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Hemophilia Foundation



2019 - CALENDAR **OF EVENTS**

Ocotber 23 Community Dinner – "Empowered: Tools for Self Advocacy"

Hodel's Country Dining | Bakersfield, CA

November 2

So Cal Unite for Bleeding **Disorders Walk** Griffith Park | Los Angeles, CA

November 10 Men with Bleeding Disorders **Dinner and Movie**

> District and Alamo Drafthouse | Los Angeles, CA

Santa Barbara Holiday Party December 7

> Santa Barbara Zoo | Santa Barbara, CA

December 14 Snowflake Festival

Santa Ana Zoo | Santa Ana, CA

December 18 Riverside Holiday Party

Mission Inn Hotel | Riverside, CA

December 29 Men with Bleeding Disorders -

LA Rams Game

Los Angeles Coliseum | Los Angeles, CA

January 25, 2020

Industry Forum Mt. Saint Mary's University | Los Angeles, CA

HEMOPHILIACTION

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The Hemophilia Foundation of Southern California

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Harry and Juanita Boessler in honor of Tyler and Michael United Way of Greater Los Angeles in honor of Ms. Lisa Marie Valarao

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A LETTER FROM THE BOARD PRESIDENT

The Hemophilia Foundation of Southern California has been busy these past few months. Our most recent event, Familia De Sangre, was a huge success with 700 people in attendance. This conference was a great opportunity for us to provide much-needed information to the Hispanic community not only to families in California but out of state as well.

Our next big event, the 11th Annual Unite for Bleeding Disorders walk, will take place at Griffith Park on November 2. The Walk is one of our main opportunities to raise money to send our kids to summer camp at The Painted Turtle. For those of you who have sent your children to camp in the past, I'm sure you have heard stories about what an amazing experience camp is. It is truly a gift that the Hemophilia Foundation of Southern California takes on the tremendous task of fundraising to send our kids to camp, but we need your help! Please visit www.uniteforbleedingdisorders.org/event/socal for more information on how to sign up, form a team and start fundraising! You can still participate and solicit donations from friends and family, even if you aren't able to attend the walk in person. We

look forward to seeing as many of you as possible. Not only is this a great opportunity to raise money for a wonderful cause, but it is also a chance to meet other people from the bleeding disorders community.

I also would like to welcome Michele Warner to our staff as HFSC's Director of Development. Michele has been involved with the Hemophilia Foundation of Southern California for several years and has served as a Board Member. We are very excited to welcome Michele in her new role, and I'm sure many of you will have the opportunity to meet her at some of our events, if you haven't already.

Sandy Knight, HFSC Board President

A LETTER FROM THE EXECUTIVE DIRECTOR

The summer whizzed by and now we are preparing for our biggest and only fundraiser of the year, our 11th Annual Unite for Bleeding Disorders Walk! I truly hope the community can come together to support one of our most important programs, Camp Blood Brothers and Sisters. We just celebrated our 40th year! Camp is hosted by the most amazing facility, The Painted Turtle, who are incredible at bringing out the best in each child. Camp costs the foundation \$100,000 each year and I hope you can all support our goal of funding every child who wants to attend. It's also a perfect opportunity for you to share and spread awareness about bleeding disorders with friends and family! By the way, it's an 80's themed Walk so find your best outfit and come out and join us.

Michelle Kim, HFSC Executive Director





WELCOME TO OUR NEW FALL INTERN!

My name is Karen and I am currently a senior at California State University, Long Beach studying for my bachelor's degree in Health Care Administration. I am excited to intern for the Hemophilia Foundation of Southern California for the next few months. After attending an event hosted by the foundation back in June for the first time, I felt passionate about getting involved and helping the community. For the next few months, I hope to gain a lot of insight and handson experience while interning at the foundation.



