

Utah Hemophilia Foundation



Happy NEW YEAR 2024

Get ready
for a great
new year
with the UHF!

Volume 2
Issue 3

2023

is a WRAP!

*The UHF had a GREAT 2023 (we hope you did, too).
Here are just a few of the highlights:*

35 Campers

@ Camp Valor

43 Hours

Spent talking to local and national reps about co-pay accumulators

162+ Families

Attending UHF Events

3

Newly created UHF education videos

1 School Tool

resource created to help parents, kids, and teachers navigate BDs in the classroom

\$79,599

Provided in Financial Assistance

16+

Education Events

27 Teens

@ Teen Activities

52 Women

@ FAB Conference

5,516+

Volunteer hours donated by 60+ volunteers

14

UHF Board Members

Survey Says...

Thanks to all who took the time to fill out the recent UHF surveys. Your answers have contributed to the planning of 2024 UHF activities and programs.

Are you ready for the winners of the Amazon gift cards? **Congratulations to Amy Mulholland, the winner of the \$100 gift card and to Alex Pomeroy, the winner of the \$50 teen gift card.**



**Amazon
Gift Cards**

FACTOR UP

PAID ADVERTISEMENT

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

with ALTUVIIIIO™

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-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](#).

sanofi

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EVENTS 2024 SCHEDULE



**FEB
9-10**

WINTER TEEN WEEKEND

Salt Lake City, UT

*For all teens in the
bleeding disorders
community, ages 13-19*

SOUTHERN UTAH COMMUNITY VOICES

Dixie Convention Center & Rosenbruch Wildlife Museum

**MAR
9**

**APR
26-27**

ADULT RETREAT

Hilton Garden Inn, Layton, UT

*For all adults in the
bleeding disorders
community, ages 18+*

EVERYBODY'S HERE

Marriott University Park Hotel & Hogle Zoo, SLC, UT

**JUN
22**

Utah Hemophilia Foundation



772 East 3300 South, Ste 205
Salt Lake City, UT 84106

western@hemophiliautah.org

801-484-0325



TEEN RETREAT

*For all teens in the
bleeding disorders
community, ages 13-19*

Best Western Plus CottonTree Inn, Sandy, UT



**JUL
12-14**



**AUG
5-8**

CAMP VALOR

Camp Wapiti, Tooele, UT

*For kids with bleeding
disorders, ages 8-14,
siblings, and children of
affected parents*



UHF GOLF CLASSIC GOLF TOURNAMENT

Jeremy Ranch, Park City, UT



**AUG
26**



**SEPT
20-22**

FEMALES & BLEEDING (FAB)

Hilton Garden Inn, Layton, UT

*For women in the BD
community,
ages 12+*



FAMILY FEST & RESOURCE FAIR

Loveland Living Planet Aquarium, Draper, UT



**NOV
9**

Stay up to date on all UHF programs & activities



MORE INFO:

HEMOPHILIAUTAH.ORG

PAID ADVERTISEMENT

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



Happy New Year!

By: Kari Woolf,
Board President



Happy new year from the UHF Board to each of you! We welcome everyone who joined our community in 2023 and want you to know that you are fully seen, and fully supported here. This is an amazing group of people who will willingly offer guidance, love, and laughter (the best medicine of all) on your journey.

We're so grateful for all the memories we shared together in the past year—from the adult retreat and the FAB women's conference to another great year of camp and our family-focused events. Whatever the venue or occasion, we look forward to seeing you every chance we get! And we acknowledge all of the industry partners who add so much to our community and make many of our programs possible.

Speaking of industry partners, one of my favorite things is to meet new partners at our exhibitor events. They always ask a version of the same question: What is it about this group that makes it so different? It's hard to put a finger on, but I think we all feel it. It has something to do with the fact that we consider each other family. And that we grieve our heartaches and celebrate our triumphs as one. It has a lot to do with our amazing Executive Director, Jan Western, whose heart is huge and worn proudly on her sleeve. Whatever our secret sauce is, you all play a part in making this group distinctively special.

As a board, we're excited about 2024 and look forward to sharing new ideas and programs to meet our community's needs. One we're particularly excited about is bringing back the Utah Hemophilia Foundation scholarship program. If you are (or have) a college-bound student, watch for more details later this year about the application process. We hope the new year is filled with good things for each of you. Please let us know how we can make it so!

Warmly,
Kari Woolf



Utah Center for Bleeding & Clotting Disorders at University of Utah Health

We are here to help you!

