



Kicking off the year with the Teen Winter Weekend, February 9-10, 2024

# The Linking Factor

UHF Quarterly Newsletter

### In this newsletter:

Legislative Update

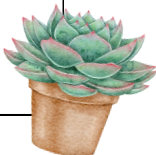
Save the Date: Upcoming Activities

UHF Scholarship Information

News from the HTC

A Message from the UHF Board President

2024: We're Off to a Great Start



Spring Forward:

## A Great Season of UHF Events Awaits



What is Spring's favorite type of pickles? **Daffo-Dills**

We are not **"pollen"** your leg! The UHF invites you to **"spring"** into some great activities. We have an upcoming celebration (World Hemophilia Day) and an activity for teens to teach friends about bleeding disorders (Escape Room). Last **"bud"** not least, adults - **"leaf"** your kids at home and get away from it all (the Adult Retreat). We promise - these fabulous activities will not **"succ!"** For all the details, visit [www.hemophiliautah.org](http://www.hemophiliautah.org).

# Legislative Update

Even though the new year is only a few months old, the Utah Hemophilia Foundation has already been involved with several legislative initiatives, which impact the bleeding disorders community. Here are the latest details on the issues that affect you.

## UHF Impact on National Issues

- The UHF, along with 21 other health organizations, submitted a joint letter to Sen. Mitt Romney, encouraging his support in reforming the practices of pharmacy benefit managers (PBMs) and improvements to the Drug Act. The UHF, also, met with legislative aids to Sen. Romney, Rep. Burgess Owens, Rep. John Curtis, and Rep. Blake Moore, to discuss the critical nature of PBM reform.
- Jan Western, director of the UHF, submitted comments to the National Institute of Standards and Technology opposing government march-in rights for drug research and development. To read a copy of these comments, please visit the UHF Facebook page.



## 2024 Utah Legislative Session

For the second year, Senator Curtis Bramble and the Utah All Co-Pays Count Coalition (UACCC) worked tirelessly on legislation to prohibit insurance plan co-pay accumulators. Unfortunately, the Utah insurance lobby is a powerful force. Despite his best efforts, Senator Bramble could not agree with insurance representatives on bill language that would affect real change for Utahns with chronic illnesses paying for expensive medications. Hence, SB 152: Cost Sharing Amendment Substitute, did not move forward.

The UACCC will continue to work together to apply pressure on the Utah Department of Insurance to implement the US District Court decision that copay accumulator programs are invalid. Click the button below for further background information on this issue.

## The UHF Advocacy Committee Needs YOU!

Would you like to influence issues that affect the bleeding disorders community? Share your voice and join the UHF Advocacy Committee. Members will meet quarterly to discuss how we can address the challenges of living with a bleeding disorder and affect change. Please contact Jan Western at the UHF office, for more details. Famed anthropologist, Margaret Mead, said, *“A small group of thoughtful people could change the world. Indeed, it's the only thing that ever has.”*





*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



**RSUP TODAY**  
to attend these  
great events...

## ***World Hemophilia Day***

**Celebrate with us on Wednesday, April 17**

*Gardener Village, 1100 West 7800 South, WJ 6:00 pm*

A fabulously fun event for the entire family. Come and let us celebrate YOU! Enjoy making a personal time capsule, selfie stations, wish ribbons for the global community, and space to share your story and voice. This event is for the ENTIRE bleeding disorders community. Plus you can enjoy the seasonal festivity of Gardner Village. Dinner is included.

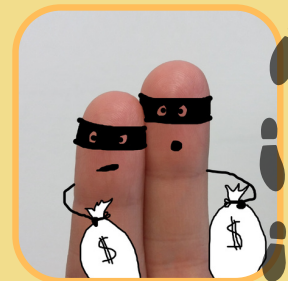


## **TEEN ESCAPE ROOM**

**Saturday, April 20 11:30 am**  
**Get Out Games, 202 West 400 South, SLC**



Teens in the bleeding disorders community, ages 13-19, are invited. You may bring one friend with you that would like to learn more about bleeding disorders. We'll have fun working together to escape the "Big Heist" and enjoy a delicious lunch.



**RSVP by  
April 10**

## ***UHF Adult Retreat***



**Friday, April 26 -  
Saturday, April 27**

**@ Hilton Garden Inn  
762 W. Heritage Park Blvd.  
Layton, UT**

For members of the bleeding disorders community, ages 18 and older.

