INFUSIONS

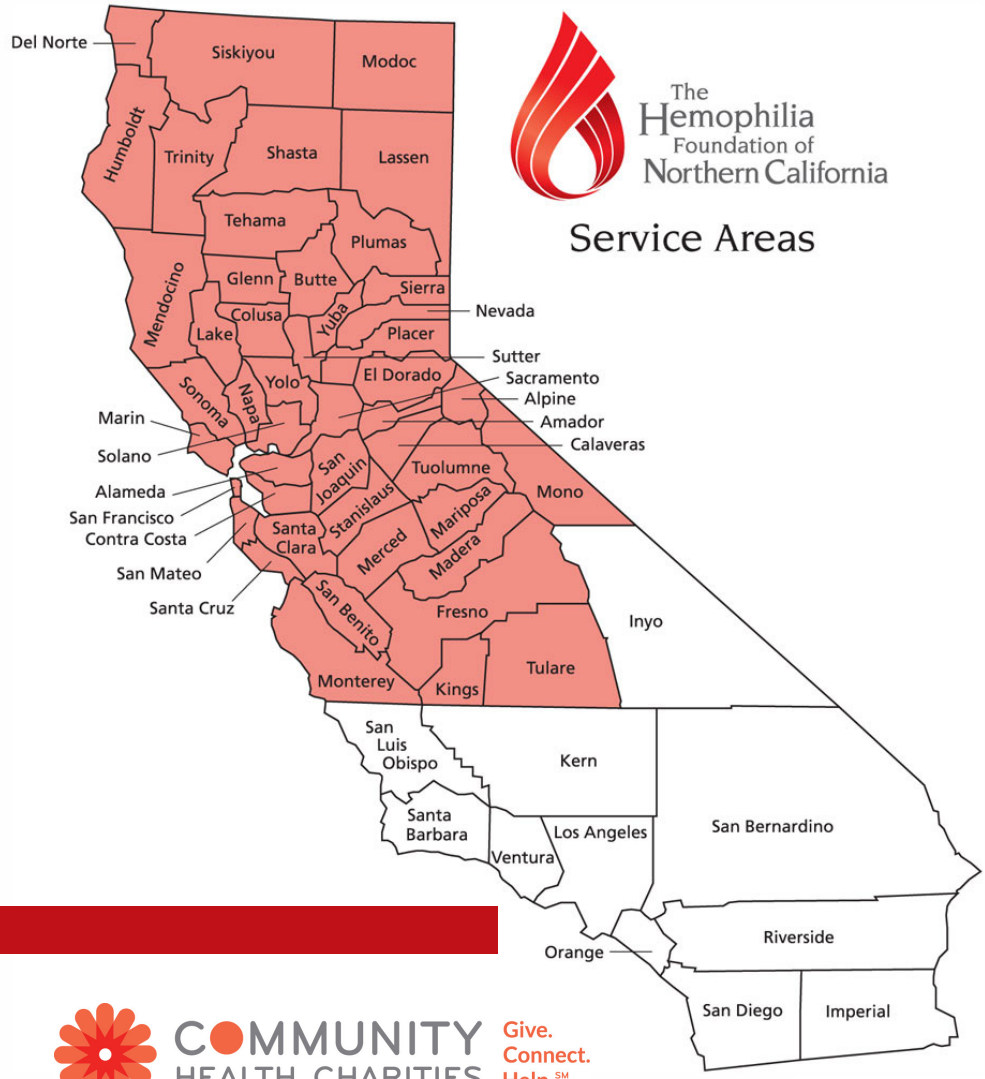
NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA · SPRING 2015

Expanding our influence

The Hemophilia Foundation of Northern California is proud to add 21 new counties to our service area as the official National Hemophilia Foundation chapter affiliate this year, effective March 1. We also continue our member status with the Hemophilia Federation of America.

Our mission: To serve the needs of people impacted by bleeding disorders through enhancing quality of life by providing support, education, outreach, advocacy and research through our affiliated national foundations.

There are many nonprofits that serve our bleeding disorders community in California, across the nation and around the world. We look forward to serving our foundation's mission and having further reach to make an impact hand in hand with our sister organizations.



Partner organizations

NATIONAL HEMOPHILIA FOUNDATION
www.hemophilia.org

COMMUNITY HEALTH CHARITIES
Give. Connect. Help.℠

HCC

HFA
Hemophilia Federation of America™

25 years of giving
15 years of camp
Taylor Family FOUNDATION
1990 - 2015

Western States
Federal Hemophilia Treatment Centers
California+Hawaii+ Nevada+Guam

From Baxter's BioScience to Baxalta...

Baxter's BioScience is expected to become Baxalta in mid-2015.

At Baxter's BioScience, we see a world of endless possibilities for our patients. And although our name may be changing to Baxalta, our commitment to you is as strong as ever. At our foundation is an enduring heritage of innovation and advocacy. Your life is our inspiration to make a meaningful difference, so you can dream big, and experience life. We are excited about the future and hope you are too!

