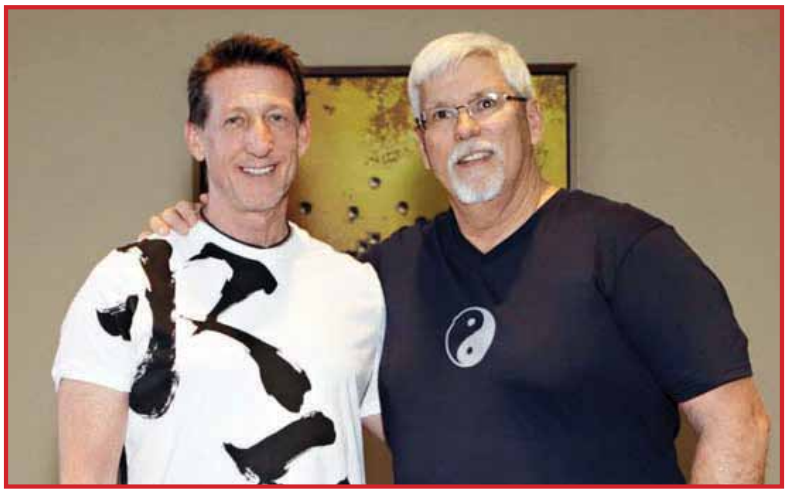
Factor Nine News

The Coalition for Hemophilia B Summer 2014

Topics in Hemophilia

How Tai Chi Saved Me

By Rick Starks



David-Dorian Ross, TaiJiFit Developer/Instructor, and Rick Starks

Let me first introduce myself, my name is Rick Starks, born in June, 1954, if you do the math, I'm 59 years old. I have hemophilia B, am considered severe (less than 1% of factor), and have had a heart attack at age 56. I have had bilateral hip replacements; I have been told my ankles are almost fused, mostly grinding bone on bone and have caused me severe, constant pain for about the last 6-7 years.

As a hemophiliac in the 1980's, I too contracted Hepatitis C, as most of us did. Some people feel I have had a hard life, but I don't feel that way, not at all. I've been blessed with a loving wife, strong sons and an amazing daughter (who also has moderate B).

My story begins in the early 70's. Bruce Lee appeared on the big screen making most of us at that time seek out some form of martial arts.

I enrolled in the Dacascos Academy of Kung Fu in Denver, and trained for some time. Life slowed down my progression into the arts for a while - you know, marriage, bills, a job, kids - .everyday things. I found something was missing so began training in Tae Kwon

Continued on page 3

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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 have been providing specialized products for people with rare conditions and blood disorders for over 45 years. Our long-standing history and focus on improving the lives of small patient populations have led us to develop the kind of experience necessary to make a positive impact on the hemophilia B community.

Our mission is simple—to protect and enhance life.

Emergent BioSolutions is a different type of company, and we 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

 IXI-014-0414


Dacascos Academy of Kung Fu

Do, achieving the rank of 1st Dan and opening a small school. Injuries slowed me down even more and I was no longer able to train. Then bilateral hip replacements, some more life, a move to rural Nebraska (don't get me wrong, I love it here), a heart attack, everyday things again, and I became quite sedentary. My ankles became so painful that I could no longer walk more than a block or two. I found some carbon fiber braces that helped with the pain, but they resulted in severe muscle cramps. The couch became my best friend.

I knew I could no longer sit around waiting for the end, so I began to learn Qi Kung and experimented with Tai Chi through videos and DVDs. Being in a very small, rural area, there was not the benefit of local training. I was at least beginning to move a little again. Searching online one day in 2013, I found an advertisement for TaiJiFit. As it stated, "a revolutionary mind/body fitness program that utilized the moves of Tai Chi and is for everyone regardless of age, or physical limitations." I found out that they were offering a train for persons interested in becoming instructors. I signed up.

The day arrived for my first session. David-Dorian Ross, the TaiJiFit founder and the actual instructor welcomed me in. Not having slept well the night before, up every couple of hours with leg cramps, I was tired, but excited to be there. Mind you, prior to this day I had limited range of motion in most extremities, could not stand more than an hour without ankle swelling and pain. We began training, DDR (as we call him) put on some music and had us begin to move gently, slowly adding in TaiJi (Tai Chi) movements and focusing on our breathing. For a brief moment, I forgot about the pain, feeling a warmth spread through me, a mental focus, seemingly razor sharp, and I was smiling! Four hours later we broke for lunch - I'd been training for 4 hours! That night, I slept through till moring without a single leg cramp.

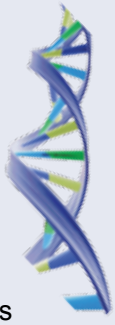
I've continued training, almost daily. I've attended more training sessions and found a new energy and purpose. I walk my dog several days a week and 5 days a week, lead a small group in my tiny town in TaiJiFit. The pain that was a constant with me, gone. The high blood pressure that led to my heart attack, resolved. Flexibility and strength, greatly improved. My braces? They now sit in the closet, collecting dust. I no longer need them, though I do occasionally look at them, reminding myself of where I was.

I have a new purpose in life, to bring TaiJi (Tai Chi) to our community, tp our brotherhood of "bleeders." There is not one person that would not benefit from it. I was fortunate enough to lead a group through a session at the recent Coalition for Hemophilia B Men's Retreat in Carefree, Arizona. I hope they enjoyed playing - that's what the masters call it, playing. If you are traveling and just happen to be going through southwest Nebraska, look me up. I'll be smiling, maybe in the park, playing...

