INFUSIONS

NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA · SUMMER 2019

Camp Hemotion 2019

Match in the gas tank! BOOM BOOM. Camp Hemotion, a place where strangers become friends and friends become family. Where we all come together to sing camp songs, swim in the pool, challenge ourselves on the ropes course and our high swing. This year we took the campers out of this world to explore the stars, moon, and galaxies. From our astronaut swim to our alien hunt that was a huge hit throughout the week, we made sure that each astronaut or alien of ours had an experience to never forget.

This year was Camp Hemotion's 41st year of running their program. Being surrounded by trees, wildlife, and our Bleeding disorder family in the beautiful Coarsegold. From old traditions to new traditions, celebrating birthdays, self-infusions, and even capturing the two aliens that were roaming around our campsite! It was on the final night of camp at our campfire that we were able to reveal that the two aliens that were on our campsite were Maddy and Julian from our staff! Luckily, all they wanted to do was to bring back all the fun

Continued on Page 4


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LET'S GO

Learning for Experiential Education

By Patrick "Big Dog" Torrey

At GutMonkey, we talk a lot about "adventure education." What does that mean? An adventure is an unusual, exciting, and somewhat risky endeavor with an unknown outcome—think Frodoand the ring here. Adventure education seeks to create experiences that let us explore not onlythe literal terrain of that adventure, but also what it teaches us about ourselves, our capacity,and the shared capacity of a community—think *Fellowship of the Ring* here.

I started working with this model 22 years ago, with teens in the remote wilderness of northern Idaho. The kids I worked with had troublesome stories that had hardened them deeply. These were kids who had been on their way to jail, who believed in violence as power, who believed they were bad people. How do you teach a different way of framing yourself? How do you teach self-love and forgiveness? And more important, how do you show people what they are capable of, and how to be vulnerable in front of other people?

There is no PowerPoint deck or book report that will engage the core of a teenager to grapple with himself. To help teens discover the best version of who they are, an adventure is the ticket. Taking a young person on a literal quest gives us a way as mentors and teachers to quietly introduce the inner journey; we can begin to talk about the really unknown, risky stuff called "feelings." When teens get to experience themselves in new ways, it helps them open up about beliefs they've been holding about who they are, what they can and can't do, and who they want to be. These beliefs and values are all based in emotions, and we can't change behavior or make logical choices unless feelings are validated and understood.

When I started working in the hemophilia community 17 years ago, I saw so many immediate parallels: these teens were trying to navigate their journey to young adulthood, struggling with self-infusion, for example. I saw adult counselors still carrying trauma from the blood contamination of the 1980s and 1990s. I immediately recognized a use for adventure education to build metaphors that would help people tackle these complex issues of self-efficacy, adherence, positive risk as a tool for growth, and making change when change is hard. Let me share a story that captures what I'm talking about.

Years ago, I was running a program at a hemophilia summer camp, and I asked a group of early teens, "Does anyone know how to play poker?" One of the kids knew how to play, so we played a quick round. I held up an invisible hand of cards, and he quickly caught on. "Okay," I said, "you've got a two, five, six, and two jacks." "I've got three kings, a seven, and an ace." Then I asked the group which one of us had the better hand. Everybody responded, "You do!" I nodded. To my poker partner, I said, "Okay, for now, put down your 'cards.' Now, raise your arms, and get them way out there in front of you like you're carrying a huge box." Once his arms were really, really far up in the air and out in front of him, I said, "That's your pile of poker chips." The kid grinned. He was rich! Then I showed him all my chips, as if I held them in just one hand: "I have one red, two whites, and one blue." Again I asked, "So, who's got the better hand of cards?" They all pointed at me. "Great. I've got the better hand, but let's take a look at how we're going to bet."

I told my opponent, "You have a lower hand, but how are you going to bet with all those chips?" Everyone responded that my opponent was going to bet BIG. I then asked how I would probably bet, and everyone responded, "Conservatively, even though you've got the better hand." I mused, "Sure...or I might go all in, but if I lose, that's it, I'm done. The thing is, poker chips are a lot like self-confidence. When you've got a lot of it, you can bet big, and lose big. On the flipside, if you don't have much of it, you tend to live small, and you're really, really cautious about the steps you take, and what you choose to do. If you make that choice to go all in, and you lose, it can be really easy to lose the self-confidence that you do have, and not want to get back in the game."

