Hemophilia Federation of America’s
VIRTUAL SYMPOSIUM 2020
AUGUST 24-29, 2020
www.hemophiliafed.org/Symposium
OUR SPONSORS
We thank the following companies for their generous support. With their sponsorship, we have been able to bring the bleeding disorders community together to share information, learn new advancements and build a network of support, all through a unique online experience. We thank our sponsors for shifting their support to our virtual experience and recognizing the importance of supporting the community, even during a global pandemic.

VIRTUAL CONFERENCE SPONSORS

DIAMOND | BioMarin | Genentech | Novo Nordisk | Takeda
PLATINUM | Bayer | Sanofi Genzyme
GOLD | CSL Behring | Pfizer
BRONZE | Grifols | HEMA Biologics | Kedrion Biopharma Medexus | Octapharma | Spark Therapeutics | uniQure

TRACK SPONSORSHIPS

INHIBITOR | Genentech | HEMA Biologics
SPANISH | Genentech
HEMOPHILIA | BioMarin | Genentech
VWD | CSL Behring

Many thanks to our virtual Symposium platform sponsors:
Colburn Keenan
Sanofi Genzyme | Takeda
With their support, we’re able to provide the community with access to the virtual event at no cost!
DEAR FRIENDS,

We are so excited to have you join us for our first-ever virtual Symposium. We believe our online event will provide the same great educational content, access to sponsors and exhibitors, and fun activities you typically find at our in-person events. We recreated and reimagined the entire event with YOU in mind! From the virtual lobby, to our video-chat Rap Session rooms, to our Final Night Event, every decision was made to recreate the in-person hugs we’re missing out on this year when we all need them the most. And even though we did not get to meet in person, we’re thrilled to bring the community together safely in a virtual environment.

When we chose the theme for this year’s Symposium — Charting Our Future — we played on the nautical history of our host city of Baltimore, but more importantly emphasized HFA’s goal of improving the quality of life for our community now while always looking into the future. Little did we know as Symposium approached, the shift in sails that would take place and the need to grow and adapt to the new normal. No matter the circumstances, our future is always directed at bringing the community together.

Despite these unprecedented times, we remain true to our advocacy roots and to strive to be a valuable resource for our families. Therefore, let me give you an idea of what to expect this week. You are participating in the largest annual, family-focused conference within the bleeding disorders community in the country. This is your opportunity to learn and grow. Please take advantage of all that we have to offer; sessions focused on your individual bleeding disorder, advocacy, and topics that span all disorders will be available to you throughout the week. Programming for adults, kids and families were thoughtfully chosen over months of planning by committees made up of community volunteers, staff and advisors. The other fantastic opportunity this week is networking. Please use the virtual environment to get to know others, learn from them and share your experience and wisdom.

The pages of this program outline the many great opportunities you’ll have to connect with community members and bleeding disorders experts, be entertained — including an amazing Final Night Event — and gain a better understanding of our community. Our staff is available to assist you in navigating through the virtual platform. Please do not hesitate to reach out as we learn and enjoy our time together.

Finally, I’d like to thank you for being a part of our virtual Symposium and for bringing your unique perspective to our gathering. It wouldn’t be the same without you! We need each other now more than ever. Let’s stand together. Let’s chart our future together.

REGARDS,

Sharon Meyers, EdD, CFRE
President & CEO
Hemophilia Federation of America
A full agenda with complete dates, times, and session and activity descriptions will be sent via email to registered participants and will be available online at www.hemophiliafed.org during Virtual Symposium.

Symposium Sponsors ................................................................. 2
Welcome ................................................................................. 3
How to Navigate Virtual Symposium .............................................. 5
Learn More About HFA! ............................................................. 6
Can’t Miss Activities ................................................................. 6
Final Night Event Virtual Variety Show ........................................ 8
Can’t Miss Sessions .................................................................... 9
Virtual Exhibit Hall & Exhibitors ................................................... 10
Our Sponsors ............................................................................ 12-24
Additional Information ............................................................... 25

Tips for a Better Virtual Experience

• Some sessions will lead to Zoom, so we recommend downloading the Zoom app before joining.
• Pop-up blockers might change your experience, so we recommend turning off pop-up blockers.
• Use Briefcase to save downloads and information you want to keep.

If at any time you experience trouble logging in, please email symposium@hemophiliafed.org. If you experience trouble navigating once logged in, visit the Help Desk, found in the Lobby, to chat with technical experts.

BE SOCIAL!

As you’re enjoying your online educational experience, share a selfie or family photograph using #HFA2020.

