

# HEMOHERALD

Unite for Bleeding Disorders Walk 2021 • September 25th • Milwaukee

**DONATE NOW AT GLHF.ORG**

**Thank you** for supporting GLHF through the Unite for Bleeding Disorders Walk! GLHF hosts fundraising events throughout the year to raise dollars and awareness for the bleeding disorders community of Wisconsin. Proceeds from these events directly support programs such as our emergency financial assistance program, Camp Klotty Pine and family camp, state and federal advocacy efforts, scholarships, the Wisconsin Bleeding Disorders Conference and other educational programs. See inside to learn more. Thank you for the impact you are making!

## Let's Talk: Mental Health

In January 2021, GLHF partnered with Believe Limited, Mental Health Matters Too and Mental Health America's Wisconsin Chapter for a special screening of **Let's Talk: Mental Health**.

The 40 minute film took viewers on an immersive journey through the lives of five members of the U.S. bleeding disorders community, as they open their hearts and lives to share their struggles with mental health issues like depression, suicide, social anxiety, addiction, and gang violence.



**ZACH FECHTER**  
Self-Care Bingo Raffle  
Winner and Unite Walker



A live talk back with **Believe Limited's** Co-Founder and CEO, **Patrick James Lynch**, and **Mental Health Matters Too's** Founder, **Debbie de la Riva** followed the screening. Here, participants were able to ask questions and talk openly about mental health with their peers.

This virtual screening kicked off the beginning of GLHF's Mental Health Awareness month. Throughout the month of February, participants completed tasks on their Self-Care Bingo boards by completing physical, mental, social, spiritual and practical acts of self-care.



**BeneFix**  
Coagulation Factor IX (Recombinant)  
Room Temperature Storage

\*BeneFix was approved February 11, 1997.

# EXPERIENCE MATTERS

BeneFix is FDA approved for **once-weekly prophylaxis** (for patients  $\geq 16$  years old) and **on-demand use** to fit your dosing needs—from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.\*

Not actual patients.



**More than 20 years\* of experience**—the first recombinant treatment for individuals with hemophilia B



**Designed with viral safety in mind.** More than 150 quality control tests are done on each batch of BeneFix



**The convenience of the BeneFix Rapid Reconstitution (R2) Kit** with a range of vial sizes



**Ask your doctor about BeneFix dosing** options to meet your needs



## What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

**FOR ONCE-WEEKLY PROPHYLAXIS  
(FOR PATIENTS  $\geq 16$  YEARS OLD)  
AND ON-DEMAND USE**

## Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called “inhibitors,” which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.



R<sub>x</sub> only

### Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit [www.Pfizer.com](http://www.Pfizer.com) or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

### What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

### What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

### How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

### See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

### Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take. Your doctor may need to test your blood from time to time. BeneFix should not be administered by continuous infusion.

### What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

### What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

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

### How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

### What else should I know about BeneFix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-13.0, revised April 2021.





## HOPE IS HEALING

THE HEMOPHILIA OUTREACH CENTER TREATS THE FOLLOWING DIAGNOSES:



We replace worry with confidence, loneliness with support, and anxiety with hope – through comprehensive care and specialized services for people with bleeding disorders, education for doctors and nurses, and support for families.

## COMING TO WAUSAU



For 47 years we have been serving Green Bay, expanding our services to include comprehensive care for patients and support for their families. And we're still growing. Starting in 2021, we'll also be in neighboring Wausau – so no one there has to face their bleeding disorder alone.

## DONT' FIGHT YOUR BLEEDING DISORDER ALONE.



To help you grow in faith in yourself and give you hope for the future, we provide the right resources from comprehensive care to practical support.