The next day we ran a ropes course activity called the Flying Squirrel. You're in a harness, wearing a helmet, and you're attached to a rope that is rigged to a pulley high up in the trees. At the command "Flying!" your group runs while pulling your rope, and you fly up in the air like Superman!

Continued on Page 9

Camp Hemotion *Continued from Page 1*

experiences that they had at camp to share with all their friends and family at home.

Each year an outstanding staff member and camper who almost exemplify Camp Hemotion are awarded the Todd Smith Award. This year our staff award went to Lisandro Rios. He had stepped up throughout the week and made sure that every camper and staff member he encountered was having a great day. Lisandro was consistently providing a helping hand to our staff as well as keeping watch on his cabin. There was never a day where we couldn't see his shining smile throughout camp.

The camper award went to Manny Eseroma. Just like we always wish, Manny was a camper who was always willing to try something new. He made friends with many campers and was always in great spirits. We all look forward to watching Manny grow further into our program.

Camp Hemotion provides a safe place for many campers to test their boundaries, by either climbing up the rock wall or even learning how to face their fear of swimming in a pool. There's never a dull moment from our morning aerobics lead by Vohn, Cup and Onion tradition at every mealtime and even at the Gaga pit where we all fight our battle to be the Gaga Champion.

Now, as the sun fades away and all the galaxies in the night sky became visible, our camp was near the end of its 41st year. As we all embraced our new brothers and sisters under the stars one thing for sure is certain, Camp Hemotion is no regular place. It's a place in the forest where obstacles, hurdles, and lifelong friends are made. A place where we see no differences and we drive each other to do the best in every way possible. This we hope, that as we leave this magical forest and into the real world, our campers and staff take with them the hurdles they've jumped and apply it to everything that they do. Camp Hemotion, oh how I thank you. For the memories that you have given me and for the friends I've met. There is no other place in the world where I would want to be but in the magical forest of Coarsegold California attending the one and only Camp Hemotion.

