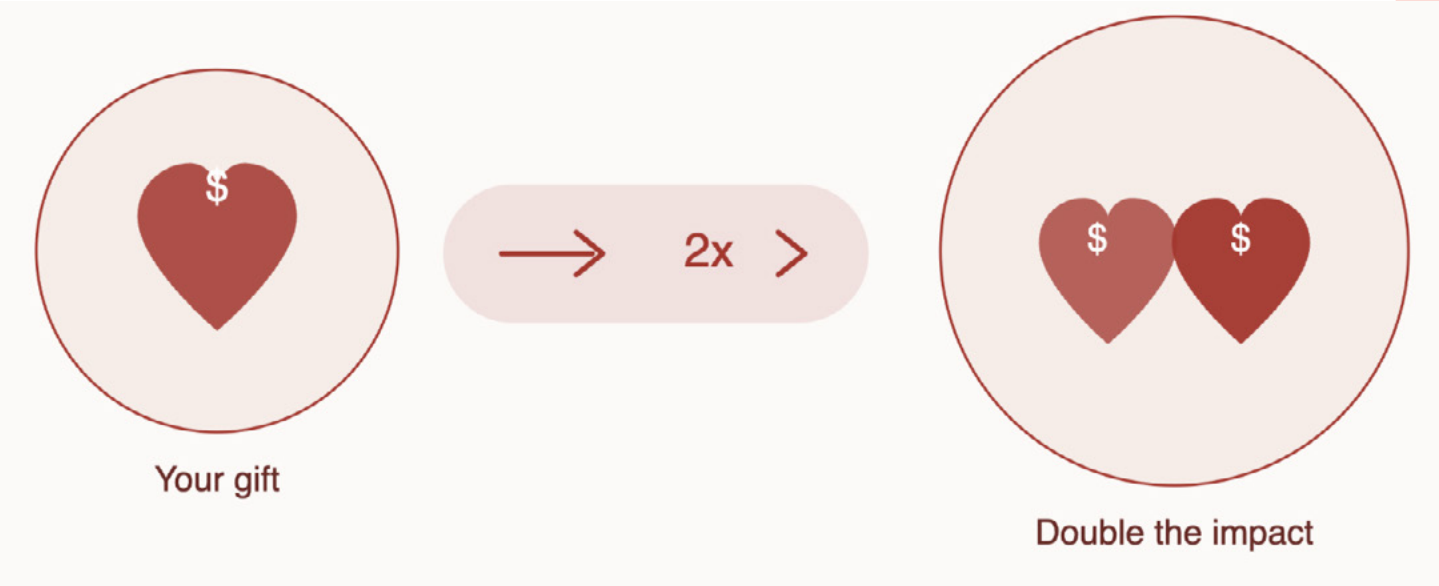
Infuse Your Impact: Unlock Your Employer's Matching Gift for NorCalBDF



Your support of NorCalBDF makes a difference at every level. A gift of any size helps fund camp scholarships, educational programs, The Female Factor, Men's Meet Ups, and community celebrations across our 20-county service area. And if your employer offers a matching gift program, that support could go even further.

Many companies will match their employees' charitable contributions dollar for dollar, sometimes even two to one. A $25 gift becomes $50. A $100 gift becomes $200. That is real money reaching the families and community members who depend on NorCalBDF programs throughout the year.

Getting Started Is Simple

1. Check with your Human Resources department or log in to your company's giving portal. Many employers use platforms like Benevity, YourCause, or CyberGrants.
2. Search for "Northern California Bleeding Disorders Foundation." Our Tax ID is **94-1638703**.
3. Follow the prompts to submit a match request.

If you have already made a gift this year, it is not too late. Many companies accept retroactive match requests within the same calendar year.

We Are Here to Help

Not sure if your employer participates? Give us a call at (510) 658-3324 or send an email to charlette@norcalbdf.org. We will walk you through it.

It takes about five minutes to check, and your generosity could go twice as far for the bleeding disorders community right here in Northern California.

WFH, World Federation of Hemophilia Report

I have been attending the World Federation of Hemophilia Congresses since 1990. I know I am getting close to the congress when I start seeing people limp. That tell-tale "hemo" walk is very distinctive. Their knees don't completely extend due to extensive bleeding to their joints. Some are in wheelchairs, some on crutches, and there are some who have amputations. They have lost these limbs because the treatment for hemophilia is too expensive in their countries and amputation is the preferred solution. These are my people.

Old friends greet me. Some of these people I only see at these congresses every other year, but we have worked on global projects on Zoom now. I have been going to these meetings since 1990. Much has changed. AIDS is no longer a topic as it is now a manageable chronic disease. The challenge today is providing treatment for all. The vast majority of people with hemophilia in the world get no treatment and die very young. The WFH gets donations of medicine and distributes it as humanitarian aid. My work involves collecting data in these countries to help them advocate for better care.

My focus at this congress is to attend sessions on aging, because I am frequently asked to speak on the topic. The move from just survival 30 years to the current era of far better treatment is palpable in much of the world. This has led to a growing over 65 population. Unfortunately, we have less support for aging people in the way of in-person gatherings, since the advent of social media. More are staying home, alone. It is well known that loneliness leads to worse health outcomes. We need to do more.

