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EXECUTIVE CORNER

Dear Friends,

Children need a father in their life, and with children with a bleeding disorder, it is even more important! Teaching lessons of responsibility, supporting a child in all they do and setting an example of what a male role model should be are all important.

When we started infusions, my wife took the lead, but I recall the day it occurred to me during a drive to work: if something happened to my wife and she was unable to infuse, what would we do? How could I expect my young daughter to infuse on her own and take responsibility, if I shied away from my responsibility as a father? We continue to split the duties of infusions, appointments and everything else that comes along with having a bleeding disorder.

I feel a big part of my job is to keep my children safe and managing their healthcare is part of that role. Heather and I encourage our children to be active — to see the benefits of teamwork — but more importantly teach the importance of being active.

Through Kinzie’s activities we have been able to teach important lessons about caring for her bleeding disorder. Not infusing can prevent her from doing what she loves and may affect others at times, such as teammates or others counting on her. I am lucky enough to help coach my children, as much as my schedule allows, which has presented more opportunities to teach them.

Josh Hemann
Board Chair

Above: Board Chair Josh Hemann with his family aboard the U.S.S. Midway at this year’s Symposium in San Diego.
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ON THE COVER.
Former HFA Board Member, Mickey Price, of California poses with his two girls at this year’s Symposium in San Diego.
**Pilot Program Aims to Improve Infusion Tracking**

The National Hemophilia Foundation has announced a two-year pilot program aimed at improving the efficacy of patient infusion logs and reporting through a partnership with Audaire Health Inc., specialty pharmacies and hemophilia treatment centers.

Audaire Health is providing an easy-to-use data tracking tool that can instantly record infusions, bleeds and other adverse effects to the patient’s care team and specialty pharmacy. NHF hopes the program will show the benefit of not only patient adherence, but the cost savings associated with an integrated data system that operates at multiple touchpoints along the patient’s care. NHF will present initial findings of the program this fall.

**TV Series Addresses Tainted Blood Scandal**

The Canadian Broadcasting Corporation launched “Unspeakable,” a TV series which tells the true story through the eyes of two families caught in the tainted blood scandal of the 1980s. The series follows an incredible, decades-long saga with people struggling to survive, find compensation and deal with bureaucracy.

“Unspeakable” is based on emotionally-charged personal accounts as well as Andre Picard’s “Gift of Death: Confronting Canada’s Tainted Blood Tragedy,” Vic Parson’s “Bad Blood: The Tragedy of the Canadian Tainted Blood Scandal,” and the Royal Commission of Inquiry into the Canadian Blood Tragedy lead by Justice Horace Krever.

Binge watch the eight-part drama at www.sundancetv.com/shows/unspeakable or www.cbc.ca/unspeakable/.

**It’s Time for Summer Sports**

Baseball, softball, soccer, golf, swimming. It’s the time of year when summer sports are in full swing! Our Sports Toolkit has great tips for making it through the season, including a printable card to provide valuable bleeding disorders information about a child for their coach. Check out bit.ly/HFASportsToolkit.

**Back to School Toolkit**

While school is over in most parts of the country, it’s never too late to prepare for going back to school in the fall. Our Back to School Toolkit features tools intended to help educate the educators and relieve some stress in sending a child back to school. Check out bit.ly/HFABacktoSchoolToolkit.
Creating the path for advancements in hemophilia gene therapy research

Spark Therapeutics has created a place for patients and caregivers TO LEARN ABOUT THE SCIENCE OF GENE THERAPY RESEARCH, which is being investigated for hemophilia.

“It is incredible to think of what a transformative advance gene therapy could be—it has been my career focus for the past two decades to solve this challenge.”

Katherine A. High, MD, president and chief scientific officer

“My career has been focused on delivering cutting-edge medical care for patients with hemophilia. I’m excited that gene therapy could potentially be brought to people I have cared deeply about for so many years.”

Leonard Valentino, MD, medical strategy lead, hematology

Spark Therapeutics has created a place for patients and caregivers TO LEARN ABOUT THE SCIENCE OF GENE THERAPY RESEARCH, which is being investigated for hemophilia.

For residents of the U.S. only
Jasmin Wyatt and Dylan Edwards are emerging leaders in the bleeding disorders community with a shared interest in public policy and passion for advocacy. This summer, they have joined Hemophilia Federation of America’s Policy, Advocacy and Government Education team for a 10-week internship at the HFA headquarters in Washington, D.C.

It is clear why they chose to apply for HFA’s summer internship. Jasmin writes “Health policy is important to me, as I believe everyone should have access to healthcare. The issue of hemophilia in health policy is especially close to my heart. My younger brother, a hilarious and energetic 11-year-old, has severe hemophilia B. He is lucky enough to have affordable and accessible healthcare, but not everyone is as privileged. I am dedicated to fighting for everyone’s right to care, and would love to do so for something so important and close to me.”

Dylan says “While writing this statement, I glimpsed the scar on my left arm from the bleeding timing test that did not diagnose my von Willebrand’s Disease. My parents, young and unconnected to our community, were clueless that most doctors preferred newer, more accurate methods to test patients for bleeding disorders. This began a 13-year journey to my diagnosis. I was integrated into the community through the Northern Ohio Hemophilia Foundation and began to grow as a community member before my diagnosis. All these years later, I have infinite reasons to be thankful for this community. I met my partner of five years at Camp Bold Eagle in Michigan, our community has introduced me to countless friends, and given my career aspirations a sense of direction.”

