Family Camp 2014 — Mission Possible!

It began with an appearance by “Bond, James Bond!” And then the Mystery of the Missing Camp Awards was presented, and our Spy Camp week was underway. Dressed in an array of trench coats, fedora hats and magnifying glasses, our Spies-in-Training began their week with a “Spy Kit” containing binoculars, a decoder ring, passport, fake moustaches, a badge, and dark sunglasses. Throughout the week, they searched for clues to lead them to the location of the missing awards. Some groups (Parents?) even went so far as to kidnap NEHA’s Executive Director Kevin Sorge, and Camp Director Heather Case, tying them up and parading them around Camp while trying to get the truth out of them. Fortunately they escaped without revealing any secrets!

The mystery was solved on the last day when it was determined that the Vieira’s (Eleanor and Mattie) had something to do with it, and the awards were discovered accidentally “hidden” at the bottom of a snacks box!!! Our Spies did their job with many insightful guesses.

The rest of Family Camp was a trilling success too. The waterfront was the most popular place due to some fantastic warm weather. Arrows were shot, wooden cars were built, projects were painted, and joints relaxed (YOGA). New songs were learned and some skits introduced at the evening Campfires by our color groups for the first time. The Adventure Club visited the Flume and Cannon Mtn Tramway on their field trip. Our Counselors once again were Rock Stars! Overall everyone pitched in to make this one of our best Family Camps!

Our new Program Director Heather Case gave the following comments:

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From The Director

Dear NEHA Member,

Summer has come and gone for the most part once again; it seems everyone I have spoken with feels like it passed ever so quickly, more so than in past years.

As I have said before, this was yet another excellent year in the continuing story of NEHA Family Camp. Please allow me to take this opportunity to reflect and extend our deepest thanks to all who make the camp a true success, and in particular, the warm welcome that was extended to Heather Case. There is no baptism by fire quite like Family Camp!

In recent years, since around 2012, I often comment on the “coalescence” of our counselors – something that I had greatly anticipated for many years. This is what I hoped to be the turning point where many of our young counselors would truly experience the real essence of the camp and forge deeper personal relationships, where fun remained a big part of the experience, but giving more of oneself more often became a higher priority.

The essence of our success really lives at the counselor level and their ability to turn four days into an unforgettable experience for themselves and our campers. The coalescence – where we have finally arrived, pays many dividends on so many levels but perhaps most importantly, it establishes a solid foundation to build and accelerate upon, both in and out of the community.

To all of our counselors and counselors in training, it is our distinct honor and pleasure to have you as part of our camps and our community. It is because of your direct influence that we have so many outstanding people consistently contributing to make our world a better place. We thank each and every one of you for your dedication, enthusiasm, and outstanding ethics.

Best wishes to all for a wonderful fall season.

Warmest Regards,

Patrick Mancini
NEHA President
Atención, NEHA la Conferencia en Español

La Asociación de Hemofilia de New England (NEHA) les invita al evento a celebrar el mes de la Hispanidad con un simposio educativo. Estará en DoubleTree by Hilton en Danvers, MA, el 27 y 28 de septiembre. Este evento es gratuito. Incluye una noche en el hotel, comida y la oportunidad de conectar con otras familias y con los trabajadores de NEHA. Por favor confíme su participación con Heather al 781.326.7645. El evento será completamente en español. Ojalá que toda la comunidad latina con trastornos hemorrágicos venga!

The New England Hemophilia Association (NEHA) invites you to attend an educational event to celebrate Hispanic Heritage Month. The event will take place at the DoubleTree Hotel by Hilton in Danvers, MA on September 27-28. The event is free. It includes one night at the hotel, food, and the opportunity to connect with other families and the staff of NEHA. Please RSVP by contacting Heather at 781.326.7645. The event will be entirely in Spanish. I hope that the entire Latino community who is affected by a bleeding disorder will come!

A Visit To Nepal

Ujjwal Bhattarai, father of a child with hemophilia, a NEHA member, and chairman of the board of Save One Life, visited the Nepal Hemophilia Society (NHS) in his home country on June 28. Ujjwal met more than half of the 77 families that are sponsored by Save One Life. For those families who live outside of the capital city of Kathmandu, representatives of their local chapters came.

Ujjwal distributed sponsorship funds to everyone gathered, and also explained Save One Life's evolving vision to include activities that focus on more sustainability—including scholarships and micro-enterprise grants—in addition to sponsorship.

Five graduates of Save One Life's sponsorship program are now successfully employed after competing for public service sector jobs. Other former beneficiaries have entered the workforce as health assistants and small business owners. Some are studying to become engineers. Ujjwal remarks, "This is a matter of huge pride for Save One Life to be able to impact lives of people with hemophilia successfully."

