



Utah Hemophilia Foundation

# The Linking Factor

August/September 2022

Volume 2 Issue 2



## UHF Golf Tournament: A Great Day "FORE" Raising Money

What's green and full of holes? On Monday, August 29, more than 130 golfers were able to answer that question. It was the beautiful golf course at Jeremy Ranch, the site of this year's Utah Hemophilia Foundation Golf Tournament.



For 26 years, the UHF Golf Tournament has challenged the golfing skills of all participants, and provided an incredible day of fun. Jeremy Ranch was a phenomenal partner, helping us to provide the best golfing experience, yet.

A beautiful mountain backdrop and a few four-legged guests (as seen in this photo) made for a very memorable day.



We are grateful for the tremendous generosity of all involved with this year's tournament. The UHF raised more than \$90,000 to continue much needed programs and services for Utahns with bleeding disorders.

A shout out of appreciation and heart-felt thanks to all the volunteers and sponsors that made everything run so smoothly. It is their kindness and support that made this day such a HUGE success!



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# 2022 Golf Tournament

## Thank You for Donating Prizes for our Raffle & Silent Auction



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# Board Update

By: Kari Woolf, Board President



Dear UHF Community:

What a spring and summer we've had at the Utah Hemophilia Foundation! Our list of in-person events has grown (hello, Teen Retreat, Camp Valor, Everybody's Here, and Community Voices!), and we couldn't be happier to be together again. We appreciate every member of this community and all the support, enthusiasm, openness, and caring you provide to one another. Thank you for letting me be a part of it all.

In Board news, we welcomed Zac Redford to our ranks in July, and his perspective--as someone directly affected by a bleeding disorder--has been so very valuable. If you know Zac, you also know how much fun he is, so we're all really enjoying all the dimension he adds to our board. Thanks for serving, Zac!

We also held our primary annual fundraiser, the Fore a Cure Golf Tournament, at the end of August. It was a gorgeous day at the amazing Jeremy Ranch course, and all the golfers had a great time supporting our cause. Thanks to everyone in the community that helped field teams, solicit prizes, and volunteered that day. And a HUGE thanks to David Ohlson, who has put heart and soul into this event for many years.

We also want you to be aware of the many organizations in our area that sponsored the tournament. Please return the favor with your own business whenever the opportunity presents.

And speaking of fundraising, don't forget to do your Amazon shopping using AmazonSmile and choose the Utah Hemophilia Foundation as the charity to receive half a percent of all your purchases. It might not sound like much, but it adds up! In fact, the UHF has already received about \$2,000 this year in donations from Amazon through this program. AmazonSmile paid out more than \$355M to charities in the first half of this year alone, so let's get our fair share of that goodness--and then some!

Thanks again for all you do. I look forward to seeing many of you at our Women's Retreat later this month!

-Kari



# Matt Chapman

Reginal Account Manager

Learn more about  
our focus on  
the rare bleeding  
disorder community

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# What's Happening?

**September - December 2022**

We've still got plenty of great activities before the year comes to an end. Mark your calendars and watch for more info coming to your email, very soon.

*Thursday, October 27*

## **MISSION: PET**

Draw, scavenge for things around the house, answer questions in the chat, respond to polls, and do a little research; all to help accomplish the "secret" mission. This interactive challenge is a little silly, a lot of fun, and hopefully thought-provoking. A great [virtual activity](#) for the entire family!

*Saturday, November 12*

## **FAMILY FEST & RESOURCE FAIR**

*Loveland Living Planet Aquarium, Draper, UT*

The UHF is turning 64 - come and celebrate with us!

There will be a host of bleeding disorders information and a lot of fun!

*Thursday, December 1*

## **HEALTHY COOKING DEMONSTRATION**

A [virtual family activity](#), featuring Chef Mike Hargett  
Cook right along with Chef Hargett as he instructs  
how to prepare a delicious meal for your family.



