Infusions
SUMMER 2020

Farewell Letter from Kim Ross LCSW UCSF Children's Hematology Oakland

Kim Ross (far right) and colleagues pose as the superheroes they are!

NEWS

It is with mixed emotions that I am writing to tell you that I will be retiring from UCSF Children's Hospital Oakland on May 15, 2020. After 32 years at Children's Hospital, I am ready for the next chapter of my life. I have been so very fortunate to have come to the Hemophilia Program in 2008, after working in the ICU, the Pediatric HIV Program, and the Early Childhood Mental Health Program at Children's Hospital.

I remember very clearly when I came to the Hemophilia Program. My team was Dr Matsunaga and Jim Riddel Nurse Practitioner! I was in great hands! There was so much to learn, and the patients and families taught me so much. As I started meeting families, I would ask what it is like for them to live with bleeding disorders. Some mothers would share their own history of growing up with fathers and brothers who had hemophilia at a time when treatment was not very available or effective. Their family members suffered with horrendous pain, and some of their loved ones passed away from complications of their

Continued on Page 7

IN THIS ISSUE

ABBREVIATIONS RESOURCE

This resource provided by:

Contact us at www.hemofoundation.org
6400 Hollis Street | Suite 6
Emeryville CA, 94608
510-658-3324

Commonly used acronyms in Bleeding Disorders

504 plan Section 504 of the Federal Education Code
AAC Actual Acquisition Cost
ACA Affordable Care Act
ACO Accountable Care Organization
ACT Access to Care Today - Achieving Cures Tomorrow
AIMM Alliance for Integrated Medicine Management
APCC Activated Prothrombin Complex Concentrates
ASH American Society of Hematology
ATHN American Thrombosis and Hemostasis Network
AV Actuarial Value

BATs Bleeding Assessment Tools
BB Blood Brother
BCRA Better Care Reconciliation Act
BDC Bleeding Disorder Community
BS Blood Sister
BU Bethesda Units

CAP Consumer Assistance Program
CBC Complete Blood Count
CCIIO Center for Consumer Information and Insurance Oversight
CDC Centers for Disease Control (and Prevention)
CHC Community Health Center
CHIP Children's Health Insurance Program
CHIPRA Children's Health Insurance Program Reauthorization Act (2009)
CME Care Management Efforts
COB Coordination of Benefits
CON Certificate of Need
CO-OP Consumer Operated and Orientation Plan
CRISPR Clustered Regularly Interspersed Short Palindromic Repeats
CSHCN's Children with Special Health Care Needs
CSR Cost-Sharing Reduction

DD Developmental Disabilities
DIA Dad's in Action

EAC Estimated Acquisition Cost
EAP Emergency Assistance Program
ECP Essential Community Provider
ED Emergency Department
ER Emergency Room
EHB Essential Health Benefits
EOB Explanation of Benefits
EPO Exclusive Provider Organization

FDA Food and Drug Administration
FED Family Education Day
FIX Factor IX deficiency
FFT Food for Thought program
FPL Federal Poverty Level
FQHC Federally Qualified Health Center
FSA Flexible Spending Account

GT Glanzmann's Thrombasthenia

HAF Hemophilia Alliance Foundation
HAV Hepatitis A Virus
HBV Hepatitis B Virus
HCBS Home and Community Based Services
HCC Hemophilia Council of California
HCR Health Care Reform
HCV Hepatitis C Virus
HDHP High Deductible Health Plans
HFA Hemophilia Federation of America
HFNC Hemophilia Foundation of Northern California
HHS US Dept of Health and Human Services
HMB Heavy Mestrual Bleeding
HSV Herpes Simplex Virus

HTC Hemophilia Treatment Center
HTRS Hemostasis and Thrombosis Research Society

ICF Intermediate Care Facility
IHCP Individualized Health Care Plan
IEP Individualized Education Plan
IPA In-person Assisters Program
ISTH International Society on Thrombosis and Haemostasis
ITI Immune Tolerance Induction
ITT Immune Tolerance Therapy

LTC Long Term Care

MASAC Medical and Scientific Advisory Council
MIA Moms in Action
MCO Managed Care Organization
MIQ Menorrhagia Impact Questionnaire
MLOF My Life Our Future

NACCHO North American Camping Conference for Hemophilia Organizations
NHF National Hemophilia Foundation
NOW National Outreach vonWillebrand
NYLI National Youth Leadership Institute

OEP Open Enrollment Period

PEP Parents Empowering Parents
PCC Prothrombin Complex Concentrates
PCCM Primary Care Case Management
PCMH Patient-centered Medical Home
PCP Primary Care Provider
PDL Preferred Drug List
PMPM Per-member Per-month
POS Point-Of-Service Plan
PPO Preferred Provider Organization
PSPD Platelet Storage Pool Disorder
PTSD Post Traumatic Stress Disorder
PTSS Post Traumatic Stress Syndrome
PUPs Previously Untreated Patients