A follow-up meeting with board of directors of NHS allowed for an exchange of ideas - from requirements of transparency and accountability in the nonprofit world to how the society can better serve the needy via Save One Life by building a stronger organization.

ECO-TREK: A Hemophilia App for Gamers

Mobile video gamers looking for the next app for their smartphone or tablet now have an option developed specifically for the hemophilia community. Baxter Healthcare Corporation has created a free multi-game app, called Eco-Trek, primarily for people between the ages of 15 and 32. Yet based on the reactions of pre-release product testers, Baxter expects that Eco-Trek will appeal to people of all ages, from adolescents waiting to be seen at hemophilia treatment centers, to older adults that enjoy competing in video games.

Eco-Trek, which is available to everyone regardless of their treatment, is the first socially connected video game

(Continued on page 4)
NEHA’s Popular “Couples Retreat” Ready to Go!

On October 4-5, 2014, and in conjunction with Inalex Communications, NEHA will once again host our popular Couples Retreat. Designed for married or long-term couples, the retreat will be held at the beautiful Sea Crest Beach Hotel in North Falmouth, MA (on the Cape). The event will include presentations and discussions from two professionals, Lisa Merlo-Booth, MA and Jack Kakolewski, Ed.S. Both presenters will work together for part of the day and then break into two sessions for further discussions. The session begins at 10:00am (breakfast served at 9:00am), and includes lunch at noon, and dinner at 6:00pm, followed by a one-night stay at the Sea Crest Hotel. The entire event is offered at no cost to participants. We are pleased to have the daytime program hosted by Baxter; and the evening dinner and hotel stay hosted by NEHA.

This program tends to be very popular and “sells out” quickly as we only can take 20 couples, so please register soon to reserve your space in the class. Cancellations must be made 7 days in advance to avoid fees, and to permit anyone from a potential waiting list to attend. To register for the program, please call the office at 781-326-7645. If sold out, ask to be put on Waiting List. Deadline for registration is September 12, 2014. For any questions, please contact the NEHA office at 781-326-7645.

Gamer App (Continued from page 3)

designed for the hemophilia community. With hemophilia-specific content and Facebook score-sharing built into the game, Eco-Trek is a first-of-its-kind mobile app. A national leaderboard will create competition among players in Eco-Trek’s three online adventures, each of which have 10 levels:

- **Bushwhacked!** – Find your way through a forest maze without losing supplies from your backpack
- **Alpine Summit** – Compete in an uphill race against the clock, dodging obstacles along the trail
- **Roughin’ It** – Set up camp and complete specific tasks while pesky critters try to get in your way

“We are really excited about Eco-Trek because it’s simple, interactive, and offers important educational information about hemophilia A and ADVATE [Antihemophilic Factor (Recombinant)], while you’re competing in fun activities,” said Jeff Schaffnit, senior director of US Hemophilia Marketing. “For teens and young adults with hemophilia, this type of format can make it a lot more fun to gain knowledge on hemophilia.”

Eco-Trek is a free app available for download from the Apple App Store and Google Play. For more information, contact your Baxter representative.

My Life, Our Future Enrolls 1,000 Participants

We are excited to announce that over 1,000 people have enrolled in *My Life, Our Future*, a joint project of the National Hemophilia Foundation, the National Thrombosis and Hemostasis Network, the Puget Sound Blood Center, and Biogen Idec. The number marks a significant milestone in achieving our goal of genotyping as many people in the U.S. with hemophilia A and B as possible. More than 40 hemophilia treatment centers have enrolled in *My Life, Our Future*, and the program is regularly expanding to new locations across the country. Both HTCs in Connecticut have been approved for inclusion and others in New England are in the application process.

By participating, you can help our community make knowledge hereditary. Your genotype can provide meaningful information about your hemophilia today, including identifying your unique mutation. More than 61 new mutations have

(Continued on page 5)
Opportunity To Attend FDA Patient Drug Meeting

As you may know, the US Food and Drug Administration (FDA) recently announced that it has scheduled the Patient-Focused Drug Development Meeting on bleeding disorders for Monday, September 22, 2014. The meeting is being held immediately after NHF’s Annual Meeting in Washington, DC, to maximize participation by community members. We need your help to make this meeting a success.

This meeting is part of FDA’s new Patient-Focused Drug Development Initiative, enabling FDA officials to hear directly from patients about living with a particular condition and treatments that matter most to them. FDA believes it can make better review decisions if it has a more robust understanding of patients’ daily lives in living with a disorder and their tolerance for benefit/risk tradeoffs.

