COLORADO CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
cohemo.org

THE COLORADO BLOODLINE

news from your local nonprofit for all bleeding disorders

Quarter One Newsletter

January 23rd, 2020

PROGRAM & EVENT CALENDAR

A Note from Your Executive Director

Greetings Community,

My first 6 months as Executive Director with the Colorado Chapter have been a fun filled adventure, and I'm excited to enter the new year – and new decade – together with you to make a difference in our community. In the spirit of new, we are excited to offer a new format for communicating with you: The Colorado Bloodline, our quarterly electronic newsletter. This piece will highlight key events in the Chapter as well as notable news, research, and education items from around the globe. We will use our monthly Program Update to take a deeper dive on program events and activities occurring 10-90 days out. Collectively we hope you will find these pieces intentional and informative, and as tools you can use to plan your engagement with our work. We are all in this together and I look forward to a landmark year that showcases the great progress moving our state forward.

Alongside,

Perry





UPCOMING EVENTS

January 25h: Backpack + Bleeders Climbing in the Springs

February 9th: Education Series Dinner: Takeda presents...

February 15th: Backpack + Bleeders, Snowshoeing in Frisco!

February 26-28th: Washington Days

March 8: Backpack + Bleeders, Bleeders on the Slopes at Winter Park

March 29th: Education Series Lunch, Genentech: Science of Connection

April 17th: State Advocacy Day

April 17-19th: Education Empowerment Days

BACKPACK + BLEEDERS

We are committed to trailblazing the way for those affected by bleeding disorders. We encourage our community members to step out into nature, to forage ahead on their own path of independence. And we are here to help you every step of the way. Just because it's cold out doesn't mean we cannot enjoy our backyard!

Snowshoeing Mayflower Gulch in Frisco, February 15th

REGISTRATION CLOSES MONDAY FEBRUARY 3RD

This half day adventure will be led by our beloved Camp friends from Breckenridge Outdoor Education Center on this scenic hike for all. Join us as we hike and discus the importance of winter hiking awareness in the beautiful Mayflower Gulch located in Frisco, CO.

Bleeders on the Slopes at Winterpark March 8th

REGISTRATION CLOSES FEBRUARY 21ST

We challenge you to join your bleeding disorder community to discover and strengthen your outdoor winter skills. To make this possible, NHF Colorado is providing a full ski experience at Winter Park that includes lift ticket, rentals, and a $20 food voucher that can be used at all Winter Park owned areas. There are only 50 lift tickets available and 25 lessons available so act fast!

BACKPACK + BLEEDERS INFORMATION AND REGISTRATION

NATIONAL HEMOPHILIA FOUNDATION APPOINTS NEW PRESIDENT AND CEO

LOOKING TO CONNECT?

Are you new to Denver or the Bleeding Disorder Community? Or do you feel as if you serve more of that veteran role as someone who has successfully navigated and achieved autonomy in the community?

The Connections Program is designed to connect families together, where new families can learn from more experienced families about living with a bleeding disorder.

Your participation is completely voluntary and can be withdrawn at any time upon your request. Your information will not be used for any other purpose or released to any other parties.

NHF CO Consent to Contact Form



Dr. Leonard A. Valentino

PRESIDENT
&
CHIEF EXECUTIVE OFFICER

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

The Board of Directors of the National Hemophilia Foundation (NHF) announced on January 17th that Dr. Leonard A. Valentino will be the foundation's next President & Chief Executive Officer. Dr. Valentino will take the helm on February 17, 2020, and work to advance the foundation's mission of education, advocacy, and research. Dr. Valentino was a standout candidate who was identified through a national process.

Dr. Valentino brings more than 35 years of clinical and research experience related to bleeding disorders to the role, aligning with the board's strategy of a more research-focused agenda. Prior to his most recent work with Spark Therapeutics, a biotech startup, he founded and led the Hemophilia and Thrombophilia Center at Rush University Medical Center in Chicago, where he successfully balanced a $10 million budget to support research grants, research and clinical teams – keeping the patient and their families as his core focus. Additionally, he has held leadership roles with key industry groups. In these roles, Dr. Valentino was responsible for managing the global medical teams who successfully led strategic planning for multiple worldwide hemophilia product launches.

