Camp Warren Jyrch (CWJ) heads back to the YMCA Camp Benson, in Mt. Carroll, Illinois the week of July 31 to August 6. Noelle, John & Taylor – the Camp Planning Team – are working hard to get everything ready including some special “out of this world” events for our first year back.

We talked with one of the returning campers and asked what they are most looking forward to. She said, “I cannot wait for everything – but I think just being with my old friends and meeting new ones. I know I will be tired by light’s out at 10:00, but I still cannot wait to tell scary stories in the dark.”

“I have been going since I was 8 and I am now 13. This is the only time each year that everyone – and I mean everyone has a bleeding disorder. Cont. on Pg. 11
A full list of Illinois HTC’s and their satellite HTC’s can be found at www.bdai.org/hemophiliatreatment

Resources

Mission: The Bleeding Disorders Alliance Illinois exists to improve the quality of life for persons affected by hemophilia and other inherited bleeding disorders.

Contact Information
Bleeding Disorders Alliance Illinois
(312) 427-1495
www.bdai.org
National Hemophilia Foundation
(800) 424-2630
www.hemophilia.org
Hemophilia Federation of America
(800) 230-9797
www.hemophilafed.org

Resource Information
Bleeding Disorders Legal Hotline
(800) 520-6154
Centers for Disease Control & Prevention
(800) 311-3435
www.cdc.gov
Committee of Ten Thousand (COTT)
(800) 488-2688
www.cott1.org
LA Kelley Communications
(978) 821-6197
www.kelleycom.com
Assessia Health
Formerly: Patient Services Incorporated (PSI)
(800) 366-7741
www.uneedpsi.org
World Federation of Hemophilia
(514) 875-7944
www.wfh.org

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nbanales@bdai.org
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mherrera@bdai.org

MISSOURI
The John Bouhasin Center for Children with Bleeding Disorders
Saint Louis Univ. Dept of Pediatrics
Missouri/Illinois Regional Hemophilia Center
1465 South Grand Blvd.
St. Louis, MO 63104
(314) 577-5332

Saint Louis University Center for Bleeding & Thrombotic Disorder Hemophilia Treatment Center, Adult Program
St. Louis University Hospital,
West Pavilion Cancer Center
3635 Vista Avenue at Grand Blvd.
3rd Floor HemOnc
St. Louis, MO 63110-0250
(314) 577-6178

Washington University Center for Bleeding & Blood Clotting Disorders-Adult Program
(HTC 737, Great Plains Region)
660 South Euclid Avenue,
MSC 8125-22-1101
St. Louis, MO 63110
(314) 362-8814

WISCONSIN
University of Wisconsin Hospital and Clinics Comprehensive Program for Bleeding Disorders
5105 University Avenue
Madison, WI 53705
(608) 890-9495

Comprehensive Center for Bleeding Disorders
The Blood Center of Wisconsin
P.O. Box 2178
Milwaukee, WI 53201-2178
(414) 257-2424

Hemophilia Outreach Center
2060 Bellevue Street
Green Bay, WI 54311
(920) 965-0606

The Bleeding Disorders Alliance Illinois
Spring 2022
2
Two years ago, as we began this unknown journey, as serious as the situation was, many of us saw a light at the end of the tunnel. This virus would be controlled, quickly and efficiently returning our world to pre-pandemic days. Now – over two years later – we are increasingly aware of significant, on-going reasons which lead us to adapt and change.

Where do each of us turn to adapt successfully? I often look to the past exploring for learned lessons. Looking at the history of the bleeding disorders community, coming face-to-face with challenges like this pandemic are not new. This community has come together facing significant hurdles with fortitude and strength with an uncanny ability to work together forging ahead to an ever-stronger future.

We did this as an organization Spring 2020. As it became clear that all BDAI programs and services must go to virtual, we all dug in – including many of you – creatively finding the means to support this amazing community – and surprisingly even help it to grow.