HFA is thrilled to welcome Dylan and Jasmin to the team. They will live and work in Washington, D.C. for 10 weeks where they will undertake a variety of projects designed to help them develop a deeper understanding of state and federal health care policy, engage in collaborative policy and advocacy activities, learn about HFA’s full spectrum of programming and services and how it serves the national bleeding disorders community, as well as improve their own skills, knowledge and abilities to further their participation in the public policy process.
Getting to Know Jasmin & Dylan

Jasmin:
★ Lives in California
★ Current undergraduate student studying Political Science
★ Volunteers with many programs, including Literacy for Life and the student ambassador program at her college
★ Serves on the executive committee of her school’s student government as Clubs Director

Dylan:
★ Lives in Ohio
★ Current graduate student studying Public Administration with a focus on public health
★ Participated in HFA’s Young Adult Advocacy Summit in fall 2018
★ Interned for Ohio Senator Sherrod Brown in D.C. during the summer in 2016

Throughout the summer, Jasmin and Dylan will chronicle their experiences in a blog on HFA’s website, titled “Intern Introspective.” Follow along and learn more about internship opportunities at www.hemophiliafed.org, search “intern.”
Advocacy work at the state level is ever-increasing in importance, as local legislatures are addressing health care issues. With the 2019 legislative season winding down more across the country, we turned to advocates from across the country to ask why participating in state advocacy days is important and about the successes achieved by the hard work of individuals and member organizations.

Celebrating Successes
A look at recent, state-level advocacy work

Texas
“We have worked with Representative Tom Oliverson over the last 2 years, and he has become a strong supporter of our community as we have talked about issues that affect our community. In 2017, he came to our state conference and talked to attendees about the importance of telling our story so it is more than just an issue — there is a face to the story when it is discussed in the legislature. This year, Representative Oliverson introduced a bill in the Texas House recognizing March as Bleeding Disorders Awareness Month in perpetuity in Texas, which passed!”
~Heidi, Texas
Heidi, pictured with Representative Oliverson, and Lone Star Chapter of the National Hemophilia Foundation Executive Director, Melissa Compton.

South Carolina
“Attending our state advocacy days is important so local legislators can see, meet, and hear the stories of their bleeding disorders community. Approaching our state lawmakers to build relationships and share our concerns with current healthcare issues is the most direct way to have our voice heard. The highlight of the day for me was right before our Lt. Gov. Pamela Evette made the state proclamation for March as Bleeding Disorders Awareness Month, she mentioned, “I’ve seen you all around the state house today.” At that moment, I realized, we have really made an impact. If our state leadership didn’t know about bleeding disorders before that, they do now.”
~Aaron, South Carolina
SC state Representative Ivory Thigpen, with Aaron and his son, Logan

South Carolina
“ Asking for a proclamation is a great way to be able to reach out and connect with your local county or city representative. I think that we are all wired to help each other out and to feel good when we do, so asking them for this is an easy way to create a win-win for everybody.”
~Amy, South Carolina
Amy, with her husband Ken at the ceremony proclaiming March as Bleeding Disorders Awareness month in her county.
**Advocacy Profile**

**Rhode Island**

"Participating in bleeding disorders advocacy at the state level was a great way to educate my local elected officials about the challenges facing the bleeding disorders community. In particular, getting to meet in-person with the governor was a very special experience, and a valuable opportunity to raise awareness about key issues such as health insurance and preexisting conditions."

~Danny, Rhode Island

Danny with Rhode Island Governor Gina Raimondo, who issued a proclamation designating March 2019 as Bleeding Disorder Awareness Month.

**New Hampshire**

"I started advocating because I thought it would be a good lesson for Seth but in the end it turns out it was a great lesson for me also. We both learned that meaningful change begins at the state level. If we don’t tell our representatives what we need they will never know."

~Cristelee, New Hampshire

John, Cristelee, and son Seth, pictured with U.S. Senator Jeanne Shaheen.

**Virginia**

"When the Virginia Hemophilia Foundation chapter had a state advocacy training day, our family knew it was time to get involved. It turned out to be an incredible experience. Our newly elected delegate, Debra Rodman, connected with our issue and we ended up becoming friends through the experience. She was part of the wave of new freshman delegates who pushed through Medicaid expansion, and brought health insurance to 400,000 more Virginians.

This last year, we watched the Step Therapy and Accumulator Adjustor protections happen at our state level. I truly believe that our hemophilia community (along with other medical advocacy groups) helped spread the awareness of how severely these policies can affect constituent’s financial security. By bringing stories behind the bills, behind the statistics, we can help our elected officials understand the importance of legislation."

~Sarahbeth, Virginia

Sarahbeth’s family poses outside the Virginia state house in Richmond, Virginia.

**North Carolina**

"I believe advocating is a wonderful thing and everyone should do it. It helps us connect with people on a personal level and to see that we are humans wanting the best for everyone."

~Joseppe, North Carolina

Joseppe’s younger brother, Jean, (left) is who inspires Joseppe at North Carolina’s legislative day.
Archive Project Will Preserve Bleeding Disorders History in National Museum

Hemophilia Federation of America believes paying tribute to and preserving the bleeding disorders community’s legacy of advocacy, sacrifice and treatment advancements is important. HFA has been preserving that history by collecting the significant stories and artifacts which best represent the community.

In March, HFA made a donation of artifacts related to the history of bleeding disorders to the Smithsonian Institution’s National Museum of American History in Washington, D.C. This donation, which consisted of items generously given by community members, is a huge step in formally preserving the history of the bleeding disorders community for future generations.

