


THE LINKING FACTOR

News and updates from the Utah Hemophilia Foundation

www.hemophiliautah.org

 Utah Hemophilia Foundation



Update on SB 139: Prescription Cost Amendments

Bill to curb accumulators tabled during legislative session



For the past nine months, 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 to introduce legislation that would curtail the implementation of copay accumulators into insurance plans. Unfortunately, after months of strategizing and hard work, the Prescription Cost Amendments bill (SB 139) was "tabled" in Senate committee hearings and did not make it to the floor for a vote.

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 life-saving prescription drugs, making it more difficult for people living with chronic illnesses, like bleeding disorders, to adhere to a treatment plan. Patients should not be punished for using these 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!

Where do we go from here?

Rest assured, the fight against co-pay accumulators is not over! The UACCC is now "gearing up" for the 2023 legislative session. New strategies are in the works and your help is needed, now more than ever. In the coming weeks, the UHF will email out more information on how to connect with your legislative representatives. It is never too early to reach out to them and to 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 the legislative members to know how expensive it is to manage a bleeding disorder. Most importantly, we want legislators to know they can do something about it! If you have made a connection with your representatives, let us know! We'll publish your tips in future newsletters

To learn more about co-pay accumulators and/or to find out how to contact your legislator, please visit the UACCC website: www.utaccc.com.

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
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 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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 HemMobile is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition. Pfizer will not have access to any personal information you enter into HemMobile.

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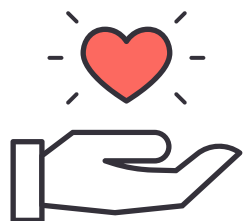


Tips for Your Procedure Prep

Anticipating an upcoming procedure? The HTC staff now recommends contacting them, at least, 30 days in advance to make sure all treatment plans and paper work are in place. Unfortunately, insurance companies are taking quite a bit longer to provide pre-authorizations. Allowing the staff this 30 day window will help ensure your procedure does not experience any delays. For a check-list with more helpful tips for procedure prep, please click below.

Welcome to these New HTC Team Members

At your next appointment, you just might see a few new faces. At the adult clinic, we welcome two new team members: nurse, Kim Ashbaker, and physical therapist, Jacquelyn Gravelle. Starting in the Fall of 2022, Dr. Sashi Goteti will join Dr. Jessica Meznarich in the pediatric clinic @ PCH. Additionally, we welcome Liz Davies to the team of pediatric nurse coordinators.



Generous Hearts & Hands are Helping the UHF



For the seventh consecutive year, our friends at **Cementation** provided holiday assistance, of cash and gifts, to help five families in the bleeding disorders community this past Christmas.

We are so blessed by their generosity and cannot express enough thanks to the employees of this wonderful company. Additionally, the UHF gives a *SHOUT OUT* to board member, Tyler Mertlich, for helping to make this all possible!

L-R: Jan Western (UHF), Ophet Sengchnh (Cementation), Tyler Mertlich (Cementation & UHF Board), Qersland Rith (Cementation)

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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You Are Invited...

to more great UHF events



Sat, April 9



World Hemophilia Day Celebration

Blue Sky Lodge, Wanship

Celebrate with us at a beautiful Summit County resort. Enjoy interactive stations focusing on the importance of joint health. *Sponsored by Sanofi Genzyme*

Thurs, May 12

FamilyLink Event

Top Golf, Murray

Join professional golfer, Perry Parker, for a night that will inspire you to to never giving up on your dreams. *Sponsored by CSL Behring*

Thurs, May 19

So Utah Community Voices

Washington, UT

Dinner, networking, and information on the latest products for managing bleeding disorders. Fun and prizes for the entire family.



Thurs, June 2

M-Powered

Location TBD

A night of camaraderie and empowerment just for women. *Sponsored by: Bayer*

Sat, June 25

Everybody's Here

Location TBD

A great family event to kick-off summer event, with a chance to learn all about new products & techniques for managing bleeding disorders.



Fri-Sun, July 15-17

Teen Retreat

Camp Wapiti, Tooele

A weekend of networking, education, and a whole bunch of fun for teens with bleeding disorders, carriers, and siblings, ages 13-19.

Mon-Thurs, Aug 1-4

Camp Valor

Camp Wapiti, Tooele

Summer camp for kids with bleeding disorders/carriers, ages 8-13, and siblings/kids of affected parents, ages 10-11.



Mon, Aug 29

Golf Tournament

Jeremy Ranch

The UHF's largest fundraiser at a brand new golf course.



Matt Chapman

Regional Account Manager

Learn more about
our focus on
the rare bleeding
disorder community

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Board Update

By: Kari Woolf, Board President



March 2022

Dear UHF Community:

I've so enjoyed seeing many of you at recent events, and I'm so grateful to be a part of this beautiful community. I've always said that this group is special, and I feel that more strongly every time I have a chance to interact with you. Thank you for being who you are—and for rallying together and supporting each other in both good times and bad. The Board is honored to serve you! Here's a quick snapshot of what we've been up to:

Since our last update, Reg Ecker (our past President) and Tim Rice (our industry representative) have retired from board service. We loved working with them and wish them well in all that awaits. We also welcomed Becky Ybarra as a new board member, and Patti Eastin (from Pfizer) as our new industry representative. They both have such contagious enthusiasm and have already contributed so much to our Board. And finally, we mourned, along with many of you, the passing of our dear friend and board member, Lynn Barker. Lynn was an inspiration, and his heart and soul belonged to this community. We love and miss him and are so grateful that he and his family came into our lives.