This meeting is an incredible opportunity for FDA officials to hear directly from people affected by bleeding disorders and their family members about their daily lives and treatment preferences. To make the most of this opportunity, we need as many people with diverse experiences with bleeding disorders to participate as possible. The FDA seeks participants affected by all types of heritable bleeding disorders, including hemophilia A and B, von Willebrand disease, rare bleeding disorders and platelet disorders, and acquired hemophilia A.

People can attend in person or participate via webcast. Anyone in the community—affected individuals, family members, hemophilia treaters, researchers, advocates—can register for the meeting. People who wish to speak will be asked to submit additional information to the FDA, which will select the speakers in September. Please visit www.hemophilia.org for the meeting registration page.

NHF is also exploring ways to survey community members to engage and hear perspectives from individuals who aren’t able to attend the meeting. More information on the survey will be released in the coming weeks. Please stay tuned for more information about this exciting meeting. If you have any questions, please email Johanna Gray or call 202.484.1100.

HCV Trial Recruits Bleeding Disorders Patients

Investigators of a new clinical trial for people with both chronic hepatitis C viral (HCV) infection and bleeding disorders are currently recruiting new patients. HCV trials often exclude patients with conditions such as hemophilia, which makes this new study noteworthy and relevant to the bleeding disorders community.

The Phase 2b, multicenter trial, “Efficacy and Safety of Ledipasvir/Sofosbuvir Fixed-Dose Combination and Sofosbuvir + Ribavirin for Subjects with Chronic Hepatitis C Virus and Inherited Bleeding Disorders,” is being sponsored by Gilead Sciences. In February 2014, Gilead filed a New Drug Application with the US Food and Drug Administration for ledipasvir (LDV)/sofosbuvir (SOF), a fixed-dose combination therapy for genotype 1 HCV. Both drugs are direct-acting antivirals. LDV is an NS5A inhibitor, a drug that disrupts nonstructural proteins HCV needs to replicate. SOF is a nucleotide analog polymerase inhibitor, which blocks polymerase, an enzyme that provides instructions for making copies of HCV RNA.

The purpose of the study is to determine the efficacy, safety and tolerability of treatment with LDV/SOF fixed-dose combination for participants with genotypes 1 and 4 HCV infection, and SOF + ribavirin for participants with genotypes 2 and 3 HCV infection.

This trial is recruiting people exclusively with inherited bleeding disorders and chronic HCV infection (either mono-infected or HIV-1/HCV co-infected). Learn more about the study, including eligibility information and recruitment sites, by going to clinicaltrials.gov.

My Life Our Future (Continued from page 4)

already been discovered through the program. Genotyping may also accelerate the scientific breakthroughs of tomorrow. Once 5,000 people have enrolled in My Life, Our Future, scientists will be able to apply to research the data and samples.

With a quick test, you can contribute to a brighter future for generations to come. Visit MyLifeOurFuture.org to see if the program is available at your HTC. The program is continually expanding to new locations across the country so check back regularly!

Already been genotyped? Share your experience and become a Voice for Progress!
“A wide range of emotions and little sleep. Overall, an amazing week!” This is what I have been telling people who have asked about my first experience at NEHA Family Camp. What a week it was! From set up to clean up, we had help at every turn. Thank you to all the parents, families, volunteers, medical staff, and NEHA staff who made it all happen!

Particular highlights for me include: kayaking with other moms, the counselor campfires on third beach, seeing so many counselors and campers perform at campfire, the overwhelming number of campers who self-infused for the first time, watching everyone have such a great time at the SPY games on Friday afternoon, and being part of such a warm and wonderful community.

As we look to plan camp next year, please let me know if you are interested in sitting on the camp planning committee and/or have any excellent ideas for themes! I received quite a few suggestions at camp from campers: pirates, Wild West, theatre camp, science camp, and mermaids to name a few!

Even through Family Camp is over, the warm feeling of our wonderful experience will continue in our community for a long time. We’re already thinking about next year!
This past May was NEHA’s 5th Annual Walk, and it was better than ever before. The walk is the NEHA community’s largest gathering and brings people together from Maine to Rhode Island. Over 700 kids and adults had a wonderful day walking, playing with the animals at the petting zoo, dancing, playing, picnicking and meeting old friends and new ones. Some former activities are still going strong like the Texas BBQ luncheon sponsored by Bayer which fed well over 600 people. Our newest activity was the “Barn Babies”, an organization that brings many small animals for children to hold and feed. Their fenced out area was crowded all day long and a popular place for the kids.

The Walk itself is a highlight for many, and also attracts many newer families to the group. We had several NEW walk teams this year, and already established teams get larger and larger each and every year! Some Teams hold personal fundraisers all year long, and then roll their earnings into the walk team totals.