MEN'S RETREAT IRVINE RANCH OUTDOOR EDUCATIONAL CENTER



HFSC had an amazing time hosting the Men's Retreat at the Irvine Ranch Outdoor Educational Center on Sunday, April 28, 2019. Thank you to all the dads, teens and young boys who came out to network, socialize and build new friendships. The ice breakers were hosted by community members Scott Burnett and Ivan Giron. The morning HFA sessions included "Dad: It's an Action Verb" presented by Mark Burowski and "But I Can't Bring Home the Bacon: Coping with Male Role Expectations" presented by Dave Robinson. The men were able to connect with one another while playing "Mission is Possible." All youth worked together in "Breakout Box" activity to build on their creative and critical thinking skills.

Then, the youth were off to make some wacky science experiments while the teens headed off to do the "Amazing Race." The afternoon activities included, BB Guns and Archery where everyone was able to show off their skills! We want to thank Novo Nordisk, Takeda, Octapharma and CSL Behring for their support to make this event possible. Thank you HFA for your support and thank you to all our amazing volunteers: Ivan Arevalo, Scott Burnett, Ivan Giron, Grace Hernandez and Rigo Manzo!

OUR NEW DIRECTOR OF DEVELOPMENT

MEET: MICHELLE WARNER



I am thrilled to be joining the amazing team of dedicated professionals and passionate advocates at the Hemophilia Foundation of Southern California (HFSC) as their new Director of Development. Having worked in fundraising for over 15 years for various nonprofit organizations, most recently as a Senior Development Manager at the March of Dimes, I am excited to use my experience to help support HFSC and all those living with hemophilia and other bleeding disorders in my community. As the mother of a son with severe Hemophilia A, this role is especially personal and meaningful.

I currently reside in Huntington Beach with my husband, Doug, and our son, Cole.



VOLUNTEER SPOTLIGHT QUINCY NAKAMURA



Quincy Nakamura was HFSC's 2019 summer office volunteer. Quincy temporarily moved in with his aunt in Culver City during his volunteer days and went back to Renton, Washington at the end of August to finish his senior year. He aspires to one day become a biomedical engineer to further help the bleeding disorders community. During his time volunteering, he had the opportunity to engage in graphic design, which is one of his hobbies. He helped to design the logo for T-shirts, redesigned the case statement format, and looked for decorations for the 2019 So Cal Unite for Bleeding Disorders Walk. He also enjoyed attending the Pain Management Conference in July as a volunteer and interacting with the community. Although he could only volunteer for five weeks, he wishes he could've stayed longer to take part in more events and learn more about the bleeding disorders community. Thank you, Quincy!