## 2021 UNITE WALK TEAMS

#STADLERSTRONG

AMO'S WALKERS

BLOOD BROTHERS AND SISTERS

COUSIN'S CREW

CRAZY GRANDMA INCORPORATED

CSL PLASMA SOUTH MILWAUKEE

EMMETT AND THE PETES

HELENA'S HELLIONS

HEMOPHILIA WARRIORS - WISCONSIN

HOC ROCKS

KEGAN'S CREW COMING THROUGH

MIA'S MINIONS

OCTAPHARMA PLASMA - SE WISCONSIN

RAZIEL'S RED ACES

STEAMPUNK SAFARI

TEAM CCB

TEAM ZACH

TEAM RUMNEY

TEAM VINCENT

THUNDER BUNNIES

WALK ALONG FOR JAX AND SEAN

WOLTRING BOYS



# **Join us at our 2022 Best Bloody Events!!**

**MILWAUKEE'S BEST BLOODY  
ITALIAN COMMUNITY CENTER  
2/20/2022**

**MADISON'S BEST BLOODY  
GARVER FEED MILL  
5/22/2022**

**GREEN BAY'S BEST BLOODY  
LOCATION TBD  
JULY 2022**

**Try Bloodys from amazing local bars and restaurants,  
vote for your favorite and drink for a cause! Proceeds  
from these events help support GLHF's programming  
throughout the year!**



## THANK YOU TO OUR AMAZING LOCAL SPONSORS!

ACCREDITO

PFIZER

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GENENTECH

SANOFI GENZYME

HEMOPHILIA OUTREACH CENTER

TAKEDA

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[UNIVERSITY OF WISCONSIN  
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VERSITI

## SPECIAL THANKS TO:

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## THANK YOU 2021 FACTOR CLUB MEMBERS!

PEOPLE WHO  
INDIVIDUALLY  
RAISED OVER \$500!

DANIELLE LEITNER BAXTER

HELENA BAXTER

LINDA EGGBEEN

TRACIE FECHTER

ZACH FECHTER

SNOW JACOBSON

THOMAS KONOP

AMY LEDEBOER

BEVERLY PETERSON



## THANK YOU 2020 FACTOR CLUB MEMBERS!

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HELENA BAXTER

TRACIE FECHTER

ZACH FECHTER

SNOW JACOBSON



# Congratulations to our 2021 Scholarship Recipients!



**SAMUEL GEBHARDT**

Studying Information Technology  
at UW-Stout

Education Scholarship Recipient



**COLIN ORTH**

Studying Music Performance  
at UW- Stevens Point

Education Scholarship Recipient



**AIDAN NELSON**

Studying Exercise Physiology  
and Physical Therapy

Jacob N. Shanberge Recipient\*

\*This scholarship is a result of the generosity of Dr. Shanberge's family and other donors and was established to assist one student annually who, like Dr. Shanberge, has a passion for science.

SANOFI GENZYME 




## Here for you.

As a CoRe Manager, I'm here to  
be a source of education for you  
and others living with hemophilia.

**Heather Williams**

CoRe Manager for Minnesota,  
Montana, North Dakota, South  
Dakota, Wisconsin, Wyoming

### Let's connect.

608-977-0785  
heather.williams@sanofi.com  
rareblooddisorders.com  
   @HemophiliaCoRes



# We Need Your Help!

## WI State Assembly Bill 184 And Senate Bill 215 Will Protect Patients!

### WISCONSIN PATIENTS RELY ON COPAY ASSISTANCE PROGRAMS TO AFFORD THEIR MEDICATIONS

- ✓ Patients in Wisconsin use copay coupons and vouchers from manufacturers and nonprofits to afford their prescribed medications and manage their health.
- ✓ Many patients who use copay assistance have no generic alternatives available for their treatment.

### NEW POLICIES ALLOW PLANS TO “DOUBLE DIP” & INCREASE PROFITS AT THE EXPENSE OF PATIENTS

- ✓ At least two-thirds of health plans in Wisconsin have policies that do not count the value of copay assistance towards a patient's out-of-pocket cost responsibility.
- ✓ Sometimes referred to as “copay accumulator adjustment programs,” these policies increase patient costs and allow insurers to double their profits at the expense of patients.

### WISCONSIN SENATE BILL 215 WOULD ENSURE COPAY ASSISTANCE COUNTS FOR PATIENTS

- ✓ Assembly Bill 184 and Senate Bill 215 would ensure out-of-pocket payments made by patients – whether directly or on their behalf – are counted toward their annual deductible and/or out-of-pocket maximum for prescription drug benefits..
- ✓ Insurers retain plan design flexibility while ensuring copay assistance counts toward patient out-of-pocket cost responsibilities.

