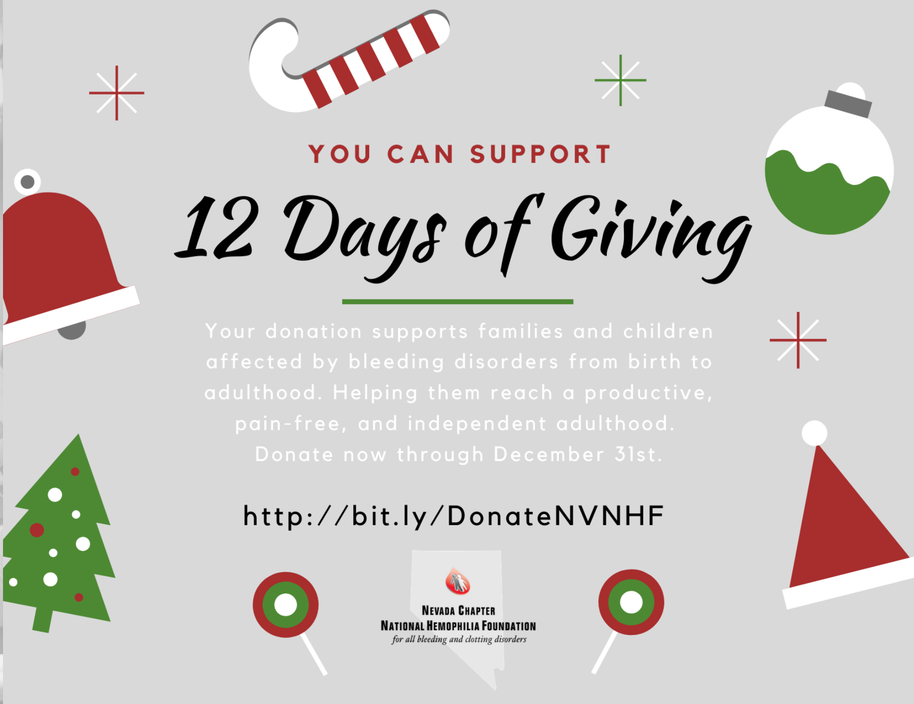
Nevada Chapter Newsletter

Winter 2019

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org



YOU CAN SUPPORT

12 Days of Giving

Your donation supports families and children affected by bleeding disorders from birth to adulthood. Helping them reach a productive, pain-free, and independent adulthood. Donate now through December 31st.

http://bit.ly/DonateNVNHF

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

Hemophilia News & Views

Mission

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

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."

Contact Us

Nevada Chapter of the National Hemophilia Foundation
222 S. Rainbow Blvd. Suite 203, Las Vegas, NV 89145 I Phone: 702-564-4368 I Fax: 702-446-8134 I www.hfnv.org

Our Team

Betsy VanDeusen
Executive Director
Phone: 702-564-4368 x100
bvandeusen@hemophilia.org

Maureen Magana-Salazar
Chapter Bilingual Program Manager
Phone: 702-564-4368 x101
mmagana@hemophilia.org

Kaley Dingeman
Development Manager
Phone: 702-564-4368 x 102
kdingeman@hemophilia.org

Board of Directors

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Kayla Faase, Communications Intern & Contributing Editor

SWIRL. SIP. BID. REPEAT!

WINTER WINE FEST

Wine Tasting. Wine Pull. Silent Auction.

Friday, February 7th – 6 pm
Brio Tuscan Grille Town Square

Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

RSVP: http://bit.ly/WinterWineFest2020

Benefitting Families and Children with Bleeding Disorders

TICKETS ON SALE NOW!

General Admission Tickets:

$35 in Advance

$40 at the door

Includes two hours of tasting a variety of wines and appetizers on the heated patio at Brio Town Square.

VIP Experience Tickets: $75

Includes early entrance to the event at 6 pm, access to premium wines and high-end hors o'doeuvres in the VIP Tasting Room, custom Winter Wine Fest wine glass and two raffle entries.
Limited to 30 tickets.

Letter from Our Executive Director / Mensaje de nuestra Directora Ejecutiva

Dear Friends,

I want to extend a heartfelt thank you to everyone who made 2019 a success. We have a had a year of constant changes, new challenges, and amazing success stories.

The resilience, perseverance and dedication of our Nevada bleeding disorders community continues to inspire me to find new ways to meet our mission of finding the highest quality of care and quality of life through peer support, education, and advocacy for those affected by bleeding disorders.

Watching a community of support grow for the bleeding disorders is amazing – as new donors, supporters and volunteers join our dedicated community of supporters to make a difference every day.

Thank you. It is through your support that we are able to look forward to 2020 with a sense of possibility as we work to make positive change for the bleeding disorders community.