Here is an example of that. An analysis of community participation in virtual programming from 2020 and 2021 showed an amazing 51% of all people came from outside the Chicago metropolitan area. We have all worked so hard - for so long – exploring ways to best reach more people throughout all of Illinois. Because of this “awful” situation, becoming more comfortable with technology brought us closer together.

Now – as we move to the next phase – back to in-person with strong COVID guidelines – I challenge us to keep finding even more ways to connect. One thing already in place is that as many activities as we can, will be hybrid – both in-person and virtual. No longer will distance and/or transportation be a barrier to education and community-building programming for people with inherited bleeding disorders in this state. Using your computer, tablet, or phone you will be able to continue to virtually join – from where you are most comfortable - via videoconferencing.

The other important change – is increasingly – BDAI will come to you. We launched the Community Action Network (CAN) – with the goal of creating a network of involved members of this community from throughout the state. Hopefully, you – but if not you – someone near to you – will work with the BDAI staff supporting education, advocacy, and consumer services locally.

We will launch this by travelling throughout the state over the coming months to meet and talk with you over dinner or even a cup of coffee about your life with your bleeding disorder and how we can help more. And – because this organization is yours – we do want your thoughts on how you may be able to get more involved in the community. If you would like to host a gathering in your community, please reach out to me. I am looking for people to help me bring people together.

I do want a couple important asks before I close. First, communication is key, and we have some serious issues with this at the current time. Our Facebook page was hacked last fall causing us to lose all 1,000 followers. Please like our new page – BleedingDisordersIL. Social media continues to be a strong way for us to spread the word about everything.

Second, we updated our database recently and are in the process of refreshing information. Two essential elements we need are your zip code with the +4 extension and email address.

These are key to strengthening supporting you
with our advocacy work. This allows us to also add your Senate and House District into your record – which likely will be vital as we continue to face insurance and access issues.

Finally, and this is personal and from the heart, May was Mental Health Awareness Month. The world is tough right now and living with a chronic bleeding condition can add tremendous stress. If you need help or want someone to talk with, please do not be hesitant to reach out to ask. We have included in this issue of the FactorNet a list of resources. In addition, know that your HTC is there for you and if you need to do not hesitate to reach to me at BDAI. I will do everything in my power to help you get connected to the supports you need.

If I have one wish in closing – it is that we all accept that you do not have to be crazy to go into counseling/therapy. Trust me – if you need it – you will find it amazing to have someone to be a sounding board – someone for just you to talk to confidentially about anything weighing you down. At times, the power of simply saying something out loud in a safe space can be so freeing.

I look forward to seeing and/or talking with many of you over the next few months.

Until then – take care,

Your Executive Director,

Bob Robinson

Relatable Research from NHF

Dr. Annette von Drygalski shared findings from research that may impact you in a recent session of the NHF Research Journal Club.

Did you know research teams have made a potential link between joint disease and high blood pressure? People living with hemophilia who experience joint inflammation have a higher rate of hypertension – the clinical term for high blood pressure. That means they are at higher risk for heart disease, stroke and more. At any age and lifestyle.

Why? When there is a joint bleed, the process in which the body repairs the joint is called vascular joint remodeling. Over time, this process can cause the structures in the vascular system to be less flexible, and they become thicker and stiffer. This can increase the pressure of how blood is delivered throughout the body, causing the system to work harder.

How was this discovered? Dr. von Drygalski and the team of researchers she worked with, found that people with hemophilia and signs of increased vascular joint remodeling, have high blood pressure. The group then studied biomarkers of type IV and type VIII vascular collagen during hemarthrosis – which is bleeding into the joint. They studied thirty adults living with hemophilia during 91 visits using ultrasound to monitor the flow of blood, plasma markers, and collagen markers. They found an increase in vascular biomarkers in the bloodstream during joint bleeding. The researchers feel there may be the possibility of this impacting the entire system of the body, not just the joint. Dr. von Drygalski and her colleagues published these findings in February of 2021.

This new research supports the hope for further exploration on the impact of joint bleeds on long term health.