Legislation championed by Sen. André Jacque (SB-215) and Rep. Paul Tittl (AB-184)

**TAKE ACTION!** Stop by the Advocacy Booth at the Unite Walk. In less than 5 minutes you can register for Phone2Action to keep informed about WI advocacy issues and send a quick (cut and paste) email to your State Senator or Representative to let them know this issue matters to the bleeding disorders community!



# sign up for Phone2Action

Stay Informed and Take Action About Current Legislative Issues. Sign up for Phone2Action Today!

**Phone2Action** is a new software system that allows GLHF to connect with you regarding our state advocacy work. It gives us the opportunity to share any immediate action needed on current legislative issues through email and/or text updates. It also creates easy-to-share content for you to use to help educate legislators and friends by sending emails or posting on social media platforms. Learn more.



Sign up today. It's easy and free. Then, as needed, GLHF will send you information and updates that you can personalize and share with your elected officials with just a few keystrokes.

When you sign up you'll receive a free Advocate Pin!



## UPCOMING EVENTS 2021 – 2022

**NOVEMBER 10, 2021**

GENE THERAPY SYMPOSIUM



**FEBRUARY 20, 2022**

MILWAUKEE'S BEST BLOODY



**MAY 22, 2022**

MADISON'S BEST BLOODY



**JUNE 10-12, 2022**

WISCONSIN BLEEDING  
DISORDERS CONFERENCE



**NEW!**

**JULY 2022**

GREEN BAY'S BEST BLOODY



**AUGUST 2022**

CAMP KLOTTY PINE



**SEPTEMBER 24, 2022**

UNITE WALK

# NUWIQ®

Antihemophilic Factor  
(Recombinant)

# wilate®

von Willebrand  
Factor/Coagulation  
Factor VIII Complex  
(Human)



Resources for patients & caregivers, support for those navigating care,  
reliable educational materials, and uplifting community connection.

### *Factor My Way Assistance*

*Free trial, co-pay assistance, and  
real-world insurance know-how  
for eligible patients.*

### *Factor My Way Connection*

*Meet experts and join our online support  
community to help you access resources  
and build relationships.*

### *Factor My Way Events*

*Join scheduled live and on-demand  
digital information programs  
and events.*

### *Factor My Way Learning*

*Learn-as-you-go, practical information  
about bleeding disorders, treatment,  
and lifestyle management.*

 **Join Today!**



**factormyway.com**

**For personalized assistance, contact your local  
Octapharma Representative:**

**Kathy Prince**

Phone | 847.530.1254

E-mail | [kathy.prince@octapharma.com](mailto:kathy.prince@octapharma.com)

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Date of preparation: 2/2021. NUW-0342-CAD

**octapharma**



## CELEBRATION OF *Unity & Strength*

I am so happy to be here with you, the compassionate, caring, members of our wonderful Unite for Bleeding Disorders community. Today we are united in our determination to improve the lives of those we love and hold dear.

A pinwheel catches the wind  
and turns it into movement.  
In the same way, Unite catches  
the energy of people throughout  
the country and turns it into action.

That's why the pinwheel is a  
perfect symbol of our community's  
commitment to support all  
those with bleeding disorders.  
To turn obstacles into opportunity.

Together, we're changing lives.  
Each and every one of you plays a role.

Because of you,  
those we have lost will never be forgotten.

Because of you,  
treatments will be available  
someday to all who need them.

Because of you,  
people will live longer, happier lives.

Because of you,  
people will have more hope  
and hope is beautiful.

All these things will happen  
because you've chosen to say,  
"If not me—who? If not here—where?  
If not now—when?"

So, let's all lift our pinwheels.  
United in our commitment.  
United in our resolve.  
United in our strength.

Now, let's walk. Together, we are the future;  
we are the change. We can make it happen!





## CELEBRATION OF *Unity & Strength*

Estoy muy feliz de estar aquí con ustedes, los compasivos y afectuosos miembros de nuestra maravillosa comunidad, Unite for Bleeding Disorders. Hoy estamos unidos en nuestra determinación de mejorar las vidas de aquellos a quienes apreciamos y amamos.

Un molinillo atrapa el viento y lo convierte en movimiento. De la misma manera, Unite capta la energía de las personas en todo el país y la convierte en acción.

Es por eso que el molinillo es un símbolo perfecto del compromiso de nuestra comunidad de apoyar a todas las personas con trastornos hemorrágicos. Convertir obstáculos en oportunidades.

