



The Linking Factor

Volume 2 October 2023



In a preliminary victory for consumers, a federal judge in the District of Columbia set aside federal regulations that disadvantage people who rely on copay assistance to afford their medications. The ruling is welcome news for patient groups that have long opposed copay accumulator adjuster programs (CAAPs): health plan strategies that prevent copay assistance from counting towards consumer cost-sharing obligations.

The ruling comes in a lawsuit filed by the HIV and Hepatitis Policy Institute and two diabetes groups against the U.S. Department of Health and Human Services (HHS). Plaintiffs challenged HHS's 2021 rule that allowed health plans to implement CAAPs. The 2021 rule, plaintiffs alleged, was internally inconsistent and conflicted with existing federal statutes and regulations. HFA and other patient advocates, led by the Aimed Alliance, filed a brief supporting the plaintiffs' position.

In the Sept. 29 ruling, the court accepted plaintiffs' argument that HHS's regulation relied on two contradictory and unsupported interpretations of the term "cost-sharing." Because governing precedent holds that "it is not for the court to choose between competing meanings" of an ambiguous term, the court instead vacated the 2021 rule and remanded it to HHS for the agency to reconsider its interpretation of the relevant language. As a result, the full impact of this decision may not be known until Centers for Medicare and Medicaid Services (CMS) completes these revisions, but this is a substantial step in the right direction.



*Shared with permission from the Hemophilia Federation of America. Originally published in the *Washington Wire*, an online newsletter.

Now Available -

NEW TOOLS FOR YOUR BLEEDING DISORDERS TOOLBOX



When sending your child with a bleeding disorder to school, you may have a few questions.

The Utah Hemophilia Foundation would like to help you answer these questions with the

The School Tool

A collection of of bleeding disorders resources created for both parents and teachers to help:

- Explain bleeding disorders to school staff.
- Introduce your child to their teacher.
- Work with the school to create an Individual Health Plan (IHP) and Section 504 Plan.
- Answer frequently asked questions and dispel myths about bleeding disorders.
- Prevent bullying.

AND MUCH MORE....

The UHF gratefully acknowledges the contributions made by the Utah Center for Bleeding & Clotting Disorders and The Utah Parent Center in the creation of the SCHOOL TOOL; and funding provided by PFIZER, which made it possible.





NEW! Menstrual Tracking Toolkit

Hemophilia Federation of America is proud to provide digital and printable tracking tools for women, girls, people with the potential to menstruate, people with bleeding disorders and those who have not yet been diagnosed. The thoughtfully-prepared tools help you record your bleeding experience to improve awareness and conversations with providers.

What You'll Find:

- Digital and printable logs to track menstrual bleeding.
- Two types of logs—measure by volume loss or by the Pictorial Blood Assessment Chart (PBAC), which tracks the number of products used.
- Education for both patients and providers to improve the conversation with your providers.
- Videos, downloads and additional resources created especially for females.
- Link to HFA's Learning Central course for females.



Learn more and download logs

Scan to find the NEW Menstrual Tracking Toolkit. Download the logs to begin tracking by volume or by PBAC. Track your menstrual bleeding and download more logs whenever you need them.

Learn More About HFA's Blood Sisterhood

HFA is proud to offer Blood Sisterhood, a national program to educate and support females* with bleeding symptoms, a diagnosed bleeding disorder, who are seeking a diagnosis or who are carriers of a bleeding disorder gene. To stay connected and engaged, HFA offers SisterSpace, monthly virtual chat especially for females, as well as webinars and sessions for females at our annual Symposium.



Scan to learn more about Blood Sisterhood and to join the SisterSpace monthly chat.

*also available to transgender and non-binary community members

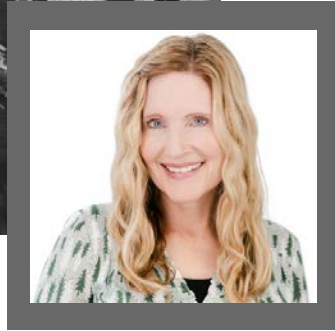
We're Listening



At Pfizer Hemophilia, we have always been deeply committed to listening to what you have to say. Our programs and resources are all designed in response to the needs of the hemophilia community.

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

—Your Pfizer Hemophilia Team



Board Update

By: Kari Woolf,
Board President



Dear Friends -

I had the chance to make a quick stop into the FAB Women's Conference last month, and let me tell you...was it ever worth the trip! There's something so powerful when women come together to support one another and tell their stories. Maybe I'm particularly sensitive to women's issues because my first grandchild (the oldest daughter of an oldest daughter of an oldest daughter of an oldest daughter...see a pattern here?) was born that very morning.

I recently saw a post that said, "The circles of women around us weave invisible nets of love that carry us when we are weak and sing with us when we are strong." I feel that so strongly when it comes to our community—and not just with the women, but with each one of you. It's such an honor to bear witness to what this community has and continues to experience: the heartache, the joy, the pain, the triumphs—it's all part of the experience, and we bear it best together.