Cont. Pg 12
SAVE THE DATE
Ultra-Rare Meet-Up Conference

Mark Your Calendars – September 9-11, 2022
Chicago Marriott Southwest at Burr Ridge
1200 Burr Ridge Pkwy, Burr Ridge, IL 60527

* Calling community members living with an Ultra-Rare Bleeding Disorder(s). You and your family/caregivers are invited to participate in this special opportunity to learn more about your disorders and build a stronger peer network.

* This event – while hosted by Bleeding Disorders Alliance Illinois – is open to all people with the conditions listed to the left – no matter where they live in the United States.

* We are looking for up to 50 people to participate.

* Scholarships - including accommodations, food and transportation - will be available for community members and their family/caregivers with these conditions.

For more information, questions or to be added to invite list, please contact:
Bob Robinson, brobinson@bdai.org.

210 S. DesPlaines St.
Chicago, IL 60661-5500
312-427-1495
info@bdai.org
www.bdai.org

Supported by Grants from:

Global Genes
Allies in Rare Disease

Hemophilia Alliance

Broadening Education, Awareness & Community for these Ultra–Rare Bleeding Disorders:

* Factor I Fibrinogen
* Factor II (FII) deficiency, also called Prothrombin Deficiency
* Factor V (FV) Deficiency
* Factor VII (FVII), or Proconvertin Deficiency
* Factor X (FX), or Stuart-Prower Factor Deficiency
* Factor XI (FXI) Deficiency
* Factor XII (FXII), or Hageman Factor Deficiency
* Factor XIII (FXIII), or Fibrin Stabilizing Factor Deficiency
* Alpha-2 Antiplasmin Deficiency
* PAI-1 Deficiency
* Bernard Soulier Syndrome
* Glanzmann Thrombasthenia
* Gray Platelet Syndrome
* Hermansky-Pudlak Syndrome
* Platelet Function Disorder, Hereditary (nonspecific)
* Platelet Release Defect
* Platelet Storage Pool Disease
* Hereditary Thrombocytopenia
* Hereditary Hemorrhagic Telangiectasia
* Ehlers-Danlos Syndromes
Spotlight on Our Community

With each FactorNet newsletter, we will celebrate accomplishments from members of the Illinois bleeding disorders community. Please feel free to share submissions through our Facebook page - BleedingDisordersIL - or group - Community Action Network (CAN).

Amazing doesn’t even begin to describe the group of wonderful Illinois leaders representing the bleeding disorders community at the Building the National Research Blueprint - SME (Subject Matter Expert) Workshop on April 8-9 in Washington, DC. Pictured Left to Right Row 1: Kneeling: Sammie Valadez, Dalia Arreola, Shatara Jenkins Row 2: Noelle Simpson, Ifikar Hadar, Esmeralda Vazquez, Bob Robinson, Dwayne Jenkins Row 3: Nathan Schaefer

The Hemophilia Federation of America Symposium was held in San Antonio in April. Veronica Ruiz, one of the leaders of our Hispanic Alliance, takes a second to share a photo with Lily Schwartz, Associate Director and Shanna Garcia, President of the Board of Directors.

The community came back together for the first Community Connections Weekend in two years. The theme With a Little Help from Our Friends was celebrated with participants taking a picture and adding it to this fun poster. This was a way to do a group photo while still practicing social distancing. Cont. Pg. 7
Xander Mills turned out a star performance this spring as one of the leads in “Disney’s High School Musical” at the Glenbard South HS. Xander is finishing his Junior year, and this was his first time dipping his toe into the performing arts. Here he is after the performance being cheered on by his family and friends.

Congratulations Jasmine Valadez for being the Valedictorian of her graduating class for Hall Hight School Class of 2022. Jasmine will attend University of Illinois in Champaign in the fall where she plans to study business.