QHP Qualified Health Plan
QOL Quality of Life

RFD Rare factor deficiencies
rFVIIa Recombinant Activated Factor VII
RHC Rural Health Care

SBC Summary of Benefits and Coverage
SEP Special Enrollment Period
SHOP Small Business Health Options Program
SNF Skilled Nursing Facility
SPA State Plan Amendment
SPP Specialty Pharmacy Provider
SSDI Social Security Disability Income
SSI Supplemental Security Income

THSNA Thrombosis and Hemostasis Summit of North America
TPA Third Party Administrator
TFF The Female Factor
TTFF The Taylor Family Foundation
VWD Von Willebrand's disease
VWF Von Willebrand Factor
WFH World Federation of Hemophilia

NEWS

Volunteer Experience

by Madeleine Wing

While in quarantine, I, like many of us, have had a lot of time to think and reflect about everything that has happened this past year. In such trying times, it is especially important to remember all of the amazing friends, experiences, and support we are lucky to have in our HFNC community.

This past year, I became more involved with HFNC as both a volunteer and community member. Though I had attended HFNC events in the past, I volunteered last year at my first HFNC event, the Unite for Bleeding Disorders Walk. I enjoyed having the opportunity to chat with walk participants as they checked in, sharing in the excitement of the day. Handing out t-shirts to walkers, and selling raffle tickets were also on the agenda for the day. I especially enjoyed being able to participate and volunteer for the event with other members of my family in support of our family walk team, Kurtie's Birdies.

Not long after the walk, I was off to Camp Hemotion as a junior camp counselor. The numerous gaga ball games, catchy camp songs, daily alien hunts, too many games of black magic to count, and so much more made camp special, but what made camp magical were the amazing people that I was able to meet there. Extensive training and great support from other counselors made me feel instantly welcome. My first experience at Camp Hemotion was unforgettable, and I know that I will make many more memories there in the years to come.

Madeleine (second to left) with her family at Unite for Bleeding Disorders Walk 2019

As August rolled around, so did HFNC's annual Vine and Hops, and Golf Day events. At both of the events, I was responsible for helping to check in attendees. I also checked in the bidders and/or golfers, ran credit cards, and helped to solve problems that popped up. I also helped to set up the silent auction items, collect bids, distribute small fans to groups on the golf course, as well as clean-up after the event. I enjoyed the event as a volunteer, being able to enjoy a small Camp Hemotion reunion, and spending time getting to know other members of the community better.

Come November, I had an opportunity to volunteer at my first Family Education Day. Being an all-day event, I was able to do many tasks throughout the day such as running check-in, breakfast set-up, constructing the red carpet for that evening's movie premier of Bombardier Blood, and best of all, taking pictures as a member of the "paparazzi" while everyone began to enter the theater for the film! Instructions for each of the tasks were very clear and there was a lot of time between activities to take a break and eat some of the delicious food that was served. As a volunteer, I was able to complete every activity with other volunteers, making the event even more enjoyable.

After Family Education Day, I became a junior board member for HFNC. As a part of this role, I reorganized HFNC's Bloomerang database, condensing accounts into groups by housing and ridding the system of any duplicate accounts that may have existed, ultimately making communication between the foundation and the community more efficient. Through quarantine, I continue to regroup the information stored in the database so that it is more accessible and organized to ensure that HFNC can gain a better reach to the community. With the help and instruction of other wonderful volunteers and staff, I was able to get the hang of the Bloomerang database in no time.

One of my most memorable experiences was volunteering at Family Camp this past January. Reuniting with familiar faces as well as coming to know many new ones was what made Family Camp such a joyous experience. As a volunteer, I helped to decorate the camp, guide families to their cabins, answer questions that camp attendees had, and lead a small group of campers through the many fun activities that Camp Arroyo had to offer,- such as rock climbing, awesome art projects, and music therapy. With a semblance of the energy of Camp Hemotion and it's own unique traditions, Family Camp made for a great weekend that

Continued on Page 5

I have many awesome memories and a cool paracord bracelet to remember it by.

Most recently, I attended Washington Days, the advocacy event in Washington D.C. attended by community members from around the United States. Upon first arriving at Washington Days, I will admit that I was slightly terrified of speaking to the representatives but NHF ensured that our entire group knew the information we were lobbying for inside and out, and most importantly, reassured us that we would do great. In the end, our small group from HFNC did just that, securing co-sponsors for our bill and overall support for the Bleeding Disorders community. Being able to speak with members of Congress and their aides was one of the most unique and inspiring experiences that I ever had. The nation-wide bleeding disorders community as well as the congressional representatives themselves were more than supportive, making this event truly amazing. You can't help but feel motivated to take more action in the community after attending Washington Days...the energy is contagious!