To read the entire press release follow the button below.

Read More

NHF COLORADO ACADEMIC SCHOLARSHIPS

NHF Colorado strongly believes in the importance of education and investing in the bleeding disorder community. The chapter awards two scholarship annually, The Colorado Family Fund Scholarship and The Jana Marie Lambert Memorial Scholarship.

Education Series: Food For Thought

Presented in Spanish

Delievered by Takeda

February 9th

1:00pm-3:00pm at El Jardin Restaraunt

Maintaining a healthy lifestyle that balances proper nutrition and emotional well-being is especially important for people with a blood disorder. This presentation of Food for Thought considers how Incorporate healthy choices and stress relief into your daily routine.

More Information and to Register

The Jana Marie Lambert Memorial Scholarship is an annual scholarship in the amount of $1,500 to a member of the Colorado Chapter of the National Hemophilia Foundation. Jana became active in the Hemophilia community when her son Carter was diagnosed with both Hemophilia B and Von Willebrand's disease. After her son's diagnosis, Jana herself was tested and found to have a non-specific platelet disorder, suspected to be vWD. The Jana Marie Lambert Memorial Scholarship was established in 2016 to honor Jana's life. Born on December 1st, 1968 in DeSoto, TX, Jana died from complications due to breast cancer on April 25, 2015 in Broomfield, CO.

The Colorado Family Fund Scholarship of $1,000 is supported by the chapter who belives in supporting and helping create our future leaders.

Applications will be available soon!

ADDITIONAL SCHOLARSHIPS

Beth Carew Memorial Scholarship, deadline February 26th, 2020

The Beth Carew Memorial Scholarship Program is an annual competitive educational scholarship sponsored by the Colburn-Keenan Foundation.

This scholarship was created in honor of Beth Carew. She was one of the few women to be diagnosed with hemophilia A. Beth Carew died in 1994 of complications associated with Hemophilia. Beth was an outspoken advocate for the needs of families with bleeding disorders and for the needs of women who were affected by bleeding disorders in any way. She was a kind and compassionate soul and a relentless fighter. She lived and died with the challenges of hemophilia. She was truly a woman of whom we all can be proud.

The number of scholarship awards vary and the scholarship amounts range from $500 – $6,000 annually and are not renewable.

More Information on Beth Carew Memorial Scholarship

Disclaimer

The medical information in this newsletter is for information purposes only and is not to be taken as medical advice. If you have any questions or concerns always consult with your medical provider.



ADVOCACY AND YOU

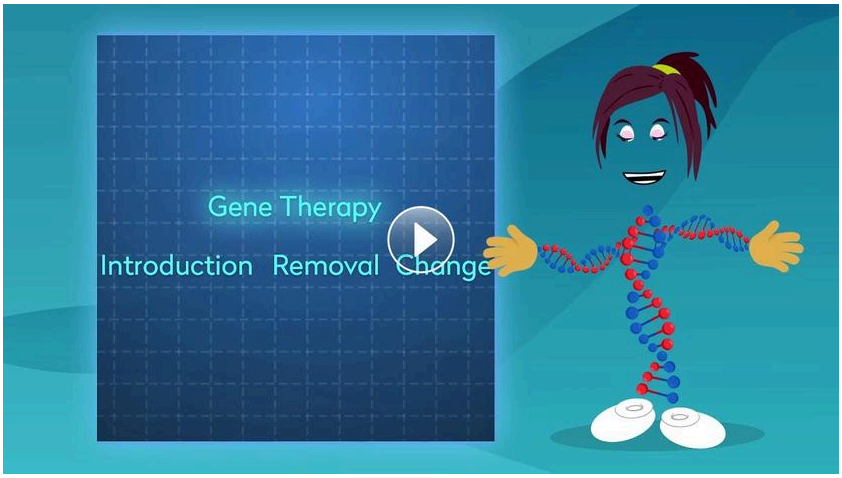
The National Hemophilia Foundation (NHF) has advocated for the needs and interests of people affected by hemophilia and related bleeding disorders for almost 60 years.

