



THE EXPERIENCE OF A LIFETIME

Have you ever had the desire to climb Mt. Everest?

Meet Derek Nelson, a member of Utah's bleeding disorders community. Derek made a recent climb to Mt. Everest Base Camp and, by doing so, he realized a life-long dream.

Read about his experience and learn why it was important for him to tackle this incredible challenge.

Derek Nelson is a member of Utah's bleeding disorders community. He and his amazing wife, Krisdee, have two daughters and two sons with hemophilia.

What inspired you to make this trip?

Spending time at Everest Base Camp has been on my list of things to do for nearly 25 years. There's a sense of mystery to the high Himalayas that I have always found myself drawn to. I wanted to see the mountains and experience the unique culture of this area. I have always loved the history of people trying to climb the mountain and the modern-day stories of the climbers who have overcome challenges in their lives to reach the summit.

Of all your experiences, which are most memorable?

The best part of the trip was visiting the people with hemophilia in and around Kathmandu. It amazes me how the ties of hemophilia bind us together no matter where we live on the planet. I could pick up a conversation (assuming it was in English) with any of the locals, and hemophilia was always the starting point of a beautiful interaction.

We rented a movie theater while we were there. The Nepal Hemophilia Society invited all its members to watch a screening of *Bombardier Blood*, and almost 200 people showed up. The film had been translated with subtitles into Nepali, and to watch this with the locals was magical. When the movie showed Chris reaching the summit of Everest, spontaneous cheering filled the room. I may have shed a few tears as the locals with hemophilia told me about their goals after the film.

You must have had so many challenges. What was the most difficult part of your journey?

The physical trip up to base camp was difficult. It took a good deal of training beforehand, and I was often tired at the end of each day of trekking. But there was so much beauty along the way. Not only the mountains, but the prayer flags, the prayer wheels, the Sherpa people, and the high-elevation monasteries that we visited.

Witnessing the poverty in Nepal was also very hard on me. We visited the HTC in Kathmandu, and they have so little to work with. I saw patients who had extreme joint disease and very little access to medication. I wished so much that I had more power to change this.



A breathtaking view of Mt. Everest.



Do you have any advice for someone who, also, has the dream of experiencing Mt. Everest?

Do it! Put it on your goals list and make it happen. You never know how long these types of experiences will be available to any one of us. No matter what your goal, do something today that gets you a little bit closer.

(Left) The hemophilia care unit at the hospital in Kathmandu

How has this experience changed your life?

I love pursuing goals. I believe that life is meant to be lived, and climbing mountains is a great metaphor for the challenges we face in life. I have found that the more we challenge ourselves, the more we grow. And the more we grow, the more fulfilling life becomes.

There was a lot about this trip that scared me, but I did it anyway. At Camp Valor, we teach our kids that growth happens when we get out of our comfort zones. It applies to adults too. I felt so grateful for my life as I watched the sunrise over the highest peaks in the world, and so grateful for the wonderful people in it that make it even more meaningful.



(Left) The bleeding disorders community in Kathmandu celebrates World Hemophilia Day. (Right) Derek with a Nepalese family. "The people of Nepal are so welcoming, and we were treated with extreme kindness everywhere we went."

A Little Bit of UHF

FUN

The Adult Retreat was an amazing chance for couples to get away from it all and enjoy time with friends. Dr. Dave Robinson delighted us with presentations focused on improving our relationships. Ryan Rushton and Penni Smith of the HTC reminded us of important insurance tips and taught self-infusion techniques. Everyone walked away with a caricature of themselves as a fun souvenir. All in all, it was a GREAT weekend!

Thank you **Bayer, CSL Behring, DrugCo, Genentech, InfucareRx, Novo Nordisk, Octapharma, Sanofi, and Takeda** for your support of the Adult Retreat!

Adult Retreat

April 28-29
Courtyard Marriott, Layton



Everybody's Here

Summer Picnic

June 10
Lorin Farr Park, Ogden



The UHF kicked off summer in a big way at the Everybody's Here picnic. Families gathered for bleeding disorders information, games, prizes, lunch from Goodwood BBQ, topped off by a trip to the Eccles Dinosaur Museum.