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

- Improved access to care by advocating for less barriers to accessing care and treatments
- Held 35 events offering over 180 hours of educational programing and 49 hours of peer support and community building programming
- Helped 32 families when they needed it most with emergency financial assistance

I have one final request for 2019. **Will you make a brighter future possible by making a year-end gift?** Your donation supports people affected by bleeding disorders from <u>birth to adulthood</u> – helping them reach a <u>productive, pain-free, and independent future</u>. Please donate now through December 31 to make a brighter future possible!

With warmest regards and heartfelt thanks,

Betsy VanDeusen
Executive Director

Queridos amigos,

Quiero extender mi sincero agradecimiento a todos los que hicieron del 2019 un éxito. Hemos tenido un año con muchos cambios, nuevos desafíos e increíbles historias de éxito.

La adaptabilidad, la perseverancia y la dedicación de nuestra comunidad de trastornos de la coagulación de Nevada continúan inspirándome a encontrar nuevas formas de cumplir con nuestra misión de encontrar la más alta calidad de atención médica y calidad de vida a través del apoyo de la comunidad, la educación y la abogacía para los afectados.

Ver a una comunidad de apoyo crecer para los trastornos de la coagulación es increíble, con nuevos donantes, colaboradores y voluntarios uniéndose a nuestra comunidad dedicada de colaboradores para marcar la diferencia cada día.

Gracias. Es por su apoyo que podemos esperar el 2020 con un sentido de esperanza mientras trabajamos para lograr un cambio positivo para la comunidad de trastornos de la coagulación.

Estos son solo algunos de los puntos destacados de este año que usted ayudó a lograr:

- Mejoramos el acceso al cuidado médico por abogacía para tener más acceso a cuidado y tratamientos
- Celebramos 35 eventos ofreciendo más de 180 horas de programación educativa y actividades de fortalecimiento comunitario.
- Ayudamos a 32 familias cuando más lo necesitaban con asistencia financiera de emergencia

Tengo una última solicitud para el 2019. **¿Podrías hacer el futuro más brillante al hacer un regalo de fin de año?** Su donación apoya a las personas afectadas por trastornos hemorrágicos desde el nacimiento hasta la edad adulta, ayudándoles a alcanzar un futuro <u>productivo, sin dolor e independiente</u>. ¡Done ahora hasta el 31 de diciembre para hacer posible un futuro más brillante!

Con un cordial saludo y un sincero agradecimiento,

Betsy VanDeusen
Directora ejecutiva

2020 Calendar of Events

CALENDAR OF EVENTS

1/16	Hispanic Meet-Up, LV
1/18	Genentech Dinner, LV
2/7	Winter Wine Fest, LV
2/19	Genentech Dinner, Reno
2/20	Ladies Night Out, LV
2/22	Family Community Event, LV
2/26-28	Washington Days, DC
3/7	Sanofi Dinner, LV
3/21	Leaders In Training, LV
3/28	Spring Education Fest, LV
4/16	Bayer Dinner, LV
4/17	World Hemophilia Day, LV
4/25	Latinos Unidos Luncheon, LV
5/2	Golf Gets In Your Blood, LV
5/13	Takeda Dinner, Reno
5/16	Outdoor Family Event, LV
5/21	Ladies Night Out, LV
6/8-13	Camp Independent Firefly, CA
6/20	Play Group: Children's Museum, LV
6/27-28	Couple's Retreat, LV
7/11-15	Teen Camp, CA
7/16	Hispanic Meet-Up, LV
7/24	Leaders In Training, Elko
7/24-25	NNV Family Conference, Elko
7/25	Elko Unite For Bleeding Disorders Walk
8/1	Renee Paper Picnic, LV
8/5-8	Nat'l Bleeding Disorders Conference, Atlanta
8/20	Mother/Daughter Night Out, LV
8/22	Tahoe Family Day, Tahoe
8/29	Bayer Dinner, LV
9/9	Education Dinner, Reno
9/12	Reno Unite For Bleeding Disorders Walk
9/18-20	Familia De Sangre, CA
9/26	Las Vegas Unite For Bleeding Disorders Walk
10/5	Education Dinner, Elko
10/29	Trunk or Treat, LV
11/7	Takeda Dinner, LV
11/11	Ely Holiday Event, Ely
11/19	Father/Son Night Out, LV
11/21	Bikes In Your Blood, Henderson
12/5	Annual Meeting, LV
12/9	Elko Holiday Event, Elko
12/10	Reno Holiday Event, Reno

IMPORTANT DEADLINES

2/28	Junior Counselor Applications Due
3/31	Camper Applications Due
4/15	Teen Camp Applications Due
5/30	Travel Grant Requests for National Bleeding Disorders Conference Due
6/30	Travel Grant Requests for Familia De Sangre Due

This is a DRAFT Calendar. Dates & topics subject to change. Please check the Chapter website at www.hfnv.org and request an updated calendar periodically.

Young Adults and Insurance

Considerations When Deciding on a Health Coverage Plan

For more information, visit b2byourvoice.com to download *Young Adults and Hemophilia B.*

This content is brought to you by Pfizer.

