



Hemophilia News and Views

Winter Edition 2016

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Chapter News

Happy New Year! Time is passing by faster and faster each year. As we look back and reflect on 2016, we are grateful and pleased for the chapters success, but most of all to know that we served more than 500 families in 2016! With your involvement, our chapter continues to thrive and grow. Thank you for your support!

To help achieve the significant growth in program and services in 2016, Anne McGuire was promoted to Chapter Events Manager and we have the new addition of Maureen Salazar-Magana as our part-time bilingual Program Manager. Congratulations Anne and welcome Maureen! We would also like to thank the Hemophilia Treatment Center

of Nevada for their partnership and support and of course, our many sponsors!

It was wonderful seeing many of you at our Las Vegas, Reno & Elko Holiday parties in November and December. Attendance was at an all-time high and your continued support for camp is heart-warming as we raised over \$1,000 from the holiday raffles for camp. Thank you!!!

We are pleased to announce our new website. Some of the exciting new features include registering online for programs and events and the ability to complete an assistance or scholarship application. Please check it out at hfnv.org and let us

know what you think!

As we head into 2017, please continue to reach out to us with your many ideas to improve or add to our programs and services. If you are interested in becoming more involved in the chapter as a volunteer, donor, or Advisory Board Member please contact us. The chapter needs you!

The NHF Nevada Advisory Board of Directors, Anne, Maureen, and I wish you and your family a wonderful holiday season and a healthy and happy New Year!

Kelli, Anne and Maureen

HEMOPHILIA TREATMENT CENTER OF NEVADA

What Can The HTC Do For You?

Saturday, February 4th

1:00 pm – 4:00 pm

The Texas Hotel

2101 Texas Star Ln

North Las Vegas, NV 89032

Mark your calendar and plan on joining us to learn more about your Hemophilia Treatment Center. Food and Beverage will be served.



Leadership Begins With U

Introducing Leadership U, a paid summer internship* for full-time college students whose lives have been touched by hemophilia. Work alongside leaders at Bayer, while learning how to become a future leader in the hemophilia community.

*Includes lodging and transportation costs

Now Accepting 2017 Summer Internship Applications at the **NEW**

LivingWithHemophilia.com/Lead

Applications are due no later than:
Tuesday, January 31, 2017 at 11:59 p.m. ET



Bayer

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

Nevada Chapter of the National Hemophilia Foundation 2017 Program and Events Calendar

February 4, 2017 1:00 pm

What Can the HTC Do for You?
Texas Station Hotel-Las Vegas

February 24, 2017 6:00 pm

Silent Auction and Wine Tasting Event
Tivoli Village-Las Vegas, NV

March 8-March 10, 2017

Washington Days

March 23, 2017

Nevada's Big Give

April 1, 2017

Spring Education Fest

April 10, 2017

State Legislative Day
Carson City, NV

April 22-23, 2017

Leaders In Training

May 1, 2017

Golf for the Kids
Red Rock Country Club

May 6, 2017

Hispanic Heritage Event

June 13-17, 2017

Camp Independent Firefly
Big Bear, CA

July 21-23, 2017

Northern Nevada Family Weekend
Elko, NV

August 24-26, 2017

NHF Annual Meeting
Chicago, IL

September 16, 2017

Reno Walk & 5K
Bartley Ranch Park

September 23, 2017

Las Vegas Walk & 5K
Floyd Lamb Park

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* Full terms and conditions apply. Call 1-888-229-8379 or visit www.hematologysupport.com for more information.

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USBS/MG155/15-0007(2) 09/16



We are pleased to announce two awards available now!

The **Advocacy Award** is open to any individual with a bleeding disorder or a caregiver, who invests time and volunteers to better the Nevada bleeding disorder community. A monetary gift is given to the recipient of this award.

The **David Ostrove Memorial Educational Scholarship** will be available for any individual with a bleeding disorder who is accepted to a secondary school, part or full-time, in the fall of 2017.

Forms are available on our website www.hfnv.org and the deadline to apply is April 1, 2017.

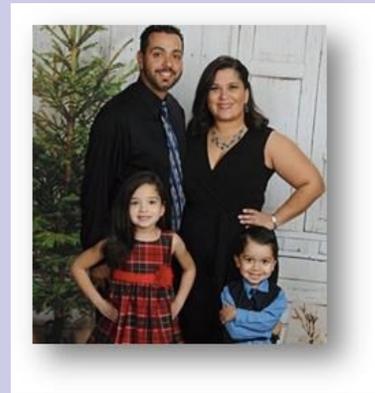
Are you headed to college next year? Now is the time to start looking for scholarships that are available to those with bleeding disorders. For more information on scholarships please visit this website, www.kelleycom.com/scholarships.html

Meet Maureen!