Baxter is a registered trademark of Baxter International Inc.
USBS/MG1/15-0020(1) February 2015

Baxter

The Hemophilia Foundation of Northern California

Executive Staff and Board of Directors

Dawn Pollard
PRESIDENT

Peter Barbounis
VICE-PRESIDENT

Pamela Morris
SECRETARY

Victor Chao
TREASURER

Cathy Mancuso McClelland
Suzanne Goldman
Tina Lau
Robert Toledo
BOARD MEMBERS

Staff

Patrick Dunlap
EXECUTIVE DIRECTOR

Lonnie Wood
EXECUTIVE ASSISTANT

Contact Information

6400 Hollis Street, Suite 6
Emeryville, CA 94608

Office hours: Mon-Fri,
8:30 a.m. to 5 p.m.

www.hemofoundation.org

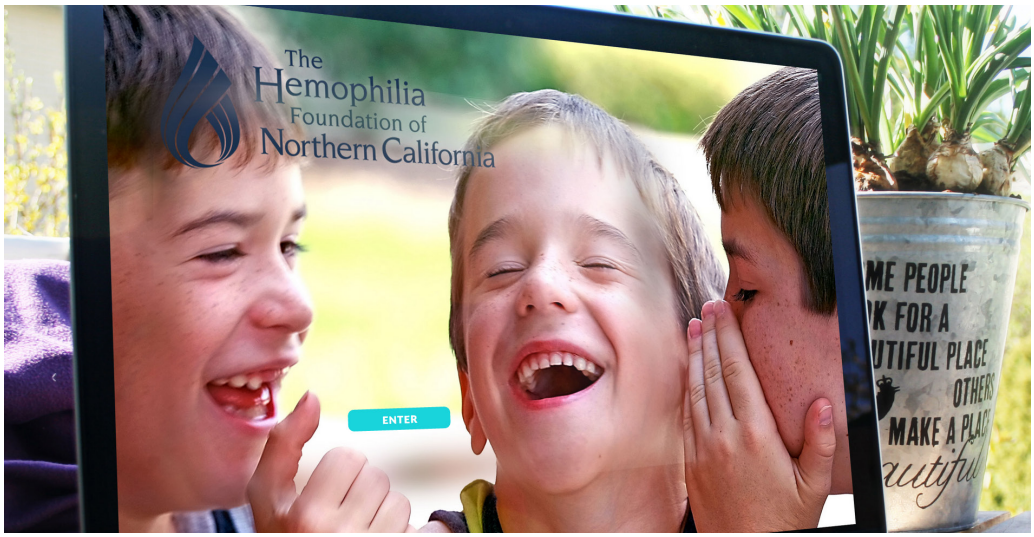
(510) 658-3324 phone
(510) 658-3384 fax

Donate your vehicle to support NHF and HFNC
Donate your car, boat, motorcycle, truck or other vehicle to NHF's Vehicle Donation Program. Visit NHF at www.hemophilia.org and click the "vehicle donation program" link, or call 1 (855) NHF-4-CAR. A representative will explain all of the details — including how to schedule free pick-up service that's convenient for you.

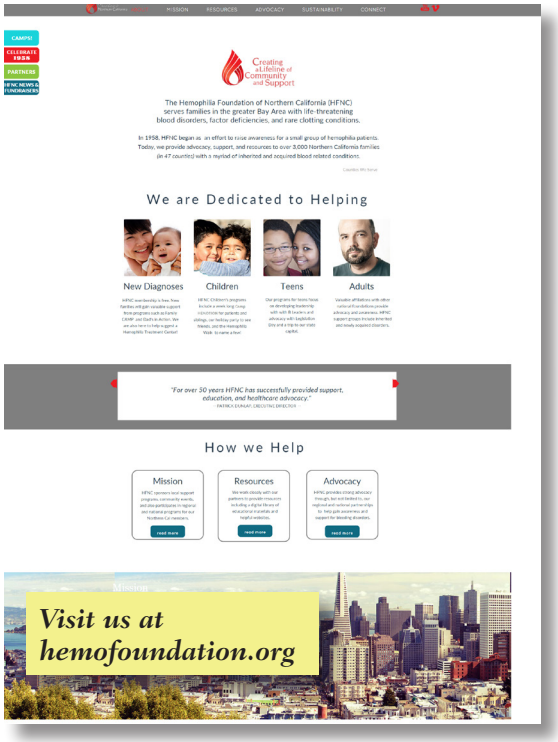
HFNC is going green!
Help HFNC reduce waste and cost by receiving *Infusions* via email. If you would like to make the switch, please email Patrick Dunlap at patrick.dunlap@hemofoundation.org.

Creating a Lifeline of Community and Support

News



Website gets a facelift



HFNC is pleased to announce that our website recently got a much-needed facelift, bringing hemofoundation.org a modern, interactive look for those seeking more information on our porgrams and services.

"This dramatic upgrade to our website brings us up to the standard set by Northern California," HFNC Executive Director Patrick Dunlap said. "These changes will make it easier for our community to get the updates they need on our programs and services."

The still-evolving site now features links for each of the many programs offered by HFNC, sections dedicated to advocacy and fundraising, and a live calendar of upcoming events.

We welcome your feedback on the new site and hope you find this improvement to be helpful to your family as you navigate the bleeding disorders world.