Here is Josh Christman opening the Varsity season as a sophomore pitcher for his High School Baseball Team. He and his twin brother, Jacob, started playing baseball as soon as their mother Sara got the “go-ahead” from their HTC. They both have been stars ever since. In fact, they are past CSL Behring Junior National Champions for BDAI. Watch out match leagues!
Our federally funded Hemophilia Treatment Centers (HTCs) has been the proven model of care for the inherited bleeding disorder community since the 1970s. The staff at these centers of excellence – are just that – because their entire focus is on bleeding and clotting disorders. Key to their success is not only the understanding of the conditions but also the relationships developed with our community and families. This article is the first in a series where we will talk with an Illinois HTC team member about some facet of their work.

Recently, we had a conversation with Rachel Bercovitz, MD – the Medical Director of the Lurie’s Children Hospital’s HTC to discuss the steps her team is taking to improve care through communication.

Why communication? There is documented research showing that many healthcare risks are taken when traditional means of communication are not improved and perfected. These scientific studies have shown that refining policies, processes and systems have a direct relationship to reducing medical errors and improving patient safety. With this, increasingly providers are realizing that when technology is used in harmony with provider expertise, provider-patient relationships thrive. By learning and implementing some straightforward techniques and strategies – while it might seem hard at first – once everyone gets used to them – they have been shown to definitely improve the patient experience.

It seems the main area currently needing improvement is when families are in crisis. If you do not know – Lurie’s as the name states – is a children’s hospital – and serves young people from all over the Chicago metropolitan area – and sometimes even further. When a bleeding disorders family has an emergency, it is often best to use a local, community hospital and then reach out for an HTC consultation. Connecting to the HTC Team during this time becomes a critical priority to the family. Dr. Berkovitz has worked with the Lurie’s HTC Team to encourage the use of straightforward technology resources, teach people how to better use hospital resources and include steps to pre-plan for these situations as part of the Comprehensive visit. It is her hope that by focusing on these actions, current and new patients – and their families - will be able reach the treatment team more quickly and efficiently getting the assistance needed promptly.

Thanks to Dr. Berkovitz for sharing these incites with the community on improving communication. Please feel free to share your thoughts and feedback with Dr. Berkovitz at rbercovitz@luriechildrens.org or me at brobinson@bdai.org.

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### 3 Steps to Better Communication

**Step 1: Establish a myChart Account**
MyChart is an application for your smartphone or tablet which puts your health information in the palm of your hand and helps you conveniently manage care for yourself and your family members. It also has a messaging application. This allows you to quickly and easily – not only in an emergency but in any situation – send a direct message to any member of the HTC care team.

**Step 2: Use the Hospital Paging System Effectively**
If and when you call the hospital operator, you are advised to not hold; but to leave a detailed message. And then, stay by your phone for the return call. You will receive a call back. It may take a while as attending physicians are quite busy, but these calls are always returned.

**NOTE:** Dr. Berkovitz shared that data is tracked on all calls. She reported that there is a surprisingly high percentage of returned calls which are not answered by patients.

**Step 3: Always make sure your Bleeding Action Plan (BAP) is in place and up to date.**
This plan is developed with each patient/caregiver and the HTC Team at the Comprehensive Visit. It includes a complete medical picture of the patient and all details for treating the bleeding disorder. It is meant to be a tool to share with other medical teams – including emergency personnel. It is not only important to work closely with your HTC team to ensure the BAP is thorough, but also to review it regularly.
The Spring 2022 session of the 102nd General Assembly was a very productive one, including a number of accomplishments balancing the Illinois State budget, increasing fiscal stability, expanding healthcare access and affordability, investing in major increases in equity, violence prevention, education, and public safety.

Included, are some highlights you may find important.