Juntos, estamos cambiando vidas. Todos y cada uno de ustedes juegan un papel.

Gracias a ti, los que hemos perdido nunca serán olvidados.

Gracias a ti, algún día los tratamientos serán disponibles para todos los que los necesiten.

Gracias a ti, la gente vivirá vidas más largas y felices.

Gracias a ti, la gente tendrá más esperanza y la esperanza es hermosa.

Todas estas cosas sucederán porque has elegido decir: "Si no soy yo, ¿quién? Si no es aquí, ¿dónde? ¿Si no es ahora, cuando?"

Entonces, levantemos todos nuestros molinetes.  
Unidos en nuestro compromiso.  
Unidos en nuestra determinación.  
Unidos en nuestra fuerza.

Ahora, caminemos. Juntos somos el futuro; somos el cambio. ¡Podemos hacerlo realidad!





# Comprehensive Gene Therapy Symposium

Wednesday, November 10 • 6:00 pm - 8:30 pm

Gene therapy to treat bleeding disorders brings new hope but also brings many questions.

- Who will be eligible for treatment?
- Will private insurance or programs like Medicaid or Medicare cover it?
- Will state or federal legislation need to be passed to regulate or monitor?

We will cover these questions and more with patients, healthcare providers, biopharmaceutical companies, and legislators at a virtual seminar focused on Gene Therapy.

Go to **glhf.org** to register now!

## Specialty Pharmacy. Experienced Care.

At Accredo, we understand it can be difficult to live with a chronic or complex illness and subsequent care.

As one of the nation's leading and largest providers of specialty medications, our dedicated therapy teams work diligently to coordinate solutions for the challenges of those living with a bleeding disorder.

With accurate and timely delivery of medication, as well as expert guidance through ongoing therapy directives, you can trust Accredo to provide experienced care.

Contact us for more information.

Patients call: 866.712.5200  
Prescriber offices call: 866.712.5007  
[hemophilia.com](http://hemophilia.com)



# Camp Klotty Pine 2021



“We are incredibly grateful to all of the kids, families, camp staff, HTC staff and GLHF staff who stepped up to make camp safe and as “normal” as possible.”

– Danielle Leitner Baxter, Executive Director





## Message from Camp Director, Karin Koppen



In another unexpected year, Camp Klotty Pine brought campers from across Wisconsin together for a safe and much needed week of camp. Campers were resilient as they faced challenges throughout this past year, but let's be real, it's been hard on all of us. Bringing our camp family back together this year felt extra special. Campers

found a little bit of normalcy around the fire, heading up the alpine tower, or racing across the field in an epic capture the flag game. These moments and connections carry us all through as we dream about next summer and returning to camp.





# What in the World is an LIT?

You've just picked up your camper after a week at Camp Klotty Pine, and somewhere in between the retelling of all the stories and inside jokes they tell you, "When I get older, I want to be an LIT."

## An LIT? Is this ANOTHER acronym from Camp?!

Camp Klotty Pine's Leader-In-Training (LIT) program is a stepping stone for former campers ages 15-18 to move into future camp leadership roles. This three-year comprehensive program focuses on skill building, leadership development and service learning as ways to not only build competent counselors, but ambitious leaders for the future.

During the Camp session, these budding leaders are trained to work alongside their cabin counselors to create a magical camp experience for our campers. They play a hands-on role in behavior management, camp programming, safety, and most importantly fun!

Who better to encourage and support our campers through their first infusion, poke, or time away from home than someone who has been there themselves? As former campers, who also live with bleeding disorders, these individuals know first-hand how transformative and empowering the camp experience can be.



*"I want to show children with bleeding disorders that there is a whole community of support. As a camper, I was able to lean on that support group when I needed to. A family far from home but close to heart. Being an LIT gives me the opportunity to show kids their family far from home."*

- 2021 LIT



*"When I first found out about my disorder I was confused and anxious. Now I look forward to being able to help others understand their disorder and to embrace their differences."*

- 2021 LIT

Want to be a LIT summer 2022? Email [kfrederick@glhg.org](mailto:kfrederick@glhg.org) to get on the mailing list and receive program updates, training dates, application information and deadlines.