The Adult Retreat is the PERFECT time to connect with other adults in Utah's bleeding disorders community and learn from one another's experiences. You will, also, learn about new products and services from Industry representatives. Interactive presentations will focus on the power and importance of strong communication in your relationships. Infusion instruction will be available for all who want to learn. Your overnight lodging room, meals, and all supplies are included with your registration.





# President's Message

By: Kari Woolf,  
Board President



## *Hello, UHF Community!*

Your board of directors is honored to serve you and excited about our upcoming plans. In addition to all the amazing programs the UHF traditionally offers, we're bringing back our scholarship program this year. Thanks to your help with fundraising efforts—and wise stewardship of those funds—we were able to allocate money to help students pursue their educational goals. Eligible candidates are those directly affected by a bleeding disorder, parents of a child with a bleeding disorder, or carriers. If you're interested, please see the application materials Jan Western recently sent out via email.

The other topic we've been discussing lately is mental health. This feels very relevant for humanity at large right now, but particularly so for the bleeding disorders community. While we're not mental health professionals—and don't even pretend to play them on TV—we are thinking about ways to support mental health in simple ways at our events...and bringing people together to talk about their challenges and triumphs. Being open with others who can understand what we experience is one of the most powerful ways we can support each other.

Finally, we're so excited to welcome three new board members into our fold this month:

***Tabitha Allred***, who works in community health engagement, is pursuing her Master's Degree in public health, and will bring her first-hand perspective on von Willebrand Disease.

***Angela Kouri***, who is a physical therapist at the pediatric clinic. She is interested in legislative advocacy, mental health for our community, and representing kids.

***Ron Webb***, a retired military and teaching professional who has a strong connection with our camp program, thanks to his daughter, our very own Becky Ybarra.

We're thrilled to welcome these three incredible voices onto our board and look forward to giving you a chance to meet them at upcoming events.

Warmly,

*Kari Woolf*



2024

# SCHOLARSHIP PROGRAM

The Utah Hemophilia is pleased to offer a limited number of scholarships for the 2024-25 academic year. These scholarships are available to members of Utah's bleeding disorders community, including those who have a diagnosed bleeding disorder, are a carrier, and/or a parent of a child with a bleeding disorder.

Scholarships will range from \$500 to \$1,500 and are intended for post-high school education and training. All awarded scholarship funds must be used before December 31, 2024.

For further eligibility requirements and to access to the scholarship application, please click on the link below. **All scholarship applications and requested documentation are due May 31, 2024.**

**QUESTIONS? PLEASE CONTACT JAN WESTERN:**



[western@hemophiliautah.org](mailto:western@hemophiliautah.org)



801-484-0325





# FACTOR UP with ALTUVIIIIO™

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

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.



Jessica Steed  
jessica.steed@sanofi.com  
602-321-0372  
Serving AZ, CO, and UT

## INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehf] 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](#).

sanofi

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



## New Hematology Clinic in Lehi

The Utah Center for Bleeding & Clotting Disorders is excited to announce the opening of the Outpatient Center at Primary Children's – Lehi Campus, 2250 N Miller Campus Drive in Lehi. Now, families can choose to visit their bleeding disorders health care team at the location that is most convenient for YOU!

**Appointments for the new Lehi Clinic can be made by calling 801-662-4000** (the same number for making appointments at the SLC clinic). Annual comprehensive visits at the Lehi location will be held the third Wednesday of odd numbered months. General hematology and “bleed” clinic visits will be held weekly, every Wednesday and Thursday.



**W E L C O M E**

**Alicia May, DPT**

*Joining the team at the  
Utah Center for Bleeding and Clotting  
Disorders @ University of Utah Health*

Alicia was born and raised in Sandy, Utah, She obtained her undergraduate degree from Westminster College, where she, also, played four years of collegiate soccer. In 2021, she graduated from Pacific University as a Doctor of Physical Therapy.