Over $125,000 was raised for the chapter to be used for Family Camp, Research, Advocacy, Educational Events, and Social Gatherings. There has been a big revenue jump the past two years, and some of that can be due in thanks to the NEHA Board stepping in with their large team donations. This year, NEHA produced the second largest Walk revenue total in the country!

NEHA also incorporated the “Incentive Prize” program for fundraisers to earn specialty prizes for different levels of fundraising.

This is an “all hands on deck” event that brings smiles to everyone involved! Next year’s date will be early June. Mark your calendars now!!
New Practice Guidelines On Hemophilia Care Models Under Development

The National Hemophilia Foundation (NHF), under the guidance of its Medical and Scientific Advisory Council (MASAC), is undertaking a multi-year project to develop evidence-based clinical practice guidelines (CPGs) in hemophilia. Considering the many changes in the healthcare environment, including the increased emphasis on evidenced-based care and the regional variability in clinical practice, NHF determined that the first guideline would focus on evaluating different care models for hemophilia management, including the comprehensive care model of the hemophilia treatment centers (HTCs). The goal of this guideline will be to support patient-centered clinical decision-making and optimize hemophilia care for each patient.

NHF and MASAC have long been engaged in advancing the standard of clinical care and issuing treatment recommendations for all bleeding disorders. In 2012, the NHF held a strategic summit to assess the US healthcare environment and develop a plan to assure that individuals with hemophilia and other bleeding disorders have access to high-quality care. One of the key recommendations of the summit was for NHF to initiate the development of evidence-based clinical practice guidelines that would be eligible for inclusion in the US Department of Health and Human Services' National Guideline Clearinghouse (NGC). Inclusion in the clearinghouse will reflect a rigorous methodological standard and will be advantageous to acceptance by insurers.

For this project, NHF is partnering with McMaster University, which has an international reputation for its work in CPG development. The McMaster team has provided methodological support in defining the composition of the guideline panel, managed conflict of interest and will conduct the key elements of guideline development—literature search and review, evidence profiling and grading the evidence. Drs. Holger Schunemann and Alfonso Iorio of the Department of Clinical Epidemiology and Biostatistics at McMaster University will be serving as co-principal investigators for the project.

In accordance with criteria established by NGC, NHF and McMaster have built a diverse guideline panel with appropriate expertise and experience from within and outside the hemophilia community. Each panel member has gone through a thorough conflict of interest and subject matter expertise review appropriate for his/her role on the panel. In addition to representatives from McMaster, the panel includes: healthcare professionals from the field of hematology and other specialties; patients and caregivers; those with broad public health backgrounds; and methodologic experts. Consistent with NGC practice, to avoid the risk of undue influence and maintain panel independence, the panel membership is not disclosed at this early stage in the process. The guideline report will disclose panel composition, and contain a full review of the selection process, as well as each member's conflicts of interest and selection criteria.

The first guideline panel meeting was held on June 21, 2014, during the annual International Society on Thrombosis and Haemostasis (ISTH) meeting in Milwaukee, WI. At this meeting the panel members reviewed the scope of the guideline and the questions that will be addressed by the guidelines. In preparation for the meeting, the McMaster team prepared a background document on hemophilia and types of care models, along with information on the guideline development process.

Over the next nine to 10 months the McMaster team will complete a systematic review of the literature and an assessment of the quality of the evidence. A final meeting of the Guideline Panel will be held in May 2015. At this meeting, the panel will be asked to review evidence summaries and analyze the balance of benefits and harms, the values and preferences that inform the recommendations. Based on these factors, the panel will decide on whether to make strong or weak recommendations for or against proposed interventions.

NHF anticipates completion of the guideline project on models of hemophilia care by the end of 2015. We will update the community periodically throughout the process.

Facebook
Everyone’s on FACEBOOK! And so are we! Follow NEHA’s activities, events and achievements on Facebook. Just search for New England Hemophilia. Become a friend and get all of the latest news and updates from the chapter. Post pictures of NEHA events and remember the Good Times!
Results from a six-year study of patients with hemophilia A and B produced interesting findings. The Hemophilia Inhibitor Research Study (HIRS) enrolled 1,163 patients from 17 federally funded hemophilia treatment centers (HTCs). One of the goals was to predict which patients were at highest risk for development of inhibitors, antibodies to infused factor.

“A Study of Prospective Surveillance for Inhibitors Among Persons with Haemophilia in the United States,” was published in the March 2014 issue of *Haemophilia*. The lead investigator was Michael Soucie, PhD, Division of Blood Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC) in Atlanta.

