

The Linking Factor



Co-Pay Accumulator Bill to Return in Utah's Upcoming Legislative Session

For the past year, the UHF has been a member of the Utah All Co-Pays Count Coalition (UACCC), a group of more than 15 Utah health care agencies working on legislation to stop insurance companies from implementing copay accumulators into insurance plans. During the 2022 legislative session a bill was introduced but, unfortunately, it never made it to the floor for a vote.

So, here we are, coming up on another legislative session, and the UACCC is thrilled to announce that a new bill will be introduced.

As you may know, co-pay accumulator programs exclude assistance payments from counting toward a patient's annual deductible or out-of-pocket maximum. These programs undermine access to medications prescription, making it more difficult for people living with chronic illnesses, like bleeding disorders, to adhere to a treatment plan. Patients should NEVER be punished for using any assistance programs. In many cases, this is the ONLY way in which you can afford your medication.

Currently, most insurance providers carry an accumulator provision. If you have not used a co-pay assistance program you may not even be aware of the accumulator provision in your plan... but, they exist and they are very unfair!

It is never too early to reach out to your representatives and share your story. We want every member of the Utah State Legislature to see the faces of people with bleeding disorders and to hear your stories. We want every legislative members to know how expensive it is to manage a bleeding disorder and that co-pay accumulator legislation is needed. Most importantly, we want legislators to know they can do something about it!

Finding Your Representatives

Please reach out!

To find your legislator and for more information on copay accumulators, please visit the official website of the Utah All Co-Pays Count Coalition (UACCC): www.utaccc.com. Click on the RESOURCES tab.

This website has a lot of valuable information to educate you about this issue. In fact, why not email your representatives a direct link?

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MARK YOUR CALENDAR

Legislative Day

Friday, January 20, 2023

10 am - 1 pm

@ the capitol building

MORE INFO COMING SOON

Jivi[®], now with up to **7 YEARS OF DATA.**

Talk to your doctor about the study.



Scan this QR code to learn
more about the data at
[JiviExtensionStudy.com](https://www.jiviestensionstudy.com)

Board Update

By: Kari Woolf, Board President



Dear UHF Community:

It was so wonderful to see so many of you at our “Everybody’s Here” event last month. While I was there, I had the chance to talk to a new industry rep who echoed something I’ve always felt: this community is *special*. Thank you for being what MAKES it so special.

It was also such a great experience to attend the Females and Bleeding Disorders Conference in September. FAB is an apt name for this event, because it had a little bit of everything a women’s retreat should: laughter, tears, deep discussions, games, support, creativity, good food, and the company of amazing women and teens. The guest speakers were inspirational, and the sharing we did with other was powerful. A huge thank you to everyone who attended—and to Octapharma for sponsoring this annual event.

We’ve had a lot of great discussions as a Board lately to consider ways we can serve you even more effectively. We’re also in the process of putting together an annual report that will hit your inboxes in January as a way to report to our members on the foundation’s health, priorities, and accomplishments. And finally, we’re welcoming Krisdee Nelson to our board! Krisdee was my very first hemophilia mentor, and I’ve been in awe of her knowledge, courage, and compassion ever since. We’re so excited to have her join our ranks and look forward to her ideas and perspective.

We hope you enjoy a wonderful holiday season with your loved ones. And if you’re like me and rely on Amazon for a lot of forgotten items or last-minute shopping, don’t forget to use AmazonSmile and designate the UHF as your charity of choice. Every little bit we earn helps us run more of the programs that have filled our calendars and brought us back together again.

-Kari

Jan

20
10:00 am

Legislative Day
Utah State Capitol

Feb

23
6:30 pm

Community Voices
Location TBD

Mar

23
6:30 pm

So. Utah Outreach
Location TBD

Apr

8
28-29
6:00 pm

World Hemophilia Day
Location TBD

Jun

10
10:00 am

Adult Retreat
Courtyard Marriott, Layton, UT

Jul

14-16

Everybody's Here
Ogden, UT

Teen Weekend
Best Western CottonTree Inn, Sandy, UT

Aug

Jul 31- Aug 3

28

Camp Valor
Camp Wapiti, Tooele, UT

Golf Tourney
Jeremy Ranch, Park City, UT

Sept

TBD

FAB Conference
Location TBD

Oct

5
6:30 pm

Community Voices
Location TBD

Nov

11
10:00 am

Family Fest & Resource Fair
Loveland Aquarium, Draper, UT

2023
UHF Programs & Events

SAVE THE DATES!

More information coming soon



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Learn more about
our focus on
the rare bleeding
disorder community

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WE HAD
A GREAT FALL,
Y'ALL!



It turns out, Humpty Dumpty wasn't the only one to have a great fall.

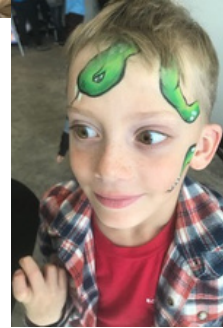
Okay, maybe our fall was not quite like Humpty's, BUT, the bleeding disorders community did gather this fall for some great fun. From the annual Females & Bleeding Conference (September) to the Family Fest (November), and a few fun virtual activities in between; more than 70 families came together to enjoy some amazing networking opportunities, education, and good times.