Hepatitis C Clinical Trial for People with Bleeding Disorders

By Dr. David Clark

Gilead Sciences has announced that they are recruiting patients for a Phase II clinical trial of their hepatitis C drugs Ledipasvir and Sofosbuvir (Sovaldi). This will be the first hepatitis C clinical study to include patients with inherited bleeding disorders. Sofosbuvir has already shown good efficacy in treating hepatitis C and was recently licensed by FDA. This is an opportunity for early access to an advanced Hepatitis C therapy for individuals in our community.



The trial protocol is attractive, particularly for patients with genotype 1 or 4, and particularly for patients with fairly advanced disease and/or comorbidities such as HIV infection. If you have HCV and a bleeding disorder, and live near one of the study centers, we recommend you review the study, preferably with your physician, and consider participating.

Additional information including a list of study centers can be obtained under the study "Efficacy and Safety of Ledipasvir/Sofosbuvir Fixed-Dose Combination and Sofosbuvir + Ribavirin for Subjects With Chronic Hepatitis C Virus (HCV) and Inherited Bleeding Disorders" at http://clinicaltrials.gov/ct2/show/NCT02120300?term=bleeding+disorder+hcv&rank=1.

RIXUBIS
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For more information, contact your Baxter representative today:

Laini Vogel

Phone: (201) 312-7533

E-mail: laini_vogel@baxter.com

To learn more, visit www.RIXUBIS.com.

Baxter

Does Fish Oil Increase the Risk of Bleeding?

By Dr. David Clark

Omega-3 fatty acids (OFAs), primarily from fish oil, are recommended dietary supplements for many people because of their heart-healthy benefits. However, some older studies have suggested that large amounts of dietary fish oil may result in a greater risk of bleeding. This raises the question whether hemophilia patients should avoid fish oil supplements.

The concern started with studies in the late 1970s of the Greenland Inuits who have a very fish-rich diet. The investigators found that bleeding times in the Inuit people were prolonged compared to normal healthy Danes and that they tended to have frequent nosebleeds. Further study showed that their platelets were markedly enriched in OFAs and had inhibited aggregation characteristics. (Platelets are specialized blood cells that aggregate or stick together to form a plug to stop bleeding.) Interestingly, similar effects have not been found in Alaskan Eskimos with fish-rich diets.

The question since that time has been whether fish oil supplements have a significant effect on bleeding. Many physicians, particularly surgeons, continue to be concerned about the bleeding possibilities and often recommend that patients discontinue fish oil supplements prior to any invasive or surgical procedure. Since hemophilia patients already have bleeding issues should they also avoid fish oil supplements in spite of the cardiovascular benefits?

Although a number of studies have shown that OFAs do affect platelet function, a large number of other surgical studies have shown that there is no clinically significant effect on bleeding at doses of 1 4 g/day. There have not been any studies in patients with hemophilia, so there is no definitive answer for our group. Patients with bleeding disorders who have cardiovascular risk factors and might benefit from fish oil supplements should discuss the situation with their physicians.

The Coalition for Hemophilia B

FACTOR NINE SANTA PROGRAM

The Factor Nine Santa Program is in this issue on page 19 and will be in our Fall issue as well.

NEW YORK SYMPOSIUM

Every year we fly in families on a lotto basis to attend our New York Symposium and come as our Guests to attend our Fundraising Dinner as well. Airfare for families, hotel and meals are included. Next year our Fundraising Dinner is on Friday March 6th 2015 at the Water's Edge Restaurant overlooking the skyline of Manhattan. Our Symposium follows on Saturday, March 7, 2015 at the Grand Hyatt Hotel in New York City. Lotto forms will be coming soon! Lotto forms will be in the Fall Newsletter mailing. If you are not on the mailing list, you will not receive the lotto forms! Winners will be announced on December 1st, 2014.

3rd ANNUAL MEN's RETREAT

Our Third Annual Men's Retreat will be held the weekend of March 20-22, 2015. Lotto forms will go out with the Fall Newsletter. Winners will be announced on December 1, 2014

1st ANNUAL WOMAN's RETREAT

We are Delighted to announce our First Annual Woman's Retreat which will be held the weekend of April 10-12, 2015. Lotto forms will be in the Fall newsletter.

WILLIAM N. DROHAN SCHOLARSHIP FUND

Application forms for the William N. Drohan Scholarship fund for people with hemophilia B or a sibling of a person with hemophilia B will be posted on our website in December 2014.

BeneFix®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

℞ only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-934-5556.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing
difficulty breathing
chest tightness
turning blue (look at lips and gums)
fast heartbeat
swelling of the face
faintness
rash
hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE BeneFix. BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Store the diluent syringe at 36° to 86°F (2° to 30°C). Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

Different storage conditions are described below.

Product labeled for Room Temperature Storage
Store at 2° to 30°C (36° to 86°F).
If you have the product kit labeled for room temperature storage, it can be stored at room temperature (below 30°C or 86°F) or in the refrigerator (2° to 8°C or 36° to 46°F).

Product labeled for Refrigerator Storage
Continuous refrigeration
[2° to 8°C (36° to 46°F)]
If you have the product labeled for storage in the refrigerator (2° to 8°C or 36° to 46°F) and you have not taken the kit out of the refrigerator, then the expiration date printed on the package still applies. You can store the product at room temperature (below 30°C or 86°F) for up to 6 months or until it has reached its expiration date, whichever comes first.

If you have taken the product kit labeled for storage in the refrigerator out of the refrigerator and stored it at room temperature (below 30°C or 86°), then use the product within 6 months from the time you took the product out of the refrigerator or until it has reached its expiration date, whichever comes first. If you cannot remember when you took it out of the refrigerator, then subtract one year (12 months) from the date that is printed on the end flap of the carton package. The date you get is your new expiration date. Throw away any product that has gone over the new expiration date.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use BeneFix for a condition for which it was not prescribed. Do not share BeneFix with other people, even if they have the same symptoms that you have.