Angel & Areli Hernandez

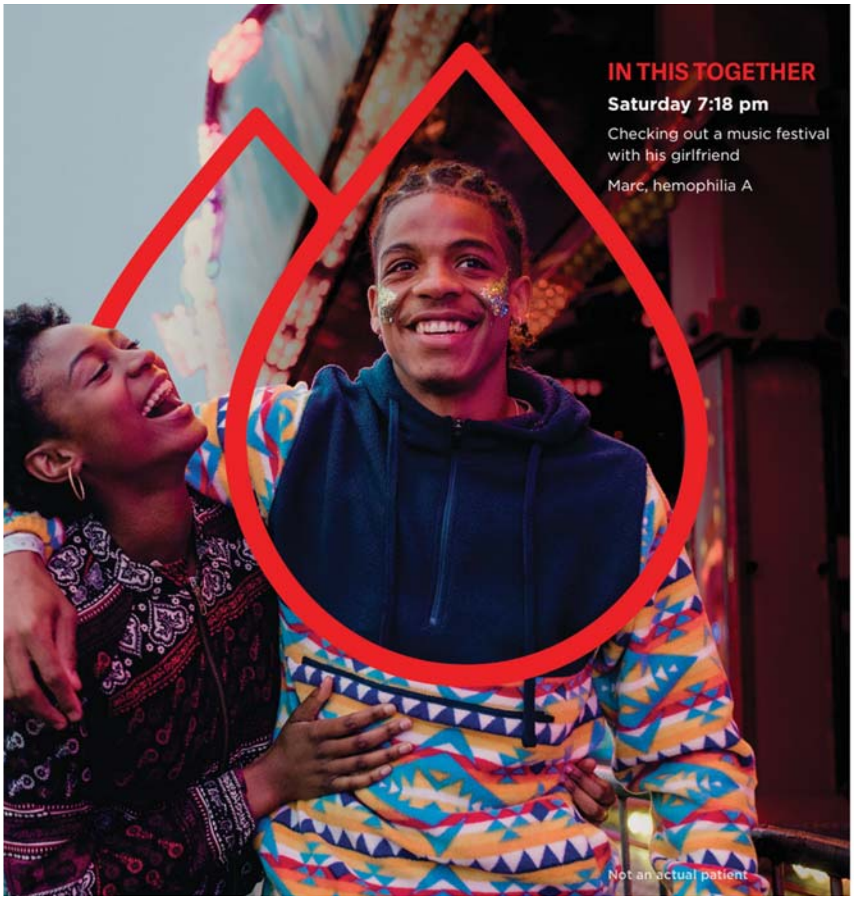
Community Spotlight: Kari Peepe

Kari Peepe has been a true leader in our community. She finds a way to give back to her bleeding disorder family as a volunteer, fundraising through her walk team. Take it away Kari!

“It’s hard to believe it’s been almost 9 years since we started our journey of trying to get Scarlett diagnosed. She was 2 at the time. Social services had been called because someone was alarmed of the amount of bruises they saw covering every inch of her body. It took over a year of trips to Stanford and countless pricks and sticks before we found out she had a very rare platelet storage pool disorder. . . And so did I.

I instantly went into research mode, trying to find out as much as I could about this disorder that would be keeping my child from playing any contact sports and living a “normal existence” and I found nothing. I trolled through every social media group I could. Scoured through countless websites and articles. And what I found was nobody talking about platelet disorders and more astonishingly nobody talking about females with bleeding disorders. This left me feeling alone and hopeless, so I decided to start writing about those feelings and sharing them with others. I started networking. I became obsessed. Along with two other women I started a Facebook group that focused on women with bleeding disorders and I started several different social media platforms about platelet storage pool disorder including my blog A Touch of Scarlett. A place where I highlight the ups and downs of being females diagnosed with a bleeding disorder.

Through this journey we’ve shared our stories, sought advice, mentored others and more importantly finally found others like us. Starting my blog thrusted me into a community I am forever grateful for. Our support and involvement in the Bleeding disorder community have given us the tools to venture down this road without the fears we started off with. Scarlett has been fortunate enough to grow up knowing our “normal” is different than others . . . and that’s OK. We both often find ourselves saying we’re grateful for our diagnosis because it’s made us who we are and given us friendships we wouldn’t find anywhere else.”



CALENDAR

October 3-5, 2019	NHF **Bleeding Disorder Conference, Anaheim, CA**	**NHF**
October 18-20, 2019	**Female Factor Retreat, Monterey, CA**	**HFNC**
October 20-23, 2019	**HFA Young Adult Advocacy Summit, Washington D.C.**	**HFA**
November 2, 2019	**Family Education Day, San Jose, CA**	**HFNC**
November 2, 2019	**Bombardier Blood Screening, San Jose, CA**	**HFNC**
November 13-14, 2019	**WFH Global Forum, Montreal, Canada**	**WFH**
December 2, 2019	**Giving Tuesday**	**HFNC**
December 5, 2019	**Healthcare Access Forums, Sacramento, CA**	**HCC**
December 7, 2019	**Holiday Party, Oakland, CA**	**HFNC**
December 8, 2019	**Posada, Morgan Hill, CA**	**HFNC**
December 14, 2019	**Holiday Party – Fresno, TBD**	**HFNC**
January 17-19, 2020	**Family Camp , Livermore, CA**	**HFNC**
January 17-19, 2020	**NACCHO, AZ**	**AHA**
February 22, 2020	**Asian Infusion, TBD**	**HFNC**
March, 2020	**Bleeding Disorder Awareness Month**	**HFNC**
March 7, 2020	**Emerging Therapies Forum, TBD**	**HFNC**
March 27, 2020	**Annual Meeting and Community Crab Feed, TBD**	**HFNC**
March, 2020	**Washington Days, Washington D.C.**	**NHF**