Spread a smile with HFNC and Amazon

amazon smile Prime

Supporting: Hemophilia Foundation Of Northern California
Ben's Amazon.com Today's Deals Gift Cards Sell Help

Did you know you can support HFNC with your purchases on Amazon.com at no cost to you? Simply go to http://smile.amazon.com/ch/94-1638703 and log in with your existing Amazon username and password and Amazon will donate 0.5% of your purchase price to HFNC. Be sure to replace your Amazon.com bookmark with smile.amazon.com to ensure all your purchases get credit!

Female Factor flourishing

By Ashley Gregory and Christa Parra

In the summer of 2013 a few mothers, wives, caregivers, carriers and women with von Willebrand's Disease and other bleeding disorders began getting together to supporting each other through the difficulties we face taking care of ourselves and loved ones with and without a bleeding disorder. Through these meetings, we discovered the issues and challenges we face as minorities in the bleeding disorders community and saw an opportunity to fill a need for support and fellowship.

Out of those first gatherings was born the idea of The Female Factor Group. Our name is meant to include every female in the bleeding disorders community, and we learned that even if we aren't affected with a bleeding disorder, we have one thing in common: is self care of mind, body and soul. Until the group was formed, these needs weren't being addressed within our community and amongst ourselves.

Since then, we have organized many events, including educational dinners exploring topics such as pain management, navigating the HTC world, 504's and IEP's, sustainability of our group within the chapter for future generations, how to access better treatment for carriers and patient advocacy. Our roundtable meetings are lively and electric with hot topics. With the recent addition of 21 new counties in the HFNC service area, we are preparing to offer this much-needed community service into a larger area. Although our meetings are currently in English, we see the need to provide Spanish and Cantonese content.

Many participants have expressed the need to become trained in advocacy, and we are currently seeking grants to provide advocacy training from HCC to enable The Female Factor to attend the legislative days hosted by the Hemophilia Council of California and the National Hemophilia Foundation and meet with lawmakers to effect change in policies and medical care locally and nationwide.

We have recently been made aware of the need for outreach to the younger group

Continued on page 19

Dads group comes to Fresno

By Brent Mascorro

HFNC's Dads in Action program recently continued its program expansion with the first ever DIA event in Fresno.

Thirty-five attendees participated in a fun-filled interactive learning day at Fresno State University. An hourlong educational program in the Planetarium led by a university professor kicked off the event. The group then enjoyed lunch and a wonderful bleeding disorder presentation by former HFNC board president and HFA representative Doug Hartsough.

After a great group discussion, the party really started with more than 3 hours of bowling, billiards and music.

Thank you to the Fresno area community members for coming out and participating in a wonderful day of learning and supporting. Dads in Action's next event is April 25th at the Oakland A's game. Contact HFNC office for more information.

Book on Ryan White on the way

A new book on the life of Ryan White is set for release nearly a nearly a quarter-century after the death of the Indiana teenager who became an early face of the AIDS epidemic.

The Indiana Historical Society will host a book launch event April 1 for its new book, "The Quiet Hero: A Life of Ryan White," written by Nelson Price.

White's mother, Jeanne White-Ginder, and Olympic diving champion Greg Louganis, who had befriended White, will attend that downtown Indianapolis event.

White became a national figure during the AIDS scare of the 1980s after suing his Howard County school district for the right to attend classes.

He developed AIDS after receiving a tainted blood transfusion to treat his hemophilia. White died on April 8, 1990, at age 18.

Calendar

April
6 Blood Brotherhood - Santa Rosa Men's Support Group/Peer Support
9 Baxter Facts First - Salinas
13 Board Meeting - call
17 World Hemophilia Day
22 Female Factor - Los Gatos
25 Dads In Action Oakland A's Game - Astros
26 Hemophilia Third Party Event - "Rookies"

May
1 Baxter Facts First- "True Identity" Oakland
2 NHF Walk
6 Female Factor - Monterey- Biogen
11 Board Meeting - in person
11- 13 HCC Future Leaders - Sacramento
13 Leg Day Sacramento
16 Biogen Spanish Education Day - Fresno
15-17 B-leaders Retreat

June
6 Board of Directors Retreat
14-20 Camp Hemotion

July
12 Female Factor - Picnic-Zumba
13 Board Meeting - call
15 or 16 Biogen Idec Hemophilia - Emeryville - Educational Dinner
25 Blood Brotherhood BBQ East Bay
25 Baseball Clinic HFNC
26 First Day HCC Coastal Bike Ride end day August 1
TBD Speeders for Bleeders
31 HFNC Scholarship applications due