- HB4238 Creates major expansion of community-based mental health and substance abuse treatment programs. Designed to reduce waitlists, address workforce problem, and add trauma-informed services, all in response to the skyrocketing demands created by COVID..
- HB4264 Funds the Getting to Zero (GTZ) programs which will reduce racial disparities in HIV/AIDS services and care, as well as addressing social determinants of health for people living with HIV/AIDS.
- HB4343 The Equity in Medicaid Omnibus makes numerous changes to increase equity in the Medicaid program, reduces artificial enrollment barriers, and expands coverage. Major items include:
  > Continues 12-month redetermination after the end of the Public Health Emergency maintaining continuity of coverage for individuals and families with frequent monthly income fluctuations
  > Requires HFS to use ex-parte redeterminations for AABD (Aged, Blind, Disabled) populations and persons with zero income whose eligibility is unlikely to change over time instead of making them regularly reapply.
  > Reduces the penalizing and inequitable consequences of Medicaid liens and estate recovery by expanding hardship waivers for families and ending mandatory liens and allowing estate recovery waivers so that families are not forced to impoverish themselves to care for an elder
  > Increases outpatient pediatric psych rates to allow children’s hospitals to expand behavioral health services to meet COVID related demand
  > Requires Medicaid to cover midwifery services
  > Increases Spouse Resource Allowance for the first time in 10 years
  > Expands access to healthcare for undocumented persons to those 42 years old and up
  > Allows for Medicaid coverage of peer support recovery services
  > Expands Medicaid dental coverage to services like preventative, restorative as well as certain surgical procedures
  > Allows coverage of acupuncture

Spreading the Word During Mid-Term Elections:

ACTION ALERT: Mid-term elections take place this fall. Your elected officials will be in their districts – at the same community events you are likely to attend. Make the opportunity to meet them to share your bleeding disorders story. You will only have a few moments – so be ready to capture their attention quickly. If they want to learn more, they may invite you to sit down for a meeting. If this happens or you need any other help with advocacy, telling your story or answering a question which was asked which you didn’t have the answer let us know – we will gladly support you.

https://p2a.co/OmE3UFf
The Bleeding Disorders Alliance Illinois
Spring 2022

> Creates mental health well-being screening program for grades 7-12 in schools
> Increases rates for Medicars

- HB4595 Protects FQHC, Ryan White HIV/AIDS clinics and hemophilia clinic participation in federal 340B discount drug program and puts certain limits on PBMs and insurance companies.
- HB5142 Recent studies indicated over 600,000 Illinoisans who are uninsured but are eligible to be covered by either Medicaid or the Obamacare ACA Marketplace with premium assistance; this puts a check box on tax returns, which when checked will automatically notify filer they are eligible for health insurance at low cost or no cost and directed to the enrollment process. Due to conservative budgeting because of COVID and the uncertain economy, larger than anticipated increases in sales taxes and corporate income taxes, boosted by federal and state COVID relief, resulted in a large one-time surplus during the current fiscal year (2022). These one-time revenues will be expended in numerous ways. Here are the which may benefit you:

> $1.8 billion in tax relief for Illinois families, including direct property tax and income tax rebate checks, grocery tax and gas tax relief, and expansion of the earned income tax credit
> Expanded state Earned Income Tax Credit (EITC) to 20% of federal credit, made people 18-15, 65 and up, and Individual Tax Identification Number (ITIN) filers eligible. Made the credit refundable to expand the number of families eligible for refunds
> One time income tax rebate check. Rebate of $50 per filer and $100 per dependent, up to 3 dependents (Not available to high income households)
> One time property tax rebate check, equal to your property tax credit (on your state income tax form) or $300, whichever is less
> Freeze on sales taxes on groceries for a year (state will reimburse cities and towns for lost revenue)
> Gas tax freeze
> Back-to-School sales tax holiday Aug 5-14

What Each of Us Can Do To Help!

Tell Your Story - We need to hear from you about your difficulties getting your bleeding disorders medication and/or care – or any problems with insurance. Write it down or video it. Either way is great. Send it to BDAI staff for us to use in Advocacy efforts. We need to have these as we talk to elected officials.

Plan a visit with your elected official at their district office. Call the office. Tell them you are a constituent and you would like to schedule an appointment. If you would need help with what to say – give us a call – or we will go with you.

Join us in Springfield or on a Virtual Advocacy Day. Watch for the dates and time to be announced this Spring.