We were pleased to lend UHF support to a bill that was introduced (SB139 – Prescription Cost Amendments) that sought to eliminate copay accumulator adjustments. If you're impacted by these, you know all too well what they mean. If not, the quick summary is that they allow insurance companies to take the copay assistance funds provided by many factor manufacturers, but not apply them to the subscriber's deductible or out-of-pocket maximums. Senator Vickers from Cedar City introduced this bill, and a UHF family was able to testify on its behalf. While it didn't make it to the floor this session, it planted important seeds that we'll nurture again next year.

We've also been busy helping to set the agenda and budget for 2022. We're excited about the introduction of Community Voices events this year that will give members more time to share perspectives, challenges, and advice with one another. And we're grateful to have ended another year in strong financial shape, thanks to excellent fiscal management by our executive staff and board treasurer, Kim Nmezi! That said, we always need to keep a focus on fundraising so we can provide (and expand) the services the UHF provides to you. So watch for details on events you can support this year...and don't forget to use AmazonSmile for all your online shopping needs so that every purchase you make benefits the UHF with no additional cost to you.

Wishing you health, happiness, and a heavenly spring!

Kari

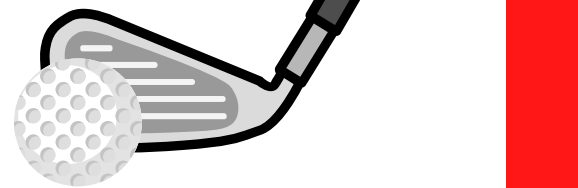
UHF Golf Tournament

At a fabulous NEW venue



Jeremy Ranch.... here comes the UHF ***Monday, August 29, 2022***

We are thrilled to announce a new location for the 2022 UHF golf tournament - Jeremy Ranch. This championship golf course will bring new challenges (and the same 'ole fun) for all participating.



This can be the biggest and best UHF fundraiser in the history of UHF fundraisers - but, we need your help! Please think of those in your circle that can support this event. Contact Jan Western at the UHF office for all the information. The details will be ready to email or post to your social media pages. **THANK YOU!**



YOUR AMAZON SHOPPING **MAKES THE UHF SMILE**

Make a Great Buy - Support a Great Cause
How shopping on Amazon can help the UHF

- Visit smile.amazon.com
- Select "Utah Chapter - National Hemophilia Foundation" as your charity. Each time you order, Amazon donates 0.5% of your purchase price to the UHF.
- Place your orders through smile.amazon.com. If you have Prime, it will be linked.
- Invite your friends to do the same.



As of January 1 ...

**The UHF has received more than
\$1,700 from your purchases made
through AmazonSmile. THANK YOU!**

Keep on shopping!!



Quick Pics of Family Glamp

Covid-19 did not spoil the fun of the UHF's very first family camp, last August. Fifteen families gathered at the Homestead Resort to enjoy traditional camp activities in a "glamorous" setting. Just for fun, we emphasized the *GLAM* of family camp and treated families like the celebrities they are by living it up, Hollywood-style. As always, families enjoyed bleeding disorders education and community connections at all levels. A HUGE thanks to all who made Family Glamp possible!



Upon arrival, families walked the red carpet, where our own Family Glamp "paparazzi" snapped photos.



Welcome to Hollywood! Volunteers are the HEART of any UHF camp. This year, a few "celebrity" volunteers helped out.



Family Glamp offered education for each age group. Parents convened to discuss various topics, including the successes and challenges of raising children with bleeding disorders. Campers and teens enjoyed their own pertinent education sessions, including a session on bullying.



Our fabulous HTC team was on hand for teaching self-infusion techniques.



As always, a variety of fabulous camp activities kept the fun flowing in abundance.





A FABulOUS Weekend for Women with Bleeding Disorders

Last October, 52 women from Utah & Idaho's bleeding disorders communities met for an amazing weekend of networking and support.

Kudos to **Octapharma** for their help in making it all possible.



Fun Friday evening activities gave our ladies the chance to kick-back, relax, and enjoy getting to know one another.



Below (L-R): Jan Western, Utah Hemophilia Fdn; Kymm Shaw, Snake River Hemophilia & BD Assoc; Marlyn Walker, NHF—Idaho Chapter.



Presentations included discussions on diagnosing vWD, menstruation, healthy intimacy, and maintaining positive mental health.

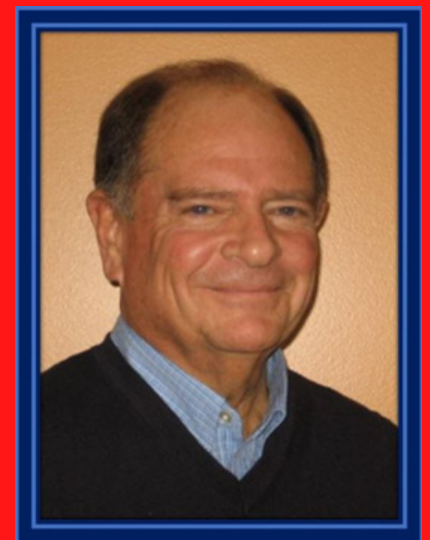


The conference closed with a service project for Primary Children's Hospital and an exercise to remind these women just how amazing they are.

We Will Miss You, Lynn Barker!

The UHF is profoundly saddened by the passing of our friend, Lynn Barker. Those of us who knew Lynn were, truly, touched and blessed in many ways. He was a man of great integrity, graciousness, and compassion.

Lynn was recognized and revered in the pharmaceutical industry, where he worked for more than 40 years. Lynn was a long time UHF volunteer and, most recently, a Board member. May we all smile a little brighter because of the friendship and love Lynn so freely gave to all of us.





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.

The Linking Factor

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