

# THE LINKING FACTOR

MARCH 2023

WWW.HEMOPHILIAUTAH.ORG



*(L-R, above) Bonnie Webb, UHF Vice-President; Kari Woolf, President; Jan Western, Director; spend time during the 2023 Utah Legislative session to advocate for the ban of insurance plan co-pay accumulators.*

*(Below) Mac Haddow and Ashley Bowen; UHF community members meet in the Capital for Legislative Day.*

## UHF VOICES IN ACTION

It takes a lot of voices to bring attention to a cause and on January 20, at the Utah State Capital, UHF volunteers did just that.

As part of the Utah All Co-Pays Count Coalition Legislative Day, members of the UHF community met with their legislators to educate them about SB 184: Prescription Cost Amendments. This bill would ensure that all co-pays, including those received from manufacturer assistance programs, would count towards a patient's overall deductible. Community members that were unable to attend in person phoned and emailed their legislators, urging their support.

Throughout the session, community members Ashley Bowen and her Dad, Mac Haddow, testified in committee hearings how critical this legislation is for patients with bleeding disorders and other chronic conditions.

## SB 184 TABLED IN LEGISLATIVE SESSION

Unfortunately, in the last days of the 2023 Legislative session, SB 184: Prescription Cost Amendments, was tabled in the House Business & Labor Committee. Senator Curtis Bramble, the bill's sponsor, made it known this bill to curb insurance co-pay accumulators was his top priority. However, despite passing easily through the Senate, there was too much influence from insurance lobbyists in the House and it failed to pass out of Committee.

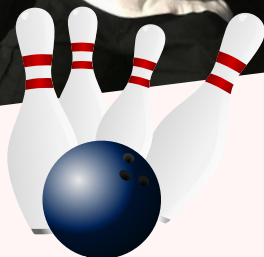


## WHAT DOES THIS MEAN FOR THE FUTURE?

The fight against co-pay accumulators is not over! Although this session ended in disappointment, this is the most success this bill has achieved. We will need even MORE help in getting the word out about this issue. The ONLY way this can be done is with your help. Your representatives cannot effect change if they do not know about these issues Please join in as we continue this fight!



## UHF Teens "BOWLED" Over by Kick-Off Event



An afternoon of bowling, laser tag, pizza, and big shoes were all that was needed to kick-off a year of great UHF teen activities. Eighteen teens gathered on Saturday, March 18, to renew friendships and laugh with one another. Future teen activities will include a service project in May and the **Teen Retreat, July 14-16**. For more information on teen events, check out the UHF website ([www.hemophiliautah.org](http://www.hemophiliautah.org)).

*Paid Advertisement*

## 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

HemMobile is a registered trademark of Pfizer Inc. 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.



# Board Update

By: Kari Woolf, Board President



As a foundation, one of our primary goals is to advocate for the Utah bleeding disorders community. We had a chance to do just that during the 2023 Utah legislative season. We were part of a coalition supporting a bill to eliminate copay accumulators. These copay accumulators prevent manufacturer copay assistance programs from counting toward a patient's deductible, and they're affecting more of our community each year. We had a strong sponsor for our bill and were able to pass it from the Senate Business and Labor Committee to a full Senate floor vote, where it passed unanimously. Unfortunately, the opposition found a foothold in the House, and our bill didn't make it to the Governor's desk.

While this was a disappointing outcome, I'm so proud of the way our community showed up and told our stories to those in power. Change doesn't always happen as fast as we'd like it to, but telling our stories is such a powerful way not only to impact hearts and minds, but to own our narrative and take pride in who we are--as individuals and as a collective. Hearing members of our community speak to their legislators (and even the press!) about what it means to have a bleeding disorder was so very moving, and I'm confident that we planted some important seeds for future change.

Speaking of stories, have you checked out the new Utah Hemophilia Foundation video? Many thanks to Scott Muir for putting heart and soul into helping us tell our stories through such a powerful medium. Click on the link below to view it and be sure to share it! Particularly as we ramp up for another successful golf tournament, we want people to understand all the good that a donation to the Utah Hemophilia Foundation can do. We're all part of building the story of our future, so let's step up, speak out, and link arms as we influence it for good.