Help us identify a Legislative Champion. Do you already have a relationship with one of our State elected officials. Help us get to know them better.

Volunteer - Become part of the Bleeding Disorders Advocacy Committee to help shape the plan and actions of the community’s efforts to address our advocacy agenda.

You can see the full budget here: [https://ilga.gov/legislation/102/HB/PDF/10200HB0900sam003.pdf](https://ilga.gov/legislation/102/HB/PDF/10200HB0900sam003.pdf)
This information was taken from a report prepared by Representative Greg Harris. If you would like to see the complete report it is available at: [https://www.gregharris.org/wp/2022/04/18/end-of-session-update-budget-summary/](https://www.gregharris.org/wp/2022/04/18/end-of-session-update-budget-summary/)
"It is so great to not be different for at least one week of my life"

We asked what she would tell new campers and their parents. “It is hard for my friends back home to really understand my disorder – But not at Camp Warren. In addition to all the fun and friends, you also learn so much about your bleeding disorder from the other campers and the doctors and nurses from the Medical Cabin.” I learned to self-infuse my first year at camp. I now really like helping to support other campers getting their Self-Infusion Award when they are ready.”

BDAI has been hosting Camp Warren Jyrch since 1973. It has been continually held every summer until the start of the pandemic in 2020. This will be the first year back in person. We are taking every precaution to protect the campers, counselors, and staff. COVID Guidelines will be released shortly on the BDAI website. Also – if you are not yet comfortable attending in person, we will be offering virtual sessions.

Applications are available on our website at www.bdai.org. If you have any questions about the application, the program, are a new camper family and need advice/assistance in making the decision to attend, or any other questions, please reach out to - Noelle at nsimpson@bdai.org!
Relatable Research from NHF - Continued

In the conclusion of her presentation, Dr. von Drygalski encouraged people living with hemophilia of all ages to maintain prophylaxis to avoid joint bleeds. She also recommends you talk to your doctor about the potential for hypertension and the long-term risks. In addition to an active lifestyle and eating healthy for optimal health, it is important to recognize that there may be a need for further intervention to prevent serious health conditions because high blood pressure may be present. This is an important conversation to have with your healthcare team.

If you missed the session, it is available to view on the research section of the NHF website www.hemophilia.org, as well as find the abstracts to the articles reviewed.

For more information, please contact Samantha Carlson, LMSW NHF’s Senior Manager of Research Programs & Partnerships at scarlson@hemophilia.org.

BDAI is your bleeding disorders advocacy organization. You can make an impact on the community in so many ways. Here are just a few ideas:

* Make sure BDAI has your current contact, email and bleeding disorders information.

* Introduce BDAI to a new person or family that you know with a bleeding disorder.

* Consider getting involved in a BDAI activity – like Advocacy, Outreach, Fundraising

  * Share your own ideas with us – Call us today

  * Explore Board leadership – Reach out to the Board

  * Sign up to talk with new families

* Fundraise for BDAI by Creating a UNITE Walk Team or creating a DIY fundraiser
  - or how about asking for gifts to BDAI for your next birthday or anniversary?

  * Create an Awareness Campaign on Bleeding Disorders including BDAI
MARK YOUR CALENDARS FOR THE ILLINOIS UNITE FOR BLEEDING DISORDERS WALK!

WHEN: OCTOBER 1, 2022
WHERE: BROOKFIELD WOODS FOREST PRESERVE
@ 31ST ST. WEST OF 1ST AVE. BROOKFIELD, IL.

The Walk is ON THE MOVE!

United we care.
United we walk.
United we celebrate.