If you would like more information, talk to your doctor. You can ask your doctor for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® Coagulation Factor IX (Recombinant) Prescribing Information LAB-0464-8.0, revised November 2011.

Wyeth®

Manufactured by Wyeth Pharmaceuticals Inc.

Marketed by Pfizer Inc.
July 2012

Pfizer

17+ YEARS* YOUR EXPERIENCE MATTERS

BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

I LIKE TO STAY ACTIVE. I HAVE NO PLANS TO CHANGE THAT.

BeneFix is the most prescribed recombinant factor IX treatment FDA approved for hemophilia B.†

- **Demonstrated bleed control in patients with moderate and severe hemophilia B**
- **Established safety record**
- **BeneFix Rapid Reconstitution (R2) Kit—designed for patients, by patients—offers a full range of dosing options**

IMPORTANT SAFETY INFORMATION FOR BENEFIX

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash or hives.
- Your body can make antibodies, called "inhibitors," which may interfere with the effectiveness of BeneFix.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

WHAT IS BENEFIX?

BeneFix® Coagulation Factor IX (Recombinant) is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

Please see brief summary of full Prescribing Information on next 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.

*BeneFix was approved February 11, 1997.
†IMS National Prescription data October 2013.

Download your free HemMobile™ app.
HemMobile helps you keep track of your infusions and any bleeds you might have.

Join Our Hemophilia Community

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Manufactured by Wyeth Pharmaceuticals Inc.
BUS640301-01

Marketed by Pfizer Inc.
Printed in USA/April 2014

Pfizer

BIOGEN IDEC AND SOBI TO DONATE 1 BILLION INTERNATIONAL UNITS OF CLOTTING FACTOR TO SUPPORT TREATMENT OF HEMOPHILIA IN DEVELOPING WORLD

World Federation of Hemophilia Humanitarian Aid Program to Receive 500 Million International Units Over 5 Years

Biogen Idec and Swedish Orphan Biovitrum AB (publ) (Sobi) (STO: SOBI) announced their intent to produce one billion international units (IUs) of clotting factor therapy for humanitarian aid programs in the developing world at the World Federation of Hemophilia (WFH) 2014 World Congress. Initially, the companies have committed to donating up to 500 million IUs to the World Federation of Hemophilia over five years to support its efforts to raise the standard of care for people with hemophilia in the developing world. The remaining 500 million IUs of clotting factor will be made available for future distribution.

This donation is expected to enable a predictable, sustained humanitarian supply of factor therapy and improve the quality of patient care and outcomes in the developing world. Hemophilia is a rare, chronic, inherited disorder in which the ability of a person's blood to clot is impaired. This can lead to recurrent and extended bleeding episodes. According to the WFH, an estimated 400,000 people worldwide are living with hemophilia and of these, more than 300,000 individuals live in areas where there is limited access to diagnosis and treatment. The commitment of one billion IUs of factor is intended to enable physicians to treat more than 75,000 joint bleeding episodes, more than 2,000 life threatening bleeding episodes as well as conduct thousands of elective surgical procedures that would not be possible without access to clotting factor.

"All of us at Biogen Idec are dedicated to making life better for people living with hemophilia," said George A. Scangos, Ph.D., chief executive officer of Biogen Idec. "Hemophilia occurs all over the world, and this donation will provide some level of care to thousands of people who otherwise would not have access to treatment."

"Our dialogue with the hemophilia community consistently highlights sustainable global equity as a major unmet need in the field," said Geoffrey McDonough, president and chief executive officer of Sobi. "This donation is consistent with our patient-centered approach, and has the potential to transform the treatment model for people with hemophilia in developing countries. We are proud to partner with the WFH in their work."

"The WFH humanitarian aid program would exist in name only if not for the generous donations we receive from companies such as Biogen Idec and Sobi," said WFH President Alain Weill. "Their generosity today brings us 500 million steps closer to making the WFH vision of treatment for all a reality."

Under the terms of the agreement with WFH, at least 85 percent of donated factor will be Antihemophilic Factor VIII (Recombinant), Fc Fusion Protein for the treatment of hemophilia A, with the remainder comprised of Coagulation Factor IX (Recombinant), Fc Fusion Protein for the treatment of hemophilia B. The donation of Antihemophilic Factor VIII (Recombinant), Fc Fusion Protein is contingent upon approval of a Biologics License Application currently under review by the U.S. Food and Drug Administration (FDA). Shipments for humanitarian programs are expected to begin in the second half of 2015.

Countries eligible for the WFH program use less than 1 IU of FVIII per capita. Due to the lack of treatment, people with severe hemophilia in these countries often do not survive to adulthood.

About the World Federation of Hemophilia
For 50 years, the World Federation of Hemophilia (WFH), an international not-for profit organization, has worked to improve the lives of people with hemophilia and other inherited bleeding disorders. Established in 1963, it is a global network of patient organizations in 122 countries and has official recognition from the World Health Organization. Visit WFH online at: www.wfh.org.

The Coalition for Hemophilia B in Ohio!

On July 26th, The Coalition for Hemophilia B held a meeting in Dublin, Ohio at the Columbus Marriott Northwest. Over 30 members of the Hemophilia B community met for a day of networking, education, and sharing. Kids were taken to the world famous Columbus Zoo for a day of fun and exotic animals. Informational sessions were presented to the group by Nayan Heath, Kim Isenberg, Brenda Adamson and our very own chairman, Dr. David Clark. For more information on our upcoming meetings in Houston, Nashville, and Indianapolis, visit: www.coalitionforhemophiliab.org

The Coalition for Hemophilia B Across the US!