Dr. Sashi Goteti considers himself a global citizen as he was born in India, raised in Canada, and educated in Dominica and the USA. He is passionate about improving the quality of life and access to medicine for his patients, especially those who are under-served.



Dr. Goteti moved to Utah with his wonderful wife and daughter, who recently turned one. With his family, he loves traveling, hiking, and trying new vegan cuisines.

Dr Goteti will join Dr. Meznarich at Primary Children's August 29th, seeing patients in clinic later in September.

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# 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)

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

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MAT-US-2100002-v2.0-06/2021



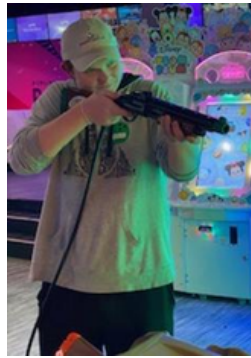


What happens when 18 teens with bleeding disorders and 10 incredible volunteers spend two nights at the Best Western Cotton Tree Inn in Sandy?

You get the **UHF TEEN WEEKEND**. (And what a **FABULOUS** weekend it was!) Amazing educational workshops, delicious food, tons of laughter, and games galore were all the rage this weekend.

Jessica Steed from Sanofi, kicked off Friday with a presentation on creating community. Saturday was spent with Mark Spalding, teen counselor and member of Utah's BD community, who led a remarkable and thought-provoking discussion on the "Nuts and Bolts of Being Human." Volunteer, Leo Tellez, led all in an improvisation challenge, which got us all thinking (and laughing) outside the box. Additionally, our HTC team led small group discussions, giving teens the opportunity to share their struggles and successes. Saturday night ended at *Round One* Arcade in the South Towne Center, where teens enjoyed karaoke, bowling, arcade games, and all the pizza they could eat.

Can't wait for the next UHF teen activity? Well, neither can we! Watch for more details coming to your email, very soon. We hope you can join us!!





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

### My work is guided by:

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PP-HEM-USA-1480-12

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Printed in USA/May 2021



## A Glimpse into the Mad Science of Camp Valor

August 1-4, 2022; Camp Wapiti, Tooele



It's been two long years since we have been at Camp Valor and it sure felt good to be back. This year, 27 kiddos registered to attend (and for 19 of those kiddos, it was their very first time).



The main goals of Camp Valor include: teaching kids how to independently manage their bleeding disorders; creating a safe space to engage in traditional camp activities; allowing kids the chance to develop friendships with other kids "just like them;" and focusing on things they CAN do, not the things they can't do.

*Camp would not be possible without the help of MANY incredible volunteers.*



*Climbing the rock wall, drumming, knot tying, 9-Square, and learning the strategies of chess were just a few of this year's favorite activities.*



*Our favorite "mad science" experiments included cracking open geodes, making elephant toothpaste and slime, using Mentos to send diet Coke rockets to the sky, making hover crafts, and learning all about "creepy" critters.*



*The swimming pool and a myriad of water games made the heat bearable.*



*Of course, the focus of Camp Valor is teaching kiddos about their bleeding disorders; which includes learning to self-infuse. The best part of camp is celebrating with those kiddos who learn to "poke" themselves for the very first time.*



**SHOUT OUT TO EVERYONE WHO WORKED SO HARD TO MAKE CAMP VALOR SUCH A SUCCESS!**

A very special

Thank you!



...To these wonderful volunteers, FLO & GLENN GRAHAM, who shared their time and talent to make this beautiful quilt, honoring friends of Camp Valor that are no longer with us. This quilt was presented at Camp Valor in a special evening ceremony, which featured beautiful memories shared by Craig Price.

WE ARE  
**FAB**



## FAB CONFERENCE (FEMALES & BLEEDING)

September 23-25, 2022

For women and girls, ages 12 and older

**Best Western Plus CottonTree Inn**

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## 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](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

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

### The Linking Factor

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