- Kari Woolf

# 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](mailto:jessica.steed@sanofi.com)

Facebook: @HemophiliaCoRes



[www.rareblooddisorders.com](http://www.rareblooddisorders.com)



© 2021 Genzyme Corporation. All rights reserved.  
MAT-US-2100002-v2.0-06/2021



To these UHF events  
**You Are Invited**

**April 8 World Hemophilia Day Celebration**

Location: Cucina Toscana, Salt Lake City

**April 28-29 Adult Retreat**

Location: Courtyard Marriott, Layton

**May 6 Mind Body Alliance Family Summit**

Location: University Marriott, Salt Lake City

**June 10 Everybody's Here**

Location: Ogden

**July 13 M-Powered: A Group for Women**

Location: TBD

**July 14-16 Teen Retreat**

Location: Best Western Cotton Tree Inn, Sandy

**Aug 28 Golf Tournament**

Location: Jeremy Ranch, Park City

**July 31-Aug 3 Camp Valor**

Location: Camp Wapiti, Tooele

**Sept 8-10 Females & Bleeding Conference**

Location: Best Western Cotton Tree Inn, Sandy

**\*Event information is available at [www.hemophiliautah.org](http://www.hemophiliautah.org)\***



# News from the HTC

The Utah Center for Bleeding and Clotting Disorders (UCBCD) at Primary Children's Hospital is excited to introduce to you two new team members:



**Angela Kouri, DPT**, moved from Albuquerque, New Mexico to Salt Lake City, in March 2022. She is an acute care physical therapist at Primary Children's Hospital and, recently, joined the hemophilia team two days per week to work alongside Heidi.

Angela is married to her best friend, Drew, and they have two young boys that keep them busy. They love spending time outdoors, swimming, and trying out new foods and restaurants.



**Leanne Rohrbach-Stange, CSW**, is a pediatric medical social worker at Primary Children's Hospital in Salt Lake City. Leanne joins the UCBCD at Primary Children's the first week of April in a new role at the HTC as the Health Equity Specialist. The aim of this new role is to reduce health disparities across our patient population.

Her particular areas of interest include working with children and their caregivers affected by acute and chronic illnesses who experience forms of grief associated with medical trauma. Alongside her partner, she takes great joy in exploring all of the Intermountain West has to offer by bike and boat, among other means.

## Change in Your Insurance? Please Contact the HTC, ASAP!

In our ever changing world of insurance and medical care, we understand that there are concerns that arise in getting medications. If your insurance has changed or is changing, please notify the HTC with those changes, ASAP. If they are not made aware until after the insurance has changed, there is often a lag in obtaining factor medications.

This, also, goes with specialty pharmacies. Insurances have been changing their preferred specialty pharmacy, throughout the year, and it has created difficulties for patients. Please notify HTC staff of any changes to your insurance and/or specialty pharmacy, as soon as possible.

### Southern Utah Clinic Dates - Appointments Available

Pediatric Clinic: May 1-3, 2023

Adult Clinic: October 2023 (exact dates TBD)



**Pediatric Clinic** @ Primary Children's Hospital: 801-662-4700  
After hours contact: 801-662-1000, ask for the hematologist on call

**Adult Clinic** @ University of Utah: 801-213-8371  
After hours contact: 801-581-2121, ask for the hematologist on call

# Back to SCHOOL

## WAIT...

### It's not even summer, yet!

We, definitely, don't want to get ahead of ourselves but, we are just so excited to let you know...

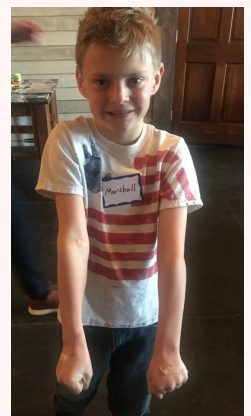
Thanks to a generous grant from **Pfizer**, the Utah Hemophilia Foundation is working on a brand new project we are calling, **THE SCHOOL TOOL**. This will be a one-stop resource about bleeding disorders to share with your child's educators to help them better understand your child's needs while in the classroom.

**In fact, you can help us get this tool ready!** Is there specific information you would like your child's teacher to know about bleeding disorders? What tools would be helpful in order for you to work with your school administration? Please contact Jan Western to share ideas: [western@hemophiliautah.org](mailto:western@hemophiliautah.org) or 801-484-0325.



At the UHF's recent Southern Utah Community Voices event, 15 families gathered in Washington, UT, to learn about new bleeding disorders products, practice their self-infusion skills, and network with one another.