NHF Nevada is excited to announce that we have hired Maureen Salazar-Magana as our part-time bilingual Program Manager. Maureen started working at a telecommunications company (Cox Communications) right after she graduated high school.

During her 12 year tenure there, she held several positions such as Front Counter/Customer Service support to Employee benefits to Customer Care Quality Assurance. Maureen is fully bilingual (Spanish) and resides with her husband and two kids; daughter Sofia who is 8 and son Andres who is 5. Maureen has been part of the hemophilia community since 2011 when her son was diagnosed with severe Hemophilia A. Maureen had no history of bleeding disorders in her family so it was a shock to get this news. Being part of the Hemophilia community is what led her to want to apply for the Program Manager position.

Maureen enjoys spending time with her family and also being a Girl Scout troop leader for her daughters Brownie Troop! If you need to reach Maureen, you can email her at mmagana@hemophilia.org or call her at the Nevada Chapter 702-564-4368.



Wednesday, March 8 - Friday, March 10, 2017 *Save the Date!*

NHF's annual Washington Days empowers individuals in the bleeding disorders community to impact the legislative process.

Join us to:

- Meet face-to-face with lawmakers and staff who shape national healthcare policy
- Become more informed on critical issues that affect your continued access to quality care
- Learn effective grassroots advocacy techniques



Interested in Attending? Contact Kelli Walters at kwalters@hemophilia.org for more information.

Thank you!

The chapter received a wonderful surprise at the Reno Holiday Party! The chapter received a \$10,000 donation from the **Nevada Odd Fellows and Rebekah Home Board Committee of the Grand Lodge and Rebekah Assembly**. The check presentation was made by Bruce and May Beth Hiscock in memory of their daughter, Tammy Boswell.

The Hiscock's requested that the donation go towards sending children to Camp Independent Firefly next summer. On behalf of the NHF Board of Directors, and the families that we serve, we offer our thanks and gratitude for the awe-inspiring donation from the Nevada Odd Fellows and Rebekah Home Board Committee of the Grand Lodge and Rebekah Assembly and Bruce & Mary Beth Hiscock.



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Tel: 323.204.8974

Acceso 24/7 a Farmacéuticos con Experiencia

Nuestros farmacistas son especializados en el tratamiento de Hemofilia y están disponibles para contestar sus preguntas 24 horas al día, 7 días por la semana.

Cadena de Suministro de Factor de Coagulación Segura

Obtenemos nuestro Factor de Coagulación exclusivamente de Centros de Distribución de clase Mundial. Siempre recibirá el producto que necesita, cuando lo necesite. Calidad e Integridad de su producto está garantizado.

Monitoreo de Cumplimiento de Normas y Programas de Adhesión

Nos mantenemos en contacto regular con usted para apoyar la adherencia a la terapia prescrita. Personal de la farmacia siempre confirmará la cantidad de medicamentos y suministros que usted tiene en la mano antes de programar su próximo envío.

Coordinación de Servicios de Enfermería

Pacientes con Hemofilia requieren coordinación y atención de alta calidad y apoyo. Vamos a coordinar los servicios de enfermería de salud a domicilio si es requerido por su médico.

Comprensión de los Beneficios De Seguro

Le ayudamos a comprender cómo obtener el máximo provecho de sus beneficios de seguro y reducir los costos de su propio bolsillo lo más bajo posible. Ofrecemos la confirmación inicial de cobertura, incluyendo beneficios de farmacia y médica.

Llene su receta hoy



“Su farmacia preferida especializada en hemofilia para la comunidad latina”

We did it!