Being involved with the bleeding disorders community has provided my family and I with so much support, many memories, and endless opportunities. Any and all of the events that HFNC puts on have made me feel closer to this community, and volunteering at the events makes me feel as though I am giving back to the community. With that said, working at many of the HFNC events has helped me to realize how much I love working for this community, something I hope to be able to act on for the rest of my life. I know that I will enjoy and forever be thankful for volunteering for, and being a part of the community. I look forward to seeing all of you at the next HFNC event once quarantine has ended.

Madeleine's aunt Dawn Pollard and her mom, Michelle Wing show their spirit at our walk in 2019

UPDATE

Advocacy Program Update

Thank you to our sponsors for supporting March is Bleeding Disorders Awareness Month!

Look who received materials including awareness raising stickers, educational postcards, red aprons, red ties, instructions on contacting your mayor and more!

1 HTC

2 Community Members

1 Specialty Pharmacy

These amazing supporters of bleeding disorders awareness will continue their efforts to ask each city to declare March as Bleeding Disorders Awareness Month as soon as our areas open back up from sheltering in place due to COVID-19 pandemic.

Please contact ashley.gregory for your materials to have your city declared March as Bleeding Disorders Awareness Month!

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.[1]

ADVATE
[Antihemophilic Factor (Recombinant)]
REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

Prophylaxis with ADVATE prevented bleeds[1]

- ADVATE was proven in a pivotal clinical trial to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)
- The efficacy of ADVATE was studied in a multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20–40 IU/kg every 48 hours, or pharmacokinetic-driven, 20–80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis
  - 98% reduction in median annualized bleeding rate (ABR) from 44 to 1 when 53 patients in the clinical study switched from on-demand to prophylaxis
  - 0 bleeds in 42% (22/53) of patients during 1 year on prophylaxis

ADVATE 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.

What should I tell my HCP before using ADVATE? (continued)

- 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.

For Full Prescribing Information, visit www.ADVATE.com.

Reference: 1. ADVATE Prescribing Information.

Takeda

bleeding disorder. I felt the pain and grief of these mothers, and could understand the challenges for these mothers who now had children with the same condition.

Some parents and providers said to me, "hemophilia is not so bad", and "it's much easier to deal with now". But I couldn't help noticing that the children were still going through so much: having to be more careful, being told they couldn't do certain things, wanting to do what the other kids were doing, getting bleeds, suffering with joint pain, and having to get infusions that could be very traumatic. I've always said, "bad is bad", and I knew that while things about hemophilia might be better now, it is no "piece of cake". So from then on, my focus was to see how I could help the kids to make their bleeding disorder less difficult and less scary.

One of my social work roles was to support the parents so they could more effectively support their kids. I tried to help with outside stressors and emotional issues, so parents could focus on their children.

Another role was to work directly with the kids, explaining their condition in ways they could understand and adding to their understanding as they got older. We held Infusion Groups and tried to do fun and distracting things during their clinic visits, such as medical play. I loved this time with the kids; they were all so amazing and each one was my favorite!! I have the funniest and fondest memories of all of them. How lucky am I?!?

Another thing I noticed immediately when I came to the Hemophilia Program was the well-established Bleeding Disorders Community. As a medical social worker you dream of a community for your patients and families that will help them to know they are not alone. Patients and families need to know there are others who understand what they are going through and that there are people they can learn from, as well as cry and laugh with. The Hemophilia Foundation of Northern California brings the community together through the many events they sponsor: Family Camp, Family Education Day, Familia de Sangre, Asian Infusion, Camp Hemotion, Parents Empowering Parents, The Walk and other fundraising events. I have been very fortunate to participate in many of these events over the years and with each event, I have noticed parents and kids making connections. Many times I have seen the relief on their faces as they realized they were not alone.

Kim with colleague, Debbie Jett RN

The Bleeding Disorders Community goes far beyond families meeting other families. The connection with the staff of HFNC, the volunteers who make events happen, the healthcare teams, the people who provide factor, they all make this a community with a whole lot to give. I have met the most amazing people who all have been fully committed to this community and who have worked as a team to insure that the patients get what they need (physically, medically, socially, emotionally).

While I am excited to be retiring, I feel a great sense of loss. We won't be able to see each other before I go, but I will carry everyone I've met in my heart with the fondest memories. I hope you will keep me in yours, and I hope our paths will cross in the years to come. Please remember to reach out to get and give support to each other.