## WE'RE IN THIS TOGETHER.

**Sunday 4:07 pm**

Enjoying a game of checkers with his wife

Alan, living with hemophilia A with inhibitors

Not an actual patient

### Let's make today brilliant.

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

 [bleedingdisorders.com](https://bleedingdisorders.com) | 

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Versiti is proud to sponsor the

# Unite for Bleeding Disorders Walk!

This year's event raises awareness and funds to support patients with bleeding disorders.



## CCBD + Pharmacy

More than **3 million** Americans are living with a bleeding or clotting disorder. Every day, Versiti Comprehensive Center for Bleeding Disorders' expert physicians provide unrivaled, complete **care** and **education** for these patients, including a patient-focused **pharmacy** program that helps enhance care at the CCBD.

We're proud of the work we do, and we're grateful to everyone participating in this year's Unite for Bleeding Disorders Walk.



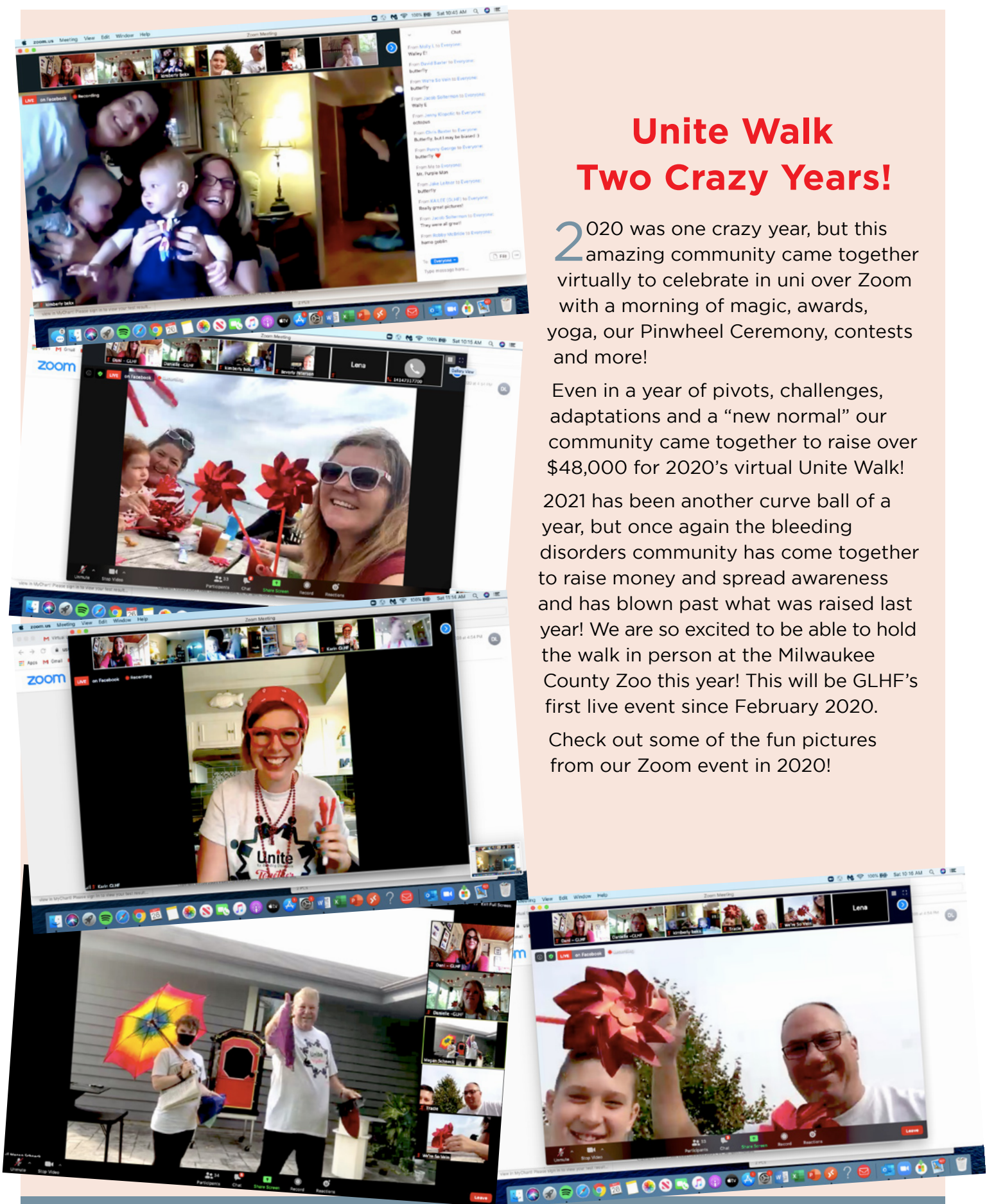
## Unite Walk Two Crazy Years!