For young adults with hemophilia, having insurance is a crucial step in becoming independent; the annual costs of treating hemophilia can make access to health care coverage a necessity.[1] Appropriate health insurance can be provided through an employer and is an important factor to consider during a job search, but there are other options to explore for purchasing insurance outside of employment as well.

Timing can be key: There may be a waiting period before a recently hired employee is covered under a new policy, or there may be open-enrollment dates to keep in mind for other health insurance options.

Questions to Ask About Health Insurance Plans

When deciding on a health care plan, here are some of the important points to consider, as well as the definitions of some key terms in understanding health insurance.

What are the plan's exclusions and/or limitations? *Exclusions are health care services for which your health insurance or plan doesn't pay.*[2]

Is clotting factor covered?

Does the plan offer product choices for clotting factor?

Does the plan cover visits to your primary care provider and your hemophilia treatment center?

Are referrals required, and if so, for which services? *A referral is a written order from your primary care doctor for you to see a specialist or get certain medical services.*[2]

Is there a lifetime or yearly limit or cap? *A limit or cap is the maximum benefit paid by the insurer; some insurance companies have caps on certain costs.*

What are out-of-pocket costs for the in-network providers versus the out-of-network providers? *Out-of-pocket costs are your expenses for medical care that aren't reimbursed by insurance. Out-of-pocket costs include deductibles, coinsurance, and co-pays for covered services, plus all costs for services that aren't covered.*[2]

What is the annual deductible for in-network providers versus out-of-network providers? *A deductible is the amount you pay for covered health care services before your insurance plan starts to pay.*[2]

How much is the monthly premium? *A premium is the amount paid for the insurance coverage.*[2]

> "It is important for [young adults], especially those with a chronic condition, to realize the necessity of having health insurance, as well as knowing what it takes to maintain that insurance."
>
> — Joy Mahurin
>
> Reimbursement Specialist

Maintaining Health Insurance

People living with hemophilia should keep in mind the potential for a lapse or gap in health insurance. In most cases, young adults may stay on their parents' policies until age 26.[3] However, it's important to be aware of the potential for a lapse in coverage after age 26 and prior to having a policy of one's own through an employer or the Health Insurance Marketplace. One option to retain medical coverage is Consolidated Omnibus Budget Reconciliation Act (COBRA) coverage. Other options may be state-sponsored individual Health Insurance Portability and Accountability Act (HIPAA) insurance plans and even Medicaid (for those who are disabled or who meet income requirements). In addition, for those who struggle to keep up with health care costs, some National Hemophilia Foundation (NHF) chapters have programs that can assist with paying deductibles, co-pays, and premiums.

References: **1.** Chen SL. Economic costs of hemophilia and the impact of prophylactic treatment on patient management. *Am J Manag Care.* 2016;22(suppl 5):S126-S133. **2.** US Centers for Medicare & Medicaid Services. Glossary. Healthcare.gov Web site. https://www.healthcare.gov/glossary/. Accessed March 28, 2019. **3.** US Department of Health & Human Services. Young adult coverage. HHS.gov Web site. https://www.hhs.gov/healthcare/about-the-aca/young-adult-coverage/index.html. Accessed March 28, 2019.

PATIENT AFFAIRS LIAISONS

Patient Affairs Liaisons are Pfizer hemophilia employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to hemophiliavillage.com/support/patient-affairs-liaison-finder or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).

Community Spotlight: The Hendrickson Family

Life with A Bleeding Disorder: A Look into The Hendrickson Family

By Kayla Faasse

Bleeding disorders are a group of conditions that result when the blood cannot clot properly. There are different types of bleeding disorders, but the two most common ones include Hemophilia and Von Willebrand's Disease. With these kinds of diseases, you are very lucky if you can know about it from a young age because the sooner the better.

Jillian Hendrickson was one of those lucky people who knew she had Von Willebrand's disease when she was a kid. The Nevada Chapter of the National Hemophilia Foundation is the first organization that the Hendrickson family has truly been involved with and "it has been life changing."

What kinds of obstacles do you face daily?

Jillian: "The challenges of going to school and work and having issues with nosebleeds and bruises. We have to take medication all the time for that and I have to take infusions one to three times a week."

What are your concerns with your son being at school?

Jillian: "At school a lot of people disregard it and it's just not taken seriously. The HTC center is actually going to his school to do a skills and education session with the nursing staff, principal, and all the staff members so that they can take better care of Parker and any other child with bleeding issues. Everything is treated a little differently with him."

How does it impact each of you differently? What are your different perspectives on it?

Parker: "When people bump into me or I hit the wall, I can get bruises from that and it's really unfortunate, but I heal. In PE sometimes I don't want to participate because I feel like it's too rough for me, like flag football or any games that involve contact. I often don't want to play those but they kind of force me to because it's mandatory and school rules. If I get hit or something or it's related to my Von Willebrand Disease I must sit out. I don't feel left out when I sit out, because I'm used to it. At least I can see what's happening, I'm not just stuck in a room and I get some fresh air."