Be a Part of History

Financial Gifts
Financial gifts ensure this history is preserved into the future. Ways to donate:

- Text HFA to 243725 to receive a link to donate.
- Online at www.hemophiliafed.org/donate.
- Mail a check to Hemophilia Federation of America, 999 North Capitol Street NE Suite 201, Washington, D.C. 20002

Submit Artifacts
HFA has collected documents, articles and artifacts, but is aware there may be more memorabilia stashed in attics all across the country! We are looking for community members and organizations willing to share and work with HFA to preserve a comprehensive record of the community’s history. This could include personal items, newspaper articles, key documents, newsletters, posters from advocacy rallies or other artifacts that tell the story of endurance and resilience.

Submit a photo of something that could be added to the HFA or Smithsonian collection at history@hemophiliafed.org.

Visit www.hemophiliafed.org/archiveproject to learn more!
What is Novoeight®?
- Novoeight® (antihemophilic factor, recombinant) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery.
- Novoeight® is not used to treat von Willebrand Disease.

Important Safety Information
Who should not use Novoeight®?
- You should not use Novoeight® if you are allergic to factor VIII or any of the other ingredients of Novoeight® or if you are allergic to hamster proteins.

What is the most important information I need to know about Novoeight®?
- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia center.
- Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

What should I tell my healthcare provider before using Novoeight®?
- Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.
- Your body can make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

What are the possible side effects of Novoeight®?
- Common side effects of Novoeight® include inhibitors in patients who were not previously treated with factor VIII products, swelling or itching at the location of injection, and fever.

Please see Brief Summary of Prescribing Information on following page.
Your healthcare provider will tell you how much Novoeight® 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 Novoeight® to be sure that your blood level of factor VIII is high enough to clot your blood. This is particularly important if you are having major surgery. Your healthcare provider will calculate your dose of Novoeight® (in international units, IU) depending on your condition and body weight.

Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Development of factor VIII inhibitors

Your body can also make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly. If your bleeding is not adequately controlled, it could be due to the development of factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of Novoeight® or even a different product to control bleeding. Do not increase the total dose of Novoeight® to control your bleeding without consulting your healthcare provider.

Use in children

Novoeight® can be used in children. Your healthcare provider will decide the dose of Novoeight® you will receive.

If you forget to use Novoeight®

Do not inject a double dose to make up for a forgotten dose. Proceed with the next injections as scheduled and continue as advised by your healthcare provider.

If you stop using Novoeight®

Do not stop using Novoeight® without consulting your healthcare provider.

What if I take too much Novoeight®?

Always take Novoeight® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you inject more Novoeight® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of Novoeight®?

Common Side Effects Include:

- Inhibitors in patients who were not previously treated with Factor VIII products
- Swelling or itching at the location of injection
- Fever

Other Possible Side Effects:

You could have an allergic reaction to coagulation factor VIII products. Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:

- Rashes including hives
- Difficulty breathing, shortness of breath or wheezing
- Lightness of the chest or throat, difficulty swallowing
- Swelling of the lips and tongue
- Light-headedness, dizziness or loss of consciousness
- Pale and cold skin, fast heart beat which may be signs of low blood pressure
- Red or swollen face or hands

These are not all of the possible side effects from Novoeight®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088. Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the Novoeight® dosage strengths?

Novoeight comes in six different dosage strengths. The actual number of international units (IU) of factor VIII in the vial will be imprinted on the label and on the box. The six different strengths are as follows:

Dosage strength of approximately 250 IU per vial
Dosage strength of approximately 500 IU per vial
Dosage strength of approximately 1000 IU per vial
Dosage strength of approximately 1500 IU per vial
Dosage strength of approximately 2000 IU per vial
Dosage strength of approximately 3000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your doctor.

How should I store Novoeight®?

Prior to Reconstitution:

Store in original package in order to protect from light. Do not freeze Novoeight®.

Novoeight® vials can be stored in the refrigerator (36°F to 46°F [2°C to 8°C]) for up to 30 months or up to the expiration date. During the 30 month shelf life, the product may be kept at room temperature up to 86°F (30°C) for no longer than 12 months, or up to 104°F (40°C) for no longer than 3 months.

If you choose to store Novoeight® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- Do not return the product to the refrigerator.
- Do not use after 12 months if stored up to 86°F (30°C) or after 3 months if stored up to 104°F (40°C) or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution (mixing the dry powder in the vial with the diluent):

The reconstituted Novoeight® should appear clear to slightly unclear without particles.

The reconstituted Novoeight® should be used immediately.

If you cannot use the Novoeight® immediately after it is mixed, it must be used within 4 hours when stored at ≤86°F (30°C) or within 2 hours when stored between 86°F (30°C) to 104°F (40°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about Novoeight® and hemophilia A?

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

For more information about Novoeight®, please call Novo Nordisk at 1-844-30-EIGHT.

Revised: 11/2018

Novoeight® is a registered trademark of Novo Nordisk Health Care AG.


Manufactured by:

Novo Nordisk A/S
DK-2880 Bagsvaerd, Denmark

More detailed information is available upon request. Available by prescription only.

For information about Novoeight®, contact:

Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

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US18NEG010164 12/2018
Simplificamos lo complejo. Lo llevamos en la sangre.

Comprender la cobertura de seguros puede ser complicado. El Centro de Apoyo Hematológico (Hematology Support Center, HSC) de Takeda puede ayudar.

