



Hemophilia News and Views

Winter Edition 2017

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Chapter News

Dear Friends,

I want to extend a heartfelt thank you to everyone who made 2017 a success. We had a year of changes and transition within the bleeding disorders support and treatment community, as well as constant changes on the national healthcare front.

The resilience, perseverance and dedication of the members of our Nevada bleeding disorders community is impressive.

The unwavering support from our donors, volunteers, partners, sponsors, and supporters who stepped-up in a time of need, and continue to be there for the bleeding disorders community is amazing.

Thank you. It is through your support that we are ending 2017 on a positive note and looking forward to a successful 2018.

Here are just a few of the highlights from this year that you helped accomplish:

- Over \$26,000 Emergency Financial Assistance provided to almost 60 families in need.
- More than 30 program events offered across Nevada.
- \$900 raised toward our Giving Tuesday & Holiday Appeal Goal.
- 77 Children attended Camp Independent Firefly.

With warmest regards and heartfelt thanks,

Betsy VanDeusen
Executive Director



Nevada Chapter of the National Hemophilia Foundation 2018 Program and Events Calendar

<p><u>January</u></p> <p><i>Las Vegas</i></p> <ul style="list-style-type: none"> • 1/27 Teen Leadership Program 	<p><u>February</u></p> <p><i>Las Vegas</i></p> <ul style="list-style-type: none"> • 2/10 Couples Retreat • 2/23 Winter Wine Fest <p><i>Reno</i></p> <ul style="list-style-type: none"> • 2/24 Women's Retreat 	<p><u>March</u></p> <p><i>Las Vegas</i></p> <ul style="list-style-type: none"> • 3/3 LIT Training/Teen Leadership Program • 3/7-3/9 Washington Days • 3/17 Spring Education Fest
<p><u>April</u></p> <p><i>Las Vegas</i></p> <ul style="list-style-type: none"> • 4/16 Golf Gets in Your Blood NHF NV Golf Tournament 	<p><u>May</u></p> <p><i>Las Vegas</i></p> <ul style="list-style-type: none"> • 5/12 Women's Retreat • 5/19 Hispanic Heritage Program 	<p><u>June</u></p> <p><i>Las Vegas</i></p> <ul style="list-style-type: none"> • 6/12-6/16 Camp Independent Firefly • 6/30 Men's Retreat

You can register for all events on our website:

www.hfnv.org

Go to News & Events/Events Calendar

Please welcome Christine Bettis to the NHF Nevada Team. Christine started November 28th. Below is a little about Christine and the position she will be taking on at NHF:



Christine Bettis- **Chapter Development Coordinator**

Christine Bettis recently graduated with her MFA from the University of Nevada, Las Vegas. She is from Detroit and her background is in community outreach, education, and creative writing. She is a former AmeriCorps VISTA member and is humbled and excited to serve the bleeding disorders community here in Nevada.

If you wish to reach out to Christine, you can so via email at cbettis@hemophilia.org

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.

Staff

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Hemophilia News and Views is published 4 times a year by the Nevada Chapter of the National Hemophilia Foundation (NHF-NV). We welcome advertisers. Please contact the office at 702.564.4368 for advertising rates.

The material in this newsletter is provided for your general information only. The Nevada Chapter does not give medical advice or engage in the practice of medicine. NHF-NV does not recommend particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.



Nevada Chapter of the National Hemophilia Foundation
222 S. Rainbow Blvd., Suite 203
Las Vegas, NV 89145
702-564-4368

IN HEMOPHILIA B, THERE'S ONE THING YOU CAN COUNT ON



INNOVATION FROM NOVO NORDISK

We strive to help improve the lives of people with hemophilia

For 30 years, Novo Nordisk has been a driving force for people living with rare bleeding disorders. We take pride in striving for innovative solutions to help improve patients' lives. This motivates us to uphold the highest standards in our product research and development. This vital research is just the beginning of our commitment in hemophilia.

Through the B-HERO-S study^a in hemophilia B, we uncovered unmet needs around the impact of hemophilia on education, employment, activities, and other aspects of the lives of patients and their families.

We will continue our research and connect with patients and health care professionals to ensure we understand and respond to the specific needs of the hemophilia B community.

With a rich history, Novo Nordisk remains at the forefront of discovery. We are poised to continue to develop innovative solutions that can help improve the lives of patients with hemophilia in the future.

^aB-HERO-S = Bridging Hemophilia Experiences, Results and Opportunities into Solutions. A U.S. survey of 449 people.