HOME CHAPTER ORGANIZATION

HFNC Hemophilia Foundation of Northern California
https://www.hemofoundation.org/
Auxiliary Fresno
Auxiliary San Jose

AFFILIATED ORGANIZATIONS

NHF National Hemophilia Foundation
https://www.hemophilia.org/
NHF Chapters (See full list at NHF):

HFSA Hemophilia Foundation of Southern California
http://www.hemosocal.org/

HASDC Hemophilia Association of San Diego County
http://hasdc.org/

CCHF Central California Hemophilia Foundation
https://www.cchfsac.org/

AHA Arizona Hemophilia Association
https://www.arizonahemophilia.org/

HFO Hemophilia Foundation of Oregon
http://hemophiliaoregon.org/

HFA Hemophilia Federation of America
http://www.hemophiliafed.org/

HCC Hemophilia Council of California
https://www.hemophiliaca.org/

WFH World Federation of Hemophilia
https://www.wfh.org/

PARTNER ORGANIZATIONS

HTC Hemophilia Treatment Centers:
Stanford University Medical Center
https://www.stanfordchildrens.org/en/service/hematology
University of California at Davis
https://www.ucdmc.ucdavis.edu/hemophilia/
University of California San Francisco
https://www.ucsfhealth.org/clinics/hemophiliatreatment_center/
UCSF Benioff Children's Hospital Oakland
https://www.childrenshospitaloakland.org
Valley Children's Hospital
https://www.valleychildrens.org/

MFTC Music for the Cause
https://www.musicforthecause.org/

On Time Can Be Too Late

By Michael Joshua

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I have hemophilia, but it doesn't have me. And it won't hold me back as I prepare to head off to college in August.

On time can be too late when preparing to transition from high school to college. Because I have a diagnosis of severe hemophilia B, my mother always started preparing for the next school year before the end of the current school year. During that time she would meet with the school nurse or administrative staff for a medical packet and to schedule an in-service if necessary. My mom always told me that my medical history is my personal business, and it's up to me to decide to share with others. However, it's very important that I inform those who need to know about my hemophilia and educate them on what's necessary in case I require medical attention and assistance.

Waiting until you graduate from high school is too late to prepare for college. When you grow up with a bleeding disorder, you learn that your normal is different from the normal of people without a bleeding disorder. I researched and determined which schools were the best options for me to attend. After campus visits, I began the application process and was able to discuss my medical needs with an admissions counselor. By October, I had submitted an application for early action admission and completed the FAFSA (Free Application for Federal Student Aid). Immediately after receiving acceptance in November, I reached out to an accessibility counselor at the Office of Accessible Education to discuss available resources and what I will need to manage my disorder. I got the necessary paperwork via email, and had it in hand to present to the hematologist during my six-month visit to the hemophilia treatment center. During this visit, I was able to get my hematologist involved and discuss what I will need to move out on my own and have access to care. In January I also met with a rehabilitation counselor at the Office of Workforce Development Rehabilitation Services regarding available resources for college.

In February I attended the admitted student visit. Not only did I participate in the activities scheduled, I also took the time to personally meet the counselor at the Office of Accessible Education. Among other accommodations, it was confirmed that I would receive a private dormitory room with no additional cost. Next, I familiarized myself with the location of Student Health Services, and met the staff there. I informed the nurse about my treatment schedule and learned about their hours, their services, and campus emergency numbers. Because factor is shipped by motorized delivery service and not by the US Postal Service, there is a specific process that has to be followed in order for the package to be received. When preparing to transition from high school to college, it's very important to plan ahead, be assertive, know available resources, and establish a support network. Although it didn't take a long time to navigate this situation, if I had waited until orientation, after move-in, then the time of a shipment or an emergency would not have been the best moment to learn. A new chapter of my life begins this August, but I am ready and not afraid of the challenge. I have always challenged the limits rather than limiting the challenges. As Malcolm X once said, "The future belongs to those who prepare for it today."

Michael is set to graduate from Baton Rouge Magnet High School in 2019, with plans to study political science and English at Loyola University in New Orleans in the fall. He aspires to practice law or become a sports analyst. Michael has a strong passion for helping others and enjoys spending time with family and friends, volunteering in the community, watching sports, and participating in competitive swimming and weight lifting.

