


THE LINKING FACTOR

News and updates from the Utah Hemophilia Foundation

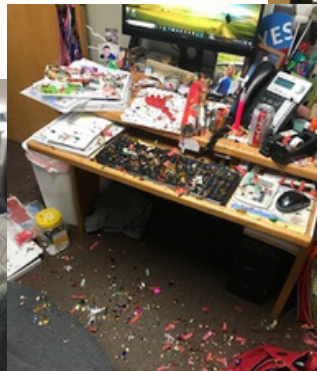
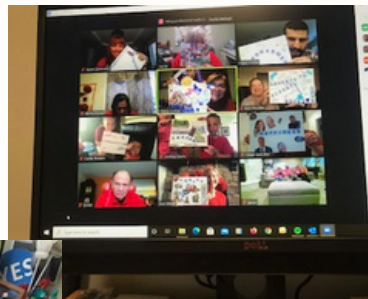
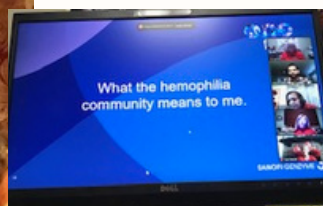
www.hemophiliautah.org

 Utah Hemophilia Foundation



It's Good to Be Together, Again

Here's just a little bit of the fun we've had so far...



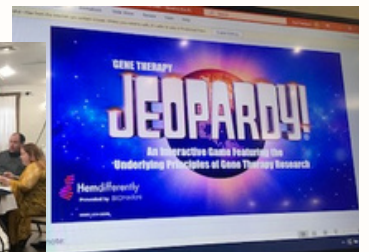
After a long spell in quarantine, the bleeding disorders community is FINALLY back together! The UHF kicked off the year with a much needed FamilyLink activity about finding courage to overcome challenges. Dine & Dialogue events featured an exciting game of gene therapy Jeopardy and a fascinating look at plasma safety.

The team at the UCBCD hosted two great virtual Q&A sessions on insurance and novel therapies; and a virtual celebration of World Hemophilia Day brought friends from around the state. Participants created "vision boards" and learned the value of dreaming big. (We, also, learned that confetti canons are easiest to clean up when shot off OUTSIDE).

Of course, the highlight of the year (so far) was being able to meet at the Homestead for an overnight Adult Retreat. More than 30 couples enjoyed learning how to nurture personal relationships (thank you, Dr. Dave Robinson), asked questions of our Industry partners, and just enjoyed the company of one another. Of course, we have many sponsors to thank for making all of these events possible:

- | | |
|--------------------|-----------------------|
| Bayer | Medexus |
| Biomarin | Novo Nordisk |
| CSL Behring | Octapharma |
| Grifols | Optum |
| InfuCare Rx | Sanofi Genzyme |

Utah Center for Bleeding & Clotting Disorders



More Great UHF Events



ARE HEADED YOUR WAY...



July 15

Dine & Dialogue

Location TBD

An interactive dinner education event on the topic of coping with anxiety and depression. Sponsored by Novo Nordisk

August 4-6

Family Glamp

Homestead Resort

A camp-like experience for the ENTIRE family (but, we're at the Homestead so, we'll GLAM it up - just a little bit).

August 19

Dine & Dialogue

An interactive dinner education event. More information coming soon...

September 14

Fore a Cure Golf Tourney

Homestead Resort, Midway

The UHF's largest fundraiser. We need sponsors, foursomes, prizes, and volunteers. Can you help us?



September 23

Dine & Dialogue

An interactive dinner education event. More information coming soon...

October TBD

Q & A: Infusions

Virtual Event with the Staff of the

Utah Center for Bleeding & Clotting Disorders



Your chance to ask the HTC staff your questions about infusing.

October 28

Females and Bleeding

Conference (FAB)

Little America Hotel

A conference for all women in the bleeding disorders communities of Utah, Idaho, and Nevada, ages 12 and older.



November 13

Family Fun Fest & Resource Fair

This is the Place Heritage Park

A fun, family event to end the year with a bang.