For the past several years, Alicia has been working as an acute care PT, with a strong interest in project management and continuous improvement within the organizational setting. She is thrilled to work with the UBCD team and looks forward to providing excellent patient care to the bleeding disorders community. **WELCOME ALICIA!**





# SELF-INFUSION AND PIV BOOT CAMP

Patients and Families

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**MAY 7, 14, 21, 2024 | 6:00 PM**

UTAH PARENT CENTER LOCATED @  
5296 COMMERCE DR. #302, MURRAY, UT

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To Register, please call 801-662-4580 or email  
[penni.smith@imail.org](mailto:penni.smith@imail.org)

Please plan to attend all **3** classes.

Registration closes: **May 1, 2024**

*Sponsored by the  
Utah Center for Bleeding & Clotting Disorders @ PCH*



*Hungry teen boys waiting for dinner because they, kindly, let the girls go first!*



## Teen Winter Weekend February 9-10 La Quinta Inn, West Jordan

This first activity of the year was very much about having fun and getting to know one another. A delightful presentation by **Mark's Museum** involved a unique game of vintage toy Bingo. Teens spent Saturday mapping out a full year of fun and meaningful teen programs. Thanks to all the fabulous volunteers that helped out and to our great teens for their enthusiasm and support. This is going to be an amazing year!



*Photos - from left to right: The girls in full-on strategic game mode. Brothers battling it out with Rock 'Em Sock 'Em Robots. Swimming is a MUST at any Teen Retreat. Our teens in caricature drawn by the very talented guest artist, Rufus.*



# Kicking Off



**So. Utah Community Voices**  
March 9 Dixie Center, St. George

It was all smiles for 17 southern Utah families, who gathered to network, ask questions about bleeding disorders products and services, learn self-infusion techniques and, most importantly, support one another. Penni Smith from the Utah Center for Bleeding & Clotting Disorders @ PCH explained to the crowd how to navigate insurance changes. Seven-year-old Michael wanted to attend this event to “meet other kids with hemophilia,” the best reason to attend UHF events. We are, especially, grateful to the Industry partners that helped make this event possible.



*thank you*



- CSL Behring**
- CUSHealth**
- DrugCo**
- Genentech**
- InfucareRx**
- Medexus**
- Novo Nordisk**
- Octapharma**
- Sanofi**
- Takeda**

*Photos - top to bottom: Members of the Hatch family enjoying their time at the event. Community members eagerly listen to Penni Smith's informative presentation on insurance updates. Kiddos with bleeding disorders loved meeting each other and playing with all the great swag items provided by our Industry partners.*





## Men's Event

March 21 Fairfield Inn & Top Golf, Murray

- It's been a hot minute since JUST the men from the bleeding disorders community were able to meet. Thank you, **Novo Nordisk and InfucareRx**, for providing this opportunity.

Twelve men met to do what men do best - eat and play golf. In addition, Cathy Tiggs, MSSA, LISW, from the UH Cleveland Hemophilia Treatment Center, led a fabulously interactive discussion on coping with anxiety and depression. Afterwards, the bonding continued as the men enjoyed practicing their golf swing at Top Golf.

The UHF is, especially, interested in more ways we can support all men in the BD community. Please reach out to Jan Western at the UHF office with your ideas and suggestions.




**Let your voice be heard!  
Take the survey!**



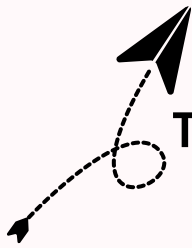
## The Fourth National HTC Patient Satisfaction Survey is now open!

**Your experience is important to us!  
If you visited your HTC last year,  
we need your voice!**

Take the survey by scanning this QR code from your phone, or go to [www.htcsurvey.com](http://www.htcsurvey.com) to fill it out online.

You can also fill out and return the survey you received in the mail.

**Surveys must be completed  
by May 31, 2024**



## The Linking Factor Newsletter

Utah Hemophilia Foundation  
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Salt Lake City, UT 84106  
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[western@hemophiliautah.org](mailto:western@hemophiliautah.org)  
801-484-0325



Registration for *Camp Valor* is opening soon!  
Do you know the theme? Here is a clue...



This is a test! This is only a test. The UHF will send a \$25 Amazon gift card to the first person who contacts Jan Western, after reading this newsletter. The second person will receive a \$15 Amazon gift card and the third will receive a \$10 gift card. This is just for fun to see who makes it all the way through. Have fun and good luck!



[western@hemophiliautah.org](mailto:western@hemophiliautah.org) or 801-484-0325