Speaking of honors, I wanted to say a heartfelt thank you to everyone who supported our golf tournament in any way. It was wonderful to see so many golfers supporting our cause, and there was more connection to why we do what we do at this year's event. I particularly want to give a shout out to all the campers who decorated and wrote their names on golf balls for the players to use. They were so touched to take a piece of y'all with them onto the course.

And lastly, we've so enjoyed having the amazing Jean McFarlane serving on our board for the past few years. She is moving on to new pursuits, and we wish her all the best!

Warmly,

Kari Woolf



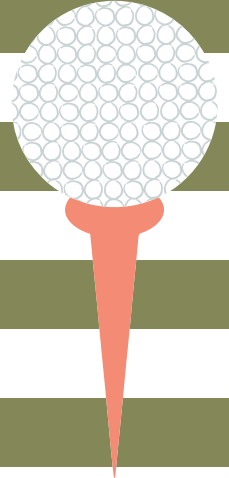
"FORE" a Good Cause Golf Tournament 2023



Golf Pro, Ben Tuaone, shared his talents with our golfers which helped the UHF raise money.



Thirty-three foursomes joined us on the beautiful golf course at Jeremy Ranch.



Board members (L-R) Krisdee Nelson, Becky Ybarra, & Bonnie Webb help out on the course.



Cory Cooper with Farmer's Insurance, (L) and David & Dale Ohlson, with Adcentives West (below), were recognized by the UHF for more than 20 years of tournament sponsorship. Each company was presented an original piece of artwork, created by our Camp Valor campers.



We are grateful for the tremendous generosity of all involved with this year's golf tournament. **The UHF raised \$98,000**, which will go a long way in providing much needed programs and services for Utahns with bleeding disorders.

A shout out of appreciation and heart-felt thanks to all the volunteers and sponsors that made everything run so smoothly. It is their generosity and incredible support that made this day such a HUGE success!

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CSL Behring
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Eagle Sponsors



Bear River Veterinary
Cory Cooper/Farmers Ins.
Julie & Ross Mertlich
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Becky & Doug Ybarra

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Explore Head-to-Head Pharmacokinetic (PK) Study Data

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Antihemophilic Factor (Recombinant)

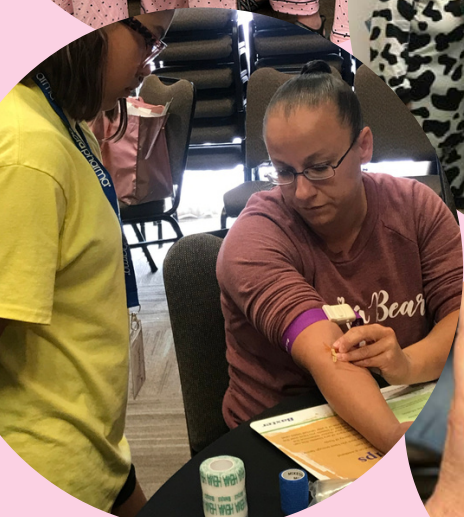
WE ARE
FAB



The Females & Bleeding Conference Was A....

FABulously

GOOD TIME!



*Our FABulous group of ladies
at the 2023 Females & Bleeding Conference*

We kicked off the FAB Conference with a pajama party and pampering and kept the fun going all weekend long.

With incredible presentations by Amber Federizo, DNP, APRN, FNP-BC, on the unique issues faced by women with bleeding disorders and fun crafts led by Sara Ceresa; all who attended enjoyed laughter, learning, and an abundance of shared experiences. Teens, also, enjoyed some fun & delicious activities, including an Easy Bake Oven cook-off.

A HUGE shoutout to **Octapharma** for their sponsorship, which made it all possible.

octapharma



Camp Valor 2023

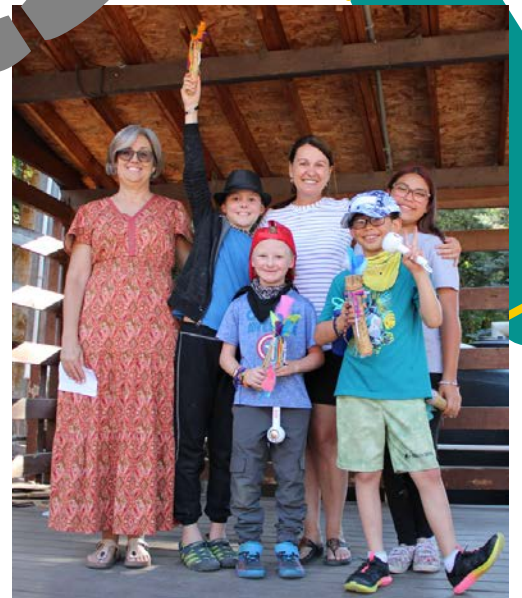
Was it Col. Mustard in the ballroom with the candlestick?