Cuando le recetan un producto hematológico de Takeda, el HSC trabaja con usted, su médico y/o farmacia especializada para ayudarle a comenzar con su tratamiento. Para ello ofrecemos:

- Apoyo financiero para gastos de bolsillo para usted, si reúne los requisitos, pudiendo cubrir hasta el 100% de lo que debe por su tratamiento
- Educación sobre seguros y apoyo para ayudarle a entender su cobertura de seguro y sus opciones

El HSC puede brindar respuestas a sus preguntas y necesidades. Comuníquese con el HSC para que lo pongan en contacto hoy mismo con un gerente de reembolsos y acceso (Reimbursement and Access Manager, RAM).

Esperamos que usted pueda asistir con su familia para el Simposio 2020 de HFA en Baltimore en el estado de Maryland.

www.hemophiliafed.org/sangre-latina/programacion/

Sangre Latina
Un Gran Número de Miembros de la Comunidad Hispana Asistió a el Simposio

By Martha Boria Negrán, Staff Writer

Simposio de HFA es una oportunidad única para reunir a la comunidad de Estados Unidos y Puerto Rico. Este año Simposio se llevó a cabo En San Diego, Ca. Con la mayor asistencia de familias hispanas que un simposio de HFA haya tenido. Este año nuestras familias contaban con una alta dosis de motivación por participar de las conferencias.

Este año aumentamos el número de sesiones para un total de 9 completamente en español y 5 grandes sesiones contaron con traducción al español en vivo. Durante nuestras sesiones, los miembros de la comunidad también tuvieron la oportunidad de conectarse a nivel personal con nuestros presentadores.

Algunos de los temas más destacados este año fueron terapia genética, kinesio taping, la importancia de nuestra salud mental, como participar de investigaciones y civismo 101, lo que llevó meses de planificación.

Para el año 2020 esperamos tener más participación hispana y así aumentar el número de sesiones disponibles con temas educativos pertinentes para satisfacer las necesidades de nuestra gente.

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www.hemophiliafed.org/sangre-latina/programacion/
Becoming mothers are often considered the natural caregivers of the family, they get a lot of praise and attention. But fathers, especially those in the bleeding disorders community, deserve praise too. We take a moment to sing the praises of these unsung heroes by highlighting two unique dads.

Meet Joey Privat

When Hemophilia Federation of America began, the office was located in Lafayette, La., which was located near Joey Privat, a hemophilia dad and life-long resident of Louisiana. He is the father of Joshua, who is now 32, and Kelly, now 42, his stepson with his ex-wife, whom he raised since he was 3. Both have severe hemophilia A.

Privat had developed a close relationship with Jan Hamilton, HFA’s first executive director and one of the founders of HFA. He would stop by the HFA office in Lafayette to chat or help out. Through his work at a specialty pharmacy, Privat was able to attend a lot of local and national bleeding disorders programs.

“I always noticed the majority of dads were not involved at the level that moms were,” he said. “That has changed today. I also felt it was important that we, as dads, play our role in the care of our children, from every day dads to super dads who were able to infuse and share in the everyday needs of our child with hemophilia.”

Hamilton and Privat wanted to find a way to encourage dads to become just as involved and engaged as moms. They used programs they discovered at other organizations in the bleeding disorders community and larger fatherhood seminars outside the community as a model to give birth to HFA’s Dads in Action program. Although Privat has passed the Dads in Action baton to others to manage, he remains an involved dad.

“I always dreamed I would have three children,” said Privat. “When I was working my first job, there was a guy who would talk about his children as if they were the most prized possession he had. I would listen and think about how I would really like to feel that someday. When Joshua was born, I was proud! I remember walking out with Joshua in my arms to the nursery and wanting everyone...
to see me with my new baby boy. I was also scared of what the future may hold for us with another son with hemophilia and the past filled with HIV and so many other new things to deal with."

Privat is now married to Jenny and the two have adult daughters Erica and Brooklyn. He’s also a grandfather. Today he’s just as close as ever with his children and, as a dad, he takes pride in seeing the special relationship his son, Joshua, has with his own children.

Meet Mickey Price

Mickey Price of California claims to be your average 43-year-old guy with severe hemophilia A, who still likes to act like he’s 16. But he’s much more than that.

His life experiences have molded him into the man, father and Blood Brother he is today. His mom passed away when he was 14 and he was moved to California with older siblings, but a drug-addicted older brother began to abuse him, so he was moved into the foster care system. His health was also part of shaping his life.

"I grew up in the ‘70s and ‘80s before the testing of blood so I contracted hepatitis C and HIV," said Price, who was cleared of hepatitis C in 2013. "I was told I would be dead by the time I hit 18."

While in foster care in Michigan, he developed life-threatening pneumonia. An attentive foster dad moved him back to California to be treated by Children’s Hospital of Los Angeles, where doctors were able to save his life. He lived well beyond 18 and has gone on to do great things in life. In the ‘90s, he was able to share his experience with HIV on the Marilu Henner and Leeza Gibbons shows.

Fast forward and he met his wife, Tanya, who was determined to have children and found a doctor willing to do sperm washing and storage. They have been married for 16 years and first welcomed Kaelee 10 years ago and then Kacie 4 years ago.

"The first moment I saw her (Kaelee), I was in tears and awe," he said. "All I saw was pure innocence and a chance to break the cycle of the strongholds that were in my family growing up. To be honest I always thought it would be cool to be a dad but never thought it was possible or would happen. I feel extremely lucky, joyful and blessed. I still have so much to learn about child-rearing and there is not a book in the world that could have prepared me."

Price says he has had a lot of great men and women who have helped mold him and guide him along life’s journey, including his “dad” — not a biological dad but someone who was there since birth.