A central laboratory performed periodic inhibitor tests using blood samples and genotyped the subjects. In all, 3048 inhibitor tests (some patients were screened more than once) were conducted. The main findings were:

- All people with hemophilia are at risk for developing inhibitors
- One-third of newly developed inhibitors were found in people with non-severe hemophilia
- One-half were older than 5 years old
- Six out of 10 people with hemophilia with an inhibitor had no symptoms
- 23 new FVIII inhibitors were identified

431 distinct mutations were genotyped, 151 of which had not previously been reported

HIRS investigators and CDC researchers determined that individuals with hemophilia of all ages were at risk for developing an inhibitor. Further, CDC now estimates that approximately 60% of people with an inhibitor have no symptoms. Without regular screening, a significant number of these patients may not be aware of it until they experience severe bleeding.

The CDC concluded that patients with hemophilia receiving care in federally funded HTCs will be tested yearly for an inhibitor by the CDC Division of Blood Disorders laboratory as part of Community Counts, its new blood monitoring program.

Source: CDC

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**NHF 66th Annual Meeting**

The National Hemophilia Foundation (NHF) is pleased to announce that registration for its 66th Annual Meeting, “Nothing About Us Without Us” on Sept. 18th to the 20th, 2014 is now open. This yearly conference attracts the entire bleeding disorders community from families, and chapter staff to providers and industry representatives.

During the three day meeting, you will have more educational sessions that you can imagine, plus fun social events to attend and plenty of time for exploring the area. There is a special medical track for researchers and physicians, with special programming for nurses, PTs, and social workers. Plus, there is a new teen track for 13-17 year olds, and a huge Exhibit Hall with lots of information, contests, giveaways and more.

Here are a few sessions you won’t want to miss:

* Pow! Splat! Wham! Comic Books, Coping and Chronic Illness  *
* VWD and the Family  *
* Ask the Experts: Inhibitors  *
* One Day at the Time: Women thriving with bleeding disorders  *
* Basics of Hemophilia  *
* Music therapy for Pain Management  *
* Healthy Cooking: Easier than you think!  *
* Hepatitis C Updates  *

This year, our meeting is in Washington DC; a tourist mecca for family-friendly museums, monuments and galleries that provide education, history and fun! And the best part is that many of them are free!

NEHA usually has about 25 -30 people plus staff attend and we hope you can join us! Check out the NHF Website at [www.hemophilia.org](http://www.hemophilia.org) for more information about the Annual Meeting and how to attend.
FDA Approves NovoSeven RT:

On July 3, 2014, the US Food and Drug Administration approved NovoSeven® RT (Coagulation Factor VIIa [Recombinant]) as the first recombinant treatment for bleeding and perioperative management approved for patients with Glanzmann’s Thrombasthenia (GT) who have refractoriness to platelet transfusions, with or without antibodies to platelets. The safety and effectiveness of NovoSeven® RT were demonstrated in the treatment of severe bleeding and the prevention of bleeding in major and minor surgical procedures for this specific patient population.

Glanzmann’s Thrombasthenia is a rare genetic bleeding disorder with limited treatment options. The condition occurs because certain surface proteins on platelets are missing or do not work, significantly impacting the blood’s ability to form an initial platelet “plug,” the first step in building a strong blood clot.³

NovoSeven® RT for the treatment of GT provides a much-needed option for this underserved patient population. Patients with GT with refractoriness to platelet transfusions who have been prescribed NovoSeven® RT will be eligible for enrollment into Novo Nordisk’s comprehensive patient assistance programs. For more information, visit www.novosevenrt.com.

FDA Approves Bayer’s Kogenate® FS Antihemophilic Factor VIII (recombinant) for Routine Prophylaxis in Adults with Hemophilia A

Whippany, NJ, May 12, 2014 – Bayer HealthCare announced today that the U.S. Food and Drug Administration (FDA) has approved a new indication for Bayer’s Kogenate® FS antihemophilic factor VIII (recombinant), for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults with hemophilia A. The approval is based on data from the SPINART study, in which 84 patients ages 15 to 50 were randomized to either prophylaxis (25 IU/kg three times per week) or on-demand therapy.

“In Bayer’s SPINART study, adult patients with hemophilia A on the prophylactic regimen experienced significantly fewer bleeding events than those using on-demand treatment,” said Marilyn Manco-Johnson, M.D., Principal Investigator of the study and Director, Mountain States Regional Hemophilia and Thrombosis Center, University of Colorado at Denver and Health Sciences Center. “Such clinical information can help healthcare professionals provide appropriate treatment advice to their patients.”

FDA Approves Biogen Idec Eloctate: First Antihemophilic Factor, Fc Fusion Protein For Patients With Hemophilia A

On June 6, 2014, The U.S. Food and Drug Administration approved Eloctate, Antihemophilic Factor (Recombinant), Fc fusion protein, for use in adults and children who have Hemophilia A. Eloctate is the first Hemophilia A treatment designed to require less frequent injections when used to prevent or reduce the frequency of bleeding.