In 1998, NHF was instrumental in securing passage of the Ricky Ray Hemophilia Relief Fund Act, which provided compensation to individuals (and their families) who acquired HIV from contaminated clotting factor products. Since then, NHF's advocacy efforts have raised awareness of bleeding disorders, protected individuals from discrimination, and ensured full access to high-quality care.

2020 Washington Days

In 2020 NHF Colorado Chapter is excited to share our voice at the federal level. NHF's annual Washington Days provides an opportunity for the community to come together to discuss key issues impacting access to care, learn about advocacy, meet with elected officials, and put a face on bleeding disorders. This year over 400 bleeding disorder advocates will flood the hill with red ties on March 27th.

IS 2020 THE YEAR OF GENE THERAPY AND HEMOPHILIA?



BioMarin Announces Three Year Updates on Investigational Gene Therapy

BioMarin recently announced updates on their ongoing clinical trial program for their investigational hemophilia A gene therapy valoctocogene roxaparvovec, which was developed for the treatment of adults with severe hemophilia A.

According to a BioMarin press release, participants experienced significant improvements in both annualized bleeding rate (ABR) and requisite FVIII replacement product usage. In one group of patients who received a larger dose of the therapy, ABR decreased by 96%. In addition, FVIII product usage in the large dose group demonstrated sustained efficacy three years post-administration.

Read More on BioMarin Three Year Update

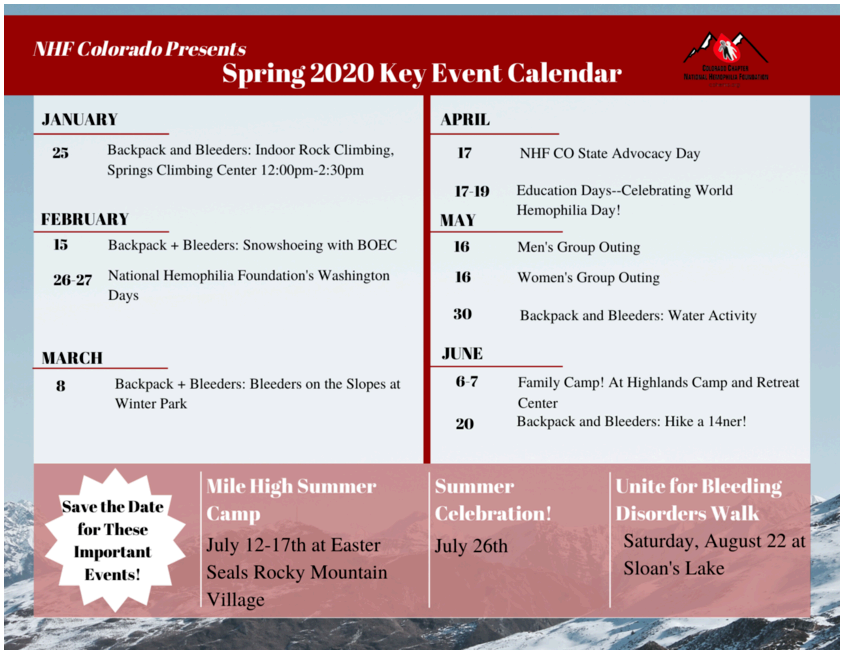
Pfizer Takes Over Development of Gene Therapy Canidate from Sangamo

Sangamo Therapeutics has handed over development of hemophilia A gene therapy candidate SB-525 to Pfizer. Up to this point, the investigational therapy had been developed by Sangamo, in collaboration with Pfizer.

Sangamo and Pfizer recently announced updated results from a phase 1/2 study of their hemophilia gene therapy candidate SB-525. Known as Alta, the dose ranging clinical study is designed to assess both the safety and tolerability of SB-525 in patients with severe hemophilia A.

According to a Pfizer press release, the Alta data presented at ASH included 11 patients treated across four varied dose groups. The data showed that SB-525 was generally well tolerated and demonstrated sustained increased FVIII levels following treatment with SB-525 through to 44 weeks, which is the extent of follow-up for the longest treated patient in the high dose group. The high dose group patients achieved normal range FVIII activity within 5-7 weeks of treatment with SB-525. It was also reported that the therapy was “generally well tolerated” across all dose groups.

Read More on Pfizer's Gene Therapy Update



CONTACT US

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