This summer Wayne Cook exhibited at FAMOHIO, Anthony Vetter exhibited for us in Indiana and Rocky Williams in Texas! It was wonderful to see and talk with many familiar faces of our B Community!

At CSL Behring

Innovation leads the way

Committed to making a difference in patients' lives

As the industry leader in coagulation therapies, CSL Behring offers the most extensive portfolio of coagulation products for patients with factor deficiencies, including FI, FVIII, FIX, FXIII, and von Willebrand factor. And we continue to broaden our efforts with a number of recombinant factor therapies in development, including rFVIII, rFVIIa, rFIX, and rVWF.

For more information about our factor products for hemophilia, von Willebrand disease, and other rare bleeding disorders, or to learn about our innovative patient programs, please visit www. cslbehring.com or call consumer affairs at 1-888-508-6978.

CSL Behring

Biotherapies for Life™

The Coalition for Hemophilia B Across the US!

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

 Printed in the U.S.A. 0513-00015805-1 July 2013

CSL Opens World-Class, Advanced Manufacturing Facility for Late-Stage Production of Hemophilia Therapies Now in Development

King of Prussia, PA — 09 May 2014

- Leading-edge science at the core of $250 million expansion to drive long-term growth in promising bleeding disorders portfolio
- CSL Behring to commercialize therapies produced in part at the facility, pending required approvals
- Opening taking place in advance of World Federation of Hemophilia 2014 Congress in Melbourne, Australia

CSL Limited (ASX:CSL), parent company of CSL Behring which is based in King of Prussia, PA, today opened the CSL Behring Biotechnology Manufacturing Facility in Melbourne, Australia. The new facility, located adjacent to the site's manufacturing plant for plasma products, is the centerpiece of CSL's $250 million expansion at its Broadmeadows site and will play an increasingly important role in the company's global operations, particularly in the late-stage development of new types of hemophilia products. It is one of the largest and most advanced facilities of its kind in the world and will produce novel recombinant therapies on a large scale for international clinical trials.

"This world-class facility is key to the ongoing success of our global R&D strategy and reflects our commitment to providing better treatment options for people who are managing certain bleeding disorders and other life-threatening conditions," said CSL Chief Executive Officer, Paul Perreault.

The company's recombinant factor development programs, which comprise the AFFINITY trial and the PROLONG trial for the study of therapies to treat hemophilia A and B, respectively, are central to its long-term growth plans. Several candidates in these trials are showing promise, including rVIII-SingleChain, rIX-FP, and rVIIa-FP.

Recombinant therapies are modified versions of naturally occurring human proteins that have been optimized to provide additional treatment options for patients. CSL has more recently developed specialist capabilities in recombinant-based research, adding to its long-standing expertise in plasma protein therapeutics. CSL's research and development pipeline currently includes recombinant therapies for a range of rare and serious disease, including bleeding disorders, inflammatory conditions and cancer.

The first therapy to be manufactured in the new Broadmeadows facility will be a novel blood clotting factor (rVIIa-FP) for the treatment of hemophilia. This is one of several longer-acting clotting factors under development by CSL that aims to reduce the number of injections required to maintain normal blood clotting in people with bleeding disorders. Clinical trials of rVIIa-FP in patients are expected to commence later this year in the United States, Europe and Australia. International recruitment is ongoing for the rVIII-SingleChain and rIX-FP studies.

About CSL
The CSL Group, headquartered in Melbourne, Australia, has a combined heritage of outstanding contribution to medicine and human health with more than 90 years of experience in the development and manufacture of vaccines and plasma protein biotherapies. With major facilities in Australia, Germany, Switzerland and the U.S., CSL has about 12,000 employees in nearly 30 countries.

About CSL Behring
CSL Behring is a leader in the plasma protein therapeutics industry. Committed to saving lives and improving the quality of life for people with rare and serious diseases, the company manufactures and markets a range of plasma-derived and recombinant therapies worldwide.

CSL Behring therapies are used around the world to treat coagulation disorders including hemophilia and von Willebrand disease, primary immune deficiencies, hereditary angioedema and inherited respiratory disease, and neurological disorders in certain markets. The company's products are also used in cardiac surgery, organ transplantation, burn treatment and to prevent hemolytic diseases in the newborn. CSL Behring operates one of the world's largest plasma collection networks, CSL Plasma. CSL Behring is a subsidiary of CSL Limited, a biopharmaceutical with headquarters in Melbourne, Australia. For more information, visitwww.cslbehring.com.

Current Event Details

September 2014

Please join us for our

Factor Nine Family Breakfast Meeting
Saturday, September 20th
8:00 am – 10:00 am

Held in conjunction with the
National Hemophilia Foundation Conference in Washington DC
Meeting room *Washington 2*

* *

October 2014

The Coalition for Hemophilia B Meeting
Houston, Texas
Saturday, October 25th, 2014

Breakfast and Free Registration 8am-9am
Meeting 9am - 4pm (includes breakfast, lunch and snack)
Houston Marriott West Loop Hotel (near the Galleria)
Parking is free – Gas and tolls are reimbursed
Room rate is $89, please book by October 10th

To register, please visit:
www.coalitionforhemophiliab.org under "events"
The agenda will be available soon!
We are happy to have Rick Starks on our Program!
Babysitting Available – Day Trip for Children – Raffles, Prizes!
Educate – Share – Support!