Penni Smith and Heidi Lane from the Center for Bleeding & Clotting Disorders @ PCH taught both kiddos and adults the techniques for successful infusion. The evening included exhibits by our Industry partners, a delicious dinner, and a Q&A session with Penni, Heidi, and Jan. It was great to be with "old" friends and have the opportunity to meet new ones.



MANY THANKS TO THESE COMPANIES FOR THEIR SUPPORT:

**Bayer**

**CSL Behring**

**Infucare Rx**

**Octapharma**

**Biomarin**

**DrugCo**

**Medexus**

**Pfizer**

**CVSHealth**

**Genentech**

**Novo Nordisk**

**Sanofi**

(Above) Marshall, age 9, proudly shows his bandages after infusion practice.

(Left) Families learning self-infusion techniques and networking with each other.



**HEMA**  
Biologics®



Learn more about our focus on the  
rare bleeding disorder community

Visit us online at [hemabio.com](https://hemabio.com)



**HEMA**  
Biologics®

The Hemophilia Federation of America is a national community-based, patient-centered organization and is committed to championing the needs of families living with debilitating bleeding disorders. The HFA advocates for safe and effective therapies and affordable health coverage. Ultimately, the HFA seeks a better quality of life for all persons with bleeding disorders. The HFA assists, educates, and advocates for people with bleeding disorders throughout the country.

The HFA offers these resources and tools, along with many others, to help with the management and treatment of bleeding disorders:

## Project Calls

Having issues with your insurance? The HFA wants to hear about them. Project CALLS (**C**reating **A**lternatives to **L**imiting and **L**acking **S**ervices) collects patient stories to better understand how insurance industry policies are affecting the bleeding disorders community. This data is then used to build a case for change on a national, state, and local level with legislators, regulators, and private payers. Once you fill out an online form, an HFA representative will contact you to review your issue. Any identifying information remains strictly confidential.

## Dateline Magazine

Is a monthly magazine available by becoming an HFA member. Basic memberships are free and, in addition to the Dateline magazine, include monthly e-newsletters and access to online educational webinars.

## Financial Assistance

Job readiness grants and academic scholarship information is available for those pursuing a college degree or a change in career paths.

## Learning Central

Learning Central offers online learning modules, accessible via computer, tablet, and mobile device. Choose from a variety of topics and learn about them at your own rate.

## News & National Updates

Whether it be about gene therapy, Medicaid, new factor products, legislative issues, or research projects, the HFA has all the latest information on issues relevant to the bleeding disorders community.

Visit [www.hemophiliafed.org](http://www.hemophiliafed.org)  
for all the latest information





**Jivi**<sup>®</sup>  
antihemophilic factor  
(recombinant) PEGylated-auct



# Jivi<sup>®</sup>, 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)**



## 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.

Recently, **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](http://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

**Lifeline applications available through the UHF website**

**[www.hemophiliautah.org](http://www.hemophiliautah.org)**



*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

# World Hemophilia Day

Celebrate with us on Saturday, April 8

Cucina Toscana, 282 So. 300 W., SLC

Learn about the science behind factor activity levels and pharmacokinetics, possibilities that bleed protection can bring, and the power that can come from telling your story. Enjoy fun and informative activities, delicious food, and supporting one another. Thank you, **Sanofi**, for making this event possible.



## UHF Adult Retreat



Strength

Friday, April 28 -  
Saturday, April 29

@ Courtyard Marriott  
1803 Woodland Park Drive  
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.

## MBA Family Summit

Mind Body Alliance

Saturday, May 6, 2023 10 am - 2 pm

University Park Marriott

480 Wakara Way, Salt Lake City

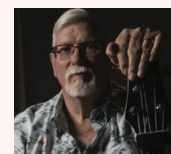
### Featured Speakers



Perry Parker



Diane Dimon, Dr. RS



Rick Stark

Enjoy discussions, activities, and interactive presentations centered on maintaining positive mental health. Something fun for every member of the family. After lunch, your family will receive tickets to visit Hogle Zoo. Thank you, **CSL Behring**, for making this event possible.

## The Linking Factor

Utah Hemophilia Foundation  
772 East 3300 South, Suite 205  
Salt Lake City, UT 84106

www.hemophiliautah.org  
western@hemophiliautah.org  
801-484-0325



Scan here for event registration