Sincerely,
Kim Ross

CSL Behring
Biotherapies for Life®

GETTIN' IN THE GAME℠ JUNIOR NATIONAL CHAMPIONSHIP

November 6–November 8, 2020
Phoenix, Arizona

CSL Behring is honored to host the 19th Annual Gettin' in the Game Junior National Championship, the first, and currently the only, sports competition for children with bleeding disorders. Participants will have the opportunity to learn the fundamentals of their respective sport, participate in a friendly competition, and have a chance to connect with fellow members of the bleeding disorders community from across the country. In addition, educational seminars focusing on the importance of physical fitness and other related topics will be available on site.

We are inviting all bleeding disorders chapters throughout the United States to each nominate 2 participants with a bleeding disorder, girls or boys, ages 7 through 18, to represent them during this national competition. Each participant will have the opportunity to choose either golf, baseball, or swimming.

Please contact your local bleeding disorders chapter for additional details on how to apply to become your **CHAPTER'S NOMINEE!**

For more information regarding the Gettin' in the Game Junior National Championship and other programs offered by CSL Behring, visit www.csljnc.com or call 1.800.676.4266 to speak with a My Source℠ Care Coordinator.

CSL Behring Patient Engagement

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

11.13.20 - 11.15.20

Walker Creek Ranch

Petaluma, CA

THE FEMALE FACTOR

Affected and Connected

Liz Schauermann
Bleeding Disorder Territory Manager

SOLEO HEALTH®
Innovators in Specialty Infusion

Soleo Health is a local provider of complex specialty pharmacy and infusion services dedicated to the bleeding disorder community and the patients we serve.

Our Bleeding Disorder Therapy Management Program is led by specialized care teams with extensive experience in Hemophilia A, B, Factor X Deficiency, Von Willebrand, and other factor deficiencies. The bleeding disorders team provides individualized services and education, which encourages your independence and enhances your care experience.

Liz Schauermann devotes her full-time work in the community to better the lives of those with bleeding disorders.

Contact Liz Schauermann, Bleeding Disorder Territory Manager, to learn more or to submit a referral:

721 S. Glasgow Avenue, Suite C
Inglewood, CA 90301
P: 866.665.1121 | **F:** 888.665.1141
C: 310.422.9621 | **E:** lseaton@soleohealth.com

www.soleohealth.com

CALENDAR

MAY		
5/3/20-5/5/20	Future Leaders	Virtual
5/5/20	Legislative Day	Virtual
5/5/20	#GivingTuesdayNow	Social Media
5/5/20	Cinco De Mayo	
5/17/20	Come Together: Quaran-Teams Unite!	Virtual
5/25/20	Memorial Day	
JUN		
JUL 7/4/20	Independence Day	
7/19/20	Emerging Therapies Forum	Virtual
7/20/20-7/31/20	Staff Strategic Planning	
AUG		
8/5/20-8/8/20	NHF BDC	Virtual
8/24/20-8/26/20	HFA Symposium	Baltimore, MD
8/31/20	Golf Tournament	Pleasanton, CA
SEPT		
9/7/20	Labor Day	
9/17/20-9/19/20	Famlia de Sangre	Los Angeles, CA
OCT		
10/4/20	Unite Walk	Oakland, CA
10/12/20	Columbus Day	
10/18/20	Family Education Day	Fresno, CA
NOV		
11/6/20-11/8/20	Gettin' In the Game Junior National Championship	Phoenix, AZ
11/11/20	Veteran's Day	
11/13/20-11/15/20	The Female Factor Retreat	Petaluma, CA
11/15/20	Vines & Hops	San Francisco, CA
TBD	Men's Retreat	
TBD	NHF Insurance Reimbursement Summit	Baltimore, MD
11/26/20-11/27/20	Thanksgiving Holiday	
DEC		
12/1/20	World AIDS Day	
12/1/20	Giving Tuesday	
12/5/20	Oakland Holiday Party	Oakland, CA
12/13/20	Posada	TBD
TBD	Fresno Holiday Party	
12/25/20	Christmas Day	

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):

HFSC 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/

FAMILIA DE SANGRE

CALIFORNIA 2020

18-20 de septiembre de 2020
Anaheim Marriot, CA

La inscripción de Familia de Sangre esta abierta.
Por favor inscríbase aqui: www.familiadesangre.org
*** Si la conferencia necesita ser cancelada debido a COVID-19, se le reembolsarán las tarifas de inscripción.**

Registration is now open.
Please register at: www.familiadesangre.org
***If the conference needs to be cancel due to COVID-19, your registration fees will be refunded.**

JOIN US

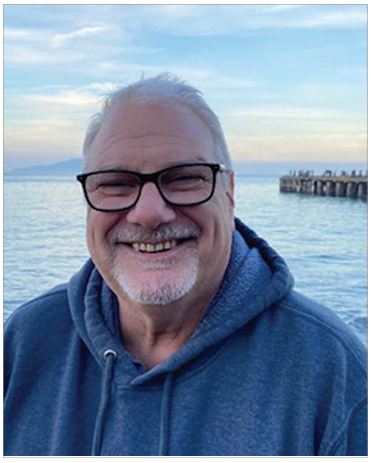
The Central California Hemophilia Foundation, Hemophilia Association of San Diego County, Hemophilia Foundation of Northern California and Hemophilia Foundation of Southern California are proud to bring you the fourth annual Familia de Sangre, a three-day bleeding disorders conference presented in Spanish. Educational sessions and networking opportunities will cover health care, education and support services. Space is limited.