My Life, Our Future Enrolls 5,000 Participants in Research Repository

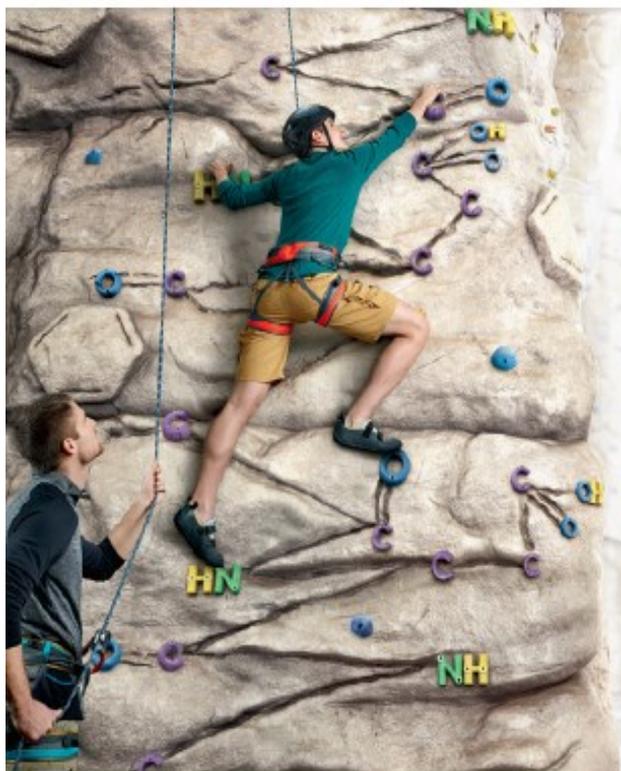
Thanks to you, the thousands who have said yes to progress, we have achieved our goal of enrolling 5,000 people in the *My Life, Our Future* research repository, making it the largest resource of its kind in the world! Beginning in 2017, qualified researchers will be invited to apply to study the repository data and further advance knowledge about hemophilia care and treatment. We are one step closer to scientific breakthroughs for our community.

As NHF CEO Val D. Bias noted during Opening Session at NHF’s 68th Annual Meeting in Orlando, FL, the people who have participated in this program are the heroes in our community helping to unlock the mysteries of hemophilia. Every participant counts and can impact future generations.

We will continue to keep you updated as the program evolves, beginning with a formal announcement to the public about this exciting milestone early next year. And don’t forget, *My Life, Our Future* is now also open to confirmed and potential carriers (those not yet diagnosed as a carrier), so encourage your family members to participate in the program today! Interested in learning more? Contact your HTC or visit MyLifeOurFuture.org.

My Life, Our Future is a partnership of the American Thrombosis and Hemostasis Network, Bloodworks Northwest, the National Hemophilia Foundation, and Biogen. Visit MyLifeOurFuture.org for more information.

Biotherapies for Life* **CSL Behring**



For adults and children with hemophilia A

REACH HIGHER

With the Long-lasting Protection of AFSTYLA

2x
WEEKLY
AVAILABLE

FDA-approved for
dosing 2 or 3 times
a week

ZERO
BLEEDS
(median ABR*)

In clinical trials,
whether dosed
2 or 3 times a week

COMPARABLE TO
NATURAL
FACTOR
VIII

Identical to
natural Factor VIII
once activated

**Zero inhibitors observed—Low incidence
of side effects in clinical trials**

In clinical trials, dizziness and allergic reactions
were the most common side effects.

Visit AFSTYLA.com to sign up for the latest news

*Annualized spontaneous bleeding rate in clinical trials (interquartile range [IQR])—0–2.4 for patients ≥12 years; 0–2.2 for patients <12 years.

Important Safety Information

AFSTYLA is used to treat and control bleeding episodes in people with hemophilia A. Used regularly (prophylaxis), AFSTYLA can reduce the number of bleeding episodes and the risk of joint damage due to bleeding. Your doctor might also give you AFSTYLA before surgical procedures.

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition. Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

Immediately stop treatment and contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure. Your body can make antibodies, called inhibitors, against FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA. In clinical trials, dizziness and allergic reactions were the most common side effects. However, these are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

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 the following brief summary of full prescribing information on the adjacent page, and the full prescribing information, including patient product information, at AFSTYLA.com.

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AFSTYLA®
Antihemophilic Factor
(Recombinant), Single Chain

**AFSTYLA®, Antihemophilic Factor (Recombinant), Single Chain
For Intravenous Injection, Powder and Solvent for Injection
Initial U.S. Approval: 2016**

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use AFSTYLA safely and effectively. Please see full prescribing information for AFSTYLA, which has a section with information directed specifically to patients.

What is the most important information I need to know about AFSTYLA?

- Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion on your own.
- Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing this medicine.

What is AFSTYLA?

- AFSTYLA is a medicine used to replace clotting Factor VIII that is missing in patients with hemophilia A.
- Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.
- Does not contain human plasma derived proteins or albumin.
- Your healthcare provider may give you this medicine when you have surgery.
- Is used to treat and control bleeding in all patients with hemophilia A.
- Can reduce the number of bleeding episodes when used regularly (prophylaxis) and reduce the risk of joint damage due to bleeding.
- Is not used to treat von Willebrand disease.

Who should not use AFSTYLA?

You should not use AFSTYLA if you:

- Have had a life-threatening allergic reaction to it in the past.
- Are allergic to its ingredients or to hamster proteins.

Tell your healthcare provider if you are pregnant or breastfeeding because AFSTYLA may not be right for you.

What should I tell my healthcare provider before using AFSTYLA?

Tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to hamster proteins.
- Have been told you have inhibitors to Factor VIII (because this medicine may not work for you).