Big shoutout to the following companies for their support: **Bayer, CSL Behring, CVSHealth, DrugCo, Hema Biologics, InfucareRx, Octapharma, Optum, Novo Nordisk, Sanofi, and Takeda.**



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

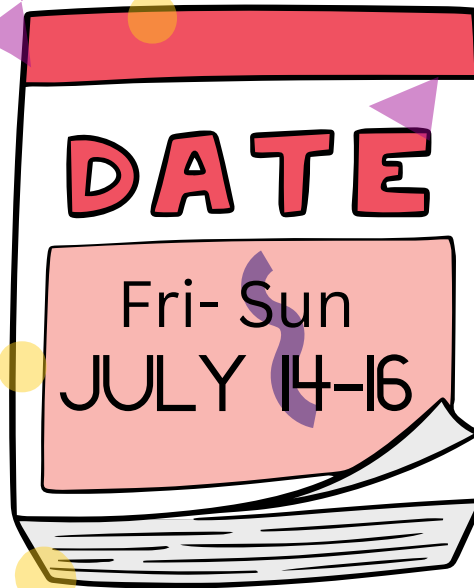
What's Next on the UHF calendar?



M-Powered

Fleming's Prime Steakhouse
Salt Lake City

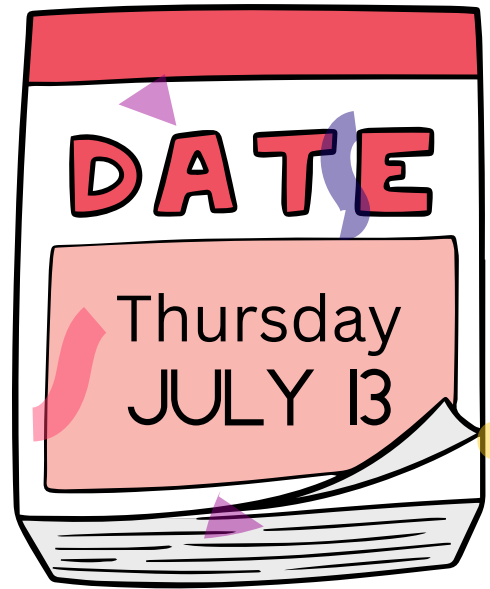
An evening for and about women in Utah's bleeding disorders community. Find strength and support in one another and find your empowerment from within.



Camp Valor

Camp Wapiti, Tooele

Was it Col. Mustard in the library with the candlestick? At this year's Camp Valor, we'll spend the week figuring out WHODUNNIT! Activities like swimming, archery, arts & crafts, climbing, and hiking will, also, be included. Hurry! Registration ends very soon.



Teen Weekend

Best Western CottonTree Inn, Sandy

Games, activities, great food, and connections with other teens in the bleeding disorders community. For all teens, ages 13-19. If you like lots of laughter and making friendships that will last a lifetime, this is the space for you!



PLEASE JOIN US!!

**Contact Jan Western @ the UHF office
to register for these events**



Board Update

By: Kari Woolf,
Board President



Dear UHF Community:

The phrase that keeps coming to mind is, "We're baaaaaaaaaack!!!" When I look at the full calendar of events for our community, I know we're back. When I see campers excited to be back around the fire pit for the second year running, I know we're back. When planning for another golf tournament to raise funds for our programs in full swing, I know we're back. And being back feels so good!

Thank you all for being patient and finding ways to continue connecting while we weathered the worldwide challenges of the last few years. And thank you for continuing to be there for each other...the very most important thing we can do. As I've met newly diagnosed families at recent events, I remember so vividly how it felt to be in their shoes. I was frightened, overwhelmed, and beset with questions about what our lives would be like. The UHF--and so many of YOU--instantly quelled those fears and showed me that we had friends in our court who would help us not just survive, but thrive.