Follow us on Facebook, Twitter, and Instagram @hemophiliafed

Watch our Facebook page each evening from Aug. 24 to Aug. 29 for an evening wrap-up video of the day’s virtual activities.
HOW TO NAVIGATE VIRTUAL SYMPOSIUM

As a registered attendee, you will receive an email with a link to join us online, which will take you to a welcome page. To sign-in, enter the email address you used to register for Virtual Symposium.

Log-in here using the email you registered with.

Once you log in, you will enter the Lobby. Be sure to check-out the welcome video from our President and CEO, Dr. Sharon Meyers, CFRE.

The Lobby features:

• **The Auditorium** — Most sessions will take place here.

• **The Lounge** — See who is attending, find friends, join a public chat, and share with your fellow attendees on the sessions you would recommend. You can also initiate a private chat in the navigation bar at the bottom of your screen.

Throughout Virtual Symposium, you can always get back to the main page by clicking on Home at the bottom of the page.

**Spanish Translation/Traducción al Español**

La traducción con nuestra plataforma en línea está disponible seleccionando la opción de idioma español en la función Google Translate en la parte superior.

**Evaluations**

When you are attending an individual session, click on the Evaluation tab within the session to complete a quick evaluation. Following your Virtual Symposium experience, please visit the Home page to complete a Final Evaluation.

Download the full agenda here.
CAN’T MISS ACTIVITIES!

Just like our in-person Symposium, we not only offer valuable educational sessions, but also opportunities to connect, celebrate, reminisce, engage and be inspired. Here you will find some of those opportunities you won’t want to miss during Virtual Symposium.

Welcome Session & Symposium Overview
Monday, Aug. 24 • 2 to 3 p.m. ET
Set sail on a week full of educational sessions and fun activities with this welcome session designed to kick off the week right and provide you with all you need to know to navigate the new, virtual platform.

Keynote Speaker
Monday, Aug. 24 • 7:30 to 8:30 p.m. ET
We welcome Lindsay Vos, patient advocate extraordinaire, to share her journey from diagnosis through battling Hereditary Hemorrhagic Telangiectasia, a malformation of blood vessels affecting multiple organs of the body. Tune in to engage, support, and understand how Lindsay’s upbeat and positive attitude has helped her to navigate the management of her chronic disorder.

Annual Awards Ceremony
Tuesday, Aug. 25 • 7:30 to 8:30 p.m. ET
Our annual recognition ceremony honors the service of special individuals who have gone above and beyond in support of the bleeding disorders community. We will have an overview of our exciting Final Night Event, reveal a fun photographic project we’ve been creating just for the bleeding disorders community, and make a special announcement about Symposium 2021!

Charting Our Future Community Photograph Project
Don’t miss the reveal of an amazing photographic experience during our Awards Ceremony, using photographs submitted by the bleeding disorders community!

Celebration of Life
Wednesday, Aug. 26 • 2 to 3 p.m. ET
Lest we forget: this special annual tradition commemorates and pays tribute to the trailblazers of our community who have passed and allows family and friends a special time to celebrate our loved ones who lost their lives due to complications related to hemophilia and other bleeding disorders.

Celebration of Life at HFA’s Annual Symposium
Stay Active—Live or On-Demand

One of the best-loved activities during our live Symposium is the Rise and Shine physical activities. For Virtual Symposium we’ll offer yoga, Zumba and other joint-healthy activities for you to attend live or to watch later, when it fits into your schedule!

- **Yoga for Joint Health** | 3 to 4 p.m. ET Monday, Aug. 24
- **Zumba** | 3 to 4 p.m. ET Tuesday, Aug. 25
- **Bodyweight Bootcamp** | 3 to 4 p.m. ET Thursday, Aug. 27
- **Yoga for Pain Relief, Anxiety and Stress** | 3 to 4 p.m. ET Friday, Aug. 28

An educational experience for the whole family, examining the science of bleeding disorders in an easy-to-understand adventure.

**Gain a better understanding of:**

- Factor 8
- Hemophilia B
- von Willebrand disease
- Rare factor deficiencies
- Joint health and more!

Originally presented at the Bleeding Disorders Conference in California in 2019, The Science Fair has been reimagined for a virtual science fair experience at HFA’s Virtual Symposium.

Built with guidance from leading clinicians and experts who helped translate the most important scientific concepts into learning opportunities for young people and families.