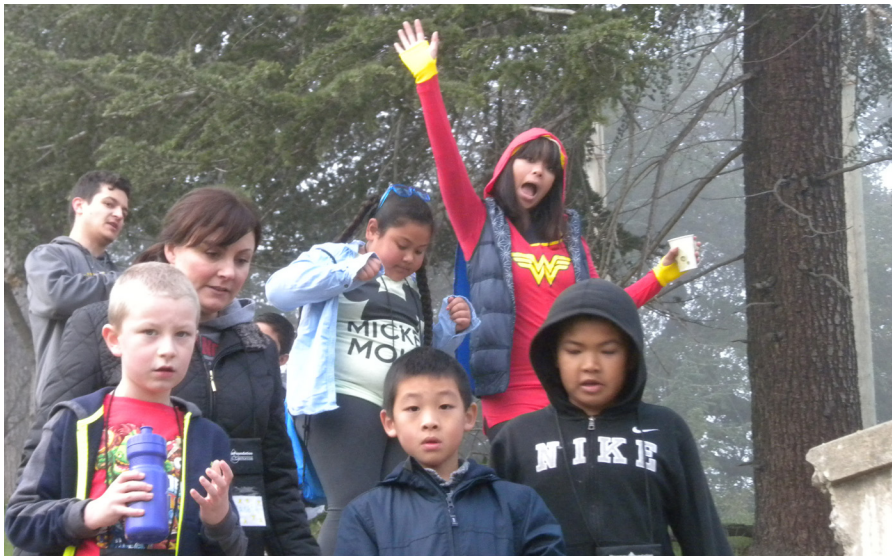
Fog fuels fun-filled weekend

We're accustomed to fog in Northern California, so a thick haze blanketing Camp Arroyo in Livermore didn't dampen spirits for the latest installment of HFNC's annual Family Camp.

This year was bittersweet, hoewver, as it marked the final year under the direction of Diana Virgil, who has been instrumental in the decades-long process of making the program what it is today.

HFNC also honored Bobbie Steinhart who founded the program in 1990 and was on hand to see the tremendous growth Family Camp has seen since its inception.

A big thank you goes out to the Taylor Family Foundation for donating the use of the site for this event year after year!



New NHF program closes gap

The National Hemophilia Foundation recently announced a new program that will help more people with bleeding disorders be able to attend Annual Meeting.

Connections for Learning provides funding for individuals with bleeding disorders to attend the meeting to gain the relevant experience and practical knowledge they need to better navigate life with a chronic illness.

NHF will provide customized educational experiences and networking opportunities at its Annual Meeting for patients with bleeding disorders who struggle with the management of their chronic illness and lack effective support due to geographic, cultural, social, and/or economic barriers.

NHF is committed to providing $100,000 in funding for the Connections for Learning Program. Already the Colburn Keenan Foundation has agreed to generously match every donation dollar for dollar up to $25,000 raised. To help launch the program before this year's Annual Meeting, we have been challenged to raise the first $7,500 by the end of March.

For more information, visit hemophilia.org.

Gene therapy proves effecitve in canines

Using gene therapy to produce a mutant human protein with unusually high blood-clotting power, scientists have successfully treated dogs with the bleeding disorder hemophilia, without triggering an unwanted immune response. In addition, the "turbocharged" clotting factor protein eliminated pre-existing antibodies that often weaken conventional treatments for people with hemophilia.

"Our findings may provide a new approach to gene therapy for hemophilia and perhaps other genetic diseases that have similar complications from inhibiting antibodies," said the study leader, Valder R. Arruda, M.D., Ph.D., a hematology researcher at The Children's Hospital of Philadelphia (CHOP).

Arruda and colleagues published their animal study results in the print edition of Blood on March 5.

Hemophilia is an inherited bleeding disorder that famously affected European royal families descended from Queen Victoria. Most commonly occurring in two types, hemophilia A and hemophilia B, the disease impairs the blood's ability to clot, sometimes fatally. When not fatal, severe hemophilia causes painful, often disabling internal bleeding and joint damage.

Doctors treat hemophilia with frequent intravenous infusions of blood clotting proteins called clotting factors, but these treatments are expensive and time-consuming. Moreover, some patients develop inhibiting antibodies that negate the effectiveness of the infusions.

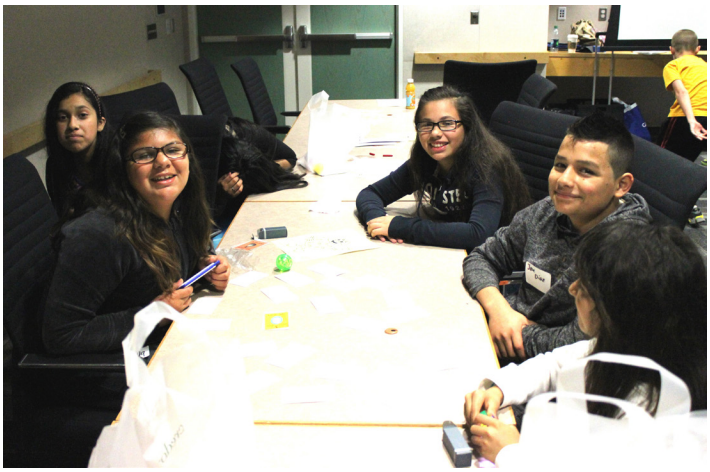
For more than two decades, many research teams, including at CHOP, have investigated gene therapy strategies that deliver DNA sequences carrying genetic code to produce clotting factor in patients. However, this approach has been frustrated by the body's immune response against vectors--the non-disease-causing viruses used to carry the DNA. Those responses, which defeated initial benefits seen in experimental human gene therapy, were dose-dependent: higher amounts of vectors caused more powerful immune responses.