The Nevada Chapter of the National Hemophilia Foundation is the first organization the Hendrickson family has truly been involved with and "it has been life changing."

Jillian: "Some of my biggest challenges are with work. Not only do I have a severe bleeding disorder, but I am a mother of someone who has a bleeding disorder. My genetic testing revealed that I have three different types of Von Willebrand's—which is extremely rare. Often people don't understand the severity of it and tend to brush it off. Explaining that even though I look fine, I have a very severe disorder is the hardest thing. It's hard to explain to my boss that I must leave for my son or for myself to take medication or go and get factor treatments. I have to maintain a full-time job and still be chronically sick."

Robert: "When I first met them, I didn't really understand the severity of it, but now I'm learning from the HTC and the Chapter. I've learned so much about it in this little time we've been here, and I feel bad for them all the time. I wish I could take it away and I could have it because it just stinks. I'm trying to voice it and get the word out. I'm trying to know more about it so I can help them in emergency situations. This is no joke from what I've been learning."


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99%
Patient
Satisfaction
Survey Data
Based on 2017 patient satisfaction survey

Bikes In Your Blood

Bikes In Your Blood raises $14,000!

Over 70 cyclists came together for a beautiful day on the River Mountain Loop to raise money for bleeding disorders! Ten teams competed for the top fundraising spot with The Infusions Pharmacy raising the most and Nevada Bicycle Club coming in 2nd.

Thank you to our sponsors, committee, donors, cyclists, volunteers and team captains who made Bikes In Your Blood a big success!

Bikes In Your Blood Funds raised could:

- Send 23 kids to Camp Independent Firefly
- Provide 28 families with financial assistance when they need it most
- Provide a year of educational programming, peer support, and skill development to 70 individuals affected by bleeding disorders.

Thank you to our Sponsors:

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Antihemophilic Factor (Recombinant)

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Demonstrated to control and prevent bleeds—
XYNTHA SOLOFUSE helps prepare you to live actively

Preparation with all-in-one reconstitution—

Prefilled with XYNTHA and diluent, XYNTHA SOLOFUSE eliminates the transfer step and vials for all-in-one reconstitution

Visit XYNTHA.com for instructions on using XYNTHA SOLOFUSE

What is XYNTHA?

XYNTHA® Antihemophilic Factor (Recombinant) is indicated in adults and children for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for the prevention of bleeding during surgery in patients with hemophilia A.

XYNTHA does not contain von Willebrand factor and, therefore, is not indicated for von Willebrand's disease.

Important Safety Information for XYNTHA

- Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction: wheezing, difficulty breathing, chest tightness, turning blue (look at lips and gums), fast heartbeat, swelling of the face, faintness, rash, low blood pressure, or hives. XYNTHA contains trace amounts of hamster protein. You may develop an allergic reaction to these proteins. Tell your healthcare provider if you have had an allergic reaction to hamster protein
- 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
- Across all clinical studies, the most common side effects (10% or more) with XYNTHA in adult and pediatric previously treated patients (PTPs) were headache (26% of subjects), joint pain (25%), fever (21%), and cough (11%). Other side effects reported in 5% or more of patients were: diarrhea, vomiting, weakness, and nausea
- 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 the Brief Summary for XYNTHA and XYNTHA SOLOFUSE on the next page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Pfizer

xyntha®　　xyntha® solofuse®

Antihemophilic Factor (Recombinant)　　Antihemophilic Factor (Recombinant)

Rx only

Brief Summary

See package insert for full Prescribing Information, including patient labeling. For further product information and current patient labeling, please visit XYNTHA.com or call Pfizer Inc toll-free at 1-800-438-1985.

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

What is XYNTHA?

XYNTHA is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia A. Hemophilia A is also called classic hemophilia. Your healthcare provider may give you XYNTHA when you have surgery.

XYNTHA is not used to treat von Willebrand's disease.

What should I tell my healthcare provider before using XYNTHA?

Tell your healthcare provider about all your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if XYNTHA may harm your unborn baby.
- are breastfeeding. It is not known if XYNTHA passes into your milk and if it can harm your baby.

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

How should I infuse XYNTHA?

Step-by-step instructions for infusing with XYNTHA are provided at the end of the complete Patient Information leaflet. The steps listed below are general guidelines for using XYNTHA. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedures, please call your healthcare provider before using.

Call your healthcare provider right away if bleeding is not controlled after using XYNTHA. Your body can also make antibodies against XYNTHA (called "inhibitors") that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests from time to time to monitor for inhibitors.

Call your healthcare provider right away if you take more than the dose you should take.

Talk to your healthcare provider before traveling. Plan to bring enough XYNTHA for your treatment during this time.