ÚNASE A NOSOTROS

La Fundación de Hemofilia del Centro de California, Asociación de Hemofilia del Condado de San Diego, la Fundación de Hemofilia del Norte de California y la Fundación de Hemofilia del Sur de California están orgullosos de traerles la cuarta conferencia anual: Familia de Sangre, una conferencia de tres días sobre desórdenes sanguíneos presentada en español. Sesiones educativas y oportunidades para establecer conexiones cubrirán importantes temas de cuidado de la salud, educación y servicios de apoyo. El espacio es limitado.

Why I serve on the HFNC Board of Directors

by Pete Barbounis



I am Pete Barbounis and I am honored to serve as the Vice President on the Board of Directors for the Hemophilia Foundation of Northern California (HFNC). It is a privilege to share my story and involvement with the foundation.

I first became aware of hemophilia 45 years ago when John, my nephew, was born with it. It hit closer to home 13 years ago when our second grandchild, Vincent, was born with Severe Hemophilia A; factor VIII deficiency.

I didn't know what to expect when I initially volunteered. I know the purpose of life is to be of service to others. I wanted to serve. I wanted to help improve the quality of life for all of those affected by hemophilia and other related bleeding disorders.

I knew volunteers filled all kinds of roles. I knew there were multiple events including fundraisers. Volunteers make things happen. They register participants, assist with decorating, gather raffle items, sell tickets and serve as mentors and chaperones at Camp Hemotion.

While I have served in many roles as a volunteer and board member, there's nothing I enjoy more than joining the youth at Camp Hemotion. It's ironic, the more I serve, the more I try to give, the more I realize I get so much more in return from being around these kids. Witnessing the strength these children have in dealing with hemophilia and other bleeding disorders, like Von Willebrand's Disease, Platelet Storage Pool Disorder and Glanzmann's Thrombasthenia gives me strength to deal with everyday struggles of life.

I hear people say they just don't have enough time to volunteer. I let them know, you don't have to have time. You simply must have a heart. When you put your heart into something the time you need will appear. The hemophilia community has taught me that I earn a living by what I get and I create a life by what I give.

Volunteering is at the core of serving others. It's a great way of paying it forward. None of us have made it on our own. We've all had people to help us along the way. I volunteer because I can and it's the right thing to do. The more I help others outwardly, the more I grow inwardly.

I encourage you to look around our community. Find a way to give of your skills, time and share your testimonies of life. Discover how you can make a difference to our kids, your kids. The first step is the hardest. I assure you, after your first interaction, after you receive your first 'thank you' from one of the kids, you'll be grateful you took that first step. You'll soon discover you are receiving far more than you are giving.

Regardless of your skill set, experiences, interests or passion, I know you can find a role that will match up with you and your desires, I hope you'll join us today.

The Hemophilia Foundation of Northern California

FOR ALL BLEEDING DISORDERS

2020

HFNC VINES & HOPS EVENT

LOG CABIN, PRESIDIO

1299 STOREY AVE SF CA 94129

A benefit for the Hemophilia Foundation of Northern California

Join us for our annual beer and wine tasting fundraiser. Enjoy tastings from local vineyards and breweries in the fabulous San Francisco Presidio. Grab your friends for this special evening supporting a great cause.

November 15, 2020

4pm - 7pm

- Charity Fundraiser
- Wine and beer tasting
- Silent auction
- Hors D'oeuvres

Get tickets at www.hemofoundation.org

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.