FAMILY RETREAT

RUNNING SPRINGS, CA

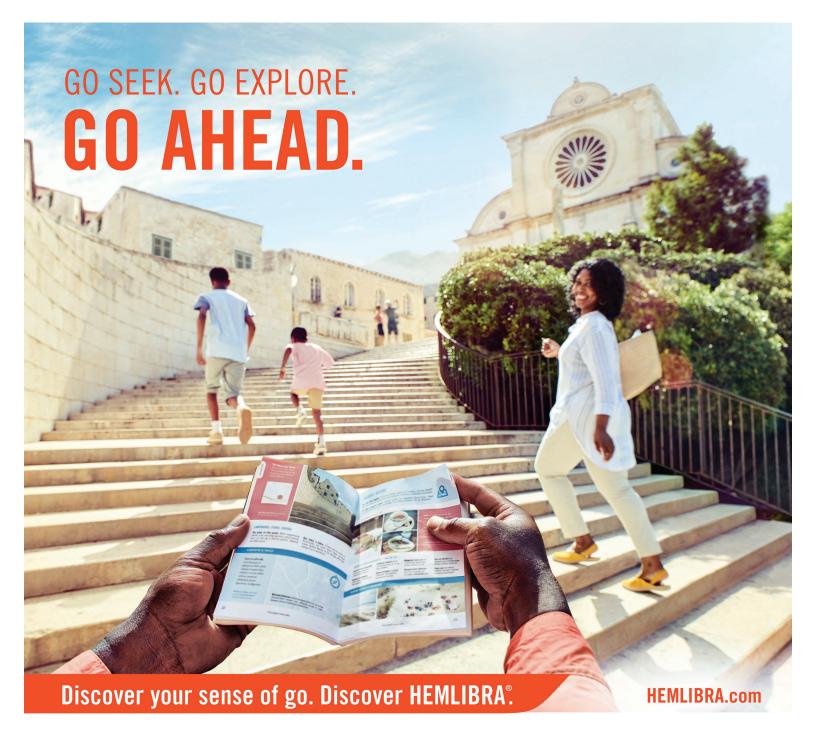
In June, HFSC kicked off the summer with ROAR!, our annual retreat in Running Springs, CA. Thank you to Platinum Sponsor, Takeda, and the Hemophilia Alliance Foundation, as well as to Dr. Doris Quon (OTC) for making it possible for HFSC to put on an amazing weekend for our bleeding disorders family! After driving through the San Bernardino National Forest, families were greeted at Pali Retreat Center with stunning views and fresh air. As they arrived and checked in to their cabins, there were activities for the kids, fun photo booths, and time to make family banners. Dinner was kicked off with the Dancing (and deflating) T-Rex, followed by presentation of the family banners, games, and a campfire with music, dancing, and making s'mores.

On Saturday morning, we were treated to a wake-up dance led by Victoria Kasinger. HFSC then welcomed speakers from Takeda who presented on Self-Infusion, Mindfulness, and Healthy Living. The presentations were followed by a CHOPPED-inspired cooking competition where teams submitted their best salsas with ingredients provided, and were judged by the Takeda team. While the adults were learning and cooking, the youth and teens participated in Laser Tag, Archery and Tomahawk throwing.

After lunch, families chose their activities including, Ropes Course, Woodshop, Swimming, Gaga, and the Triple Swing. The finale of the Retreat was the Dinosaur Scavenger Hunt. Saturday evening events included a fire show by Josh Garman, Karaoke, Movie Night, and a Night Hike and Stargazing.

Thank you again to Takeda, Hemophilia Alliance Foundation, Dr. Quon, Soleo Health for the water bottles, Accredo for the first aid kits, and to CVS for the emergency whistles. And a special thank you to all that volunteered for this event!

Save the Date for next year's Retreat! June 5-7, 2020



What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

emicizumab-kxwh

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.

Medication Guide HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- Thrombotic microangiopathy (TMA). This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion
- weakness
- swelling of arms and legs
- yellowing of skin and eyes
- stomach (abdomen)
- or back pain
- nausea or vomiting
- feeling sick
- decreased urination
- Blood clots (thrombotic events). Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs
 - pain or redness in your arms or legs
 - shortness of breath
 - chest pain or tightness
- fast heart rate

- cough up blood
- feel faint
- headache
- numbness in your face
- eye pain or swelling
- trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "What are the possible side effects of HEMLIBRA?" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take,

including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.
- You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you
 will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give
 the dose as soon as you remember. You must give the missed dose as soon
 as possible before the next scheduled dose, and then continue with your
 normal dosing schedule. **Do not** give two doses on the same day to make
 up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

 See "What is the most important information I should know about HEMLIBRA?"

The most common side effects of HEMLIBRA include:

- · redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group, 1 DNA Way, South San Francisco, CA 94080-4990

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
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MUJERES ENLAZADAS POR SANGRE



Mujeres Enlazadas por Sangre gathered at Tamayo's Restaurant in East Los Angeles on Wednesday, May 22, 2019 to learn to empower each other! Silvia Vega was able to lead a wonderful presentation where those in attendance were able to express how to deal with stress and other emotions while also dealing with one or more children or partners with bleeding disorders. We want to welcome all the new moms who came out to their very first dinner! Thank you so much Silvia Vega and Bayer for moderating such a great topic and sponsoring such a delicious Mexican buffet dinner!