Eloctate is approved to help control and prevent bleeding episodes, manage bleeding during surgical procedures, and prevent or reduce the frequency of bleeding episodes (prophylaxis). Eloctate consists of the Coagulation Factor VIII molecule (historically known as Antihemophilic Factor) linked to a protein fragment, Fc, which is found in antibodies. This makes the product last longer in the patient’s blood.

The safety and efficacy of Eloctate were evaluated in a clinical trial of 164 patients that compared the prophylactic treatment regimen to on-demand therapy. The trial demonstrated that Eloctate was effective in the treatment of bleeding episodes, in preventing or reducing bleeding and in the control of bleeding during and after surgical procedures. No safety concerns were identified in the trial.

Eloctate received orphan-drug designation for this use by the FDA because it is intended for treatment of a rare disease or condition. Eloctate is manufactured by Biogen Idec, Inc., Cambridge, Mass.

FDA Approves Octagam

On July 17, the US Food and Drug Administration (FDA) approved a new treatment for adults with chronic immune thrombocytopenic purpura (ITP). Developed by Octapharma USA, Octagam® 10% is administered intravenously. The therapy is manufactured from highly purified immunoglobulin derived from large pools of human plasma.

ITP, also called idiopathic thrombocytopenic purpura, is a bleeding disorder in which the immune system destroys platelets, which are necessary for clotting. Symptoms include the appearance of petechiae (clusters of red spots where capillaries below the skin have bled), excessive bleeding and purpura. The cause is unknown, and the treatment is supportive. The severe cases are sometimes treated with corticosteroids, but they can have no effect, and are often associated with significant side effects.

Octagam® 10% is approved for the treatment of chronic immune thrombocytopenic purpura (ITP) in adults as long-term prophylaxis of bleeding episodes. The approval is based on clinical data from a randomised, open-label trial comparing Octagam® 10% with a standard of care in 32 ITP patients, of whom 20 had been previously treated with corticosteroids.

(Continued on page 11)
Dr. James Hammel of Rogue Psychiatry in Medford, Oregon, knows firsthand about the psychosocial challenges associated with living with a bleeding disorder, many of which were recently outlined in Novo Nordisk’s Hemophilia Experiences, Results, and Opportunities (HERO) study. With more than a decade of experience working as a psychiatrist and a lifetime of experience living with von Willebrand disease, Dr. Hammel offers his unique perspective about the need for increased education and advocacy both within and outside of the bleeding disorders community.

When were you diagnosed with von Willebrand disease?

I was diagnosed during my second year at medical school. Following a routine tonsillectomy, I had to return to the operating room 3 times due to ongoing bleeding. During my third trip to the hospital, I saw a hematologist and was finally diagnosed with von Willebrand disease.

Did you work with a comprehensive care team once you were diagnosed?

Unfortunately, no – and one of my biggest obstacles was trying to manage my bleeding disorder on my own. Having a dedicated comprehensive care team probably would have helped me tremendously, and it likely would have helped me to realize that what I was dealing with wasn’t as abnormal as I originally thought it was.

What are some of the unique challenges you have faced as a member of the bleeding disorders community?

From my perspective, there is a lack of education across the board, and many health care professionals don’t know enough about bleeding disorders. It’s astounding and speaks volumes that I was at one of the best medical schools in the country but was unable to get to the right specialists to get diagnosed because of the lack of widespread knowledge about these rare diseases. As a result, some individuals with bleeding disorders don’t always receive proper medical attention or care.

We know from Novo Nordisk’s HERO study that there are a variety of psychosocial issues faced by individuals with hemophilia and those who care for them. In what areas do you see hemophilia and other bleeding disorders having the greatest effect on families?

This differs for each family, with the specific psychosocial challenges being influenced by factors such as diagnosis, age, environment, and resources available. One of the common themes is increased anxiety in every psychosocial aspect of our daily lives – and in ways in which the non-bleeding disorder community doesn’t necessarily contend with. At the same time, this gives us an opportunity for increased resilience as families and as a community.

How and why did you become involved with national hemophilia advocacy groups such as the National Hemophilia Foundation?

I’m at the point in my career where I want to be able to advocate for and support those within the bleeding disorders community to ensure we are all getting the care and attention we need. What I went through in medical school when I was finally diagnosed was traumatizing, and I don’t want anyone to go through a similar ordeal. Advocacy organizations, such as the National Hemophilia Foundation and Hemophilia Federation of America, are among the best resources for people looking for more information about bleeding disorders.