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

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

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
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use | 150 mg/mL

Genentech
A Member of the Roche Group

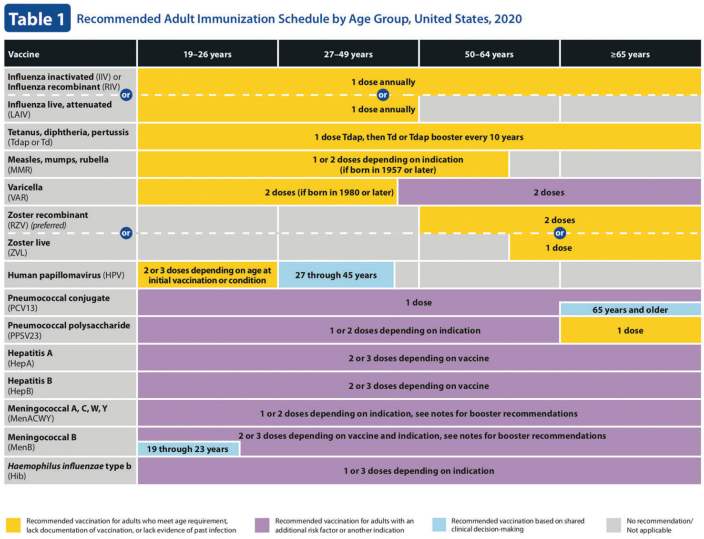
NEWS

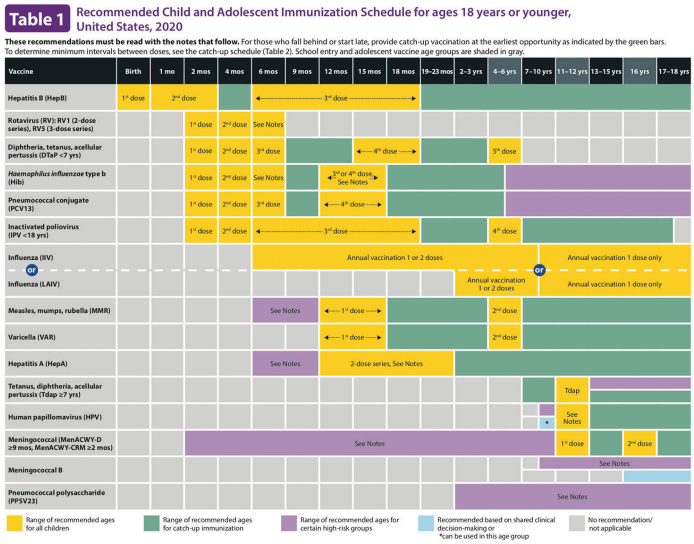
Ask the Doctor - Marion Koerper MD

Welcome to our newest Board Member, Dr. Marion Koerper!
Her column will be featured here each month as our medical advisory.

Please submit your questions to https://www.hemofoundation.org/resources/

Q. Should I as a patient with a bleeding disorder get immunized and how can I do that safely? What immunizations should I get?





A. All children should be immunized. The vaccines are safe and prevent the children from getting serious illnesses which could cause permanent damage and/or death.

With regards to hemophilia, the question is whether the immunization shot will cause a bleed.

Most immunizations are given into a muscle, so there are several ways to prevent a muscle bleed:

1. If the child is on prophylaxis, schedule the immunization to be given on a prophy day. Be sure to give the prophy dose prior to going to the doctor's office.

2. Request that the immunization be given subcutaneously (under the skin) with a small 22-23 gauge needle. Several years ago we did a study with hepatitis A vaccine given subcutaneously and showed that the immune response was equivalent to that of children who were given the vaccine intramuscularly (into a muscle), which is the way it is usually given.

3. Ask the nurse to put a small ice pack onto the spot where the immunization was given.

4. Request that the immunizations be spaced out over 2 or 3 visits to lessen the possibility of several small bleeds. Ashley, I found the charts and will attach them, one for children and one for adults.

5. Adults need to be immunized too because if they are around their own children, children's friends, children of their friends, children at camp, children at HFNC events, they could be infected if a child had not been vaccinated and was incubating a disease, e.g. measles, chicken pox etc.they could get the disease.

6. With regards to the coronavirus vaccine, hopefully one will be developed in the next 2 years that is safe and effective. If so, then every one, adults and children, should be vaccinated because this virus will likely come back.

Please see the full notes to accompany these schedules:
https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html

David Clark, PhD, Chairman of the Coalition for Hemophilia B.

Disclaimer: This article is not intended as medical advice. Readers should seek the advice of their own physician. Because information regarding COVID-19 (novel coronavirus) is ever changing, readers are also asked to check for frequent updates on the Coalition for Hemophilia B website (www.hemob.org).

Dr. Dave Clark's Updates: Coronavirus and Coagulation

APRIL 27, 2020

David Clark, PhD, is chairman of the Coalition for Hemophilia B.

NOTE: This article is not intended as medical advice. Readers should seek the advice of their own physician. Because information regarding COVID-19 (novel coronavirus) is ever changing, readers are also asked to check for frequent updates on our website.

The latest coronavirus news is all about clotting! It appears that many of the severe and fatal cases of coronavirus may involve an increase in thrombosis or unwanted clotting. We still don't know the cause of death in coronavirus patients. Initially, it was assumed to be pneumonia and ARDS (acute respiratory distress syndrome), diseases that involve inflammation of the lungs. Those might still be involved, but not necessarily in the way we thought.