As a team, the Utah Center for Bleeding & Clotting Disorders at University of Utah Health (HTC) wants to provide you with quality education and help guide the treatment of your bleeding disorder diagnosis. The highest priority for staff is to provide adult patients with high-quality care and support. Here are a few reminders as to how you can help them provide the best possible clinic experience for you:

- You don't need to wait for your annual appointment if you have a health concern. Call as soon as you suspect there might be an issue or think you may have a bleed.
- The HTC nurses will triage your issues to the appropriate staff. Same day appointments are available with the nurse or physical therapist. Often times, they can provide the necessary treatment and will consult your doctor, as needed.
- Always keep a journal or log of infusions/medications, bleeding episodes, pain, and general treatment concerns. Be sure to bring it with you to your appointment. This will help give staff a more complete picture of the issue, which is crucial to providing the best treatment.
- Be sure to complete the electronic survey after your comprehensive visit. All surveys are anonymous and it helps staff members know how to make improvements to patient visits.
- If you have concerns about your visit, you may contact Armineh Geovjian, the clinic project administrator. She is a neutral party that will help resolve your issues. She can be reached at: armineh.geovjian@hsc.utah.edu or 801-213-8371.

A Special Thanks

to all the elves at
CEMENTATION

For eight years running, our friends at **Cementation** have donated toys and gifts to UHF families who need a little extra help during the holidays. This year, these wonderful elves brought extra smiles on Christmas morning to **seven families (for a total of 30 kiddos)** in our bleeding disorders community.

Shout out to Cementation employees: Tyler, Mertlich, Ophet Sengchanh, Vickie Smith, and Craig Ellingson for coordinating all the details. We are so grateful for the generosity of everyone involved in this effort. Our Cementation friends were, DEFINITELY, on Santa's nice list, this year!



Cementation employees, Craig Ellingson (L) and Tyler Mertlich (also a UHF Board member) (R), show off a van full of incredible gifts donated to seven UHF families.



AND...

To all the amazing individuals, families, sponsors, and volunteers, who helped make this such a great year. The UHF was so much stronger with your help!



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

See half-life, clearance, and other PK data from the crossover study comparing Kovaltry[®] and Advate[®].

Visit [Kovaltry-us.com](https://www.kovaltry-us.com) to find out more.

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Antihemophilic Factor (Recombinant)



YOU "AUTUMN" KNOW... THE
Family Fest & Resource Fair
Was A "LATTE" OF FUN!!

(Sorry - we couldn't resist using these seasonal puns!)



Nearly 200 friends from Utah's bleeding disorders community joined us at the Living Planet Aquarium (Nov 11) for the last event of the year - the annual Family Fest and Resource Fair.

Seventeen Industry partners shared product information and services and made sure there was plenty of fun swag to go around. Activities included games, crafts, face painting, and a photo booth. It was a great end of the year the perfect way to kick off the holiday season.



Our thanks to the following companies for their support:

**Accredo, Bayer, Biomarin,
Colburn-Keenan Foundation,
CSL Behring, CVSHealth, DrugCo,
Genentech, Hema Biologics, Kedrion
Medexus, Novo Nordisk,
Octapharma, Optum, Pfizer,
SandsRx, Sanofi, and Soleo Health.**



7 FUN GOAL-SETTING ACTIVITIES FOR CHILDREN

Setting and achieving goals is a helpful skill that can contribute to our overall success and happiness; but it's one where, even, adults REALLY struggle. We feel the motivation with the excitement of the new year but, that motivation wanes as the months drone on.

So, how do we find the incentive to set realistic goals (and teach our children to do the same)? According to the website, BigLifeJournal.com, the secret is to make it fun. Here's are a few of their suggestions to help get you started:



Make a family bucket list

As a family, make a checklist of things you would like to do. Keep the list visible so you can monitor your progress. At the end of the year, pat yourself on the back for all you've accomplished.



Draw a 'Wheel of Fortune'

Draw a wheel and divide it into segments (like a pizza). On each segment piece, write a category: family, friends, school, etc. For each category, write a goal you would like to accomplish in a set amount of time.

Create a Vision Board

Use photos or pictures (cut out of magazines or hand-drawn) to represent your hopes & dreams.



Play '3 Stars and a Wish'

The 3 stars are things you, already, do well. The wish is something you would like to work on.

Interest Maps

Write down your interests and see if you find a pattern in the things you enjoy doing.

Ask Fun Questions

What would you do if you won the lottery? If you had a super power, how would you use it? See what goals you can set from your answers.

To read the entire article, visit:

www.biglifejournal.com/blogs/blog/5-fun-goal-setting-activities-children

THE LINKING FACTOR

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Scan here for event registration