Arruda and colleagues therefore investigated gene therapy that used lower dosages of vector (adeno-associated viral-8 vector, or AAV-8 vector) to produce a more potent clotting factor--a variant protein called FIX-Padua.

Arruda was part of a scientific team in 2009 that discovered FIX-Padua in a young Italian man who had thrombosis, excessive clotting that can dangerously obstruct blood vessels. A mutation produced the mutant clotting factor, called FIX-Padua, named after the patient's city of residence. This was the first mutation in the factor IX gene found to cause thrombosis. All previously discovered FIX mutations lead to hemophilia, the opposite of thrombosis.

FIX-Padua is hyperfunctional--it clots blood 8 to 12 times more strongly than normal, wild-type factor IX. In the current study, the

Continued on page 21



Community gathers to strengthen bonds

Families from all over Northern California gathered at Oakland Children's Hospital on March 15 for HFNC's annual Family Education Day.

New to the event this year was the first appearance of the "Powering Through" series in Northern California. Organized and moderated by community member Patrick James Lynch — the brains behind the popular "Stop the Bleeding" web series — the panel included hemo mom Lauren Barbounis, community member and volunteer Ben Martin and Olympic track and field star Jeremy Dodson.

The trio conversed with Patrick about overcoming challenges, whether related to bleeding disorders nor not, and answered a few questions from the audience.

The rest of the day was filled with educational breakout sessions to targeted groups, including men, women, teens and children.

Thanks to all those who attended, especially the large group that made the trip up from Fresno on two buses!

Delicious fundraising

HFNC's 11th annual Crab Feed was our most successful yet, raising more than $40,000 for the foundation thanks to huge ticket sales and a successful auction. And of course, the crab was delicous!

See some of our photo booth pics on pages 15.

National Hemophilia Foundation and Hemophilia Foundation of Northern California Present

HEMOPHILIA walk '15 SM

Every step makes a difference

National Presenting Sponsor Baxter

SAVE THE DATE

Saturday, May 2, 2015

Registration Check-In Time: 9:00am
Walk Start Time: 10:00am
Distance: 5K (3.1 miles)
Location: Cesar Chavez State Park
11 Spinnaker Way
Berkeley, CA 94710
Walk Chairs: Bobby Wiseman and Elizabeth Seaton

Join us to support the Hemophilia Walk! We will walk to raise critical funds for the bleeding disorders community. Your fundraising efforts are greatly appreciated!

For more information, please visit www.hemophilia.org/walk or contact: Bryan Anderson, Local Walk Event Manager, at 510.658.3324 or HFNCwalk@hemofoundation.org.

www.hemophilia.org/walk

Participate. Volunteer. Donate.

Plant-Based Inhibitor Therapy Continues to Bloom

Scientists from the University of Florida in Gainesville (UF-G) and the University of Pennsylvania (U-Penn) continue to investigate an experimental, plant cell-based approach to preventing inhibitors and allergic reactions (anaphylaxis) to clotting factor therapies in people with hemophilia. An update on their progress was published online, December 16, 2014, in Scientific American, a division of Nature America, Inc.

Lead investigator Henry Daniell, PhD, director of translational research at the U-Penn School of Dental Medicine, and Roland W. Herzog, PhD, a molecular biologist at UF-G, have, for several years, been working on a technique that involves encapsulating an orally administered "tolerance-inducing protein" such as factor IX (FIX) within plant cell walls. When ingested, the bio-encapsulated protein safely travels through the stomach before reaching the small intestines. The plant cell wall shields the FIX from being prematurely broken down by stomach acid. Eventually, microorganisms eat away the cell wall, gradually releasing the protein.

Building on earlier studies (2010) that successfully used bioengineered tobacco plant cells to prevent inhibitors and anaphylaxis in mice with hemophilia B (FIX deficiency), Daniell and Herzog are now turning to freeze-dried lettuce leaf cells engineered to trigger a high concentration of FIX. Each lettuce leaf cell contains approximately 10,000 chloroplasts, each structured in such a way to hold very large volumes of the FIX protein. Chloroplasts are subunits of plant cells, most often known as crucial components of photosynthesis. Although these chloroplast-rich plant cells are not equipped to prevent bleeding--plants are unable to make human clotting factors biologically active--they have shown an ability to induce tolerance in the immune system to FIX. Researchers have been developing this novel therapeutic approach for several years to create potential vaccines against malaria and cholera, and genetically engineered insulin to help prevent diabetes.

Daniell and Herzog recently took the next step and tested this approach in two dogs with hemophilia B. They fed both dogs their normal food along with the engineered lettuce cells converted into a green powder form. There have been no reports of anaphylaxis or

Continued on page 15

BrothersHealthcare

BONDED by BLOOD

What can you expect from us?

- We are here 24 hours a day, 365 a year. Hemophilia doesn't take a break and neither do we.
- We provide personalized services to match your family's unique needs.
- We have reimbursement specialists that track, navigate, and handle all your insurances issues; one less thing for you to worry about.
- We coordinate nursing services that come to you, on your schedule.
- We offer all factor brands with supplies delivered on time to your doorstep.
- We are community advocates, educators, volunteers, and your child's mentor.