* *

Ladies Brunch
Houston, Texas
Sunday, October 26th, 2014

For Moms, Wives, Grandma's, Sisters, and Aunts
of a person with Hemophilia B and
Women with Hemophilia B.
Please join us at the famous Palm Restaurant
10:00 am – 1:30 pm (private dining room).
If you are attending our Saturday meeting, shuttle buses
will take you to the brunch and back to the hotel.
Babysitting is available. Come *Share*, *Support* and *Connect*!
Fun Games and Raffles Prizes.

To register, please visit:
www.coalitionforhemophiliab.org under "events"
Questions? Call Kim 917-582-9077

AlphaNine® SD
Coagulation Factor IX (Human)
Solvent Detergent Treated/Virus Filtered

INTRODUCING

The AlphaNine® SD Savings Card Program

Designed specifically for the needs of patients with hemophilia B

You could save up to **$500 per month** on the costs of your prescription for AlphaNine® SD (coagulation factor IX [human]).

Restrictions apply—see inside to determine if you qualify.

Please see Important Safety Information about AlphaNine® SD on back and refer to accompanying package insert for complete prescribing details.

GRIFOLS

An Introduction to von Willebrand Disease

By Dr. David Clark

Von Willebrand Disease (vWD) is the most common inheritable bleeding disorder, affecting 1 to 4% of the population worldwide. It is caused by defective or missing von Willebrand Factor (vWF) protein circulating in the bloodstream. The symptoms of vWD vary considerably from patient to patient and include easy bruising, frequent nosebleeds and bleeding from the gums, heavy menstrual and postpartum bleeding in women and excessive bleeding during minor surgical and dental procedures. The severity ranges from infrequent mild bleeding to frequent, severe or even life-threatening bleeds. Many individuals with mild vWD are never diagnosed or are diagnosed only later in life. Severe type 3 vWD also results in hemophilia A-type symptoms due to a resulting deficiency of factor VIII (FVIII).

There are three major subtypes of vWD. Type 1 accounts for up to 70% of vWD cases and is characterized by a less-than-normal amount of vWF protein in the bloodstream. Type 2 accounts for about 25% of vWD cases and is characterized by defective vWF protein. Type 3 is rare and is characterized by an almost complete lack of vWF protein. vWF protein acts as a glue to bind platelets to each other and to the damaged blood vessels in a wound. vWF forms multimers, large groups of vWF molecules that stick together. These multimers also function to protect factor VIII from degradation as it circulates in the bloodstream. When factor VIII is not protected due to a deficiency of vWF it is degraded by activated protein C, an anticoagulant, resulting in severe hemophilia A along with vWD.

A number of families in the hemophilia community also include members with vWD, so there is a question whether the diseases are connected. Except in severe type 3 vWD where the connection is clear, as far as researchers can tell, there is no direct connection. Since the incidence of vWD in the population is relatively high, there is a significant probability that both diseases could occur in some families and in a few cases in the same individual, a clinically challenging situation.

Diagnosis of vWD is complex, requiring an evaluation of bleeding symptoms and a number of different blood tests. Diagnosis of infants and children with vWD is challenging because of a usual lack of definitive symptoms and varying vWF levels in the circulation. Normally diagnosis of the type and severity of vWD is delayed until later in childhood.

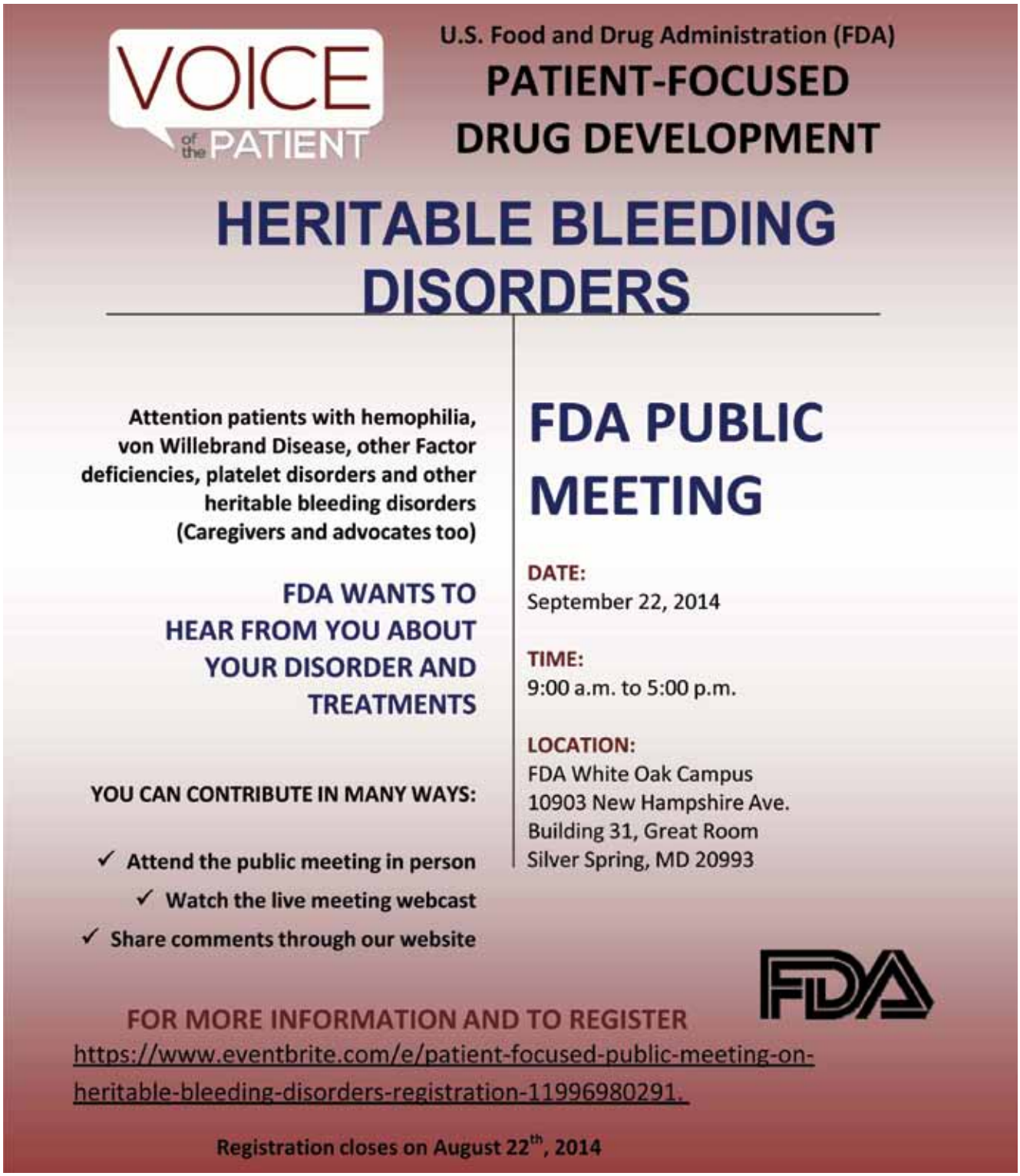
Management of vWD depends on the type and severity of the disease. Most type 1 and some type 2 patients respond to the drug desmopressin (also called DDAVP) to increase the amount of vWF in the circulation. Patients who do not respond to desmopressin may be treated with plasma-derived concentrates containing vWF or plasma-derived factor VIII concentrates that also include significant amounts of vWF. Baxter is developing a recombinant vWF product, which is currently in Phase III clinicals. Tranexamic acid, which inhibits the breakdown of clots, is also used as an indirect therapy in some cases.