Whether you've been able to attend events recently or not, I hope all of you have at least a few UHF members on speed dial. And if you don't, make that your goal at the next UHF event. Tapping into the knowledge of those who have traveled the path is so incredibly helpful. And sharing your own experience to help someone at the start of the path is rewarding, too. It's a virtuous circle--one I'm so grateful to be a part of.

Speaking of grateful, I want to thank Ryan Rushton for his service on the board. As many of you know by now, Ryan is embarking on a new career journey. His energy, enthusiasm, and willingness to ask great questions has been invaluable on our board during his time with us. Luckily for us, he and his family are members of the bleeding disorders community, so this isn't goodbye. :)

Let's all celebrate being fully back and commit to engage in all the ways we can. Hope to see many of you at camp, the golf tournament, the women's retreat, and our "Everyone's Here" event to round out a fabulous year.

Warmly,

Kari Woolf

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Explore Head-to-Head Pharmacokinetic (PK) Study Data

See half-life, clearance, and other PK data from the crossover study comparing Kovaltry[®] and Advate[®].

Visit [Kovaltry-us.com](https://www.kovaltry-us.com) to find out more.

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Antihemophilic Factor (Recombinant)



Children, ages 8 and older,
may attend with a parent.
Please attend all four sessions.

Classes taught by
Penni Smith, RN-BC



Register by contacting:
penni.smith@imail.org
801-662-4726

Classes start at 6 pm @
Utah Parent Center
5296 Commerce Drive, Ste. 302
Murray, UT 84107

Class size is limited

Register Today!

2023 Utah Hemophilia Foundation

Golf Tournament



Monday, August 28, 2023

Jeremy Ranch



The Utah Hemophilia Foundation's largest annual fundraiser that funds programs and services to help **YOU!**

Can You Help?

- Ask family and friends to sponsor a foursome
- Donate prizes to the golf raffle and auction. All new items accepted
- Volunteer the day of the event

Please contact Jan Western
@ the UHF office



FACTOR UP

with ALTUVIIIIO™

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week



HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).^{*†}

48 HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,[†] ALTUVIIIIO offered adults the longest half-life of any Factor VIII therapy.

0.7 BLEEDS PER YEAR[‡]

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[†]

In people taking ALTUVIIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

^{*}Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

[†]159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

[‡]Data based on treated bleeds.

CONNECT WITH YOUR CoRE TODAY

Learn more about ALTUVIIIIO, living with hemophilia, and treatment options from your local CoRe.



Jessica Steed
jessica.steed@sanofi.com
602-321-0372
Serving AZ, CO, and UT

INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full [Prescribing Information](#).



Hemophilia Federation of America

The HFA's **Job Readiness Grant** provides up to \$1,000 for a skills course, certification, or training. The grant can, also, cover materials needed to access the course, such as a computer, specialized uniform, or supplies. For more information, visit www.hemophiliafed.org/resource/job-readiness/



HELPING FORWARD

APPLICATION

- ✓ Complete the brief online application
- ✓ Provide a brief statement about the barriers to employment you have faced and how the specific course, certification, or program will help you gain or keep sustainable employment
- ✓ Proof of a bleeding disorder
- ✓ Your resume
- ✓ Documentation of the course, certification, or program cost
- ✓ A reference letter (optional)

EXAMPLE TRAININGS:

- Phlebotomy technician certification
- Customer service
- Dog groomer
- Medical billing and coding
- Salesforce administrator
- Veterinary assistant
- Marketing and event planning
- Fitness and nutrition coach
- Peer support specialist
- Foreign language
- Project management
- SQL certification
- Course plus subscription
- Electrician apprenticeship
- And many many more!

ELIGIBILITY

- ☀ Have a diagnosed bleeding disorder or are a carrier
- ☀ An adult between 18 to 64 years old
- ☀ Seeking assistance for a skills course, certification, or training program
**college courses considered*
- ☀ Not a past receipt of a Job Readiness Grant, an HFA board member, an HFA staff member, or the immediate family members of HFA board or staff members.



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