Here is the link/QR code to sign us a Team Captain, Donor or Participant:
bit.ly/3GWO4cr
Our Thanks to You

BDAI gratefully acknowledges our donors who have contributed to the Chapter from December 21, 2021 through May 25, 2022

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<td>Bill &amp; Mary Anne Ax</td>
<td>Veronce Ruiz</td>
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<td>Basil &amp; Isabel Batmani</td>
<td>Joseph Schuch</td>
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<td>Linda Burback</td>
<td>Martha Scott</td>
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<td>Bonita Carlson</td>
<td>Mayra Cantu</td>
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<td>Christine &amp; Anthony Clementi</td>
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<td>Valerie Dumser</td>
<td>Dan Spiroli</td>
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<td>Shari Suchan</td>
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<td>Judy Fexel</td>
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<td>Diane &amp; Joseph Gassiaro</td>
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<td>Darcy Zwieber</td>
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Pharmacokinetics is the study of the activity of drugs in the body over a period of time.
Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at HemDifferently.com.

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BIOMARIN

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THE 5 STEPS OF INVESTIGATIONAL GENE TRANSFER

One method of gene therapy currently being explored in clinical trials is called gene transfer. This approach aims to introduce a working gene into the body to determine if it can produce a needed protein.

**STEP 1**
**CREATING A WORKING GENE**
A working copy of a mutated gene is created in a laboratory.

**STEP 2**
**BUILDING A THERAPEUTIC VECTOR**
A therapeutic vector is used to protect the working gene and serves as a transport vehicle for the gene to enter the body. The therapeutic vector is created from a neutralized virus, meaning no viral genes remain inside.

**STEP 3**
**DELIVERING THE WORKING GENE**
A single, one-time infusion delivers large numbers of therapeutic vectors into the body.

**STEP 4**
**MAKING PROTEINS**
Once in the body, the new working gene is designed to provide instructions for the body to make the protein it needs on its own.

**STEP 5**
**MONITORING AND MANAGING HEALTH**
Clinical trial participants are regularly monitored to better understand the safety of the gene transfer and to evaluate its effect on the body.
At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team
TALK TO YOUR DOCTOR AND SEE IF ADYNOVATE® MAY BE RIGHT FOR YOU.

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No actual patients depicted.


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Rep phone: (314) 325-5080
Rep email: bill.laughlin@optum.com

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COMPREHENSIVE CARE
FOR BLEEDING AND
CLOTTING DISORDERS.

WE TREAT THE WHOLE PERSON,
NOT JUST THEIR SYMPTOMS.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
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<tbody>
<tr>
<td>Hemophilia A &amp; B</td>
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<tr>
<td>von Willebrand Disease</td>
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<td>Platelet Function Disorder</td>
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<tr>
<td>ITP</td>
<td>Idiopathic Thrombocytopenic Purpura</td>
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<td>Clotting Disorders</td>
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<td>Factor Deficiencies</td>
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Dr. Jonathan Roberts
Associate Medical Director/
Associate Research Director

Dr. Michael Tarantino
Chief Executive Officer/
Chief Medical Officer

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INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?
HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?
HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots. These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.
Medication Guide
HEMLIBRA® (hem-lob-rah-bruh)
(emolzubumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?
HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider’s instructions regarding when to use an on-demand bypassing agent or factor VIII (FVII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC or FEIBA), including:

- Thrombotic microangiopathy (TMA). This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms of TMA during treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - decreased urination

- Blood clots (thrombosis events). Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms and legs
  - cough up blood
  - pain or numbness in your arm or leg
  - headache
  - shortness of breath
  - chest pain or tightness
  - fast heart rate

If aPCC (FEIBA) is needed, talk to your healthcare provider in case you feel you need more than 100 units (U) of aPCC (FEIBA) total.

Your body may make antibodies against HEMLIBRA, which may slow down how HEMLIBRA works properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (e.g., increase in bleeds). See "What is HEMLIBRA?" for more information about side effects.

What is HEMLIBRA?
HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages 16 and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- Are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control during treatment with HEMLIBRA.
- Are breastfeeding. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all of the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?
See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- Stop (discontinue) prophylactic use of bypassing agents and factor VIII before starting HEMLIBRA prophylaxis.
- You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first 4 weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule.
- Do not give two doses on the same day to make up for a missed dose.

HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?
See "What is the most important information I should know about HEMLIBRA?"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1234.