One of the goals of Novo Nordisk’s HERO initiative is to advocate for improvements in quality of life and health outcomes for people living with hemophilia. (Continued on page 12)

New Products (Continued from page 10)

bruising, nose bleeds and bleeding of the gums associated with dental procedures. In addition, women with ITP may experience heavier and/or prolonged menstrual bleeding.

The approval of Octagam 10% is based on the results of an Octapharma-sponsored clinical trial that evaluated the safety and efficacy of the product in 66 patients with chronic ITP between the ages of 17-88. Of those, 81.8% attained the primary efficacy endpoint of clinical response within 7 days of dosing, which was significantly higher than the predicted responder rate of 70%. Investigators also reported no unexpected tolerability issues, even at the “maximum infusion rate.” Further, 78% of patients with chronic ITP, who had bleeding at the beginning of the trial, reported no bleeding 7 days after treatment. Side effects included headache, fever and elevated heart rate.
Why is it important for members of the hemophilia and broader bleeding disorders community to advocate for themselves?

All of us who are affected by bleeding disorders need to become more involved because, as the health care environment continues to evolve, due in part to the Affordable Care Act, it is now more important than ever that resources and funding for the bleeding disorders community are prioritized. Although treating our conditions can be expensive, bleeding disorders also are serious and can be life threatening.

What plans do you have in the future for supporting the bleeding disorders community?

As a psychiatrist, I think it is critical for us to address the unique mental health issues faced by our community members. I’m currently working on a session to be presented at the upcoming National Hemophilia Foundation Annual Meeting this September that will focus on the many stigmas and mental health issues faced by those living with these complex conditions and their loved ones. We have to pay as much attention to these issues as we do our ability to get treatment, because they are equally as important. I also plan to continue serving on the Board of Directors of the National Hemophilia Foundation.

Of which of your many accomplishments are you most proud?

I’m most proud of my 3-year-old son Nathaniel. I’ve accomplished a lot professionally and otherwise, but having him is the best thing in the world.

For more information on the HERO study findings, please visit http://www.ChangingPossibilities-US.com/Inhibitor/HERO.aspx.

The Evolution of the HTC Network

By Joseph N. Pugliese, President, Hemophilia Alliance

I have been fortunate enough to spend the last 35 years as part of the bleeding disorders community doing something that I truly love. But the role and financial support for hemophilia treatment centers (HTCs) has also changed dramatically over this period. I think it’s useful to remember how critical 340B programs are to the ongoing viability of the HTC network.

When HTCs were first recognized by an act of Congress in 1975, there were relatively few of them and they were mostly housed in and subsidized by large teaching institutions. With Congressional designation came funding from Health Resources Services Administration (HRSA) through the Maternal, Child Health Bureau (MCHB), which provided significant funding to each center to support health care services. Funding for research and surveillance HTCs from the Centers for Disease Control and Prevention (CDC) came later in the 1990s.

But in the intervening years, there have been many changes to the system. Both the number of centers and the patient population they serve have grown dramatically. What started as 26 treatment centers has expanded to almost 140. The patient populations served by the HTC network have also expanded to include hemophilia, von Willebrand disease, platelet disorders, rare bleeding disorders and, more recently, thrombosis. Unfortunately, the HRSA and CDC funding levels were static for many years and have faced significant cuts in recent years. This means that today, the average funding per center has decreased to around $30,000 which does not provide for day-to-day clinical care.

Throughout, HTCs have consistently been shown to improve patient care and reduce costs. Studies have shown that the comprehensive care can reduce the cost of care by 40-60% by reducing hospitalizations. Moreover, care in the HTC network has been shown to reduce morbidity and mortality.

Luckily, an additional funding opportunity, the 340B Drug Discount Program, was made available to HTCs through the Veterans Health Care Act in 1992. HTCs were included in the original list of health care entities eligible to participate in the program. This means HTCs can purchase factor directly from manufacturers at a reduced price. When HTCs sell factor to their patients, they are required to reinvest any proceeds back into the HTC to benefit patients. This program has considerable oversight, but HTCs do have some latitude as to how to use the proceeds. Some HTCs fund staff positions, others use funds to provide educational activities or products, and yet others support research. Many HTCs choose to designate funds to multiple categories.

It is important to know that regardless of their pharmacy provider (HTC, home care or specialty pharmacy), all patients and families in the bleeding disorders community benefit from the 340B program. All patients being served by the HTC benefit from the services and staff that are only available due to funding.

(Continued on page 13)
NEHA Golf Tournament—Openings Available!