What are the possible side effects of XYNTHA?

Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction:

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

Common side effects of XYNTHA are

- headache
- fever
- nausea
- vomiting
- diarrhea
- weakness

Talk to your healthcare provider about any side effect that bothers you or that does not go away. You may report side effects to FDA at 1-800-FDA-1088.

How should I store XYNTHA?

Do not freeze.

Protect from light.

XYNTHA Vials

Store XYNTHA in the refrigerator at 36° to 46°F (2° to 8°C). Store the diluent syringe at 36° to 77°F (2° to 25°C).

XYNTHA can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA at room temperature, carefully write down the date you put XYNTHA at room temperature, so you will know when to either put it back in the refrigerator, use it immediately, or throw it away. There is a space on the carton for you to write the date.

If stored at room temperature, XYNTHA can be returned one time to the refrigerator until the expiration date. Do not store at room temperature and return it to the refrigerator more than once. Throw away any unused XYNTHA after the expiration date.

Infuse XYNTHA within 3 hours of reconstitution. You can keep the reconstituted solution at room temperature before infusion, but if you have not used it in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

XYNTHA SOLOFUSE

Store in the refrigerator at 36° to 46°F (2° to 8°C).

XYNTHA SOLOFUSE can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA SOLOFUSE at room temperature, carefully write down the date you put XYNTHA SOLOFUSE at room temperature, so you will know when to throw it away. There is a space on the carton for you to write the date.

Throw away any unused XYNTHA SOLOFUSE after the expiration date.

Infuse within 3 hours after reconstitution or after removal of the grey rubber tip cap from the prefilled dual-chamber syringe. You can keep the reconstituted solution at room temperature before infusion, but if it is not used in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

What else should I know about XYNTHA?

Medicines are sometimes prescribed for purposes other than those listed here. Talk to your healthcare provider if you have any concerns. You can ask your healthcare provider for information about XYNTHA that was written for healthcare professionals.

Do not share XYNTHA with other people, even if they have the same symptoms that you have.

This brief summary is based on the XYNTHA® [Antihemophilic Factor (Recombinant)] Prescribing Information LAB-0516-5.0, revised 10/14, and XYNTHA® SOLOFUSE® [Antihemophilic Factor (Recombinant)] LAB-0500-9.0, revised 10/14.

PP-XYN-USA-0290　　　　Printed in USA/August 2018　　Pfizer U.S. Pharmaceuticals

Program Recap: Fall Events

October 2-5: Bleeding Disorders Conference
Anaheim, CA
2,590 community members came together for the 71st annual meeting of a three-day conference filled with educational sessions, networking opportunities and access to the Exhibit Hall. Children under 12 years old enjoyed a fun Kids Program which included numerous fun and interactive activities.

October 11: Teen Leadership Council Meeting, Las Vegas, NV
7 teen community members attended the first ever Teen Council meeting where they came together to discuss future events for the community. The Teen Leadership Council was formed to help connect teens in the community in a fun learning environment giving teens the opportunity to plan events themselves while managing a budget.

October 12-13: Women's Retreat, Reno, NV
13 women came together for an incredible weekend of reflection, relaxation, and sharing. The program was designed to further the understanding of bleeding disorders, live positivity, and develop a support network.
Sponsored by HTCNV, Octapharma, Aptevo and Factor Support Network

October 19: Product Round Robin Dinner, Las Vegas, NV
48 community members attended a product dinner to learn about available products to treat bleeding disorders. This event included networking with exhibits along with a dinner and dessert.
Sponsored by Bayer, HTCNV, Octapharma, Aptevo, CSL Behring, Takeda, Sanofi Genzyme, Genentech

October 25: Teen Leadership Council Hike, Las Vegas, NV
5 Teen Council members got together to test out a hiking path open for all teens. The hike provided a bonding experience for the members as they learned more about each other and themselves through various hiking activities.

November 6: Sanofi Dinner, Reno, NV
16 community members attended an educational dinner to help navigate through the insurance landscape of the bleeding community. They discussed the different types of insurance plans as well as define important terminology that will help to evaluate the options.
Sponsored by Sanofi Genzyme

Bleeding Disorders Conference, October 2019, Anaheim, CA

Women's Retreat, October 2019, Reno

Teen Council Test Hike, October 2019, Las Vegas

Program Recap: Fall Events

November 6: Takeda Dinner, Las Vegas, NV

25 community members attended a product dinner for a better understanding of Von Willebrand's Disease. The program provided an educational format to introduce the symptoms and types of Von Willebrand's Disease, recognize potential treatment options, and learn how emotional and community support systems can help those living with this bleeding disorder.
Sponsored by Takeda

Teen Adulting Dinner, November 2019, Las Vegas

November 15: Teen Adulting Dinner, Las Vegas, NV
11 community members attended an educational dinner targeted for teens in the community designed to teach teens good tips that follow becoming an adult. The teens were first tested on their table etiquette which lead to their dinner of salad and spaghetti. Afterwards they enjoyed a fun game of life in order to learn how to budget money and pick a good insurance company

Community Spotlight: Johnathan Cervantes

The Life of a Teen Athlete with A Bleeding Disorder

By Kayla Faasse

Johnathan Cervantes is a fourteen-year-old boy who has been passionately enjoying playing baseball for the past five years. He's going into his sixth season playing on his school's baseball team. As much as he loves playing baseball, he has his limits when it comes to playing the sport. Cervantes has learned how to balance not only being a student-athlete but being a student-athlete with a bleeding disorder, something that comes as a challenge for many people.