How should I store HEMLIBRA?
Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
Store HEMLIBRA in the original carton to protect the vials from light.

Do not shake HEMLIBRA.
If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 84°F (29°C).

After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.

Throw away (dispose of) any unused HEMLIBRA left in the vial.
Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?
Active ingredients: emolzubumab-kxwh
Inactive ingredients: L-arginine, L-histidine, poloxamer 100, and Lactic acid

Manufactured by Genentech, Inc., a Member of the Roche Group
1000 E. Middlefield Road, South San Francisco, CA 94080
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HEMLIBRA is a registered trademark of Genentech, Inc. (Japan) Co., Ltd., Tokyo, Japan. ©2021 Genentech, Inc. All rights reserved. For more information, go to www.EMIBRA.com or call 1-800-HEMLIBRA. This Medication Guide has been approved by the U.S. Food and Drug Administration Revised: 12/2021

A Member of the Biotech Group
Our center provides comprehensive care for children, adolescents and adults with bleeding problems and blood clots.

We believe in family-centered care. That means you and your family are integral members of the care team and are included in planning every aspect of you or your child’s care.

Our multidisciplinary center offers the following services:

- Comprehensive hemophilia clinic
- Thrombosis clinic
- Girls’ and women’s bleeding disorders clinic
- Von Willebrand disease clinic
- Hemostatic evaluation of infertility and pregnancy complications
- Full-service pharmacy, including 340b discount drug pricing
- Clinical trials that are looking at novel ways to treat bleeding disorders

Rush University System for Health

Hemophilia and Thrombophilia Center

Our physicians

Lisa Boggio, MD
Mindy Simpson, MD

Rush University Children's Hospital
1725 W. Harrison St., Suite 710
Chicago, IL 60612

Rush Copley Medical Center
2040 Ogden Ave., Suite 303
Aurora, IL 60504

Ashton Center for Day Surgery
1800 McDonough Rd., Suite 203
Hoffman Estates, IL 60192

To make an appointment, please call (312) 942-3034.

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As a Community Relations and Education Manager for Sanofi, I’m here to help provide support and resources for you and the Illinois community.

Kyrle Smith
CoRe Manager for Missouir, Iowa & Illinois

Let’s connect.
Call, text, video chat: 816-986-8382
Email: kyrle.smith@sanofi.com
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www.rareblooddisorders.com

The Bleeding Disorders Alliance Illinois
Spring 2022
1970
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1997
First rFIX products approved by FDA

1999
First gene therapy trial in hem B underway

2018
Late-stage trials for gene therapy in hem B underway

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## BDAI Community - Upcoming Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>7/31 - 8/6/22</td>
<td>Camp Warren Jyrch</td>
<td>Camp Benson - Mt. Carroll, IL</td>
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<tr>
<td>8/29/2022</td>
<td>BDAI Annual Meeting &amp; Awards Dinner</td>
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<tr>
<td>9/9 - 9/11/22</td>
<td>Ultra-Rare Meet-Up Conference</td>
<td>Chicago Marriott Southwest</td>
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<td>Burr Ridge, IL</td>
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<td>10/1/2022</td>
<td>UNITE Walk</td>
<td>Brookfield Woods, Brookfield, IL</td>
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<tr>
<td>10/8/2022</td>
<td>Consumer Insurance Conference</td>
<td>Crowne Plaza Chicago SW,</td>
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<td>10/21/2022</td>
<td>Wine Dinner &amp; Auction</td>
<td>Columbia Yacht Club, Chicago, IL</td>
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<td>Tinsel &amp; Tidings Auction Cocktail Fundraiser</td>
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<tr>
<td>12/3/2022</td>
<td>Annual Holiday Party</td>
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We continue to monitor the ever-changing situation regarding the Coronavirus (COVID-19) pandemic and what it means for our community. The best way to stay informed is through our website and E-mail list.

To update your contact information and subscribe to our E-mail list please email info@bdai.org with your current contact information and the subject line “SUBSCRIBE”

For more information, visit www.BDAI.org.