Later on, while we were worrying about whether we had enough ventilators to treat all the people with pneumonia, it turned out that most hospitals had enough ventilators, but what they really needed was kidney dialysis machines. Patients were having kidney failure. Doctors were also seeing problems in many of the major organs besides kidneys: the liver, heart, lung, and the brain. We are also getting caught up on autopsies: Medical examiners were seeing lungs that were thought to have pneumonia but are instead riddled with blood clots.

The Chinese reported **coagulopathies** (problems with the clotting system) early on, but with the focus on the respiratory aspects of COVID-19, not much attention was paid. Now, we are seeing patients being diagnosed with DIC (disseminated intravascular coagulation; disseminated means spread throughout the body; intravascular means inside the blood vessels, and coagulation, of course, is clotting). Patients are developing blood clots throughout their bloodstreams, which are blocking blood flow, including to major organs. This might actually be the cause of death and disease, or it could just be another step along the way to the real cause.

Medical examiners [doing autopsies on COVID patients] were seeing lungs that were thought to have pneumonia but are instead riddled with blood clots.

We do not know that much about the coagulopathies yet. We think we are seeing regular fibrin clots, rather than something else that is thickening the blood or causing it to form particles. In a normal clot, fibrinogen, a protein in the blood, gets activated to form fibrin. Fibrin is a sticky protein that binds to itself as well as to platelets, red blood cells, and other debris from an injury to form the clot. COVID patients show high levels of the fibrinogen fragments that are broken off to form the sticky fibrin. It is like pulling the plastic films off of a Band-Aid to expose the sticky parts. If you find the films lying on the bathroom sink, you can be pretty sure someone has used a Band-Aid.

Patients who show signs of thrombosis have been treated with anticoagulants, mainly heparin. Heparin binds to antithrombin, an anticoagulant, and greatly increases its activity against clotting. Heparin/antithrombin is a good anticoagulant when you don't know the actual cause of the clotting because it works on a number of different steps in the clotting system.

One thing doctors have seen in severe COVID patients is high levels of factor VIII, the clotting factor. Too much factor VIII can cause thrombosis, so that could be part of the problem in COVID. In some cases where there are increases in factor VIII during coronavirus infections, heparin resistance is "apparent" (but it is not actually taking place in the patient)—read my further clarifications on this topic. Heparin resistance is a known symptom of too much factor VIII. Basically, the body runs out of antithrombin in trying to keep up with the extra clotting caused by too much factor VIII.

Click here to read more about "apparent" heparin resistance as reported by a group of doctors in the Netherlands.

Factor VIII is made in the endothelial cells—the cells that line the inside of the blood vessels. Thus, the coronavirus could be having an effect on the endothelial cells, causing the problem (or it could have nothing to do with it—we don't know until we look, and we haven't been very good at guessing with this virus). This also raises the question of whether hemophilia A patients, who don't have enough factor VIII already, might be more resistant to severe disease. So far, we have no information on that.

More on coronavirus and clotting

ANTIBODIES AND IMMUNITY

When the body is infected by a foreign material like a virus, the immune system makes antibodies against the virus as one step toward neutralizing and removing it. Antibodies are proteins that bind (stick) to the virus and trigger the body to destroy it. In the case of SARS-CoV-2, some of the antibodies bind to the spike proteins on the surface of the virus (the proteins sticking out from the spherical surface of the virus as you've seen in drawings all over the media). The spike proteins bind to a receptor protein on the surface of cells called ACE2, which allows the virus to enter a cell and infect it. If an antibody binds to a spike protein, it interferes with binding to the ACE2 receptor and prevents the virus from attacking the cell.

This is the same kind of thing that happens to hemophilia patients who develop inhibitors. Their immune systems see infused factor IX as a foreign material and make antibodies against it. Those antibodies bind to the infused factor IX molecules and prevent them from interacting with the other factors in the clotting process.

The other thing about the ACE2 receptor on cells is that it is part of a system in the body that also helps regulate blood pressure. Many of us with high blood pressure take drugs called ACE inhibitors or ARBs that work on this system to lower blood pressure, and people have wondered whether those drugs have any effect on the infection process. However, a recent study shows that people on these drugs are not any more or less susceptible to COVID-19.

Right now, the bottom line is that we don't have a good antibody test in the U.S. The results being obtained cannot be trusted.

Back to antibodies: The human immune system is hugely complex, and there is still much we do not know about it. It makes a variety of types of antibodies that have different functions, different strengths, and different targets on a virus. Different people also make different amounts of antibodies. Studies on people with COVID-19 show variable levels of antibodies in their bloodstreams. Some people with severe disease still only make small amounts, while some with mild disease make larger amounts, plus every combination in between. Antibodies last in the circulation for different amounts of time, too. Some die out soon after an infection is over, while others last a lifetime. We still don't know much about what causes some of the differences.