There is a new focus on identifying frailty. This is a model they have been using in the UK for many years. It is a 9 point scale to determine when folks are more at risk for falling or cognitive decline. It is useful to communicate between the hematologist and the general practitioner.

There was also a session on aging in Women with bleeding disorders. When we talk about women aging with bleeding disorders, it always about heavy menstrual bleeding. There is nothing for women past menopause. They still have joint pain and it's going to get worse.

Some communicated a growing strain between the old boy's club and the new girls that want some resources. I don't think we have that in Northern California, but we all need a platform where young men and young women are sharing stories and those tips and tricks to manage their bleeding disorders together.

One of the exercises they recommended was to write a letter to yourself in the future, documenting what you have done for the world. This will help you prepare for what you need to be in ten years.

Respectfully submitted,

Randy Curtis, President

Kid's Page

...and playful adults!

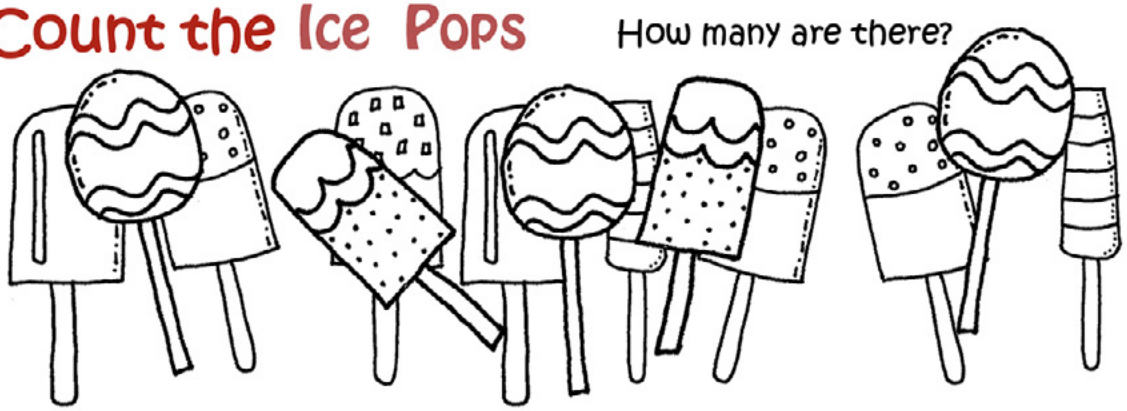
Beach Hunt

h	m	s	p	a	d	e	o	l	r
s	j	g	b	r	a	b	t	c	l
t	s	h	e	p	u	s	r	t	t
r	t	g	a	a	c	w	e	s	e
o	a	m	c	r	u	i	a	f	k
h	o	l	h	r	n	m	s	r	c
s	j	u	p	o	s	e	u	u	u
b	i	k	i	n	i	c	r	s	b
e	l	l	e	h	s	u	n	s	w

spade
swim
beach
bikini
sun
surf
bucket
shorts

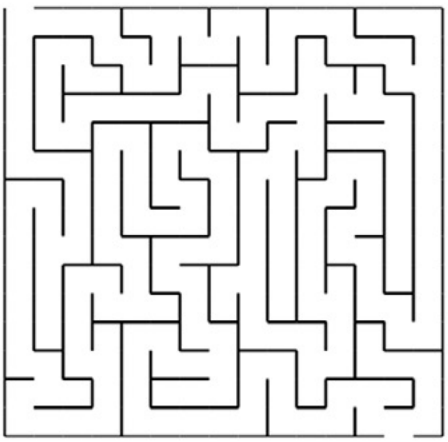
Count the Ice Pops

How many are there?



Beach Maze

Find a way to match the bucket to the spade



CALENDAR

JUNE 2026		
6/5/26	Education and Dinner with Novo Nordisk	San Francisco
6/11/26	Education and Dinner with Hema Biologics	Redwood City
6/14/25-6/20/26	Camp Hemotion	Coarsegold
6/26/26	Education & Dinner with Sanofi	Fresno
JULY 2026		
AUGUST 2026		
8/6/26	Education & Dinner with CSL Behring	Santa Rosa
8/13/26-8/15/26	Bleeding Disorders Conference	Orlando, FL
8/27/26	Education & Dinner with Pfizer	San Jose
SEPTEMBER 2026		
9/4/26-9/6/26	Familia de Sangre	Anaheim
9/26/26	Navigating Care: A Family Summit on Treatment, Advocacy & Support	Santa Rosa
OCTOBER 2026		
10/11/26	Education & Dinner with Bayer	Fresno
10/24/26	Men's Meetup	San Jose
NOVEMBER 2026		
11/7/26	Unite for Bleeding Disorders Walk	Walnut Creek
11/7/26	Education & Lunch with Hema Biologics	Walnut Creek
11/7/26	Education & Lunch with CSL Behring	Walnut Creek
11/19/26	Education & Dinner with CSL Behring	To Be Determined
DECEMBER 2026		
12/5/26	WinterFest	San Jose
12/6/26	WinterFest	Fresno
12/24/26-1/1/27	Holiday Break	NorCalBDF CLOSED
JANUARY 2026		
1/4/27	Resume Business	NorCalBDF OPEN

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

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

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Infusions

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DECEMBER 1

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