What is it like living with/ growing up with a bleeding disorder while also balancing being a young athlete?
It's hard sometimes because of my bleeding disorder, I can't really do as much as most of my friends, so I need to stay back. Having a bleeding disorder while playing sports is tough because sometimes, they don't want me to play because they think I might get hurt or they just put me on the outside of games. I still like playing sports because it helps strengthen my muscles and it gives me more energy to play more.

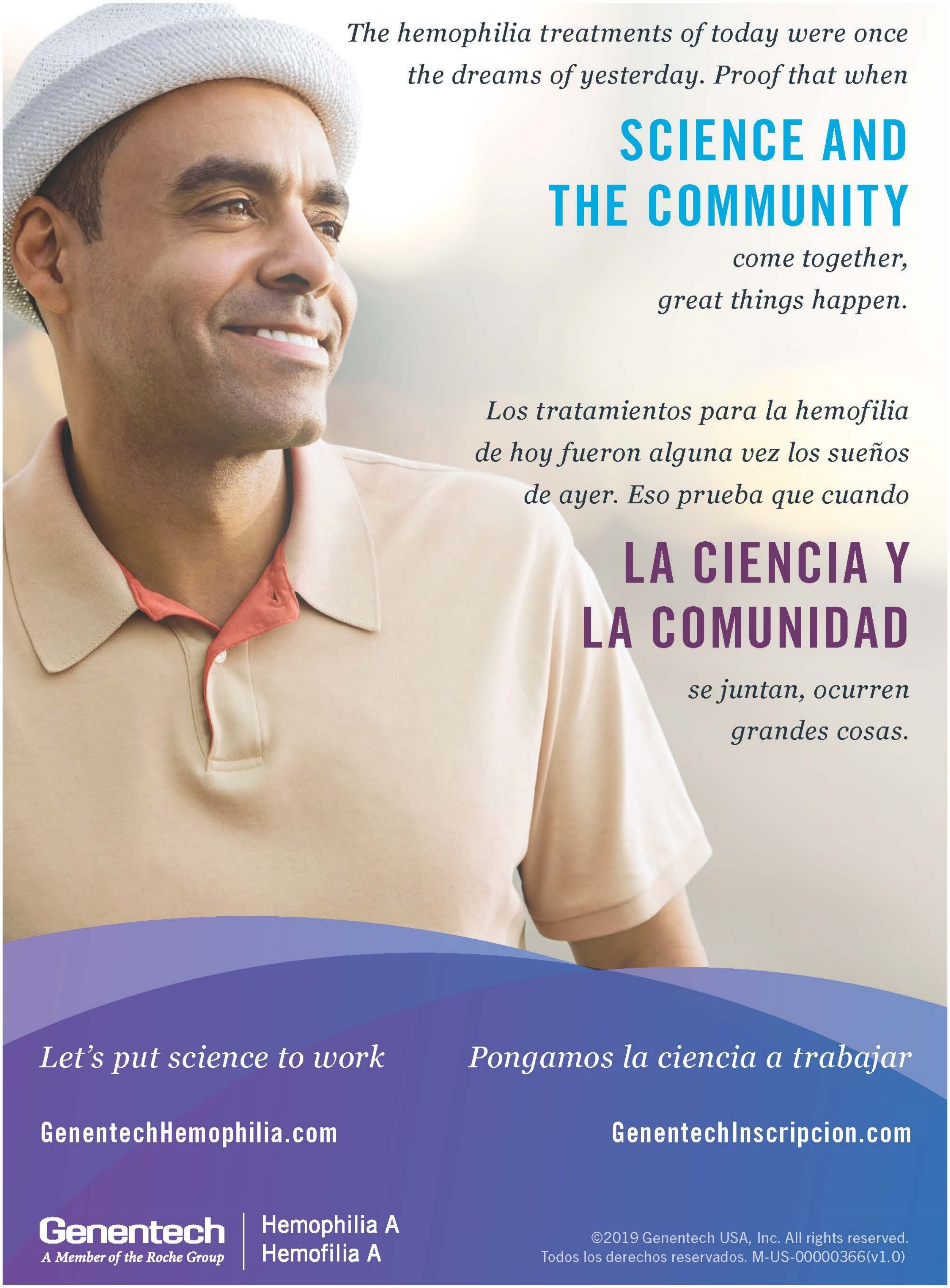
What is it like being a part of a sports team while having a bleeding disorder? What restrictions are given to you while being on the team?
It's tough when the coaches don't want me getting hurt and won't play me or they'll put me all the way out away from where the action is happening. Sometimes they'll make me go last for hitting so I'll hardly get the chance to hit.