"As a child I would have knees the size of a small cantaloupe and I would get discouraged and start feeling sorry for myself, and he would always remind me there is always someone worse off than I was, and I try to teach my kids that," said Price. "I also had two foster dads who were always there to show me how to do things and how to be independent and be assertive and advocate for myself."

To learn more about HFA’s Dads in Action and other Families programs, visit www.hemophilialfed.org/families!
CAMP BOLD EAGLE MARKS 50 YEARS OF HELPING TO SHAPE THE LIVES OF CHILDREN WITH BLEEDING DISORDERS
Half a Century of Memories

Some say summer camp is one of the best experiences for children with hemophilia and other bleeding disorders. From learning to self-infuse for the first time to meeting life-long friends, the memories made at summer camp can change people for the better and last a lifetime. To recognize the importance of summer camp, we share a portion of an article from The Artery, publication for the Hemophilia Foundation of Michigan, about the 50th anniversary of Camp Bold Eagle.

By Sarah Procario, reprinted with permission of Hemophilia Foundation of Michigan

Camp Bold Eagle — originally called Camp Bold Eagle Highlands — celebrated 50 summers of camp in July 2018. Throughout the past 49 years, Camp Bold Eagle has grown in numbers, changed directors, moved locations and survived deeply challenging times.

Hemophilia Foundation of Michigan created the first camp for children with bleeding disorders, starting in 1969. Dr. John A. Penner, a founding member of HFM, and Dr. Jeanne Lusher were instrumental in establishing Camp Bold Eagle. As the first camp of its kind in the nation, CBE accepted children from across the country. There were even children from Belgium and France.

In 1975, Camp Bold Eagle was recognized for pioneering the hemophilia camping program. Marv Williams, HFM’s first executive director, shared that HFM received an enormous amount of help from the University of Michigan, Eastern Michigan University and Michigan State University to make camp a reality. Similar to the current camping experience, camp in the early days employed counselors, CITs and college students.

In the 1980s, the camp and the entire bleeding disorders community, began to feel the devastating impact of the HIV/AIDS epidemic. In 1982, the Centers for Disease Control and Prevention reported the first HIV/AIDS cases among people with hemophilia due to the use of contaminated blood products. Around the same time, 44 percent of all people with hemophilia contracted the hepatitis C virus.

As the community became sick, so did CBE camp counselors. The counselors eventually became so sick, many were unable to work at camp, while others tragically passed away due to the virus. In 1994, the camp director, Shelley Gerson, Head Counselor Chris Althouse, and Dr. Kathy Fessler discussed camp’s biggest problem – how hard it was to find counselors. They needed staff to fill the gap while they waited for the younger campers to become old enough to become the next generation of counselors.

Fessler remembers thinking ‘medical students would do anything to get out of the hospital in July.’ Althouse, Gerson, Fessler and then Health Center Director, Sue Adkins, began to plan it out — medical students would have a health center rotation in their schedule to satisfy medical school requirements.

“The medical student program raised the bar for our staff. Everyone understood that we almost lost camp,” said Gerson. CBE would not be the place it is today without the dedication and commitment of all those who came before. CBE brings their memory and spirit with them as we continue the Camp Bold Eagle tradition. The bleeding disorders community has created a camp environment of community, understanding and support over the past 50 summers.

The article originally appeared in the Fall 2018 issue of The Artery, publication of the Hemophilia Foundation of Michigan.

Learn more about summer camp and the various camp opportunities throughout the country in HFA’s Camp Directory at www.hemophiliafed.org/campdirectory.
Sharing Insurance Concerns Just Got Easier

Project CALLS reporting form becomes shorter and easier to complete for patients and families

It’s not unusual for patients to spend untold amounts of time on hold with their insurer. Hemophilia Federation of America understands time is valuable, which is why HFA has shortened the reporting form for Project CALLS. It now takes only five minutes to report an issue.

It’s important to report issues to Project CALLS so HFA can identify trends and build a case for changing insurance frustrations experienced by the bleeding disorders community.

Give Project CALLS a few minutes of your time if you or a member of your family have been:

- Denied services or have received an exception.
- Forced by an insurance company to “fail” on a product before being allowed to use the product of your choice.
- Mandated to a pharmacy that is not meeting your needs.
- Forced to go through a lengthy pre-/prior-authorization process.
- Told you cannot use patient assistance for premium or co-pay assistance.
- Told your co-pay assistance doesn’t count toward your overall deductible.
- Affected by some other health plan practice which blocked your access to care.

Your story can help us make a difference for the entire bleeding disorders community!

Discover more about IXINITY®

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This year’s Hemophilia Federation of America Annual Symposium in San Diego on April 4–6 went out with a bang – literally. The annual educational conference, which brought together more than 1,300 people from 47 states, the District of Columbia and Puerto Rico and five different countries, ended with a spectacular fireworks display on the decommissioned U.S.S. Midway for the final night event.

HFA used this year’s The Best of Us Symposium to honor the 80+ year history of bleeding disorders as well as its 25-year existence in the community. To honor the history, an exhibit gave attendees a glimpse at significant events in bleeding disorders history, artifacts and photographs.

During the annual awards luncheon, HFA was excited to share big news — thanks to generous donations from the community, a collection of artifacts has been given to the Smithsonian Institution’s National Museum of American History in Washington, D.C.

Symposium featured sessions and tracks on hemophilia, vWD, inhibitors, rare bleeding disorders, research and advocacy. This year’s event also featured the inaugural research poster presentation, to bring patient-centered research about bleeding disorders to the community.
Thank You!