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Whether it's with a shimmer, a glow or a star—you can make a brighter holiday for someone in need.

Support a Brighter Holiday for a Nevada family by donating to our financial assistance program for the bleeding disorders community.

Your gift can help prevent a family from being evicted, keep the lights on over the holidays by covering a utility bill, provide gifts for children living with bleeding disorders, and keep food on the table over the holidays.

The Nevada Chapter offers financial assistance to qualifying families. So far this year over 50 families received help with their medical bills, utilities, and rent with over \$20,000 in assistance offered to those most in need. We need your help to continue to support families in need throughout the holidays.

This giving season, we're offering three recurring sponsorship packages; Shimmer, Glowing & Star Sponsors.

- **Shimmer Sponsors: Give \$10 per month**
- **Glowing Sponsors: Give \$25 per month**
- **Star Sponsors: Give \$50 per month**

One-time donations of any size are also welcome.

Every little bit helps. Your kindness and generosity truly make a difference.

Living with a bleeding disorder -- an early and sometimes shocking diagnosis, with frequent and demanding treatment, and the likelihood of complications -- can alter the experience of childhood and through adulthood. The Nevada Chapter provides education, advocacy, and support programs for the bleeding disorders community.

Children, families, adults, and seniors in Nevada affected by bleeding disorders depend on the Chapter for information, education, and financial support to maintain a high quality of care and life.

Hemophilia is a genetic bleeding disorder that prevents the blood from clotting normally. The main symptom is uncontrolled, often spontaneous bleeding. Internal bleeding into the joints can result in pain, swelling and, if left untreated, can cause permanent damage. Managing complicated medical treatments, facing time out of work to recover or care for a child with a bleeding disorder, and ongoing medical fees can become overwhelming for those living with bleeding disorders.

How You Can Help

- **Sign-Up for a monthly recurring donation at: <https://www.razoo.com/organization/Nevada-Chapter-Of-The-National-Hemophilia-Foundation>**
- **Send checks to Nevada Chapter of the National Hemophilia Foundation, 222 S. Rainbow Blvd. Suite 203, Las Vegas, NV 89145**

Fact or Fiction? Test Your Knowledge

<i>True or False</i>	<i>True or False</i>
Only boys have Hemophilia	Children with a bleeding disorder should not floss their teeth because flossing causes bleeding
False	False
Although hemophilia is more common in boys, girls can have hemophilia, too. Girls will inherit hemophilia if their mothers carry the gene for it and their fathers have hemophilia. Hemophilia occurs predominantly in males. von Willebrand disease, another type of bleeding disorder, affects both males and females.	Actually, flossing helps keep gums healthy, and healthy gums bleed less. So, bleeding while brushing or flossing is a sign that your child's teeth and gums should be brushed and flossed more often or more thoroughly to improve their health. Flossing regularly and having the dentist clean your child's teeth are important steps in teeth and gum care.
<i>True or False</i>	<i>True or False</i>
Hemophilia B is sometimes called Christmas disease	Hemophilia Treatment Centers (HTCs) provide multidisciplinary, comprehensive care to patients with hemophilia or other types of bleeding disorders and their families
True	True
Christmas disease was named in the 1950s after a 10-year-old boy from England named Stephen Christmas. The young boy didn't seem to have the typical type of hemophilia that healthcare providers were accustomed to seeing. So, they named his version hemophilia B or Christmas disease, and the usual type hemophilia A or classic hemophilia.	Today, there are more than 140 federally funded treatment centers and programs across the country. In fact, about 70% of people with hemophilia in the United States receive care from HTCs. The Centers for Disease Control and Prevention has found that patients who receive care at one of these specialty centers are 40% less likely to be hospitalized or to die from a hemophilia-related complication than those not getting such care.

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Winter Wine Fest

Sip, Shop and Support

Friday, February 23, 2018
6:00 pm – 8:00 pm

BRIO Tuscan Grille at Trivoli Village
420 S. Rampart Blvd. | Las Vegas, NV

Ticket Price \$30 in advance, \$35 at the door.
Purchase your tickets online at www.hfnv.org.

Presenting Sponsor 

Benefiting the Nevada Chapter of the
National Hemophilia Foundation

Give The Gift of Wine: Buy Your Tickets Now for Winter Wine Fest 2018!

Come Sip, Shop and Support NHF Nevada. We will have food, wine and awesome silent auction items for you to bid on. Tickets are only \$30 in advance, \$35 at the door!