They tell me not to run for it when it passes someone else or that I need to be in a certain spot, so I don't get hit. know my restrictions and what I need to do, but it can feel unfair that I can't do as much as my teammates. I'm often watching all my teammates playing up close while I'm stuck in the back. I really think I can be safe by myself, but I understand they want to protect me too. Sometimes it can be hard to see my whole team out there doing more than me and it can feel like they are having more fun.

What's your favorite thing about playing the sport?
Playing baseball is fun because it allows me to be active and for me to just have a blast. It allows me to do a lot of things I can't do at home. I continue playing baseball because it's so much more than playing a sport. It's the bonds you create with your teammates and the friendships you get out of it. Yeah for someone like me it can be dangerous, but it's up to you to be responsible enough to know your own limits. I keep playing because it's something I want to do and I'm passionate about, but with the knowing it can seriously injure me it forces me to be more aware of my own safety, so I don't get seriously hurt.

What is your perspective of your bleeding disorder? Do you see it as a part of yourself?
I really do think it's a part of me. My bleeding disorder is like a living thing in me and it is something that can hurt me when something happens but really, it's something that makes me more aware of myself and my own safety. It's something that alerts me.

Johnathan (Far Left) is pictured leading younger children affected by bleeding disorders at the Northern Nevada Family Conference in July 2019. Johnathan served as a Leader In Training.



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Annual Meeting & Holiday Parties

November 20, 2019—Ely
December 7, 2019—Las Vegas
December 11, 2019—Elko
December 12, 2019—Reno

All across Nevada, over 275 community members learned about living with a bleeding disorder and enjoyed the company of their bleeding disorder family at the year end gatherings and celebrations.

Creación de lineamientos para el ejercicio profesional en la VWD

Una colaboración global que busca mejorar el diagnóstico y el control de la enfermedad de von Willebrand (von Willebrand disease, VWD)

La Fundación Nacional de Hemofilia (National Hemophilia Foundation, NHF) colaborará con la Sociedad Americana de Hemofilia (American Society of Hematology, ASH), la Sociedad Internacional de Trombosis y Hemostasia (International Society on Thrombosis and Haemostasis, ISTH), la Federación Mundial de Hemofilia (World Federation of Hemophilia, WFH) y el centro médico de la Universidad de Kansas para desarrollar lineamientos para el ejercicio profesional en el diagnóstico y control de la enfermedad de von Willebrand (WVD).

“Esta colaboración tiene el potencial de ser de gran influencia para nuestra comunidad”, señala Val D. Bias, CEO de la NHF. “Este esfuerzo colectivo brindará mucha información necesaria a los profesionales médicos y jugará un rol importante para mejorar resultados que son vitales para la salud de nuestras familias. El entusiasmo de muchas partes interesadas en formar parte del proyecto de lineamientos revela mucho sobre el potencial de esta iniciativa”.

El propósito de este esfuerzo es crear y mantener lineamientos de vanguardia sobre la VWD. Dos comités de expertos elaborarán recomendaciones para el diagnóstico y el control de la condición. Los comités constan de 20 personas, incluidos hematólogos internacionales y de Estados Unidos, pacientes con la VWD y científicos con experiencia en síntesis y evaluación de evidencias, y en metodología de desarrollo de lineamientos.

Los miembros del comité identificarán y darán prioridad a las preguntas sobre los lineamientos con base en la frecuencia en la que surge una pregunta en el ejercicio profesional, el grado de variación del ejercicio profesional, la medida en la cual la pregunta ya se abordara por los lineamientos de alta calidad y las implicaciones de la utilización de recursos. Al formular las preguntas, el comité también dará importancia a las áreas donde los lineamientos podrían mejorar los resultados de la salud y la atención importantes para los pacientes con la VWD y sus cuidadores.

La mayoría de los participantes en el desarrollo de los lineamientos no tiene intereses financieros directos en las compañías con productos que se verán potencialmente afectados por los lineamientos. Además, las organizaciones patrocinadoras financian por completo el desarrollo de estos lineamientos.

OUR GOAL IN CARING FOR PATIENTS WITH BLEEDING DISORDERS IS MORE THAN PROVIDING FACTOR AND SUPPLIES.

We provide drug utilization management, patient education and patient services that promote adherence to therapies which result in improved outcomes.