A few spots remain...

REGISTER BY
July 2

REGISTER Today!

UTAH HEMOPHILIA FOUNDATION
FAMILY GLAMP
AUGUST 4-6, 2021
HOMESTEAD RESORT, MIDWAY UT

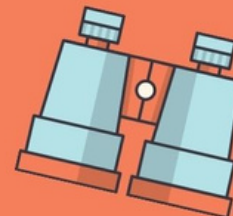
A FAMILY CAMP FOR KIDS WITH BLEEDING DISORDERS, AGES 8-13,
AND THEIR PARENTS AND SIBLINGS



A fun experience for the entire family!
It's Camp Valor but, we'll be at
the Homestead (so we'll GLAM it up a bit.)

Camp activities for kids, ages 4+

- arts & crafts
- swimming
- nature walks
- campfire singing
- team games
- crazy concoctions



Helpful hints and support for parents

Learn about bleeding disorders,
including self-infusion training

Meet other families

in the bleeding disorders community

Daycare provided for kids, ages 3 and under



Registration Deadline: Friday, July 2

www.hemophiliautah.org

*Financial assistance available

Questions?



Please Contact Jan Western at the UHF office:
801-484-0325 or western@hemophiliautah.org

Board Update

By: Kari Woolf, Board President



Hello, UHF Community!

We want to introduce you to your UHF Board of Directors. We're volunteers from the community who work in partnership with Jan to meet your needs and forward the goals of the UHF. If you're coming to the Adult Retreat, we'll be doing a quick intro and Q&A after breakfast on Saturday. We have formal board meetings every quarter and want to keep you informed about what we discuss, so watch for regular updates in this newsletter. Also, here are our names in case we haven't had a chance to meet yet. We love this community!

UHF Board Members: Kari Woolf (President), Bonnie Webb (Vice President), Reg Ecker (Past President), Tyler Mertlich (Secretary), Kim Nmezi (Treasurer), Tim Rice (Industry Rep), Craig Thurgood, David Walsh, George Rodgers (HTC Rep), Ryan Rushton (HTC Rep), Shannon Howell, and Jean McFarlane. A big welcome to Kim, Shannon, and Jean who are new to our board! And a heartfelt thanks to Dave Winslow and Doug Ohlson who recently retired from board service after many years serving this community.

As a board, we're focused on three key priorities:

◆ Meeting Community Needs

This is our key role as a board: to help set the direction of the foundation and create programs that align with the support, connections, and resources our community needs. It's all about connecting as a community, and it's one of the reasons we're all so excited that F2F events are back on the horizon!

◆ Generating Funds

Fundraising can be a challenge especially when budgets are tight and individuals and organizations alike are dealing with unprecedented change. But fundraising is a key charter of any non-profit board. The funds we raise through events like our upcoming golf tournament (September 14 at The Homestead) are critical to supporting the programs and initiatives you count on.

⇒ **ONE SIMPLE THING YOU CAN DO TODAY TO HELP:** Sign up for the Amazon Smile program—and tell everyone you know. It gives UHF half a percent of any Amazon purchases you make, and at no extra cost to you! Here's how:

- 1). Go to smile.amazon.com and choose "Utah Chapter National Hemophilia Foundation" as the organization benefitting from your purchases.
- 2). When you order things, make sure to do it from smile.amazon.com. Your Prime account and everything else about your Amazon experience remains the same—AND you have the satisfaction of supporting a good cause with no effort beyond what you do anyway.

◆ Advocating for Our Community's Needs

Advocacy can take many forms. It can be educational, community-based, or even legislative. Whatever the specifics, advocacy is all about addressing our community's needs proactively. As a board, we're thinking about issues like copay accumulators and discussing what advocacy measures may help impacted families.

At our April board meeting, we had a great discussion with a former leader in the Utah Legislature about the process of seeking legislative solutions to issues like this. Stay tuned for more details in the future! And as a heads up: we may be inviting you all to reach out to your local legislators to help them understand the issues our community faces. It's a small thing that goes a long way toward creating awareness and understanding.