How should I use AFSTYLA?

- Administer directly into the bloodstream.
- Use as ordered by your healthcare provider.
- You should be trained on how to do intravenous injections by your healthcare provider or hemophilia treatment center. Once trained, many patients with hemophilia A are able to inject this medicine by themselves or with the help of a family member.
- Your healthcare provider will tell you how much to use based on your weight, the severity of your hemophilia A, and where you are bleeding.
- You may need to have blood tests done after getting to be sure that your blood level of Factor VIII is high enough to clot your blood.
- Call your healthcare provider right away if your bleeding does not stop after taking this medicine.

What are the possible side effects of AFSTYLA?

- Allergic reactions may occur. Immediately stop treatment and call your healthcare provider right away if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.
- Your body may form inhibitors to Factor VIII. An inhibitor is a part of the body's defense system. If you form inhibitors, it may stop this medicine from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.
- Common side effects are dizziness and allergic reactions.
- These are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

What else should I know about AFSTYLA?

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

Please see full prescribing information, including full FDA-approved patient labeling. For more information, visit www.AFSTYLA.com

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YOU Sponsored by Baxalta now part of Shire We're More Than Carriers by *Laurie Kelley*

Not even 10 years ago, you might have been told that women could get hemophilia, but that it was very rare. And that probably, only about 10 women with hemophilia¹ existed in the US. Today, those statements are totally wrong. Why?

Why is the relatively small number of women as "bleeders" about to shift into the thousands and upend all our statistics? Because the belief that only males get hemophilia is no longer valid. Hemophilia has been described as mostly affecting males because the gene for hemophilia was found on the X chromosome. You probably know how it goes: men have only one X chromosome and can inherit the disorder from a mother who also has an affected X chromosome; women "carry" the disorder and pass it to their offspring. So traditionally, a woman who was dubbed a carrier might have low levels of factor, and if she showed some abnormal bleeding, she was delicately called a "symptomatic carrier." But she was most definitely not called a person with hemophilia. Not until now.

Where does that leave YOU, a symptomatic carrier—a woman with an affected X chromosome, who has low factor levels and who bleeds? You're pretty much a woman without a treatment plan, and that can be *daz*. Today, women with low factor levels who carry the hemophilia gene are calling themselves "women with hemophilia." And they're also calling for big changes: in our community's beliefs, and in how women are treated by hemophilia treatment centers (HTCs).

Silent Suffering

So many women who are labeled symptomatic carriers have suffered deeply, lacking a proper hemophilia diagnosis and appropriate treatment. "Do I consider myself a woman with a bleeding disorder?" asks Rita Epstein, mother of an adult with hemophilia. "You bet I do! During various surgical procedures over the years, I had major bleeding problems that actually caused doctors to stop the surgery. Once I was identified and pretreated as well as post-treated as a person with hemophilia, the surgical field was clear [of blood] and my procedures were easily handled."

Mary Boudreaux notes, "I've had more [bleeding] issues than my brother who has hemophilia! I've never been diagnosed with hemophilia—only as a carrier—and most doctors I see don't even want to hear about hemophilia because they say only males have that."

"I look back and think how different some of my experiences could have been, had I known I had a bleeding disorder," reflects Stormy Woods Johnson. "I could have avoided 45-day periods, a blood transfusion, and possibly four miscarriages. My ankle has given me trouble for over 15 years. It stayed swollen and painful for over three years before I finally found out I had tears in the tendon and large amounts of blood in it."

With a correct hemophilia diagnosis, so much suffering could have been avoided. But through the years, most of the US medical community grew comfortable assigning the label "symptomatic carrier" to women with signs and symptoms of bleeds who had children with hemophilia. The focus was almost always on the boys with hemophilia.

Treatment Jeopardized

Being labeled only a carrier can result in a more casual medical approach to treatment, whether for surgery, childbirth, menses, or just regular activities. Melissa Howell admits that most doctors say to her, "Oh, you're a carrier, so we don't need to do anything else."

By using the carrier label, physicians may even encourage women with bleeding issues to ignore their instinct that something is wrong. Brandi Worthington recalls, "I always thought I had anemia, and didn't know what was wrong because I bruised easily and had very heavy periods twice a month. When I got into a car accident while pregnant with my first child, I had unbearable pain. My doctor said it was just normal pregnancy pain."

Brandi ended up with internal bleeding and a huge blood clot that became infected. Her nephew had hemophilia, but no one realized she might be a carrier or have low factor levels. Five years after the accident and one month before the birth of her third child, who was diagnosed with hemophilia, Brandi tested positive as a carrier with mild hemophilia. "It was my nephew's nurse," she explains, "who said I should get my levels retested since I was pregnant again."