The Winter Wine Fest is a wine tasting event hosted by the Nevada Chapter of the National Hemophilia Foundation (501c3 Nonprofit Organization Tax ID 13-5641857) to raise funds for the Nevada bleeding disorders community. 100% of the proceeds stay in Nevada and support our programs and services improving the quality of life and care of families living with bleeding disorders. With over 200 attendees, the Winter Wine Fest is a fun opportunity to sip and socialize, while supporting a great cause.

We are still looking for additional silent auction items. If you can help, please contact Christine at 702-564-4368 or email her at cbettis@hemophilia.org.

Purchase Tickets online at www.hfnv.org.



Now Approved

A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use.

HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.



HOW SHOULD I USE HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

WHAT ARE THE OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

Medication Guide Brief Summary
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:

– confusion	– stomach (abdomen) or back pain
– weakness	– nausea or vomiting
– swelling of arms and legs	– feeling sick
– yellowing of skin and eyes	– decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:

– swelling in arms or legs	– cough up blood
– pain or redness in your arms or legs	– feel faint
– shortness of breath	– headache
– chest pain or tightness	– numbness in your face
– fast heart rate	– eye pain or swelling
	– trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See “**What are the possible side effects of HEMLIBRA?**” for more information about side effects.

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

- Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.
- HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

BEFORE USING HEMLIBRA, TELL YOUR HEALTHCARE PROVIDER ABOUT ALL OF YOUR MEDICAL CONDITIONS, INCLUDING IF YOU:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

HOW SHOULD I USE HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

WHAT ARE THE POSSIBLE SIDE EFFECTS OF HEMLIBRA?

- See “**What is the most important information I should know about HEMLIBRA?**”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

HOW SHOULD I STORE HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than 7 days at 86°F (30°C) or below.
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

WHAT ARE THE INGREDIENTS IN HEMLIBRA?

Active ingredient: emicizumab

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
 1 DNA Way, South San Francisco, CA 94080-4990
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.

This Medication Guide has been approved by the U.S. Food and Drug Administration
 Issued: 11/2017



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A LOOK BACK AT 2017...



Save The Date for the 2018 Golf Tournament!

Golf Gets In Your Blood is the golf tournament benefitting the Nevada bleeding disorders community. Hosted by the Nevada Chapter of the National Hemophilia Foundation, the tournament features competitive play on the stunning private Red Rock Country Club's Mountain Course.

Golfers will enjoy a fun day of golfing including lunch and an awards reception. The event includes a putting contest, longest drive, closest to the pin, raffle prizes and more.

100% of every dollar raised directly supports the Nevada Chapter's advocacy, education and support for those in the bleeding disorders community. The Nevada Chapter of NHF is a 501c3 nonprofit organization (Tax ID 13-5641857). Register online at www.hfnv.org or email

cbettis@hemophilia.org for a golfer registration form. Tournament is limited to 144 golfers.

- \$300 Individual Golfer
- \$1,100 Foursome
- \$75 Contest Super Ticket: Includes entry into course contests and specialty holes.
- \$50 Golf Club Rental

Sponsorship opportunities starting at \$2,000 available for lunch, specialty items, and more. Contact cbettis@hemophilia.org for more information.

- \$300 Hole Sponsor
- \$2,000 Lunch Sponsor, Specialty Item Sponsor
- \$3,500 Bronze Sponsor (Limit Four)
- \$5,000 Silver Sponsor (Limit Four)
- \$7,400 Gold Sponsor (Limit Two)
- \$10,000 Presenting Sponsor (Exclusive)

GOLF GETS IN YOUR BLOOD

Monday, April 16, 2018

Mountain Course at Red Rock Country Club
Registration 9:30am | Shotgun Start 11am