IN MEMORIAM:

DR. SHELBY LEE DIETRICH RECTOR

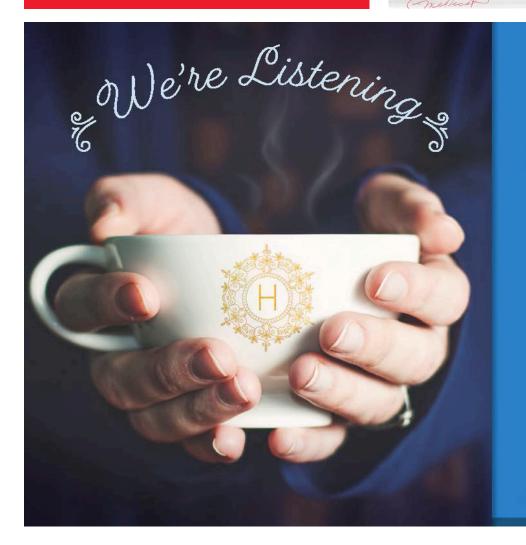
1924-2019

HFSC is heartbroken to say goodbye to Dr. Shelby Dietrich who was a brilliant pioneer and educator in the Southern California bleeding disorders community. She was passionate about improving the quality of life for her patients here, and also focused much of her work and effort on the global community.



BRAVE LAD---Dr. Shelby Dietrich, pediatrician at Orthopedic Hospital in Los Angeles, examines swollen and bruised leg of ll-year-old classy Fruitr who swifetrs from hemophilia. Casey has just completed therapy in not swimming pool at rear.

She helped launch and create the comprehensive care model at the Orthopaedic Hemophilia Treatment Center in Los Angeles in the early 1960s that so many of us have benefitted from and was a pioneer as a woman in medicine at a time when it was not considered a suitable career for women. We thank you for the incredible legacy left behind.



At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Ove the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team

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FAMILY INFO DAY

AND KICK OFF DINNER

On Friday, May 10, HFSC hosted their Family Information Day Kickoff Dinner at the Knott's Berry Farm Hotel. Attendees enjoyed a dinner and presentation on Micro Bleeds, from Martina Willis- McCullough, RN, BSN, Nurse Educator, Octapharma. The presentation was followed by roundtables hosted by community members. Children were entertained by "Spider-Man: Into the Spider-Verse" while the night ended with an impromptu karaoke session for adults.

Thank you Octapharma for your sponsorship!

















On May 11, HFSC members gathered at Knott's Berry Farm Hotel for the annual Family Information Day. The event kicked off with a Patient Panel made of community members who spoke about their bleeding disorders story, which included new treatments such as gene therapy. Moderated by Dr. Doris Quon, Medical Director of Orthopaedic Treatment Center, the panel consisted of Randall Curtis, Fiach Echandi, Matthew Compton, Elizabeth Villanueva, Marco Vizueto, Taylor Frank and Fernando Rivera. Simultaneously, Dr. Vanessa Salinas, CIBD, hosted an Ultra Rare Bleeding Disorders Rap Session for families in attendance with platelet disorders and rare factor deficiencies.

Following the Panel, Tim Ringgold, MT-BC, gave the presentation "Music Therapy for Stress Management," sponsored by CSL Behring. Everyone in the room was clapping along to the beat as Tim spoke about the importance of finding and concentrating on a beat in times of stress.

During HFSC's Annual Awards, Volunteer of the Year was awarded to Ivan Arevalo, and Advocate of the Year was awarded to Paul Clement. Scholarship winner Rachel Wile spoke about her career plans, and Camp Blood Brothers and Sisters Big Stick Award Winner Jason Sloanaker, Jr. spoke about his Camp experience. Walk Co-Chair Veronica Diaz gave a short presentation about the Unite for Bleeding Disorders Walk, encouraging everyone to create a team.