ASP CARES

JUDY PADILLA | PATIENT ADVOCATE
jpadilla@aspcares.com | (702)292- 5760

ASPCares.com

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- EDUCATION & AWARENESS
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(225)302-8036 | (225)412-0142 FAX

LifeCare Rx
SPECIALTY PHARMACY
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LAS VEGAS, NEVADA 89121
PHONE (702) 697-2105
FAX (702) 697-2107

LifeCare Specialty Pharmacy specializes in dispensing medications used for the treatment of hemophilia at home and other types of bleeding disorders

We deliver our patients care in accordance with pharmaceutical manufacturers, health Insurance plan carriers, physicians, and payers. At LifeCare Specialty Pharmacy, our team is educated and knowledgeable about hemophilia, bleeding disorders and their concomitant therapies at the comfort of the client's home.

LifeCare Specialty Pharmacy Team is dedicated to maintaining long-term relationships with our customers through our mainstream values and mission that every patient is a family and hope has no limits….

Our Target………

- Keeping You Out of the Hospital is Our Main Priority: We arrange skilled nursing with nurses that are experienced in treatment and wound management of our client bleeding disorder.
- Customized Medication & Supply Delivery: We dispense and ship home infusion therapies to your home and customize the order to your specialty needs.
- We are continuously reaching out to our patients with information, research and support with social media.
- Our community liaisons sponsor exercise events for the entire family that promote healthy activities and bonding opportunities.
- We are continually involved in our teens and young adults with bleeding disorders

ADVERTISEMENT

2019 Quarter Three In Review

Check out the impact your support is making in the Nevada bleeding disorders community:

Q3 2019 Fundraising:

Unite For Bleeding Disorders Walks —

$70,000

Supporting all programs and services!

NHFNV Programs —Q3 2019

Our mission is to improve the quality of care and quality of life for those living with inherited bleeding disorders through peer support, education and advocacy.

19 Peer Support & Community Building Hours

100 Education & Program Hours

447 Individuals Served

13 Events Offered

Communications Q3 2019:

www.hfnv.org

Average of **747** unique visitors per month.

Social Media

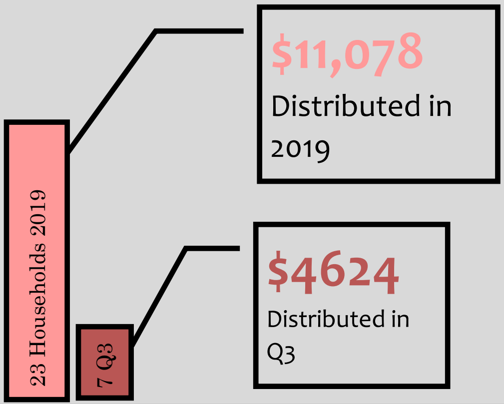
1944 followers

- Facebook—821
- Instagram—414
- Twitter—710

1622

Consumers in our database. Consumer is someone affected by a bleeding disorder or an immediate family member.

Financial Assistance - Q3 2019



Q2 2019 Volunteers:

140

Volunteers

699

Hours

SHARING OUR IMPACT

The Nevada Chapter offers programs, services, education, and support to the Nevada bleeding disorders community. We take our mission seriously and think it's important to be transparent on our progress. This section of the Newsletter offers you insight into our progress and accomplishments. It is our hope that our readers will be inspired to action by these updates—whether that be to reach out to help us where we may be falling short, or celebrate our accomplishments when we deliver!

The chapter is only as strong as its community—we look forward to your partnership to help us continue to pursue the highest quality of life and quality of care for every member of our bleeding disorders community.

National Hemophilia Foundation
Nevada Chapter
222 S. Rainbow Blvd Suite 203
Las Vegas, NV 89145

Phone: 702-564-4368
Fax: 702-446-8134
www.hfnv.org

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ACT—Access to Care Today
Achieve a CURE Tomorrow

JUNE 9-13, 2020

CAMP INDEPENDENT FIREFLY

Camp Independent Firefly is a 5-day 4-night sleep over camp for youth 7 thru 17* years of age. Campers must be 7 years old by June 9th, 2020. Activities will include horseback riding, swimming, arts & crafts and a rock wall, along with other fun activities.

*If you are 17 and interested in the Junior Counselor Training Program, you need to fill out a **volunteer** application by February 22nd, 2020.

APPLY ONLINE ONLY
Starting February 1, 2020
Deadline is March 31st

Go to hfnv.org
News & Events/Event Calendar for application link

Space is limited.
You will be notified if your camper is accepted no later than April 19th.

JULY 11-15, 2020

TEEN RAFTING CAMP

Teen Camp is a 4 day, 3 night camping and rafting trip for teens age 14-18. Campers must be 14 by July 11th. Campers will sleep in tents, make their own food, and white water raft & kayak.

APPLY ONLINE ONLY
Starting February 15th, 2020
Deadline April 15th, 2020

Go to hfnv.org News & Events/Event Calendar for application link.

Space is limited. You will be notified if your camper is accepted no later than April 19th.