(877) 276-4248 | www.brothershealthcare.com

Roundtrip travel from anywhere in the USA, meals and lodging expenses are paid for by sponsor

THE COALITION FOR HEMOPHILIA B

APPLY TODAY

June 9-14, 2015 | Camp Collins near Portland, OR
Application deadline is May 15

Download the application at
coalitionforhemophiliab.org
or to contact the Coalition directly:

Kim Phelan
The Coalition for Hemophilia B
P: (917) 582-9077
F: (212) 520-8501
E: hemob@ix.netcom.com

CHALLENGE | CHANGE | LIVE | B

PROGRAM SPONSORED BY
emergent biosolutions™

emergent
biosolutions™

As you roll ahead in life with hemophilia B

Imagine a different experience

Emergent BioSolutions is a specialty pharmaceutical company focused on improving the lives of people with rare conditions. We are a different type of company, and are determined to make a difference for people with hemophilia B and those who care for them.

Sign up for updates at:
EmergentBioSolutions.com/hemophiliaB

©2014 Emergent BioSolutions Inc. All rights reserved. IXI-014-0414

WANT TO KNOW

MORE ABOUT YOUR FACTOR OPTIONS?

When it comes to your factor therapy, you have choices. And at Biogen Idec, we recognize the importance of researching and delivering additional factors to the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.

TO LEARN MORE ABOUT THESE OPTIONS, CONTACT YOUR CoRe MANAGER:
Marilyn August | **Phone:** 925.864.0547 | **E-mail:** Marilyn.August@biogenidec.com

biogen idec.

© 2015 Biogen Idec. All rights reserved. HEM-1007117 07/14

A Better Approach to Infusion Care

- Leading national provider of customized, convenient infusion therapy
- Individual and family education and support
- Full line of factor products and assay availability

Dedicated hemophilia team, including:

- Nurse
- Pharmacist
- Reimbursement specialist
- Patient care coordinator
- Patient advocate

For more information, please contact us:

Shelley Jajeh
Phone: 650-946-8556
Fax: 800-584-0635

bioscrip®

bioscrip.com

11th Annual Crab Feed

Continued from page 11

inhibitors in the mice from the earlier study or in the dogs that recently received the plant-based therapy. "So far, it's going very well," reported Daniell. If this novel oral therapy continues to prevent treatment complications in animal models, the next step will be to replicate that success in human clinical studies.

Source: Scientific American, December 16, 2014

BrothersHealthcare

UNIDOS por SANGRE

¿Qué usted puede recibir de nosotros?

- Estamos aquí las 24 horas al día, 365 días al año. Hemofilia no toma descanso, nosotros tampoco.
- Nosotros proveemos un servicio personalizado y único para la necesidad especial de cada familia.
- Tenemos especialistas de rembolso que se encargan de navegar, lidiar, y aclarecer todos los problemas y compilación de la seguranza medica; otra área en donde no tiene que preocuparse.
- Nosotros coordinamos los servicios de enfermera(o), en la cual lo visitarán cuando usted este disponible.
- Ofrecemos todo tipos de factor con todas las herramientas medicinales que necesite, directamente entregado a usted, en sus manos, y en su casa.
- Somos abogados por nuestra comunidad, educadores, voluntarios, y hasta un consejero para su hijo(a).

Se Habla Español **(866) 591-3955 | www.brothershealthcare.com**

BAXTER'S COPAY ASSISTANCE PROGRAM

Are you eligible to save up to $12,000 every 12 months?

Introducing CoPay assistance designed for you.

Let us help pay for your medication in 3 simple steps.

1. Call us at 1-888-BAXTER-9 (1-888-229-8379).
2. Answer a few simple questions, and let Baxter handle the rest.
3. Receive eligibility information in the mail.

*Full terms and conditions apply

We've got you covered.

Call 1-888-BAXTER9 (1-888-229-8379) or visit www.hemophiliasupport.com.

Personalized support

Baxter recognizes the importance of helping you meet the challenges that life presents. Visit us at www.nava.baxter.com for a variety of resources, assistance, and individual support for living with hemophilia.

Baxter and We've got you covered are trademarks of Baxter International Inc.
September 2014 USBS/MG155/14-0044

Baxter

Half the volume
Twice the factor*

ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) is now available in a **2000 IU FVIII vial** with a reconstitution volume of only **10 mL**.

*That's **TWICE** the amount of factor of the largest vial available for other FVIII/VWF products,[1-4] so patients may require:

- **Less volume**
- **Less time**
- **Fewer syringes**

Isn't it time you tried ALPHANATE?

Learn more at
alphanate.com

Alphanate®
Antihemophilic Factor/von Willebrand Factor Complex (Human)

Indications

ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) is indicated for:

- Control and prevention of bleeding in patients with hemophilia A
- Surgical and/or invasive procedures in adult and pediatric patients with von Willebrand disease (VWD) in whom desmopressin (DDAVP®) is either ineffective or contraindicated. It is not indicated for patients with severe VWD (Type 3) undergoing major surgery

Important Safety Information

ALPHANATE is contraindicated in patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with ALPHANATE should be discontinued, and emergency treatment should be sought.