Tournament benefitting



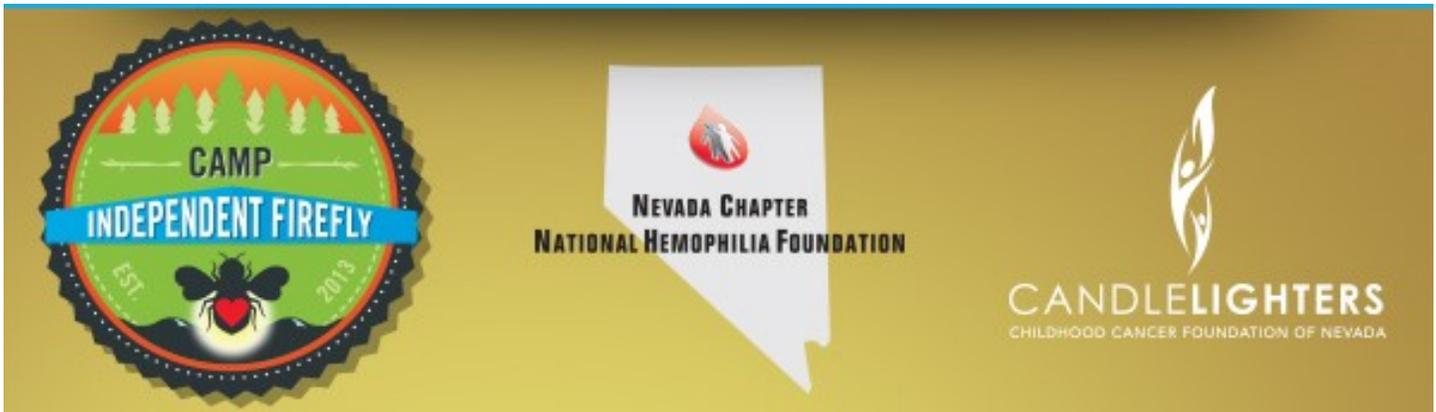


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Camp Independent Firefly
June 12-16, 2018

This years theme **TRAVEL IN TIME**

- **Camper Applications available online starting February 1, 2018.**
- **Volunteer Applications will be available online starting January 2, 2018.**

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.

To make sure you receive important information from the Nevada Chapter, please update your contact information by contacting us at mma-gana@hemophilia.org.

My Life, Our Future: Participate Through December 15, 2017

Since *My Life, Our Future* (MLOF) began in 2012, people with hemophilia A and B and their families across the country have taken part in this impactful initiative.

Thanks to you, we have been able to meet and exceed the two primary program goals, genotyping nearly 10,000 people with hemophilia, and creating the world's largest genetic hemophilia research repository. Further still, we expanded the program to include known or potential carriers of hemophilia.

As you may have heard at the recent NHF Annual Meeting, **MLOF enrollment will remain available**

through December 15, 2017, with a focus on enrolling 2,000 confirmed hemophilia carriers in the MLOF Research Repository by then.

We are more than half way towards this goal, so if you haven't already, please participate soon!

Thank you for your ongoing support of MLOF. Together, we're growing scientific understanding of hemophilia for generations to come. [To learn more, contact The Nevada Chapter of the National Hemophilia Foundation or visit MyLifeOurFuture.org.](#)

My Life, Our Future is a collaboration between the American Thrombosis and Hemostasis Network, Bloodworks Northwest, the National Hemophilia Foundation and Bioverativ.

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pioneering spirit

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Hispanic Families in the Bleeding Disorders Community

Solutions for the biggest challenges

For many Hispanic people with a bleeding disorder and their families, navigating the often-complex world of medical care (including insurance) in a language other than what is spoken at home can be challenging. Language barriers and cultural divides can send fear, confusion and anxiety skyrocketing.

To better understand the needs of the Hispanic bleeding disorders community, in 2015 the National Hemophilia Foundation (NHF) partnered with the Centers for Disease Control and Prevention on a series of focus groups with Hispanic families across the country.

These focus groups identified the following challenges, as well as possible solutions.

Challenge: Clear language understanding

One of the biggest hurdles to overcome is the language barrier. "When families are not very fluent (in English), a lot of what is communicated to the patient is lost. They may know some language, to communicate at work, but not the technical medical information the doctor is saying," says Maria Santaella, RN, MSN, pediatric program nurse coordinator at the University of Miami Hemophilia Treatment Center.

"Parents have to learn themselves what it is and how their lifestyle will change," says Felix Olaya, a bilingual education specialist at NHF. "But then, with the large Hispanic family structure, they will also have to teach Grandma and Auntie and any cousin or neighbor who may be caring for their child. Finding material that is trustworthy, easy to understand and culturally inclusive can be a real challenge."

Solution: Go to stepsforliving.hemophilia.org/es/inicio to find trusted educational information in both Spanish and English.

Challenge: Clear cultural understanding

Communication is about more than just words and accents. "Many first-generation Hispanics come from places where the medical environment is completely different, and they're completely lost in the way they're talked to about science and genetic causes. A lot of times, the families are used to thinking in more spiritual ways, in terms of treatments and coping," says Santaella.