Experiential Education *Continued from Page 3*

The group of kids from our poker game all participated in the Flying Squirrel that morning. That afternoon, as the group was walking back into camp, one of the kids said, “Hey Big Dog, I’ve got to tell you something.” He said, “Check this out. This morning, I went on the Flying Squirrel, and I was really, really scared. But I did it, and I went about halfway up. I got some really great poker chips from doing that, and then I went to ride horses this afternoon. I’m really scared of horses, but since I had more poker chips from doing the Flying Squirrel, I felt a lot better about going, and I rode for the first time, and it was awesome.”

I was so moved that this kid wanted to share all of this with me, and now we also had an opening! First, I validated that it was okay that he had been afraid, and then I praised him: it was so awesome that he’d taken the risk to gamble a little. Now it was time to take a deeper look, and ask some great follow-up questions, like “How many poker chips do you think you’ll need to be able to self-infuse this week?” or, “What are the things that are holding you back from having more poker chips in other places in your life?” or, “Where else could you be playing with more poker chips in life?”

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISRODERS

AMBER FEDERIZO, APRN, FNP-BC, DNP

Directora del Centro de Hemofilia y Trombosis de Nevada

Epigenetics, Desórdenes de estado de ánimo, Desordenes Sanguineos

RUTH HUEZO, MSW, LCSW

SESSION EN ESPANOL

KELSEY MCCLELLAND GENETICS COUNSELOR, MS LCGC

Creadora del "DNA Dialogue"

Relaciones y Genéticas

WENDY ARONSON

Instructora de Yoga

Yoga en Playa Privada

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Experiential Education *Continued on Page 9*

Experiential Education

Continued from Page 8

AMBER FEDERIZO, APRN, FNP-BC, DNP
Director Hemophilia & Thrombosis Center of Nevada
Epigenetics, Mood & Bleeding Disorders

RUTH HUEZO, MSW, LCSW
SPANISH MOM'S SESSION!

KELSEY MCCLELLAND GENETICS COUNSELOR, MS LCGC
Creator DNA Dialogue
Genetics & Relationips

WENDY ARONSON
Yoga Instructor
Private Beach Yoga

The Hemophilia Foundation of Northern California
FOR ALL BLEEDING DISRODERS

THE FEMALE FACTOR
affected & connected

THE FEMALE FACTOR FIFTH ANNUAL RETREAT

October 18-20 2019

New Spanish Track!
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Karaoke
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A metaphor that started with a silly game of make-believe, combined with outdoor adventures, gave this kid a way to talk about his self-confidence and self-esteem. As adults working with teens, we need to create space for these conversations, and seize the opportunity when a teen broaches the subject. We also need to give teens tools to help them talk about their experiences—tools like poker chips. Ropes courses, horseback riding, and a make-believe game are all opportunities to create unusual, exciting, novel experiences that leave the outcome open to individual interpretation. *Our job from there is to support kids in seeing their own value, exploring what the experience means to them, and relating it to other places in their lives—like their bleeding disorder—where they have power over how they're playing their own game.*

Pat is founder and CEO of GutMonkey, an adventure education company that provides foundational, life-changing experiences for communities with chronic health conditions, to improve health outcomes, build communities, dismantle stigma, and increase awareness. To learn more, follow GutMonkey on Facebook and Instagram, and sign up for the newsletter at gutmonkey.com.

Unite for Bleeding Disorders

By Areli Hernandez

Hi everyone! My name is Areli Hernandez and this past May 2019, I participated in my first Unite for Bleeding disorders walk. I started my team, Bruising Babes, in honor of my younger brother who was diagnosed with Von Willebrand Disease back in 2005. Because of him we were introduced to so many wonderful people and the Hemophilia Foundation of Northern California. From a young age, I learned that the Hemophilia community is not just a community, but a family. A family who always takes care and reaches out to one another in times of success and hardships. The special place where I learned about the special bond that the community shares, was at Camp Hemotion.