Everyone is hoping that COVID-19 antibodies will last a long time and prevent reinfection of people who have already had the disease. However, the evidence so far has been very mixed. The World Health Organization (WHO) has reported that there is no evidence that people who have had COVID-19 are immune from a second infection. A week ago, South Korea reported that 141 people who had recovered from coronavirus retested positive.

This could be because some people do not produce antibodies that neutralize the virus (or not enough antibodies, because we know that people's immune systems weaken as they age). It is also possible that the virus hides somewhere in the body where it can be reactivated. This happens with many viruses such as HIV and hepatitis C. It also could be a problem with testing.

One of the most important things in dealing with an infectious disease is having a good test. When you are dealing with something that you can't see, like a virus or bacteria, you need a test in order to know what you're doing. A diagnostic test for COVID-19 shows whether there is virus present in the body. By now, we have fairly accurate diagnostic tests, just not enough of them.

A test for antibodies would show whether a person has antibodies against SARS-CoV-2 in their bloodstream, either because they have an infection that the body is fighting or because they were once infected and have recovered. I won't go into all the arguments going on right now about antibody tests, but the bottom line is that we don't have a good antibody test in the U.S. The results being obtained cannot be trusted.

Many U.S. states have been scammed in trying to buy antibody tests from other countries. Many have bought tests and later found that they are only 20% to 30% accurate. Many consumers are being scammed, too.

A WORD ABOUT COVID-19 SCAMS

As with anything in our modern world, the COVID pandemic is bringing out the scammers, and some of them are very clever. For instance, with all the recent discussion about contact tracing, scammers have been contacting people and telling them they have been in contact with a person who has COVID-19. If you click on a link to find out more, you are on your way to identity theft. Please be careful, especially on the internet or social media. Here is a set of tips from the Federal Communications Commission (FCC), Federal Trade Commission (FTC), and the FBI:

Don't respond to calls or messages from unknown or suspicious numbers.

Even if the number looks legitimate, scammers often spoof phone numbers to trick you into responding. Keep in mind that government agencies will not call you to ask for personal information or money.

Do not give your username, password, date of birth, Social Security number, financial data, or other personal information over email, text message, or phone.

If you are being pressured to share information or make a payment immediately, that's a red flag.

Don't open attachments or click on links in text messages or emails from sources you don't recognize.

Verify web addresses and type them character-by-character into your browser.

Check for common misspellings or wrong domain names in a link. An address that should end in .gov might end .com instead.

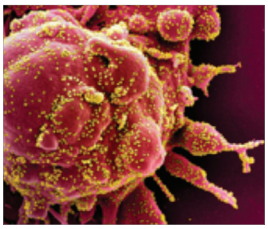
Do your research before donating to a cause or a charity. Call or look at its website to verify that it is legitimate. And never donate in cash, by gift card, or by wiring money.

If you get a message from a friend that seems out of character, call them to make sure they weren't hacked.

There are no products that have been proved to treat or prevent Covid-19 currently, so ignore any offers for products that claim to do so.

NEW VISUALIZATIONS OF THE CORONAVIRUS

One more thing before I end: Most of you have probably seen the drawing of a coronavirus that is all over the media. I came across another picture recently (shown below). It is a scanning electron micrograph (SEM), an actual picture through a microscope rather than a drawing, of a human cell from an infected patient. The cell is being attacked by the virus. The colors were added later to highlight the various components. The cell is red-pinkish and the virus particles are yellow. I had never imagined it this way before, but . . . the poor cell doesn't have a chance. It is just covered with virus particles.



The SEM was taken by researchers at the National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health (NIH). The cell is apoptotic, which means that it is getting ready to self-destruct. This is a less-well-known aspect of the immune system. Cells are programmed to self-destruct if they are too heavily infected. That way a virus or bacteria can't use the cell's internal machinery to further the infection.

Scanning electron micrograph (SEM) image of human cell heavily infected with SARS-COV-2 virus particles. Image captured at the NIAID Integrated Research Facility.

Correspondence. All correspondence related to the article should be addressed to contact@hemob.org. We will forward any questions or comments to our chairman.

Hemophilia Foundation
of Northern California
6400 Hollis St · Suite 6
Emeryville, CA 94608

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CONTACT INFORMATION

6400 Hollis Street, Suite 6
Emeryville, CA 94608

Office hours: Mon-Fri,
9:30 a.m. to 4:30 p.m.

www.hemofoundation.org
infohfnc@hemofoundation.org

(510) 658-3324 phone
(510) 658-3384 fax

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