Following lunch, attendees chose a breakout session to attend for the afternoon, including "Kinesiology Taping to Improve Joint Stability" from Dr. Michael Zolotnitsky, the Unite for Bleeding Disorders Walk Kickoff, and "Nuevas terapias en el tratamiento de Hemofilia" by Dr. Vanessa Salinas. HFSC was thrilled to welcome NFL Cornerback and Hemophilia Advocate Joshua Gordy for his session "Join the Resistance," demonstrating to the audience how to stay in shape with modified exercises. Finally, all in attendance enjoyed a day at Knott's Berry Farm.

Thank you to The Painted Turtle who hosted "Camp for a Day" in the Youth Program, and Brothers Healthcare for supplying a Mother's Day Craft. Thank you to HFSC member and designer Mesly Guzman for creating a Mother's Day Craft for the teens.

Thank you to all of our volunteers! Thank you Platinum Sponsors Octapharma and Takeda, Gold Sponsor Genentech, and Silver Sponsors Briova, CSL Behring, and Sanofi Genzyme. HFSC looks forward to seeing everyone next year on May 2, 2020.



WORLD HEMOPHILIA DAY | 2019

HFSC commemorated World Hemophilia Day by lighting up the US Bank Tower red on April 17, 2019. With 200 community members in attendance, HFSC heard from Peter Paul Colinares Carreon, a leader and advocate from the Hemophilia Advocates-Philippines (HAP) who shared his story about growing up without access to clotting factor. Then, HFSC members created gratitude trees and watched the US Bank Tower light up red! HFSC is grateful to Sanofi Genzyme for sponsoring this important event and for its commitment to the global bleeding disorders community by pledging to donate 1 billion units of factor over 10 years! Thank you!









MUJERES ENLAZADAS POR SANGRE

Mujerez Enlazadas por Sangre gathered at the beautiful Maggiano's Restaurant in Costa Mesa on Wednesday July 17, 2019 to learn how to shake, move and be more active while having a bleeding disorder! Mike Sager and Eva Felix from Pfizer did a phenomenal job by making everyone laugh and feel included! The women learned healthy tips and some basic exercise routines. Thank you Pfizer for your support!



FUTURE LEADERS AND LEGISLATIVE DAY | 2019





HFSC Teen Leadership Council members joined teens from around the state at the Hemophilia Council of California's Future Leaders Program and Legislative Day on May 6-8 in Sacramento at the State Capitol. Teens received training to lobby for healthcare access though HCC's impactful program and had the opportunity to meet with their state legislators. The highlight of the trip was when Senator Anthony Portantino brought the HFSC teens to the Senate floor. Thank you to HCC for organizing this program, and to all the chaperones who made it possible!











MOVIE SCREENING: BOMBARDIER BLOOD

On Saturday, June 29, HFSC hosted a screening of "Bombardier Blood," a documentary starring Chris Bombardier, the first person with hemophilia to climb the Seven Summits (the tallest mountains on each continent.) Held at the Laemmle Theater in Pasadena, 200 attendees gathered to watch this moving story about the road to climbing the Seven Summits and the dangerous journey up and down Mount Everest.

A Q&A with Chris and Jessica Bombardier, director Patrick Lynch, and cameraman Rob Bradford followed the screening, answering audience questions about the film and the climb. Audience members were entered into a raffle to win copies of the Bombardier Blood book.

Thank you to the crew at Believe Limited for making this impactful and inspiring film. Thank you Octapharma for sponsoring the film and our screening!

Danielle Mueller Durham Patient advocate

About Danielle

Danielle is a Hemophilia Community Liaison who has been supporting the bleeding disorders community for 8 years. She works hard to make sure everyone in the community has a voice and knows how to ask for what they need.

Connect with Danielle

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