Audrey La Bolle shares, "When I was tested, I had less factor VIII than my son with hemophilia, but I was told by the hematologist at the HTC that a diagnosis of hemophilia could only be applied to males. I was 'just' a symptomatic carrier, even though I almost bled to death several times after surgeries and giving birth."

"I am a woman. I am a hemophilia carrier. I have bleeding issues," writes Michelle Thompson in her blog.² "They are not severe, usually, but I still have them. When I go to the dentist, when I strenuously exercise, when I bump something pretty hard, and when I clumsily fall. The bruises and bleeds come and I can feel them. But that isn't good enough for my HTC. I guess they want me to look like [I have severe hemophilia], swelling like a balloon to acknowledge that I am a woman and I bleed too. But my son is moderate/mild...When he has a bleed we treat it."

Sometimes it's difficult for the HTC to accurately diagnose; stress and hormones can affect factor levels. "You know what frustrates me the most?" seethes Tela Kirk-Aguilar. "It's when you are a 'symptomatic carrier,' and get tested to see if you might have hemophilia, but your levels are too high! The HTC thinks you're fine, but you get bruising and heavy periods; or you throw your knee out while your eight-year-old tells you, 'It sounds like a bleed, Mommy.' You can't do anything about it because you can't get factor!"

Even When You Are Diagnosed

It's an uphill battle to get correctly diagnosed and treated, because it's hard to change widespread beliefs in the medical community. Even women who are diagnosed sometimes aren't believed by the general medical community, or by payers.

Stormy was diagnosed with hemophilia just 18 months ago. Though she received the correct diagnosis, "I still feel I am treated differently than a male with hemophilia."

We're More Than Carriers (continued)

Mary Haugen insists, "The diagnosis of being a female with hemophilia is essential to our treatment. It opens doors for our insurance to cover treatment, better treatment by medical professionals, and a better life."

Genny Moore, mother of a child with hemophilia, says, "The HTC should understand the importance of properly identifying hemophilia. If the factor levels show mild, moderate, or severe range, it is important that we are identified as indeed *having* a bleeding disorder in order to ensure proper treatment especially in an accident or surgery."

But Stormy warns, "It will take time for the HTCs to really embrace the fact that we have hemophilia. I think some have accepted it openly, some have accepted it with caution, and some will never truly accept it. It will take a bit of time for them to treat us by symptoms and not gender or numbers."

Appropriate treatment can change women's lives. "The two weeks of factor replacement after my last delivery made my recovery amazing," recalls Michelle. "I'm not only talking about the amount of bleeding (that was so much less too!) but also the time it took to heal from the episiotomy and to just heal in general. Wow. If I'd known before that it could be like that, maybe we wouldn't have waited 10 years before having our last child."

Women with Hemophilia—Unite!

Mentioning the subject of women having hemophilia—or "women as bleeders," as Facebook friends often call themselves—creates a flood of opinions, from men and women. Women are frustrated. Men are supportive.

"Hemophilia symptomatic carriers—are you out there?" posts Michelle. "Let's start talking among ourselves and compare stories. If research studies could be done, then there would be information out there for the doctors to finally realize that their textbook answers will not cut it when it comes to women [with hemophilia]."

What are next steps? What can you do?

1. Get your factor levels correctly diagnosed at your HTC, and discuss your bleeding history.³ Don't do this at your son's annual clinic visit, where the focus is on him. Make your own appointment. Remember, this is about YOU.
2. If your levels are 50% or lower, ask to be diagnosed as a person with hemophilia, not as a carrier or symptomatic carrier. Even women with factor levels of 60% can have bleeding problems.
3. Develop a treatment plan before dental procedures, childbirth, injuries, and surgeries. You might need a prescription for factor.
4. Invest in medical identification jewelry, just as you did for your child with hemophilia.
5. Get support from the community. Start with your local hemophilia organization—what are its opinions and poli-

cies about women being diagnosed with hemophilia? Make this a topic at your annual meeting.

We must also advocate for widespread changes in how we think about carriers and hemophilia. A carrier should never automatically be thought of as someone who has the gene for hemophilia but does not have the disorder. Women who are carriers and have low factor levels often have bleeding issues: bruising, bleeding into joints and muscles, and menstrual periods with abnormally heavy or prolonged bleeding. The moment a woman is diagnosed as a carrier, HTCs need to start investigating a hemophilia diagnosis and have a treatment plan in place.

Women who are defined as symptomatic carriers want the label removed permanently. They want to be known simply as "women with hemophilia" if their levels are lower than 50% and if they experience abnormal bleeding. If this change happens, women will have their own personalized treatment plans and access to factor concentrate.