Please reach out if you'd like to chat with any of us... And happy summer!

It's Back - Our Biggest Fundraiser and we need your help!



Alexander Cooper/Fore a Cure MEMORIAL GOLF TOURNAMENT

Tuesday, September 14, 2021 Homestead Resort, Midway



The Utah Hemophilia Foundation FORE A CURE Golf Tournament is the primary fundraiser in support of the UHF's programs and services for the benefit of Utahns with bleeding disorders.

This year, we are pleased to honor the memory of Alexander Cooper and his work in the non-profit arena. Alex was kind, generous with his time and resources, and passionate about serving those in need.

Tournament Schedule:

8:00 a.m. Golf Check-in & Brunch

9:00 a.m. Shotgun Start

2:00 p.m. Dinner & Tournament

⇒ 18 Hole Scramble Format

⇒ Brunch & Dinner Buffet

⇒ Golf Swag & Prizes

The term bleeding disorders refers to any disorder that prevents blood from clotting properly. People with bleeding disorders suffer from a wide range of complications, including: spontaneous bleeding into muscles and joints, severe nose bleeds, heavy bruising, and hemorrhaging during surgical procedures. Treatment is available but, it is expensive. Per family, costs can range between \$500,000 and \$1,000,000, annually.

The Utah Hemophilia Foundation helps families navigate the challenges associated with bleeding disorders. Programs, like our kids summer camp, teen connections, and parent support groups, (just to name a few); provide support and education, which helps families live healthier and more self-sufficient lives. Your participation in the FORE A CURE tournament ensures that these valuable programs continue and are available to all Utahns with bleeding disorders who need them.



Nine-year-old Wyatt attends summer camp to learn about managing his hemophilia



To register your foursome,
please contact Jan Western at the UHF office:
801-484-0325 or western@hemophiliautah.org

*We need foursome sponsorships, prizes, and volunteers.
Please contact a UHF staff member if you can help!*



By Alexandra Maddox
770-634-4374
AMaddoxSells@gmail.com
KellerWilliams Utah Realtors

My husband Mike has hemophilia A and all three of our daughters are carriers. Our lives were forever changed in 2013 when he received his diagnosis. Without this community we would have been lost. The education, support, and friendships we have experienced are priceless. I, truly, don't know where we would be without the Utah Hemophilia Foundation and all of you.

In the spirit of spreading awareness about bleeding disorders and to give back to this great community, I want to donate 10 percent of my commission to the UHF, from any real estate transaction referred to me by community members, friends, or family. Please feel free to contact me if I can help you with any of your real estate needs.



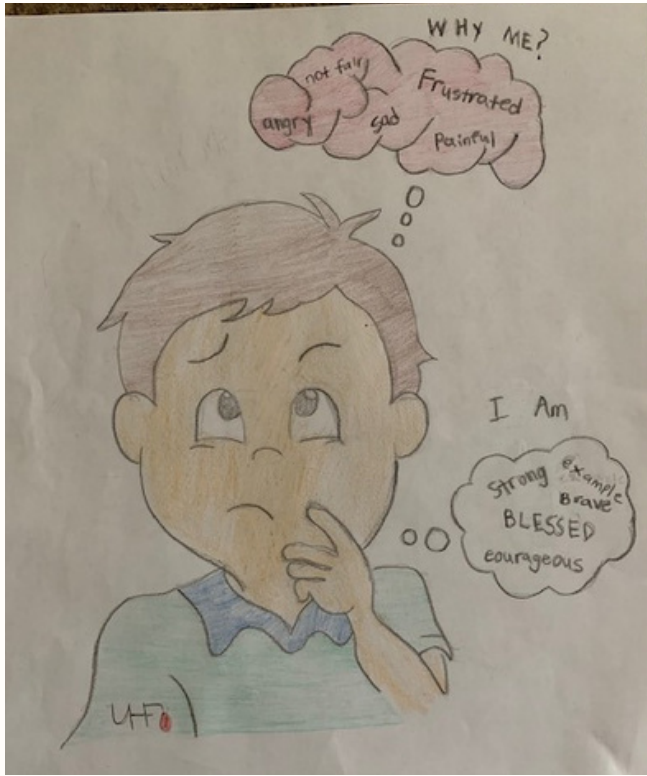
UHF
HELPING HANDS

Make a Great Buy - Support a Great Cause

How your Amazon order 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.