To the following sponsors for making Symposium 2019 a success:

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HFA’s Annual Symposium Awards

Each year, at the Symposium awards luncheon, Hemophilia Federation of America recognizes a number of individuals who have made a positive impact on the bleeding disorders community. This year, six awards were presented:

**It Takes a Village 🏡 Trudy Stringer**

Provided to an individual who goes above and beyond in uniting the community and has demonstrated a unique ability to link those in need, from the experienced bleeding disorder veteran to the newly diagnosed family.

Trudy's advocacy for bleeding disorders began in the ’70s when she started dating her first husband, Danny, who had hemophilia. Her fire for advocacy was lit when her husband contracted HIV in the ’80s from contaminated factor medication.

During a time when she was caring for and eventually losing her husband to AIDS, she rose up to put a wife, a mom, a face to the AIDS crisis. She stood up for AIDS patients when they didn’t have a voice because they had either passed away or they were in hiding. She spent countless hours attending and speaking at meetings, writing letters, walking the halls of congress and whatever else it took to advocate for her Danny and so many others for the Ricky Ray Hemophilia Relief Act.

Her formal service includes participating on Gateway Hemophilia and HFA’s board of directors. Her grandchildren now affected, so hemophilia has not gone away even if the issues are different today. She continues to make a difference for those living with a bleeding disorder and supports her family in doing the same, demonstrating that It DOES Take A Village.

**Michael Davon Community Service 🏡 Joslyn Olsen**

For extraordinary service to the community via one’s national or global volunteerism and charitable giving.

Joslyn is the founder of HemoHelper, a nonprofit designed to bring humanitarian initiatives to those with bleeding disorders in developing countries. Annually, HemoHelper provides medical donations to these countries. Last year, Joslyn delivered medication, supplies and medical identification bracelets to those in need in Guatemala.

HemoHelper receives no industry funding – she does it all on her own! Olsen also produces HemoStories, podcasts which share information and spread awareness.

**Charles Stanley Hamilton Legacy 🏡 Kathleen Byrne**

For extraordinary lifetime service that encompasses national volunteerism, professionalism and leadership.

Kathleen has been a dedicated nurse, who has been working in bleeding disorders since 1993. Seeing a need for home infusion nurses, she created her own nursing company, Infusion Ventures. Over the years, she has traveled around the country to teach children living with hemophilia, and their families, how to self-infuse.

You’ll find Byrne volunteering as a nurse at walks and family camps, retreats and inhibitor camps across the nation. She also volunteers and conducts infusion classes all over the nation. Her legacy and dedication can be seen across the country, one family at a time, building family confidence and teaching infusions.
Ron Niederman Humanitarian Award 🏆 Laurie Kelley

For extraordinary and inspirational service to the national or international community via one’s professional work or volunteer service.

Laurie, founder of LA Kelley Communications, Project SHARE and Save One Life, has spent more than 20 years in service to the bleeding disorders community. She has assisted more than 2,000 children and families living with bleeding disorders around the world, generating individual and corporate sponsorship to support families in 15 developing countries.

She founded an incredible humanitarian program which has donated 133 million units of factor to thousands of patients in need in more than 75 countries. Kelley is also the author of “Raising a Child with Hemophilia.” 🌟

Member Organization Spotlight 🏆
The Bleeding Disorders Foundation of Washington
Stephanie Simpson, Executive Director

Honors an HFA Member Organization that has created an environment within their membership that engages members, continually promotes education and consistently encourages self-advocacy.

The Bleeding Disorders Foundation of Washington offers a robust calendar of events for the bleeding disorders patients it serves, with a balanced schedule of education, advocacy and fun. Their user-friendly website is filled with eye-catching photos and videos along with an abundance of information about education, advocacy, and patient and family support. They provide a camp experience for families with a new diagnosis, a leadership camp for teens, Blood Brotherhood activities for adult men, and patient assistance for families in need.

This organization looks for new and innovative ways to serve, keeping education and advocacy as the central focus. They have established a working relationship with the Washington State Health Authority and regularly provide testimony before the state house and senate on behalf of the bleeding disorders community.

A vocal presence who practices what she preaches, Stephanie Simpson, Executive Director, regularly challenges her peers around the country to take a big-picture, long-range planning approach to leading their organizations. 🌟

Volunteer of the Year 🏆 Murali Pazhayannur

Selected by the HFA staff in recognition of tremendous national spirit and remarkable volunteerism with HFA for the bleeding disorders community.

Murali has touched many of our hearts and minds. He was born in India, diagnosed with severe hemophilia at age 4 after a tonsillectomy, and grew up in a time and place with no access to clotting factor – just R.I.C.E., or sometimes whole blood or cryoprecipitate. He lives with pain and severe damage in multiple joints from untreated bleeds. Despite these obstacles, he completed a Ph.D. in immunology and came to the U.S. at age 29, working first in research and later in computer science.

He is an engaged and active participant in programs and has led Blood Brotherhood sessions and been a Symposium speaker. He regularly shares his experiences living with hemophilia in India and the U.S., working closely with hemophilia chapters in India. He is passionate about raising awareness and improving the standard of care in the country of his birth.

He promotes awareness of bleeding disorders and actively fundraises, encouraging his own employer to support bleeding disorders. He truly understands how our Helping Hands Program is for our most vulnerable families.