Patients with severe vWD may experience joint bleeds with resulting long-term damage as well as other recurrent nasal/oral, gastrointestinal and menstrual bleeding. It has not become mainstream, but several studies have shown that prophylaxis with vWF/FVIII concentrates can result in significant improvements in the quality of life for severe vWD patients.

FDA to Hold a Special Meeting on Bleeding Disorders

As part of the renewal of the Prescription Drug User Fee Act (PDUFA V) in 2012, the Food And Drug Administration (FDA) must incorporate the patient perspective into their regulatory decision-making. To accomplish this, the FDA is holding a series of Patient Focused Drug Development meetings where they seek the input of patients in the 20 disease groups to assess the benefits and risks of certain drugs and treatment options.

On Monday, September 22, the FDA wants to hear from patients in the bleeding disorders community on topics like current approaches to treatment and what aspects of your bleeding disorder are most important to you.



Factor Nine Holiday Fund 2014!

The Coalition for Hemophilia B understands that there are families within our bleeding disorder community who are feeling the effects of the current economic situation. We thought it would be a nice idea to ask our more fortunate Factor Nine Families to make a financial donation to the ***Factor Nine Holiday Fund*** to help buy gifts for children with hemophilia this holiday season.
(The Coalition for Hemophilia B will also contribute to this fund.)

If you wish to make a donation, please send a check payable to:

The Coalition for Hemophilia B "Holiday Fund"
825 Third Avenue, Suite 226; New York, New York 10022

Please respond by *December 1, 2014* so that the Factor Nine Santa can load his sleigh with holiday gifts for all good boys and girls! 100% of your donation will be used to put a smile on a child's face.

We wish everyone a wonderful holiday season filled with love, happiness and good health!

For those families in our community in need of a little *Holiday Cheer*, we would like to help put something under the tree for your children! Just fill out this form and send it to Santa's special elf, Kim at the "East" Pole. Since the Factor Nine Santa has such a busy schedule, please send it to us ***no later than December 1, 2014.***
(Your name and information will be kept *strictly* confidential.)

Send this form to: The Coalition for Hemophilia B Holiday Cheer
Attention: Special Elf Kim
825 Third Avenue, Suite 226
New York, New York 10022

Name: _____ Phone: _____

Address: _____

_____

Please give us an exact description of the item your child is wishing for.
If we have any questions, we will contact you directly.
Holiday gifts will be purchased by The Coalition and sent to your home.

Child's Name and Age:	Child's Name and Age:	Child's Name and Age:
_____	_____	_____
Wish List:	**Wish List:**	**Wish List:**
_____	_____	_____
_____	_____	_____
_____	_____	_____

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

ALPROLIX™ /all' prō liks/ [Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ALPROLIX™ and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is ALPROLIX™?

ALPROLIX™ is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital Factor IX deficiency.

Your healthcare provider may give you ALPROLIX™ when you have surgery.

Who should not use ALPROLIX™?

You should not use ALPROLIX™ if you are allergic to ALPROLIX™ or any of the other ingredients in ALPROLIX™. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX™.

What should I tell my healthcare provider before using ALPROLIX™?

Tell your healthcare provider about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX™ may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX™ passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX™ may not work for you).

How should I use ALPROLIX™?

ALPROLIX™ should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX™ by themselves or with the help of a family member.

See the **Instructions for Use** for directions on infusing ALPROLIX™. The steps in the **Instructions for Use** are general guidelines for using ALPROLIX™. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider. Do not use ALPROLIX™ as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX™.

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

NOW FOR HEMOPHILIA B...

