Message From The President

Sean Hubbert is the President of CCHF.
Her son, David, has Hemophilia A.

Change is good. Change in the seasons; change in perspective; the flexibility to deal with and accept a change in our plans and goals. All of these are necessary if an organization is to succeed in its mission. We need to embrace change as it poses our largest source of individual opportunity for improvement. I, as the President of the CCHF Board, am very aware that we have to rise to meet the challenges and opportunities offered by change, if we are to grow as a membership organization.

To that end, we are going to present several new opportunities and options to our members to contribute to our cause, this year. We will be doing more to encourage membership, attendance and participation in community events; we will be reaching out to our constituency through more direct mail and electronic communications, to ensure that we all know the community calendar; and, we will be asking for more of a personal commitment to our goals, from all of us, this year. We will share in the work, then share in the celebration, together.

We have new faces on the Board, this year, providing new ideas and energy to all. We have a newly reformatted newsletter for you to enjoy, and we hope you find the information contained on these pages insightful and interesting. And, while not new or changed, we have reaffirmed our commitment to conservative and judicious stewardship of Foundation donations. We are committed to our cause, our members and our goals—and achieving the best for all, together.

I thank you for your continued trust in me and the opportunity to serve you again, this year.

Sean Hubbert

Calendar of Events
(Complete Calendar is online: www.cchfsac.org)

06/03/2014
CCHF Board Meeting

06/15-21/2014
Camp Hemotion

06/28-29/2014
Family Education and Fun Days

07/01/2014
CCHF Board Meeting

08/05/2014
CCHF Board Meeting

The Central California Hemophilia Foundation is dedicated to improving the quality of care and life for persons impacted by hemophilia and other inherited bleeding disorders through education, advocacy and support.


Contact Sean Hubbert at 916.296.9066 for details
Inaugural Global Symposium Seeks to Raise Awareness Regarding Significant Need for Plasma

The International Plasma Fractionation Association (IPFA) and Blood Centers of America (BCA) will hold the first-ever Global Symposium on the Future of Blood and Plasma Donations, in Sacramento, California from September 23 to 24. Hosted by BloodSource, a non-profit blood center based in Sacramento, the inaugural conference seeks to raise awareness of and address the significant patient need for plasma-derived therapies.

“There is a growing need to collect plasma,” said Paul Strengers, MD, president of IPFA. “There is a worldwide shortage and as we continue to see advancements in technology and plasma-derived medicines, the need will only increase. We must take action to address this growing concern.”

The two-day symposium will attract attendees from around the world including blood banking and plasma professionals, administrators and medical personnel, regulators, and patient advocacy groups. It will feature industry experts and international speakers who will discuss a broad range of topics including:

- Clinical developments and demand of plasma-derived medicines;
- Quality management of plasma;
- Donor recruitment and engagement;
- Maintaining a safe and secure plasma supply; and
- New developments and approaches to meet patient need (patient case studies).

This program has been developed by internationally recognized experts and will be of interest to colleagues from blood banking, patient and donor organizations, supporting industries, and regulatory authorities with an involvement in policies to meet patient needs for plasma derivatives.

Those interested in learning more about the meeting or in viewing the program may visit http://bit.ly/1fDqJrX. Online registration can be completed at http://bit.ly/Sby25b. Questions may be directed to Dr. Strengers at info@ipfa.nl.

Volunteer Appreciation Dinner and Award Ceremony

The Cattlemen’s Restaurant in Folsom, CA, was the place to be on Sunday, May 4, for the Foundation’s annual Volunteer Appreciation Dinner and Award Ceremony. Bonnie Leidheisl was named Volunteer of the Year for her adept handling of our mailing and distribution needs. Ms. Leidheisl has also graciously assumed the office of Foundation Secretary, this quarter. We would like to thank our prior Secretary, Katherine Spacek, for her years of service and have every confidence in Bonnie as her successor.

Also awarded at the event were the Foundation’s Scholarship and Life Long Learning awards. Pictured is CCHF President Sean Hubbert with Cliff Bynum, recipient of the Persons Affected By a Bleeding Disorder scholarship.
Factor and Medical Supplies to Pakistan and Mexico

Our foundation has been facilitating the shipment of factor and supplies to Pakistan and factor only to Mexico.

We have sent factor to Mexico for several years and they are truly appreciative. Because of the factor that is donated to Mexico they are able to have a summer camp for children with bleeding disorders. The physicians in Mexico require that the factor be current or only a few months outdated, Mexico cannot accept medical supplies.