This is what personalized healthcare is all about: identifying your unique medical and treatment needs, and addressing them, without limiting labels. If you're classified as a symptomatic carrier and believe you're not getting the personalized healthcare you need, call your HTC today and get the ball rolling.

1. Only women with severe hemophilia were considered to have hemophilia.
2. Michelle Thompson, "Hemophilia Symptomatic Carriers...Are You Out There?" chellebellebooks.blogspot.com, Feb. 29, 2012 (Accessed Sept. 1, 2016).
3. Labs at HTCs have more expertise in accurately measuring factor levels. Also, several tests should be performed at different visits because factor VIII levels can vary widely in response to stress and hormones. For example, stress causes an increase in factor VIII levels.

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Winter Wine Fest

Please consider joining us for our 2nd Annual Winter Wine Fest on Friday, February 24th at Tivoli Village from 6:00 – 8:00 pm. You will have the opportunity to Sip, Shop and Support for only \$25.00 per person for tickets purchased in advance or \$30.00 at the door. Tickets are available for purchase on our website, www.hfnv.org **We will have many exciting silent auction items to bid on, including two (2) round trip tickets on Southwest Airlines, a Private Wine Class for 20 and a fabulous 2 week Rental of a home in Sao Jorge, Azores (an island in Portugal!)**

We are still looking for additional silent auction items. If you can help, please contact Anne at 702.564.4368 or email her at amcguire@hemophilia.org. All of the proceeds from the event benefit those with bleeding disorders in Nevada.



HEMOPHILIA TREATMENT CENTER OF NEVADA

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NEVADA'S ONLY FEDERALLY RECOGNIZED HTC

**We are PROUD to have
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Las Vegas

3121 S. Maryland Pkwy., Suite 206
Las Vegas, NV 89109
702-732-1956

Reno

540 W. Plumb Lane, Suite 200
Reno, NV 89509
775-657-8981

Outreach Clinic Locations

Winnemucca, Owyhee Duck Valley
Indian Reservation, Ely and Elko

Comprehensive Care Plan

Our comprehensive care plan includes a diagnostic evaluation for hemophilia, von Willebrand disease and other bleeding and clotting disorders.

We maintain inventory of all factor therapies and assays to minimize delays in your care.

We promote positive health outcomes for all our patients and help coordinate home nursing services when needed.

Join our 340B Program Today!

Benefits of enrolling in HTC NV 340B

- ♦ Reduced factor costs
- ♦ Generates resources for:
 - ♦ Outreach clinics
 - ♦ Youth groups
 - ♦ School visits
 - ♦ Community educational events
 - ♦ Family retreats & summer camp
- ♦ Full time Nurse Practitioners
- ♦ Full time Social Worker
- ♦ Full time Physical Therapist
- ♦ Dental Assistance Program

Contacts:

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340 B Compliance
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**340 B Contract Pharmacy
Factor Support Network
Kelly Gonzalez**
Regional Care Coordinator
702-858-2525

Camp Independent Firefly 2017

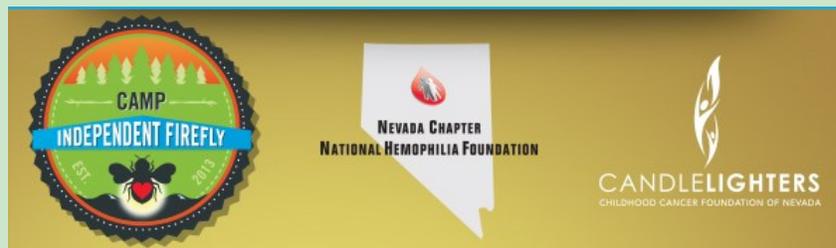
June 13 – 17, 2017

**What fun we have in store for our campers!
This year's theme is Lights, Camera, Action!**

Camper Applications will be available online—starting **February 1, 2017**.

Watch your email for a link to the online application system. **Applications are available online only.** If you do not have email or online access, call the office at 702.564.4368 asap to schedule a time to come in and fill out the application.

Volunteer Applications will be available online—starting January 1, 2017.



Do you have Hemophilia A or B? Participate in My Life, Our Future!

The Hemophilia Treatment Center of Nevada is participating in a study called "My Life, Our Future - Genotyping for Progress in Hemophilia" This is a national campaign that leaders in the community developed at no cost to the patient to help gain a clearer understanding of hemophilia treatment today while helping to advance treatments for tomorrow.