ALPROLIX™

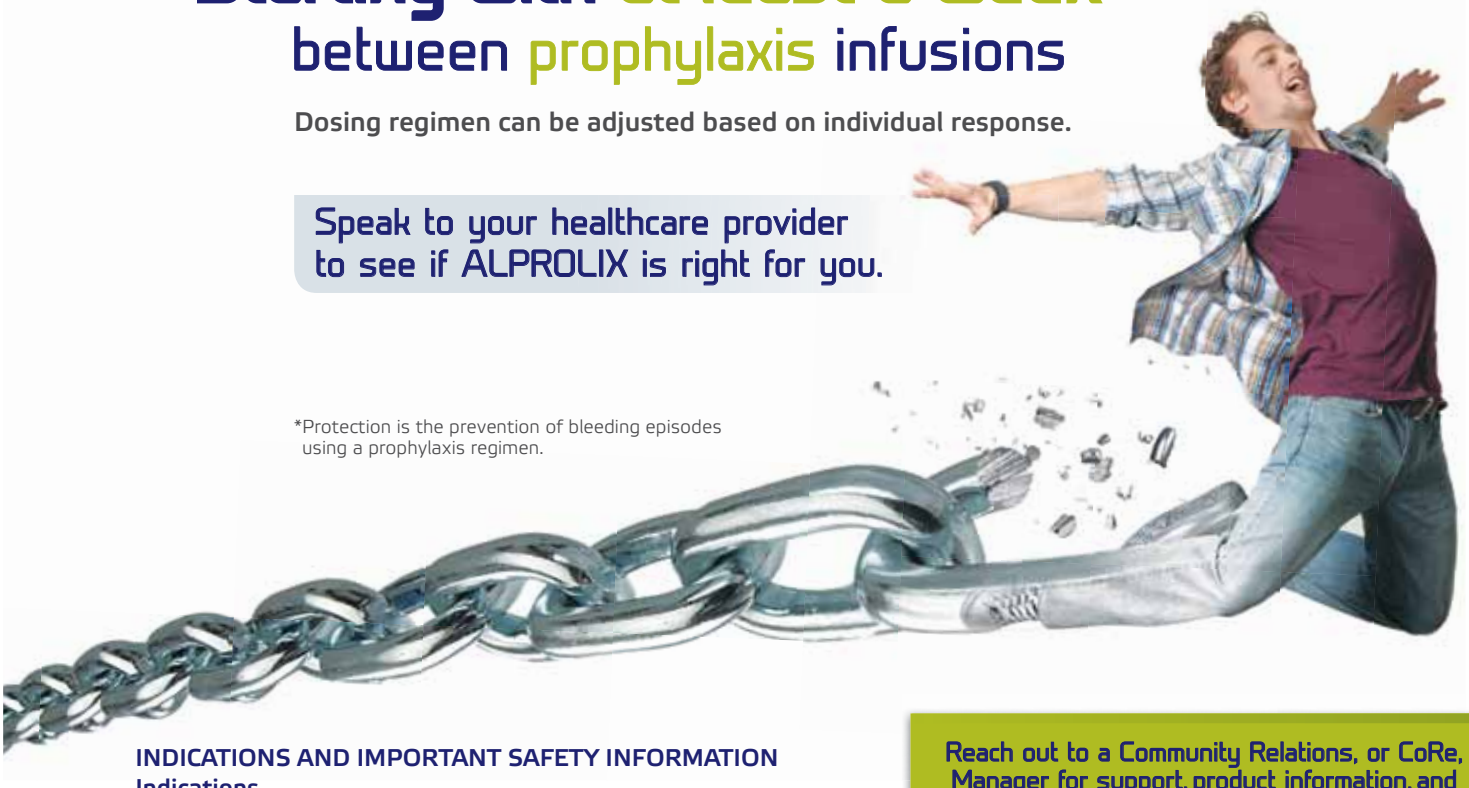
[Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Protection* from bleeds

Starting with at least a week between prophylaxis infusions

Dosing regimen can be adjusted based on individual response.

Speak to your healthcare provider to see if ALPROLIX is right for you.



*Protection is the prevention of bleeding episodes using a prophylaxis regimen.

Reach out to a Community Relations, or CoRe, Manager for support, product information, and to learn about events in your area.

Visit ALPROLIX.com/CoReManager

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 next page. This information is not intended to replace discussions with your healthcare provider.

biogen idec.

Kid's Corner

A CAMPER'S LIFE

By Joe Gassariro, 15 years old with hemophilia B

Have you ever been to a camp before? A hemophilia camp? They are both very similar, but with a few key differences. Hemophilia camps, unlike regular camps, teach you important life lessons you will need to know in the future about your condition and yourself.

The hardest part of camp for many people is actually going there. Most people know what they are comfortable with. Stay at home to read. Go watch T.V. Sleep. It is what people are comfortable with. For some people, going as a five year old (or older) into a group of people you do not know for several days, not knowing what they will do, and disconnected from home is a nightmare. It is vital that people like this know that everyone at camp wants people to have an exceptional time while they are there. The campers are even willing to get out of their comfort zones for you. The best you can do is try it out. Think of it as an experiment.

For the vast majority of people, this experiment worked quite well. So well in fact, if you ask around you will find that many of the campers have been coming for years because they have made friends.

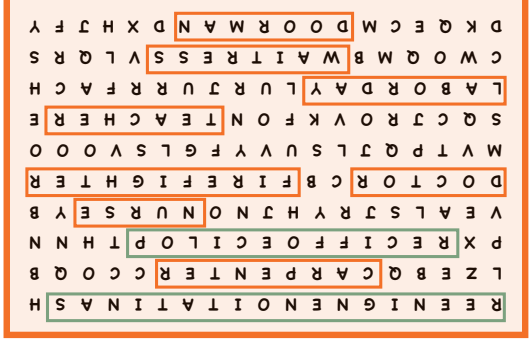
Friends you make at camp will not be like other friends at school. The friends you make will remember you the next year and a bond you will make will be strong and unique. I do not know of a place with such long lasting friendships where everyone has a similar condition.