We have been sending out dated (sometimes very outdated) factor to Pakistan for a couple of years and they also need any medical supplies i.e. needles, syringes, gauze pads, disposable gloves etc. The treatment of necessity in Pakistan is hydrotherapy. They do not have factor unless it is donated. It is a very poor country and they appreciate anything we can send them in the way of factor and medical supplies. Recently they contacted us about a 14 year old with factor IX hemophilia who had an eye injury and desperately needed factor to save the sight in one of his eyes. We were able to send a box with some FIX. I understand that the doctors are hopeful that his sight can still be saved. He has a large pool of blood that must be reabsorbed before they can attempt surgery.

If you have any outdated or soon to be outdated factor you would like to donate, please contact CCHF at cchfsac@yahoo.com. We cannot accept oral medicines.

Thank you to all who have donated in the past. The factor that would have been discarded has saved lives in these countries.

LIMITLESS.
The possibilities when you’re well cared for.

At Biomed, our commitment to the bleeding disorder community doesn’t end with skilled pharmacists, experienced infusion nurses, or dedicated customer service associates. It continues through education, training, and involvement at the local and national level by Biomed’s team of advocates who have extensive experience in the community. Improving the lives of patients and caregivers for a future of unlimited possibilities is our passion.

To learn more about Biomed bleeding disorder programs in California, contact Brent Mascorro at 916-340-5660 or bmascorro@biomed-rx.com.
Now Available

A new treatment for hemophilia B

Visit Alprolix.com

To learn more, contact CoRe Manager Marilyn August
E: marilyn.august@biogenidec.com  T: 925.864.0547

Indications and Important Safety Information

Indications
ALPROLIX, Coagulation Factor IX (Recombinant), Fc Fusion Protein, is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:
- Control and prevention of bleeding episodes
- Perioperative management
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes
ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important Safety Information
Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.
Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

Allergic reactions may occur with ALPROLIX. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called “inhibitors” against ALPROLIX, which may stop ALPROLIX from working properly.

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

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 Brief Summary of full Prescribing Information on the next page. This information is not intended to replace discussions with your healthcare provider.
What are the possible side effects of ALPROLIX™?
Common side effects of ALPROLIX™ include headache and abnormal sensation in the mouth.

Allergic reactions may occur. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: hives, chest tightness, wheezing, difficulty breathing, or swelling of the face.

ALPROLIX™ may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, “inhibitors,” against ALPROLIX™, which may stop ALPROLIX™ from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX™. Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX™?
Store ALPROLIX™ vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX™ vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX™ at room temperature:

- Note on the carton the date on which the product was removed from refrigeration.
- Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

Do not use product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX™ if the reconstituted solution is cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX™?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use ALPROLIX™ for a condition for which it was not prescribed. Do not share ALPROLIX™ with other people, even if they have the same symptoms that you have.

Manufactured by
Biogen Idec Inc.
14 Cambridge Center
Cambridge, MA 02142
U.S. License #1697
The CCHF Family Golf Day was held on Saturday, April 19 at the awesome Haggin Oaks Golf Course. Several families participated on this beautiful spring day. The day consisted of nine holes of a best ball format. And, next year I hear the “Footgolf” course will be offered as an alternative for those not quite into golf. We hope to see you there.
¿Tiene problemas con los copagos o brechas en la cobertura de su tratamiento para la hemofilia A?

Es posible que podamos ayudarlo.

Bayer ofrece una serie de programas que pueden ayudarlo a explorar cuestiones de seguro sobre su tratamiento para la hemofilia A. Si tiene problemas con los copagos o brechas en la cobertura, es posible que podamos ofrecerle ayuda. Hable con uno de nuestros especialistas de caso para obtener más información.

Llame al 1-800-288-8374 y presione 1 para hablar con un especialista en seguro capacitado.
The Central California Hemophilia Foundation hosted our annual Holiday Party on Saturday, December 7, 2013. We had the pleasure of having over 125 families attend our event. All were treated to a catered lunch of bar-b-que, incredible side dishes and yummy desserts. Volunteers assisted children with a wide array of crafts including creating peanut butter cup Christmas trees, Nutter Butter Reindeer cookies, ornaments and foam picture frames. We also provided a hot chocolate bar with a variety of sweet, fun toppings and each family was also provided a special holiday family bag filled with Christmas wishes and take a picture. Each family was also provided a personalized mug to take home with them.

This year’s music by a crowd-pleasing country & western band; the venue was a huge success. We had several running features this year: a huge success; we had several running features. Our annual event was held on February 15, 2014 at the Elk’s Lodge in Sacramento’s Pocket neighborhood. The Foundation’s annual Crab Feed was held on the following Saturday, March 23, a lively group from CCHF attended the Sacramento Kings game as they played the Milwaukee Bucks. It was a great game; the seats were very fine; and, to top it all off, the Kings beat the Bucks 124 to 107. Cousins, Gay and Thomas were in top form and scored most of the Kings points. If they play this well next season we could have a consistently winning team in the works.

Thank you CCHF for making this fun night possible. The Central California Hemophilia Foundation hosted our annual Holiday Party on Saturday, December 7, 2013.