The sponsors for the project (ATHN, Biogen, National Hemophilia Foundation and Puget Sound Blood Center) define Genotyping as the process of identifying the genetic code responsible for an individual's hemophilia. Much like a fingerprint, your genotype can provide meaningful information about your hemophilia to you and your doctor. It has the power to:

- Predict bleeding severity
- Help determine inhibitor risk
- Identify potential carriers in your family
- Aid in family planning and pregnancy care
- Serve as a critical roadmap to greater scientific understanding and new treatment approaches.

With limited funds, we would like to test as many of you as possible during 2017. The project will conclude at the end of 2017, or before, if the funds run out. The test is a simple blood draw and should not take more than 30 minutes from signing your consent to completing your blood draw.

Please call the Hemophilia Treatment Center in Las Vegas (702) 732-1956 or Reno (775) 657-8981 with questions or to make your appointment today.



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

"AFTER WORKING
WITH MY DOCTOR
AND BASED ON MY RESPONSE,
I NOW INFUSE PROPHYLACTICALLY
EVERY 14 DAYS!"

Casey, on ALPROLIX

Casey, a MyALPROLIX Peer,[™] started on a once-every-10-day prophylaxis infusion schedule and adjusted to once every 14 days.

Learn more at www.alprolix.com/findyourfit

Extended protection* from bleeds
ALPROLIX is the first factor IX offering prophylaxis infusion schedules starting every 7 or 10 days with the potential to extend based on your response.

*ALPROLIX has been proven to help patients prevent bleeding episodes using a prophylaxis regimen.

The recommended starting prophylaxis regimens are either 50 IU/kg once weekly, or 100 IU/kg once every 10 days. Dosing regimen can be adjusted based on individual response.

Children under 12 years of age may have higher Factor IX body weight-adjusted clearance, shorter half-life, and lower recovery. Higher dose per kilogram body weight or more frequent dosing may be needed in these children.

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:

- On-demand treatment and control of bleeding episodes
- Perioperative management of bleeding
- Routine prophylaxis to 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.

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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NHF Nevada has a newly re-designed Website!

We are excited to announce that NHF Nevada has a new and improved website! The website is updated daily and gives you the ability to register for programs and events! It is mobile friendly too! Check it out at www.hfnv.org. It also includes links to national resources!

To register for one of our upcoming programs and events on our event calendar. Go to www.hfnv.org, click on **News & Events** and then go to the **Event Calendar**.





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The Nevada Chapter of the National Hemophilia Foundation is dedicated to improving the quality of care and life for people with hemophilia, von Willebrand disease, and other inherited bleeding disorders through education, peer support, and advocacy.

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Emotional Protection

Chronic conditions require attention to mental health

By Nancy Mann Jackson | 11.15.2014

Originally Published November 2014

Actor and comedian Robin Williams' suicide in August helped shine a much-needed spotlight on the prevalence of depression and other mental health issues in the US and what can be done to address them.

While depression, anxiety and other mental health issues are relatively common in the general population, they are even more prevalent in people with chronic health issues. A study conducted by researchers at the Arizona Hemophilia and Thrombosis Center (HTC) in Tucson in 2009 showed that 37% of men with hemophilia experience depression, compared with about 4% of men in the general population, says Maria Iannone, a licensed associate counselor at the Arizona HTC and the study's lead author.

"Our community has an increased prevalence of depression and anxiety," says James Hammel, MD, a psychiatrist at Seattle's Virginia Mason Medical Center, who serves on the board of the National Hemophilia Foundation. "But we have a lot of hematology-based care providers around us, which should give us greater access to the overall healthcare system." Anyone whose anxiety or depression impairs normal daily function should tell a healthcare provider and receive help, he says.

The mental health-chronic disease connection

Everyone experiences stress at times, and sometimes it can lead to anxiety or depression. But people with chronic diseases often deal with constant concerns that others do not have. Simply making repeat visits to an array of doctors, and having multiple medical tests and treatments from childhood into adulthood, causes additional stress for people with bleeding disorders, according to Cathy Buranahirun, PsyD, pediatric psychologist and neuropsychologist at the HTC at Children's Hospital Los Angeles.

"We do have people who are debilitated by their hemophilia," Iannone says. For instance, internal bleeding can lead to joint pain and arthritis, nerve pain, infection and eventually joint surgery. Living with chronic pain or persistent medical problems can cause people to feel overwhelmed by the physical difficulties of their lives.

Although people with bleeding disorders may have more ongoing stressors, the mental health challenges accompanying them can be conquered. "Unlike a bleeding disorder, a mental condition doesn't have to be chronic," Hammel says. "If you're really anxious or depressed, a bleeding disorder doesn't do well. That's even more incentive to get it treated."