Here are a few photo highlights:



Fifty-four women and teens from Utah, Idaho, and Wyoming registered for the 2022 Females & Bleeding Conference. This event spotlighted issues unique to women in the bleeding disorders community. Thank you, **Octapharma**, for making this incredible event possible!

The Family Fest & Resource Fair brings families together to receive information on bleeding disorders products from our Industry partners; but, it is also the Utah Hemophilia Foundation's birthday party. Happy 63 years, UHF, with thanks to our Industry partners for making this event possible:



Accredo Health Care

Bayer

Biomarin

CSL Behring

CVS Healthcare

Genentech

Infucare Rx

Medexus

Novo Nordisk

NuFACTOR

Octapharma

Optum Rx

Pfizer

Sanofi

Takeda

An extra shout out to **Mark Wiesenberg** of **Mark's Museum**.

Thank you for sharing your toys with us and for reminding us of the importance of everyday play.



Paid Advertisement

To me, it's personal.

As a Community Relations and Education Manager for Sanofi Genzyme, I'm here to help provide support and resources for you and the bleeding disorder community.

Jessica Steed
CoRe Manager for AZ, NM & UT

Let's connect.

Call, text, video chat: 602-321-0372

Email: jessica.steed@sanofi.com

Facebook: @HemophiliaCoRes

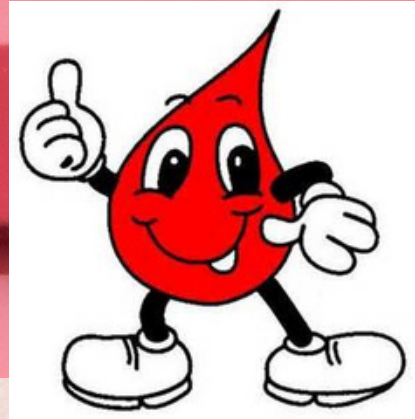


www.rareblooddisorders.com

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We need your feedback!

What information and resources do you need? What have you found helpful?

Scan the QR code or type the link in your browser to complete this 5 minute survey.



bit.ly/UCBCD22

Utah Hemophilia Foundation (UHF) and the Utah Clinic of Bleeding and Clotting Disorders (UCBCD) would like your input on their training and educational offerings.

Dedication and Personal Support



Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.



Patty Eastin

AZ, NM, NV, UT, CO, ID, WY, MT
 patricia.d.eastin@pfizer.com
 O: 480-734-4011

"Having worked at Pfizer for 17 years, I am passionate about supporting and educating the amazing rare disease community."

My work is guided by:

Compassion—Listening to your needs and addressing questions and concerns that you may have

Commitment—Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection—Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

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Put the **HO HO HO** Back in Your **HO**lidays!

Help the UHF Raise Money by Shopping Through Amazon Smile

- **Visit smile.amazon.com**
- **Select "Utah Chapter - Natl Hemophilia Foundation" as your charity. With each order, Amazon donates 0.5% of your purchase price to the UHF.**
- **Place your orders through smile.amazon.com. (It doesn't cost you anything to participate).**



Your purchases have helped the UHF raise more than **\$2,000.**

*A Special
Thanks*

to the angel
employees at
CEMENTATION



For seven 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 will bring extra smiles on Christmas morning to **six families** in our bleeding disorders community. Shout out to Board member, Tyler Mertlich, for coordinating all the details at the North Pole.

We, at the UHF, are so grateful for their kindness and incredible generosity. (In fact, we can guarantee these wonderful people will be on Santa's NICE LIST this year).

Thank you!





A FINANCIAL SAFETY NET FOR THE BLEEDING DISORDERS COMMUNITY

Have you heard about Lifeline? It is fund through which individuals with bleeding disorders receive financial help with high insurance premiums, COBRA payments, and out-of-pocket medical expenses associated with the diagnosis and treatment of bleeding disorders. Lifeline is granted by the Utah Department of Health and administered by the Utah Hemophilia Foundation. The application process includes submitting the official Lifeline application to the UHF and financial documentation such as your latest tax return, paycheck stubs, and proof of payment of insurance and household medical expenses.

In the recent Legislative session, **the Lifeline grant was cut by \$50,000**. It is very important to show that this fund is still needed in the bleeding disorders community; the best way to do this is use the money that is, currently, available. Please visit the **RESOURCES** section of the **UHF website** (www.hemophiliautah.org) for more information about Lifeline.

Do you qualify for Lifeline Assistance? Applicants must provide:

- Proof of residency in Utah for the past 12 months or longer
- Verification of the diagnosis of a bleeding disorder
- Verification that annual out-of-pocket insurance and medical expenses for all household members are greater than 7.5% of an applicant's adjusted gross income (AGI)
- Proof of United States citizenship, permanent residency, and/or hold a valid visa

If you have any questions, please contact Jan Western @ the UHF office.

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*Scan here for up-to-date information
on UHF programs & activities*