Camp Hemotion is a place where both campers and staff encourage each other to become a better version of themselves. With a few days of training, tons of bonding opportunities, countless laughs, high fives, and camp songs, we as counselors commit to making sure that we give our campers the "best week ever." Staff members, or as we refer to them Camp Counselors, learn how to work together as a team and take care of everyone that we come across, whether it be by encouraging a camper to learn how to self infuse or even by moving a caterpillar away from the steps by our pool. Because of all the great experiences and friendships that I have been able to attain from attending camp since 2009, I wanted to make sure that many more young campers are able to create their own experiences and friendships. To continuously grow with their blood brothers and sisters, no matter the distance or even time zone, that they will always be able to call Camp Hemotion their home away from home. For that reason, Bruising Babes was formed.

Starting my own team was such a memorable experience to not only myself, but also my family. Once I set up my team page and talked about it to friends, family, and even my coworkers, all the support from everyone started to naturally flow. Every time I shared my story on why I wanted to raise money for the Hemophilia community, everyone was able to notice that I take so much pride at being a camp counselor and an activities director intern. They knew that their donations could make an impact on a campers life, the same way that camp has made an impact on mine. Having my own team taught me that we are capable of doing anything that we set our minds to. Also, that there are many people who don't really know much about bleeding disorders but they are more than willing to support in any way that they can, whether it be financially or by attending the Unite walk itself! I am very humble and appreciative of all the support and love that Bruising Babes and I have received.

I hope that by sharing my story on why I made Bruising Babes encourages you and your family to start your own team for the Unite for Bleeding Disorders walk 2020. Together as a community we can make anything possible. We can make sure that the magic of camp lives on for many more years.

Women in Community Use Strength and Leadership

By Ann LeWalk, Hemophilia Federation of America
Reprinted with permission by Hemophilia Federation of America, 2019

Ashley Gregory,
Chairperson,
The Female Factor

Ashley Gregory is a spirited member of the bleeding disorders community who became involved for the same reason many donors give... because someone asked her to!

Back in 2014, a group of women in northern California were drawn together by the fact there was no programming for women who were not just moms or women with bleeding disorders but those who were affected and connected. This was the birth of The Female Factor, a program of the Hemophilia Foundation of Northern California, which provides outreach, leadership guidance, advocacy opportunities, networking, education and support to all women in the bleeding disorders community.

It has been widely-recognized that many mothers, daughters and sisters within the bleeding disorders community go undiagnosed for many years. The Female Factor works to affect change for proper diagnosis and treatment for all women affected. Gregory, the program's chairperson, a hemophilia mom and symptomatic carrier with a recent diagnosis, shared, "My personal experience influenced my decision because I knew that many other women would walk a path similar to mine and I could smooth the road ahead of them by blazing the trail."

Gregory's involvement in the Female Factor came about when she was asked by community members who were looking for a non-industry volunteer to run a women's group. The timing was just right as she had some free hours during the day. Recognizing the importance of having a woman from the community in this position, she agreed to be the chairperson.

She continues to see the value in her role, "...because to be in this position, advocating for and creating programming for women, I can approach programming and grant requests from a woman's perspective, which is unique."

The first Female Factor Women's Retreat in 2014 was an intimate group of 11 affected and connected women. Clearly there was a need and an interest in networking and learning with other women because, by 2018, the annual educational event had grown to more than 60 mothers, daughters, sisters, grandmothers and friends. As the retreat transforms into a regional program, collaborating with other member organizations in California and other neighboring states, Gregory anticipates the 2019 event to have upward of 100 participants!

Gregory may have come into her role as chairperson of The Female Factor "because someone asked her," but she has nurtured the program as though it were her own. Her impact on the bleeding disorders community is felt beyond her work with The Female Factor. She serves on the Hemophilia Federation of America Executive Committee and works to promote HFA's Blood Sisterhood program wherever and whenever able. Gregory sees herself as an agent of change who looks to provide women with opportunities to be heard.

"I hope to show women in the bleeding disorder community that there is a place, voice and resource here for them that serves their unique needs and concerns," she said.