Finding help

When people feel depressed or anxious, they often believe they are alone and that no one else understands them. Those suffering may fear others' opinions if they share their feelings, or they may believe there is no relief from the pain. But that simply isn't true. "The stigma against mental illness is rapidly going away," Hammel says. "Particularly after the tragedy of Robin Williams, we recognize that depression and anxiety are medical illnesses no different from hemophilia and other bleeding disorders."

When feelings of sadness interfere with normal life, they should be taken seriously, Hammel says. For instance, if they prevent you from going to work or school or from participating in activities you enjoy, it is time to seek advice from a medical professional.

Parents of a child with a bleeding disorder should watch for changes in their child's mood, behavior, grades, friendships, appetite or sleep, says Erin Hawks, PhD, a psychology fellow at the University of Oklahoma Health Sciences Center in Oklahoma City. Any of these symptoms can be signs of anxiety, worry or depression.

"When the individual hears from their significant other, family or friends that they are disengaged, withdrawn, unfocused, cranky or irritable, that's often when individuals start to realize there's a problem and that it needs to be addressed," says Mina Nguyen, PsyD, psychologist at the Oregon HTC and assistant clinical professor of pediatrics at Oregon Health & Science University in Portland.

When diagnosing clinical depression, mental health practitioners consider duration and persistence of symptoms, Nguyen says. If a person's feelings of depression or anxiety last all day or continue for months, treatment is likely needed. (See "Detecting Depression" sidebar on p. 40 for a detailed list of the most common symptoms of clinical depression.)

If you or a family member is experiencing signs of depression or other mental health concerns, let healthcare professionals determine whether the symptoms are chronic. "Even if it's transient sadness or stress, even if it's not diagnosable, it can still affect how well you take care of yourself or your child," Buranahirun says. "If there are any concerns, it would be a good idea to bring it up at your HTC appointment. Just open it up for discussion."

Emotional Protection

Chronic conditions require attention to mental health (continued)

Although it is becoming increasingly common for HTC's to have mental health professionals on site, all members of the healthcare team can assist with mental health concerns. Share those concerns with a healthcare provider you feel comfortable with, whether it's a social worker, physician, nurse or therapist, says Buranahirun. Any HTC professional can help guide patients or family members through the proper channels to get the help they need.

But give yourself time to find someone you have rapport with. You may need to try more than one provider to find the right fit. It's important to find someone willing to closely follow you until you are experiencing some relief from your symptoms, Iannone says.

Steps to healing

Discussing the changes in mood or feelings you are experiencing is the first step to making things better. Although you may start the conversation with your HTC doctor or nurse, he or she may refer you to your social worker, a psychologist or a counselor. "Our MDs and nurses are usually swamped with patient care and are not trained as mental health practitioners," Nguyen says.

Even though mental health concerns are fairly common for people with bleeding disorders, they don't have to be a fact of life. And forging a relationship with a mental health professional is often a vital step in moving forward. "Suffering from depression doesn't mean someone is deficient in any way," Iannone says. "Often, people can find relief when they develop a good relationship with a healthcare provider, clergy member or family member who can help lead them to a new status quo."

Medication is often part of the successful treatment of depression, anxiety and other mental health issues. Finding the right medication for each person can take time, patience and a good working relationship with a healthcare provider. "Treating depression is always a process," Iannone says. "Some folks hope they can resolve their depression with medication only. However, just taking a pill rarely works. Getting better usually also requires an educational process and lifestyle changes."

Many HTC's are working to prevent mental health concerns before they become a problem. For instance, Iannone and Buranahirun screen all patients for symptoms of depression, anxiety or similar issues. Buranahirun often provides brief, intermittent psychology consultation. "It can be very effective to catch it early, preventing the need for later work," she says.

Dealing with depression and anxiety can come in the form of social outings and networking groups, such as the Blood Brotherhood, a national outreach program for adult men diagnosed and living with bleeding disorders. At the Oregon HTC, mental health professionals regularly try to pair patients at risk for depression or other mental health issues with others of similar age or situation, Nguyen says. Building relationships with those who understand them can help people overcome persistent negative feelings.

In addition, many HTC's refer patients to local family support groups or family camps. Others sponsor camps for children with bleeding disorders or annual retreats for adults with hemophilia. "People who are depressed are more likely to be unemployed and to not feel socially connected," Iannone says. "Fortunately, the bleeding disorders community provides many opportunities through retreats, support activities and programming to help people feel more connected (and) have a place to process their experience."

Finally, people with bleeding disorders and their family members should continually closely monitor their own moods and be aware of changes. "Patients can take some responsibility to keep themselves mentally healthy," Nguyen says. "Build a support network and communicate with your providers so you can recognize and work on issues, rather than waiting until the condition is severe."

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