Many people will want to be your friend and the health staff is no exception. The health staff at camp is one of the most dedicated teams I have ever seen. They are open nearly every hour and every single day at camp to make sure you get the treatment you need. This medical team also helps you with one of the most important lessons you will have to learn as someone with a bleeding disorder, the ability to self-infuse. After a week of camp, you definitely have made progress to taking your own medicine independently.

By the end of the week of learning to self-infuse, camp activities, and phone number exchanges, it is time to go home. Going away from camp can be sad, but know that there will always be a next year to come back and have another great time.

Bleeding disorder camps are unique because they provide a chance for you to meet people that harbor many of the same differences to conjugate to genuinely get to know them. They allow people to learn about themselves, feel like you're not alone with this condition, others like you, how to be a leader, and about their condition. Camps such as these are one of the most unique places you will find, which I am very thankful. I attended 3 camps this summer in Illinois and Missouri.

Answers to Word Search on page 23



Kid's Corner

LABOR DAY WORD SEARCH

R E E N I G N E N O I T A T I N A S H
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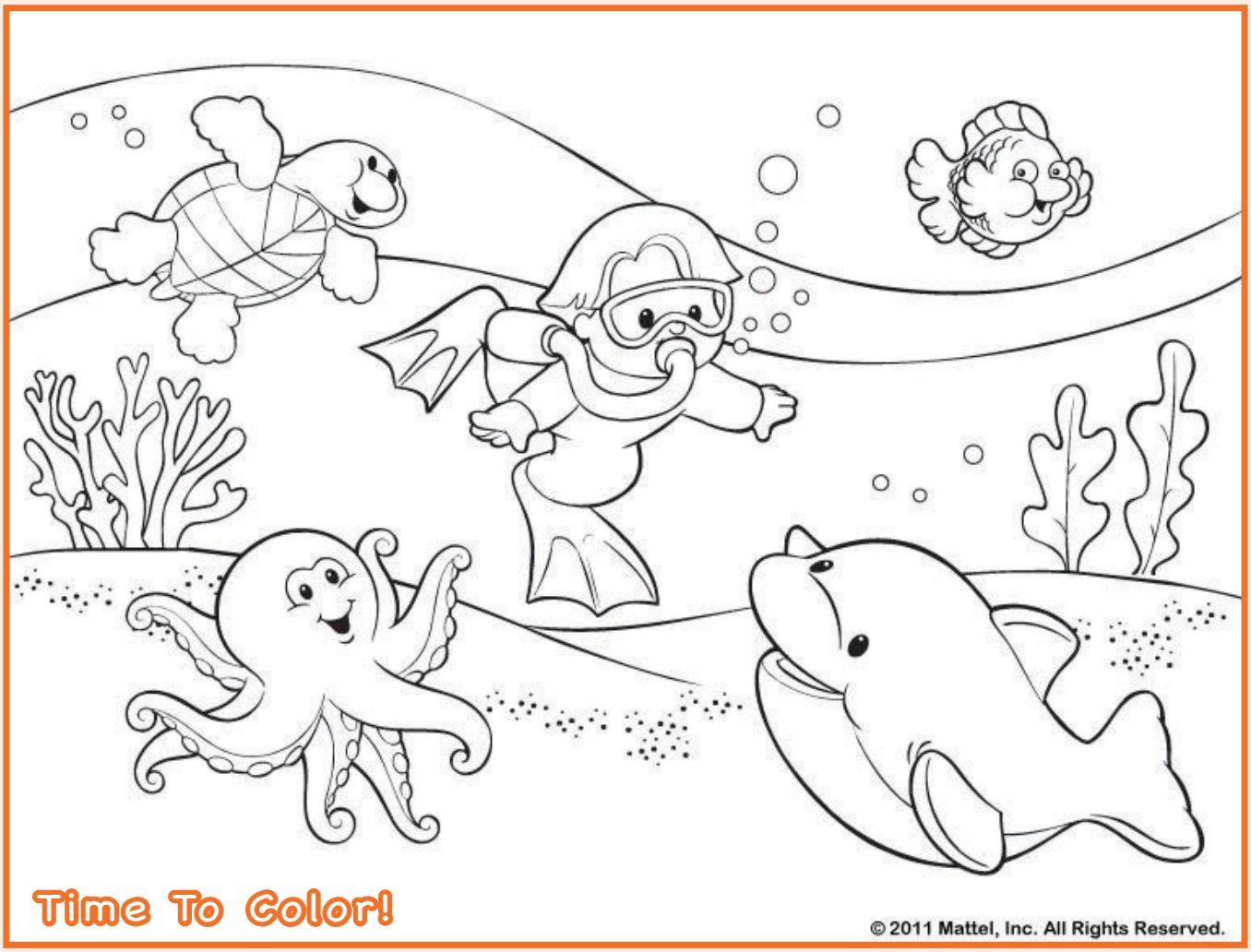
CARPENTER
DOCTOR
DOORMAN
FIREFIGHTER
LABOR DAY
NURSE
POLICE OFFICER
SANITATION ENGINEER
TEACHER
WAITRESS



Save the Dates!

The Coalition for Hemophilia B Meetings

Houston, Texas
Saturday, October 25, 2014

Houston, Texas
Ladies Brunch
Sunday, October 26, 2014

Nashville, Tennessee
Saturday, November 8, 2014

Indianapolis, Indiana
Saturday, November 15, 2014

These educational meetings are made possible through the generous support of:

Pfizer

For more information or to register, visit www.coalitionforhemophiliab.org

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