Development of activity-neutralizing antibodies has been detected in patients receiving FVIII containing products. Development of alloantibodies to VWF in Type 3 von Willebrand disease (VWD) patients has been occasionally reported in the literature.

Thromboembolic events may be associated with AHF/VWF Complex (Human) in VWD patients, especially in the setting of known risk factors.

Intravascular hemolysis may be associated with infusion of massive doses of AHF/VWF Complex (Human).

Rapid administration of a FVIII concentrate may result in vasomotor reactions.

Plasma products carry a risk of transmitting infectious agents, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, despite steps designed to reduce this risk.

The most frequent adverse events reported with ALPHANATE in >5% of patients are respiratory distress, pruritus, rash, urticaria, face edema, paresthesia, pain, fever, chills, joint pain, and fatigue.

Please see brief summary of ALPHANATE full Prescribing Information on adjacent page.

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.

References: 1. ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) Prescribing Information. Grifols. **2.** CSL Behring. Humate P Package Insert. August 2013; **3.** Octapharma. Wilate Package Insert. January 2012; **4.** Kedrion. Koate-DVI Package Insert. August 2012.

For more information: **Grifols Biologicals Inc.**
Tel. 888-GRIFOLS (888-474-3657)

© 2014 Grifols Inc. All rights reserved. Printed in USA. July 2014 A817-0714

Grifols Biologicals Inc.
5555 Valley Boulevard, Los Angeles, 90032 CA - USA Tel. 888-GRIFOLS (888 474 3657)
www.grifols.com

GRIFOLS

Biotherapies for Life® **CSL Behring**

Introducing…

My Access

Tap into My Access to help manage your condition—or your loved one's—in a cost-effective manner

designed to help you cover the out-of-pocket costs associated with your therapy

ACCESSED through the **My Source**™ program

Available for reenrollment every year

For more information or to enroll, call the My Source Hotline at **1-800-676-4266** to speak with a My Source Care Coordinator.

My Source™
Tap into it!

Visit **www.MySourceCSL.com**.

www.facebook.com/vonWillebrandandU

COAGULATION

My Source™ is a trademark of CSL Behring LLC.
©2014 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA
www.CSLBehring-us.com **www.MySourceCSL.com** COA13-11-0083 11/2013

**Skilled Pharmacists.
Experienced Infusion Nurses.
Dedicated Patient Experience Team.**

Soleo Health provides a team approach to bleeding disorder therapy management. To learn more about programs in Northern California, call **Brent Mascorro** at **866.665.1121** or **916.340.5660.**

www.soleohealth.com

Continued from page 4

of carriers experiencing bleeding symptoms, VWD and other bleeding disorder affected girls that would benefit from education and support and have discussed ways to connect and provide guidance to them through Mother/Daughter events and an outreach program sponsored by The Female Factor.

If you would like to attend any of our upcoming events, please RSVP with Lonnie at Lonnie.wood@hemofoundation.org. If you would like to be on our information distribution list please email your contact information to Christa and Ashley at hfncffg@hemofoundation.org.

MORE THAN JUST ANOTHER
LINE ON YOUR RESUME

Making a change in the world
begins by making a change in your community! Apply to be an intern through the Bayer Hemophilia Leadership Development Program and begin to learn how to be the change YOU want to see in the world.

Students enrolled full-time in college who are touched by hemophilia can apply now for the opportunity to:

- Engage in leadership training and hands-on business projects
- Learn how to support the hemophilia community as a potential future leader

Apply now for a six-week paid internship at Bayer HealthCare's U.S. headquarters in New Jersey.

In addition to working directly with leaders at Bayer, selected interns will:

- Collaborate with local hemophilia organizations and learn about efforts to support the hemophilia community and partnerships with business professionals
- Meet with healthcare public policy professionals to experience first-hand how effective advocacy relations impacts legislative decisions
- Be responsible for developing a project that will be presented to Bayer Senior Management

Start shaping your future and your community!

Apply today for the Bayer Hemophilia Leadership Development Program.

APPLICATIONS ARE DUE NO LATER THAN **Friday, March 13, 2015 at 11:59 p.m. ET**

To learn more and complete an application, visit www.HemophiliaInternship.com

Explore Bayer HealthCare's additional leadership opportunities, Step Up Reach Out and AFFIRM, at **www.hemophilialead.net.**

BAYER HEMOPHILIA LEADERSHIP DEVELOPMENT PROGRAM

PASSION + ADVOCACY + REAL WORLD EXPERIENCE

Bayer HealthCare

Bayer and the Bayer Cross are registered trademarks of Bayer. © 2014 Bayer HealthCare Pharmaceuticals, Inc. PP-575-US-1253

Hemophilia Council of California
Non-Profit Organization

LOOKING FOR FUTURE LEADERS!

ARE YOU AGES 14 – 22 WITH A BLEEDING DISORDER?

The Hemophilia Council of California (HCC) is a state-wide organization serving people with bleeding disorders. This program teaches young men and women with bleeding disorders how California government works, insurance and state programs that support their care, education and career, and how to inform others about their disease.