2020 was one crazy year, but this amazing community came together virtually to celebrate in uni over Zoom with a morning of magic, awards, yoga, our Pinwheel Ceremony, contests and more!

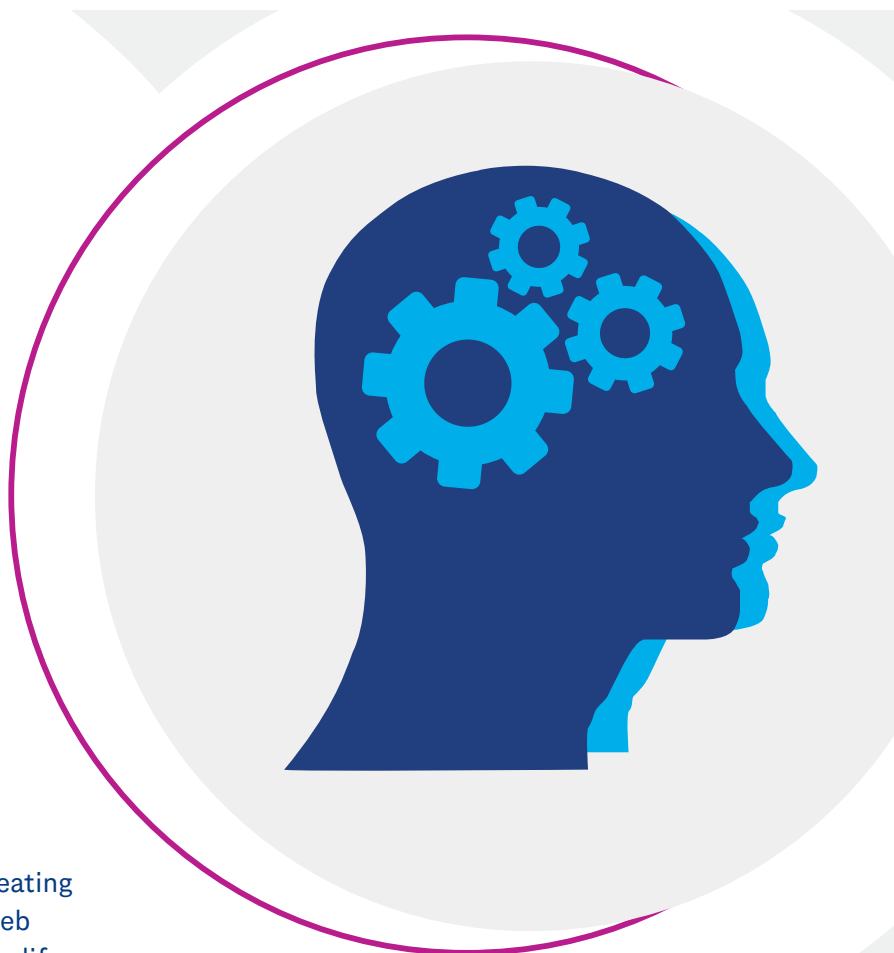
Even in a year of pivots, challenges, adaptations and a “new normal” our community came together to raise over \$48,000 for 2020’s virtual Unite Walk!

2021 has been another curve ball of a year, but once again the bleeding disorders community has come together to raise money and spread awareness and has blown past what was raised last year! We are so excited to be able to hold the walk in person at the Milwaukee County Zoo this year! This will be GLHF’s first live event since February 2020.

Check out some of the fun pictures from our Zoom event in 2020!



# WHAT'S NEXT? YOU DECIDE.



At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)  
TO SEE HOW WE'RE CREATING  
WHAT'S NEXT, TOGETHER.

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**GENENTECH IN  
HEMOPHILIA**

**Genentech**  
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