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISRODERS

Family Camp 2020

SAVE THE DATE

JANUARY

17-19

Camp Arroyo
Livermore, CA
Registration will begin on October 7th.
www.hemofoundation.org

The
Hemophilia
Foundation of
Northern California

FOR ALL BLEEDING DISRODERS

Family Education Day 2019

November 2, 2019 | 9:30AM

Evergreen Valley College
3095 Yerba Buena Rd, San Jose, CA 95135

HFNC Town Hall

Meet the board and staff of HFNC. Join the dialogue and shape the future of our community!

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What is gene therapy? What is gene editing? How will this new treatment impact our community?

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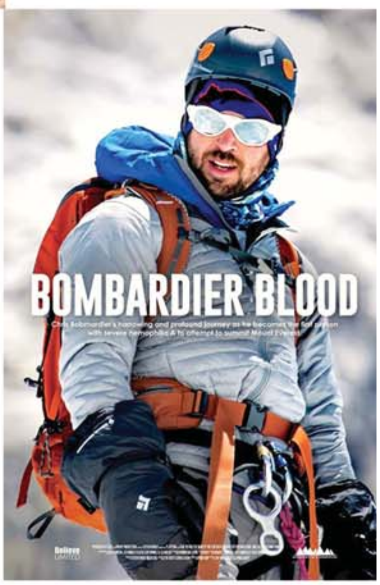

SPECIAL NORCAL PREMIERE OF BOMBARDIER BLOOD
Family Education Day

Colorado-based Mountaineer Chris Bombardier has never let hemophilia stop him from climbing some of the world's tallest mountains. In 2017, Chris partnered with hemophiliac filmmaker Patrick James Lynch and his award-winning production team at Believe Limited to film his journey through Nepal to summit the world's tallest peak, Mount Everest.

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Note: Activation requires a valid QR code from your doctor

myPKFiT™ for ADVATE Patients Mobile Application Intended Use

- The myPKFiT for Patients Mobile Application ("myPKFiT Mobile App") is intended for use by patients with hemophilia A being treated with ADVATE [Antihemophilic Factor (Recombinant)] who are 16 years of age or older with a body weight of 45 kg or higher, and their caregivers.
- The myPKFiT Mobile App is designed to make it convenient for you to record your infusion and bleed events, track your estimated Factor VIII levels following a prophylactic infusion, and export the data for review by your health care provider ("HCP").
- Your HCP can use the myPKFiT software to generate ADVATE dosage amount and frequency recommendations for routine prophylaxis using your age, body weight information, and laboratory tests that measure your Factor VIII clotting activity. Using myPKFiT software, HCPs can evaluate various prophylaxis dose regimens tailored to your individual needs and treatment plan.
- myPKFiT Mobile App should only be used by hemophilia A patients treated with ADVATE, as per the ADVATE Prescribing Information.
- myPKFiT Mobile App is not indicated for use by patients with von Willebrand disease. myPKFiT Mobile App should not be used by patients who have developed inhibitors to Factor VIII products.

myPKFiT for Patients Mobile Application is Rx only. For safe and proper use of the myPKFiT Mobile App, please refer to the complete instructions for use in the User Manual.

ADVATE [Antihemophilic Factor (Recombinant)] Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:
- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP if you:
- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA.
Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
Please see Important Facts about ADVATE on the following page and discuss with your HCP.

Learn more at www.ADVATE.com

References: **1.** Data on file: Takeda Pharmaceutical Company Limited, Lexington, MA 02421. **2.** myPKFiT for Healthcare Professionals v3.1 User Manual. 2018. **3.** Björkman S. Limited blood sampling for pharmacokinetic dose tailoring of FVIII in the prophylactic treatment of haemophilia A. *Haemophilia*. 2010;16(4):597-605. **4.** Álvarez-Román MT, Fernandez-Bello I, de la Corte-Rodriguez H, et al. Experience of tailoring prophylaxis using factor VIII pharmacokinetic parameters estimated with myPKFiT in patients with severe haemophilia A without inhibitors. *Haemophilia*. 2017;23(1):e50-e54.

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