That's the conundrum that 35 campers were trying to resolve during Camp Valor. It was a week of sleuthing and investigating; that featured games, puzzles, riddles, and mysteries of all sorts. Oh, and don't forget the most important part - learning how to solve the "mysteries" of living with a bleeding disorder.

Let's see if you can deduce from these photo "clues" as to how much fun we had. We're sure you won't need Sherlock Holmes to help you solve this mystery!



A few of our AMAZING camp volunteers



Camp Valor 2023
BIG STICK Award Recipients



The "after photo" from the Camp Valor chalk war.



Games, outdoor recreational activities, learning to infuse, educational sessions on managing bleeding disorders, delicious food, INCREDIBLE VOLUNTEERS - it was all part of Camp Valor 2023. **Thank you Bayer, CSL Behring, CVSHealth, Novo Nordisk, and the Utah Center for Bleeding & Clotting Disorders**, for your financial support of camp.

Hangin

with TEENS

Jul 14-16



How many teens in the bleeding disorders community does it take to have fun at the UHF Teen Retreat?

This year, the answer was 17!

On a warm and sunny weekend, last July, our teens (ages 13-19) gathered for fun and information, geared with their specific needs in mind.

The weekend was filled with interactive presentations about bleeding disorders, games, activities, and a lot of laughter. Teen counselor (and fellow member of the BD community) Mark Spalding, and Penni Smith and Angela Kouri from the HTC, led discussions on positive mental health, improving relationships, and transitioning into adulthood. The favorite activity, by far, was beating the heat at Cowabunga Bay.



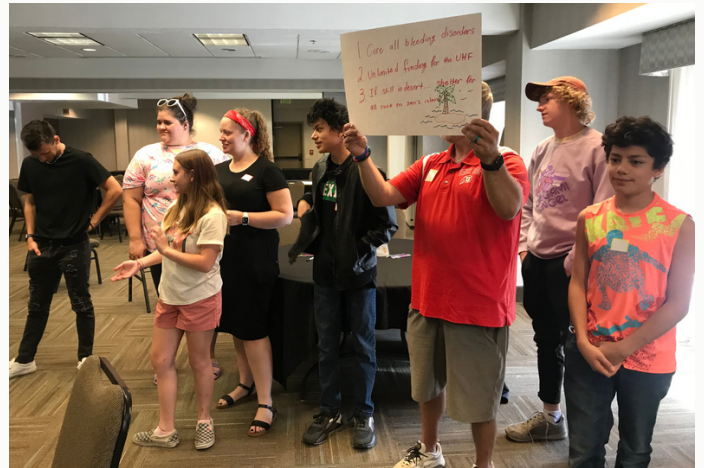
Cooling off at Cowabunga Bay



Walking up to the Wendy's drive-through for a Teen Retreat late night snack,



We can't wait until we can get together, again! **Watch for more information about upcoming teen activities.**



Interactive presentations by phenomenal presenters led to some great discussions about the challenges and celebrations of living with a bleeding disorder.

This weekend would not have been possible without the help of our amazing chaperones and these sponsors:

**CSL Behring CVSHealth Novo Nordisk
Utah Center for Bleeding & Clotting Disorders**

FACTOR UP with ALTUVIIIIO™

ALTUVIIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-eh1

Paid Advertisement

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week



HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).^{*†}

48

HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,[†] ALTUVIIIIO offered adults the longest half-life of any Factor VIII therapy.

0.7

BLEEDS PER YEAR[‡]

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[†]

In people taking ALTUVIIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

^{*}Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

[†]159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

[‡]Data based on treated bleeds.

CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIIO, living with hemophilia, and treatment options from your local CoRe.



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INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-eh1] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full [Prescribing Information](#).

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MAT-US-2301368-v1.0-03/2023

Let's Celebrate!

FAMILY FEST AND RESOURCE FAIR

*Enjoy bleeding disorders information, games, and
all sorts of fun for the entire family.
Lunch and a ticket to the aquarium is included.*

Saturday, November 11, 2023

10:00 am

Loveland Living Planet Aquarium

12033 Lone Peak Drive, Draper

RSVP BELOW





Angel Tree

Holiday Assistance

Thank you to our friends at  **Cementation**

Is your family experiencing financial stress? Are you concerned with being able to provide gifts for your children this holiday season? The UHF and our good friends at Cementation want to help.

For the eighth year, the UHF is partnering with Cementation to provide toys and gifts to Utah children with bleeding disorders, ages 18 years and younger.

If your family would like to be considered for our Angel Tree program, please click on the link below and fill out the application. **All applications must be submitted to the UHF by Friday, November 10.**

Please note, recipient families will need to be able to pick up gifts at the UHF office on December 20 or 21. Unfortunately, the UHF will not be able to mail or deliver gifts.

If you have any questions or need more information, please contact Jan Western at the UHF office.



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