Are you a Golfer? Do you enjoy being outside in a beautiful setting while pursuing your passion? Then join NEHA as we prepare to host and celebrate our 24th Annual Golf Tournament and Auction. The beautiful Cyprian Keyes Golf Resort in Boylston, MA will host our event on Monday, September 8, 2014. A shotgun start gets us going at 8:00am.

If you’re a Golfer, please consider joining us on the course this Year with 100+ other NEHA supporters. You can purchase an individual spot and we can place you with other golfers, or have some friends join you and make it a foursome. We use a scramble format and while the course is definitely a challenge, the competition is low-key.

As a bonus, Cyprian Keyes has generously donated a complimentary round of golf for each golfer at the NEHA tournament! Your participation includes breakfast, 18 holes of Golf, golf-cart, goodie bag, awards, and a wonderful buffet lunch. It’s a great way to enjoy a round of golf while supporting a worthwhile cause! Come help us fill out our Tournament with 144 players. Please contact the NEHA office at 781-326-7645 to register or for more information.

HTC’s (Continued from page 12)

from the 340B program. Educational activities or camps may be funded by 340B proceeds as well. HTC’s honor patient choice as this has always been a valued priority in the bleeding disorders community.

I think we would all agree that it remains absolutely critical that HTC’s continue to provide expert care for patients with bleeding disorders. The Hemophilia Alliance has efforts on many fronts to ensure that all HTC’s remain viable. To learn more about HTC’s and 340B, visit: www.HRSA.gov, www.hemoalliance.org, and www.HTCsareontheline.org. If you have questions about HTC’s or 340B programs you can reach me at 215-439-7173 or joe@hemoalliance.org.

“Hemophilia doesn’t stop me from having fun.”
— Charlie, 7 years old, loves windy days

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Dosing regimen can be adjusted based on individual response.
*Protection is the prevention of bleeding episodes using a prophylaxis regimen.

To learn more, contact CoRe Manager Lisa Schmitt
E: lisa.schmitt@biogenidec.com  T: 978.407.7713

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.

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

ALPROLIX™/all’ pro 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.

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Jeff Pross

Phone: (315) 460-6508
E-mail: jeffrey_pross@baxter.com

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(800) 243-4621 AHF@AHFinfo.com
www.AHFinfo.com

Sandy Williams
SAWI@novonordisk.com
774-312-0757
ChangingPossibilities-US.com

About Sandy
Sandy keeps her love for people alive through volunteering and serving at local hemophilia chapters. She is a great resource for families in need in the community. Her role as an HCS helps her reach even more families affected by hemophilia.

Hobbies
• Cycling
• Skiing
• Playing golf
• Vacationing on the beach

In her own words
“All the work is worth it when you help make someone’s journey a bit easier.”

Sandy Williams
Taking it to the streets

Hemophilia Community Specialist

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* You must be currently covered by a private (commercially) insurance plan. If you are not eligible for the XYNTHA Trial Reconstitution Program, you may still help accessing XYNTHA medicates by contacting Pfizer’s RSVP program at 1-888-527-RSVP (7787).

What is XYNTHA?
XYNTHA* Antihemophilic Factor (Recombinant), Plasma/Albumin-Free is indicated for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for surgical prophylaxis in patients with hemophilia A.
XYNTHA does not contain von Willebrand factor and, therefore, is not indicated in von Willebrand’s disease.

Important Safety Information for XYNTHA
- Call your healthcare provider right away if bleeding is not controlled after using XYNTHA; this may be a sign of an inhibitor, an antibody that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests to monitor for inhibitors.
- The most common adverse reaction in the safety and efficacy study was headache (24% of subjects) and in the surgery study was fever (43% of subjects). Other common side effects of XYNTHA include nausea, vomiting, diarrhea, or weakness.
- XYNTHA is an injectable medicine administered by intravenous (IV) infusion. You may experience local irritation when infusing XYNTHA after reconstitution in XYNTHA SOLOFUSE*.

Please see brief summary of full Prescribing Information.
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.

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Email: andrea_mcsheerry@baxter.com
CALENDAR OF UPCOMING NEHA EVENTS

For further information about these or other events, call NEHA at (781) 326-7645

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New England Hemophilia Association
347 Washington St.  Suite 402
Dedham, MA  02026
Address correction requested

Mission Statement
The New England Hemophilia Association is a non-profit organization dedicated to improving the quality of life for persons with bleeding disorders and their families through education, support, and advocacy.

Services include:
- Information and referral
- Medical symposia and educational programs
- Social and recreational activities for children and families
- Family Camp
- Teen Programs
- Spanish-language programming
- Peer support groups
- Emergency financial assistance
- Advocacy and Legislative Support

Please contact the office for more information
Phone:  (781) 326-7645
e-mail:  info@newenglandhemophilia.org
Website:  www.newenglandhemophilia.org