Many thanks to our sponsor

octapharma

for making this possible.

Tips for a Safe & Healthy Summer



As recommended by the Centers for Disease Control (CDC)

BEFORE TRAVELING, CHECK THE HEALTH AND SAFETY RISKS OF YOUR DESTINATION.

CHECK THE SAFETY MEASURES OF ALL POOLS WHERE YOU PLAN TO SWIM.

BEAT THE HEAT BY STAYING HYDRATED AND IN COOLER AREAS DURING THE HOTTEST PART OF THE DAY.

BUCKLE CHILDREN, PROPERLY, INTO CAR SEATS. MAKE SURE CHILDREN WEAR HELMETS WHILE BIKING, BLADING, SKATING, AND SCOOTERING.

We Have a Winner!



BentLee Searle, age 10, was the winner of the recent UHF art contest. BentLee's design depicts his life experiences with hemophilia. BentLee's design will be featured on a jersey worn by professional bowler Chris Ingram at the Pro Bowlers Association (PBA) Tournament in Lehi, Utah on June 26.

Chris Ingram has severe hemophilia A. At the age of 16, he started bowling as a way to stay active and help strengthen his joints. Because the PBA is in Utah, Chris wanted to represent Utah kids and bleeding disorders. Later this summer, Chris will lead a bowling activity for camp aged kids. Watch for more information about this fun event, coming soon.

- Keep vaccines of all family members up to date.
- Food poisoning peaks in summer. Beware of picnic foods left out in the sun too long.
- Protect yourself from insects. Use repellent and wear long sleeves and pants in the early morning and evening hours, when bugs are most active.



Let Your STAR SHINE

By Kari Woolf, UHF Board President

At our recent Adult Retreat, we talked about the importance of telling our stories. The discussion spurred some great ideas, including a suggestion to produce short video clips featuring members of our community. So if you want to get your story out there to create more awareness about bleeding disorders, help other community members connect with you, and aid the UHF in its mission, now is your chance! The process will be super simple. Think of it like filming a Tik Tok video—only slightly longer and with a LOT more substance. 😊

Here's what you need to do:

1. Use your webcam or even your phone, but make sure you're sitting and that your background is free of anything that would distract from you and your message.
2. Choose a spot with good lighting and wear whatever makes you comfortable (just avoid stripes or bold patterns, as they don't film well).

Record yourself briefly answering these four questions (no more than a minute each). You don't need to be scripted; speaking from the heart always works best. And don't worry about slip ups or pauses, as we'll edit those out. We'll also let you see a final cut to make sure you like the end result.

- Where did your bleeding disorders story begin?
- What are the most significant challenges you have faced?
- How has the UHF and its community supported you in your journey?
- What's the most important thing you've learned that you'd want to share with someone else in your shoes?

This opportunity is open to adults, parents, teens, and even kids! We'll feature the clips on our web site as a way to inform stakeholders about our members and mission and to help new members find people who can relate to their situations. We may also edit the footage into a single, montage-style piece that features clips from several individual videos. So let your star shine bright and tell us your story! You can email your recording to Jan (western@hemophiliautah.org) by August 1.



It is with great sadness that we acknowledge the passing of Wayne Hill, our camp chef and dear friend. Chef Wayne was an institution at Camp Valor, always endeavoring to make camp a great success. Camp will never be the same without his warm smile, endearing affect, and his famous pulled pork sandwiches He will be greatly missed and forever remain an integral part of the Camp Valor legacy.