“He’s great steward of the community and the kindest person you’ll ever meet. He literally cares about everyone and bridges the gap, especially for people that are isolated and lost by helping them make the connection with HFA,” said one HFA staff member. 🌟
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, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?
HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider’s instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including Serious Side Effects.
What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider’s instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- Thrombotic microangiopathy (TMA).
- 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
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
- Coughing up blood
- Difficulty breathing
- Decreased urination

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

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 as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. Do not give two doses on the same day 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

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 and reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors. Hemophilia A is a bleeding condition people can be born with where a lack of Factor VIII in the blood leads to easy or excessive bleeding.

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.
- Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.
- You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.
- 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.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by 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 as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. Do not give two doses on the same day to make up for a missed dose.

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 a total of 7 days or at a temperature greater than 86°F (30°C).
- 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-kxwh

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
U.S. License No. 1048

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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 Revised: 10/2018

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We all know eating a well-balanced diet is part of a healthy lifestyle, but have you ever been curious about the role nutrition plays in your well-being beyond weight and joint health?

**Addressing Fatigue**

Anemia can be caused by blood loss, a low red blood cell count unrelated to bleeding, or by not consuming enough iron. During and after a bleed, it’s important to consume enough iron to help the body recover. Women are more likely to experience anemia than men because of regular bleeding associated with the menstrual cycle. To combat anemia, be sure to make these foods a part of your diet: dark green, leafy vegetables, beans and legumes, and lean meats. Consider munching on a few squares of dark chocolate for dessert—this treat packs (on average) nearly 6mg of iron per serving!

In addition to anemia, women are more likely than men to experience thyroid disease. This little organ plays a big role in essential bodily functions. A person with low thyroid hormones may feel consistently sluggish, have trouble losing weight, and experience hair loss. High levels of thyroid hormone can cause excessive weight loss and a rapid heart rate. Eating to support thyroid health can be as simple as making sure there are enough vitamins and minerals in your diet. Iodine is an essential mineral, and can be found in high concentrations in sea foods, such as seaweed and codfish. If you’re not a fan of sea foods, you can find supplemental iodine in dairy, eggs, and prunes.

**A Body in Motion**

A body in motion tends to stay in motion, but what if I can’t keep my energy up? In addition to promoting good thyroid health and hampering anemia, a protein-focused breakfast and snacks help to sustain energy throughout the day. Overnight oats or scrambled eggs with whole grain toast offer plenty of protein and fiber to keep you full and energized until lunchtime. Veggies dipped in hummus or an apple with peanut butter are kid-friendly snacks sure to keep everyone on the go.

Caffeine is another culprit behind the mid-day slump. Try cutting back on the number of caffeinated beverages you consume each day, especially if they contain sugar or sweeteners. In addition to an energy crash, caffeine can be dehydrating, making factor replacement infusions more challenging.

Some studies, which might be considered inconclusive, have shown herbs and spices have a blood-thinning effect, but a person would have to eat large amounts on a regular basis in order to see an impact on their ability to clot. If a bleeding disorder is well managed, individuals most likely do not need to worry about the risk in consuming normal amounts of the most commonly-used herbs and spices.

People with bleeding disorders should err on the side of caution when consuming turmeric. This bright yellow spice, frequently found in Indian/South Asian cuisine, may have a more significant effect on clotting than other foods. Some people take turmeric capsules as a remedy for joint pain. The good news is that you’re free to enjoy your favorite curries on a regular basis. If you are struggling with joint pain, let your healthcare provider know.

Begin your journey to a healthy lifestyle by eating well and engaging in exercise that is right for you. If you are getting proper nutrition and exercising, but still struggling with a lack of energy, weight gain or joint pain, consult with your healthcare provider.
ADDITIONAL TIPS:

💰 People with connective tissue disorders, HIV or hepatitis may need to take a multivitamin in addition to eating a well-balanced diet to meet their nutritional requirements.

✏️ Fill half your plate with vegetables and fruits before selecting proteins and grain or starch-based foods.

📅 Once a week, prepare some healthy snacks to keep in the fridge or cupboard for when hunger strikes!

📺 Eating while watching television or playing games makes it harder to feel satisfied and contributes to overeating. Chewing gum, sipping herbal tea, and taking part in hobbies that engage the hands are good ways to replace this habit.

For healthy recipes, menu plans and more, check out www.hemophiliafed.org/fitfactor!
**ADYNOVATE** [Antihemophilic Factor (Recombinant), PEGylated] Important Information

**What is ADYNOVATE?**
- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).
- ADYNOVATE is not used to treat von Willebrand disease.

**DETAILED IMPORTANT RISK INFORMATION**

**Who should not use ADYNOVATE?**
Do not use ADYNOVATE if you:
- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

**What should I tell my HCP before using ADYNOVATE?**
Tell your HCP 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 mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

**What are possible side effects of ADYNOVATE?**
- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

**What is the recommended dosing frequency?**
- ADYNOVATE is FDA approved for children and adults with Hemophilia A. Work with your doctor to determine an infusion schedule that is appropriate for you.

**Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds.**

**38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds.**

**DETAILED IMPORTANT RISK INFORMATION (cont’d)**

**What important information do I need to know about ADYNOVATE?**
- You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

**What else should I know about ADYNOVATE and Hemophilia A?**
- Your body may form inhibitors to factor VIII. An inhibitor is part of the body’s normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

**What are possible side effects of ADYNOVATE?**
- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do 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 Important Facts about ADYNOVATE on the following page and discuss with your HCP.**

**For full Prescribing Information, visit www.ADYNOVATE.com.**

**References:**
1. ADYNOVATE Prescribing Information.
3. Data on file; Shire US Inc.
Patient Important facts about ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADYNOVATE?
Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider’s instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?
ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis). ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?
You should not use ADYNOVATE if you:
• Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]
• Are allergic to mice or hamster protein
• Have any allergies, including allergies to mice or hamsters.
• Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
• Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
• Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

How should I use ADYNOVATE?
ADYNOVATE is given directly into the bloodstream. You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider’s office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member. Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding. Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional. You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

What should I tell my healthcare provider before I use ADYNOVATE?
You should 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 mice or hamsters.
• Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
• Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
• Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What else should I know about ADYNOVATE and Hemophilia A?
Your body may form inhibitors to Factor VIII. An inhibitor is part of the body’s normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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.
I was honored to be awarded the People’s Choice Award at Hemophilia Federation of America’s first research poster session at the 25th anniversary symposium. It means a lot to be recognized for the work I hold so near and dear to my heart. I am also elated that HFA has begun to expand their research efforts, giving a platform for researchers to expose the bleeding disorders community to the many studies that exist that are of benefit for our community, particularly those in the psychosocial field.

My research study on “Gender Differences in Parenting Stress and Social Support Among Hemophilia Families” was a true labor of love. As a hemophilia mom, I know from experience parenting stress is a real concern for mothers and fathers as they face the many challenges of raising a child with hemophilia.

Hemophilia not only concerns the affected child, but the entire family unit, particularly the parents. Hemophilia parents experience significant stress due to the many challenges of dealing with a chronic illness in the family system.

There is a direct correlation between parental stress and parents’ overall health status, due to their ability to cope. Mothers and fathers often have different experiences about stress and social support, despite living in the same households.

Much research exists on various chronic illnesses, stress and social support. However, no research dealt specifically with parent gender similarities and differences in stress levels and perceived social support in families of children with hemophilia. It was important to research the gender differences in hemophilia parents to bring awareness to mothers’ and fathers’ individual social support needs, which can impact their stress levels.

This study sought to add to the body of knowledge for human service professionals and hemophilia advocates by comparing the perceptions of stress and social support between mothers and fathers.

The premise of my research stems from the belief that mothers and fathers may experience parenting stress at different levels. In addition, there may be variations in how men and women perceive the social support systems available to them. My research study sought to raise awareness of gender differences related to hemophilia patients’ parental stress and how they can better utilize social support networks as they raise their chronically ill children. Understanding the link among gender, stress and perceptions of social support is important to help parents develop coping strategies to meet the unique challenges of caring for their children with hemophilia.
This study employed a quantitative, online survey design. Two instruments measured the data: The Parenting Stress Index-Short Form (PSI-SF) measured parenting stress and the Medical Outcome Study Social Support Survey (MOS-SSS) measured social support. A demographic questionnaire was also administered. Using a purposive sampling technique, mothers and fathers aged 18 and above with children with hemophilia and residing in Maryland, Washington, D.C., or northern Virginia were recruited for the study. Two research questions and related hypotheses were developed for the study:

1. How do mothers and fathers of children with hemophilia differ in level of perceived parenting stress and level of perceived social support?

2. Is there a significant difference in perceived parenting stress among parents in the severity of the child’s hemophilia?

The results from the study revealed that mothers expressed significantly higher levels of parenting stress than fathers. The findings also indicated mothers’ perception of social support was significantly higher than that of fathers. The study found there was no significant difference in parenting stress based on the severity of the child’s hemophilia.

This study further revealed that parenting stress scores for both mothers and fathers represent significantly high levels, well above the 90th percentile. Research indicates that parents who score above 90 percent on the PSI-SF demonstrate possible clinical conditions, which may require them to seek professional help.

My study concluded that all hemophilia parents experience some level of stress and they need gender-specific social support regardless of their child’s hemophilia severity. Study findings support the need for hemophilia advocates to have a more in-depth dialogue about the seriousness of parenting stress.

The information from this study can be used to engage parents through programs and services that would help decrease stress and increase social support use to improve the health, wellness, and overall quality of life of the hemophilia family.

Dr. Gates holds a doctoral degree in human services, a master’s of public administration and a bachelor’s degree in Business. She is a human services board-certified practitioner and a personal development coach. As a result of the positive feedback received on her research study, she has developed an educational presentation for the bleeding disorders community. The parenting workshop she developed is an interactive session for mothers and fathers to engage in activities to understand parenting stress and learn how to utilize social support networks. As a staunch advocate and volunteer for many years, Dr. Gates is ready, willing and able to contribute her time and talents to share information to help parents, who like herself face challenges of parenting a child with a chronic illness.

For more information and to arrange a parenting workshop, please contact Dr. Gates at carletha.gates@gmail.com.
We've partnered with Get Out & Go Tours to lead the group on this three-day, 156-mile bike ride along the C&O Canal. The ride is fully supported with:

- A shuttle for carrying gear
- Lodging, meals and snacks
- Maps and local information cards
- Mechanical support
- Bike rentals
- Professional cycling jersey (when registered by July 31, 2019)

HFA is proud to be a charity partner in the 2019 Marine Corps Marathon and has your guaranteed entry in what will be a sold-out, exclusive race. You'll experience:

- An impeccably-organized marathon
- Choice of marathon or 10K
- Scenic course managed by the U.S. Marines in Arlington, Va., and the nation’s capital
- Pre-race Carbo Dinner
- Fundraising and training tips leading up to the race

We are taking on challenges across the United States by participating in various athletic and competitive events to raise awareness about bleeding disorders and funds for Helping Hands, our financial relief program for families in crisis.