Solution: Guides at local NHF chapters who speak Spanish are available to discuss bleeding disorders issues. Go to hemophilia.org/community-resources/chapter-directory to find the chapter nearest you.

Challenge: Not following treatment plans

Becoming familiar with the treatment schedule and feeling comfortable using needles at home can be difficult. "It can take time and practice to get used to doing this," Olaya says.

Solution: Attend summer camp. "Each local chapter offers summer camps, and it's really cool," says Olaya. "Some have family camps where the whole family can go, and it really helps families to overcome anxiety. It's great to meet others living with the same condition." To find nearby camps, visit hemophilia.org/Community-Resources/Locate-a-Camp-Near-You.

Challenge: Isolation

It's easy for people to wonder, "Why our family? What did we do to deserve this?" especially when there's no family history of bleeding disorders, says Olaya. Such feelings can lead to becoming isolated from the robust community of Hispanics living with a bleeding disorder. "You can still have a normal life with a bleeding disorder," says Olaya.

Solution: "You don't have to broadcast on Facebook about your child's condition to reach out and join a very supportive and welcoming community of Hispanic families living with hemophilia through NHF," Olaya says. Families that have been living with a bleeding disorder for a while can volunteer to help support families newer to the condition. Go to [HemAware en español on Facebook](https://www.facebook.com/HemAware.en.espaol) to connect with other families.



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PEN's Insurance Pulse 2017

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Ask the Expert

Michelle Rice

Senior Vice President, External Affairs, National Hemophilia Foundation

QUESTION: Recently I received a notice from my pharmacy benefit manager (PBM) stating that the amount paid by my factor manufacturer assistance program does not count toward my deductible and copay. Is this correct?

ANSWER: Unfortunately, yes. Health plans, specifically

high-deductible plans offered by self-insured employer groups, have implemented one of two programs designed to drive savings by ensuring that patients personally share in the cost of healthcare. The programs are often called either an "Accumulator Adjustment Program" or a "Copay Maximum Allowance Program."

QUESTION: Why were these programs implemented?

ANSWER: The PBMs argue that a patient who has no "skin in the game" will potentially choose higher-cost drugs and get unnecessary tests, procedures, and labs. PBMs also worry that a manufacturer's copay assistance programs can be used to incentivize patients to choose non-preferred drugs (such as the manufacturer's) without considering cost, because the patients' out-of-pocket cost would be zero.

QUESTION: But this means that our costs are higher, or that we may not be able to get the drug we want or need. What is NHF's position on these programs, and what is it doing to help patients?

ANSWER: NHF sees the value of using cost reduction programs or other mechanisms aimed at lowering payer costs only when generic alternatives are available or the medications are considered low value (not necessary). NHF strongly feels that adopting these programs for patients who use high-cost or high-value (lifesaving) drugs with no generic alternatives, and who have high-deductible plans, have the reverse effect—leading to increased costs for both patients and payers.

NHF is partnering with National Alliance of Healthcare Purchaser Coalitions, a national nonprofit 501(c)(6) that is a membership organization of purchaser-led healthcare coalitions (self-insured employer groups or institutions), to produce and deliver a webinar to its member agencies including self-insured employer groups. The webinar will explain the unintended consequences that cost reduction programs may have on people affected by chronic conditions requiring high-cost, specialty therapies with no generic alternatives.

HAPPY HOLIDAYS FROM ALL OF US!



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Follow us on Twitter! [@NVHemophilia](https://twitter.com/NVHemophilia)

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Want to Learn More?

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CONTACT

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LOCATIONS

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2904 W. Horizon Pkwy, Ste. 200.
Henderson, NV 89052
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The National Hemophilia Foundation is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. "Coming together is a beginning. Keeping together is progress. Working together is success."

Register for Events on NHF Nevada's Website

Our website is updated often and gives you the ability to register for programs and events! It is mobile friendly too! Check it out at www.hfnv.org.

Our website 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.

Articles in this Newsletter

provided by the following websites!

www.hemophilia.org

betteryouknow.org

stepsforliving.hemophilia.org

hemaware.org



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders



STEPS TO LIVING
Education for all life stages.

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Nevada Chapter
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*Silent Auction items
needed!*

Are you a local business, restaurant, artist, or individual who has something awesome you want to share? We are accepting silent auction donations for our annual Winter Wine Fest event, now through

January 31st. Got stuff? Email us!

cbettis@hemophilia.org.