- **Meet with legislators at the California State Capitol**
- **Learn self-reliance and leadership skills**
- **Free of charge for the youth participants**
- **We encourage young women to participate!**

Our next

Future Leaders Program

will be held

May 11-13, 2015

at the Hyatt in Sacramento, CA

Hemophilia Council of California
4629 Whitney Ave., Suite 1
Sacramento, CA 95821

More info: www.hemophiliaca.org

For questions, contact Heidi Scanlan at the Hemophilia Council of California

Phone: (916) 498-3780 • Fax: (916) 498-3782 • Hccassist@aol.com

Continued from page 8

researchers thus needed to strike a balance--to relieve severe hemophilia in dogs, by using a dose strong enough to allow clotting, but not enough to cause thrombosis or stimulate immune reactions.

"Our ultimate goal is to translate this approach to humans," said Arruda, "by adapting this variant protein found in one patient to benefit other patients with the opposite disease."

The current study tested the safety of FIX-Padua in three dogs, all with naturally occurring types of hemophilia B very similar to that found in people. Two of the dogs had never been exposed to clotting factor, and had never developed antibodies. The gene therapy injections changed their hemophilia from severe to mild, with no bleeding episodes for up to two years. They did not develop inhibitory antibodies, nor was there evidence of thrombosis.

The third dog, named Wiley, already had inhibitory antibodies before receiving the gene therapy. Wiley also experienced safe and effective treatment of hemophilia, persisting over a sustained period-- three years. The treatment also eradicated the inhibitory antibodies, the first time this occurred in an animal model with pre-existing antibodies.

Another set of preclinical safety studies in mice supported the safety and efficacy of gene therapy using FIX-Padua. Arruda added that larger studies are needed in dogs with pre-existing inhibitors, to confirm these encouraging early results.

July 25 - August 1, 2015
San Francisco to San Diego
Be a Rider • Sponsor a Rider

California Coastal Ride For Hemophilia
Benefiting All Four Hemophilia Chapters & The Hemophilia Council of California

The ride begins on Saturday, July 25 with a kick-off dinner in San Francisco and concludes with a homecoming BBQ in San Diego on Saturday, August 1. Registered riders embark on a seven-day journey along California's majestic Highway 1 for an experience like no other.

HCC

Hemophilia Council of California
4629 Whitney Ave. Suite 1
Sacramento, CA 95821

The Hemophilia Council of California (HCC) is a collaboration of the four hemophilia chapters serving California. HCC's mission is to support the four California hemophilia chapters and to imporve the quality of life of people with bleeding disorders. Help us raise awareness by joining the ride!

More info: www.ccr4h.org

For questions, contact Heidi Scanlan at the Hemophilia Council of California

Phone: (916) 498-3780 • Fax: (916) 498-3782 • Hccassist@aol.com

Baxter's NAVA program—it's all about what we can do *for you*.

Support means so much more when it's tailored just for you. That's why we created Baxter's NAVA program—a highly personalized support program for anyone affected by a bleeding condition.

Your NAVA team members will work with you one-on-one to deliver the specific resources you need to get the most out of life. Going off to school? Considering a new job? Thinking of getting married? Life is more than just your bleeding condition. That's why we give you the tools and coaching to help you set and achieve life goals.

And one more thing: NAVA program membership is free and open to anyone living with or caring for someone with a bleeding condition, regardless of treatment.

Join NAVA program now and get access to:

- **A NAVA Guide** to connect you to information and resources specific to your needs
- **A NAVA Partner** to help you set and achieve life goals—career, education, relationships, and more
- **A NAVA Mentor** who's walked in your shoes and can share their own experiences
- **NAVA.baxter.com** to access events, resources, and articles tailored just for you!

Don't miss out on what the NAVA program can do for you!

Enroll now at nava.baxter.com or 1-855-322-NAVA (6282).

Baxter

Which way next?
Navigating life with bleeding conditions

NAVA

Baxter and Nava are trademarks of Baxter International Inc. USBS/MG1/14-0902

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

The Hemophilia Foundation of Northern California

Creating a Lifeline of Community and Support

Information and Resources included with your Infusions newsletter are for informational purposes only and do not constitute any endorsement or recommendation of or for any medical treatment or product by The Hemophilia Foundation of Northern California (HFNC). With regard to medical information, HFNC recommends that any and all medical treatment you receive or engage in be discussed throroughly and frankly with a competent, licensed, and fully informed medical practitioner, preferably your Hemophilia Treatment Center providers. Opinions expressed in articles in the newsletter are not necessarily those of Infusion's editorial staff or the HFNC.

Hemophilia Foundation of Northern California is a 501(c)(3) non-profit. Donations are tax-deductible, much needed and appreciated!

The Infusions Newsletter is underwritten yearly by generous grants from Baxter and Bayer.

Infusions staff

Ben Martin
EDITING AND LAYOUT

Vincent Tinnura
CONTRIBUTING PHOTOGRAPHER(S)

Ben Martin
Christa Parra
Ashley Gregory
Brent Mascorro
CONTRIBUTING WRITER

Visit our website at *www.hemofoundation.org* for important information.

If you would like to advertise in the next issue, please contact the foundation.