The Science Fair is created and produced by BelieveLIMITED. Sponsored by Spark Therapeutics
Final Night Event
Virtual Variety Show

LIVE Saturday, Aug. 29 • 7:30 to 9 p.m. ET

Gathering top tier performers from some of the best entertainment groups in the world, Michael Jay Garner and Beyond Recreation will shape an amazing Final Night performance in the brand-new arena of virtual online performance featuring:

• Artists who have toured with Cirque du Soleil & Britney Spears World Circus Tour
• Guinness World Records record-holders
• Performers who have appeared on Broadway & in films such as The Greatest Showman

Performing LIVE from across the U.S., Mongolia, Russia and Taiwan!

The performance is followed by an opportunity for audience members to interact with performers through a live Q & A session.

Presented by Novo Nordisk
Each day we will offer a variety of sessions and breakouts in English and Spanish. Topics include new and emerging therapies, global perspectives, advocacy, insurance, pain management, mental health, research, cooking demonstrations, and more. A full agenda will be available during Virtual Symposium.

Daily Industry-Sponsored Sessions
Each day, one of our industry sponsors will provide you with an opportunity to hear about the latest product and industry information. You won’t want to miss these sessions where you’ll have opportunities to ask questions and learn about the industry’s latest happenings. During the week, you’ll hear from one sponsor each day from 5 to 6:30 p.m. ET:
- Monday—Genentech
- Tuesday—Novo Nordisk
- Wednesday—Sanofi Genzyme
- Thursday—BioMarin
- Friday—Takeda
- Saturday—Bayer

Rap Sessions
It’s an annual tradition many community members look forward to — the chance to connect with their fellow blood brothers and blood sisters and the opportunity to discuss topics in a safe space. Rap sessions during 2020 Virtual Symposium will include:
- Partners and Spouses
- Rare Disorders
- Blood Sisterhood (two rap sessions)
- Blood Brotherhood (two rap sessions)
- People of Color
- LGBT
- Sangre Latina Familias
- Parents

Note: Rap Sessions are live only and will not be recorded for on-demand viewing. Rap Sessions are open to individuals affected by the bleeding disorder or topic covered during the rap session and is closed to industry representatives unless they are affected by the bleeding disorder.

On the Horizon
We will discuss where we’ve been and where we’re going with respect to treatments and therapies for bleeding disorders with a panel discussion about where we were, where we are, and where we’re going. Each panelist will present information on topics such as our history, current treatments and emerging treatments.

Journey to Healthier Joints LIVE
Wednesday, Aug. 26 • 7:30 to 8:30 p.m. ET
Are you interested in increasing your activity level, and in turn, improving your joint health? A panel of Blood Brothers will share their experience participating in HFA’s 2019 Best of You: Journey to Healthier Joints men’s activity challenge. The Bleeders of the Great Northwest are committed to increase your knowledge and awareness of safe physical activities for people with bleeding disorders and how to build a team, using competition to improve joint and overall health.

*Your Journey to Healthier Joints Activity Challenge is supported by Cooperative Agreement Number NU27 DD001151-05, funded by the Centers for Disease Control and Prevention.

Research Poster Session
This patient-centered research poster session gives bleeding disorders community members a chance to learn about research in layman’s terms. Posters feature research on topics such as parenting stress and social support among hemophilia families, perceptions and understanding of gene therapy in the bleeding disorders community, literature review findings on quality of life and health utility for people with hemophilia, and developments in cell therapy in hemophilia.

Patients will have the opportunity to ask questions to gain a better understanding about the research and what has been done on behalf of the bleeding disorders community.

Chat with Poster Presenters | 2 to 3 p.m. ET Thursday, Aug. 27

For Children, Teens and Families
This year’s Symposium will not have activities specifically for children and teens however many sessions can be viewed as a family. Also join these sessions designed for children and families:
- **Children’s Art Session**: Join in a fun presentation of painting set to music featuring Kandinsky-inspired and nonrepresentational art!
- **Family Cooking Demonstration**: Join Blood Brother and chef Mike Hargett for a live cooking demonstration on how to make a meal for the whole family using common pantry ingredients. He will also share a bit of his experience with hemophilia and his career path.
VISIT THE INTERACTIVE EXHIBIT HALL

While you may not be able to walk through the Exhibit Hall in person, you won’t want to miss visiting our interactive Exhibit Hall. In the Exhibit Hall, you can:

- Visit product manufacturers, specialty pharmacies, and companies researching new products and therapies
- Engage in live chat and presentations with company and organization representatives
- See local and national nonprofit organizations sharing their latest information and answering your questions

Exhibit Hall Hours  | 24-hour access Aug. 24-29
Live Chat with Booth Representatives  | 2 to 5 p.m. ET Aug. 24 to Aug. 29
Post-Symposium access | Access available until Dec. 29, 2020.*

* The chat with an industry representative will not be available after Aug. 29.

Exhibitor Booths

**DIAMOND EXHIBITORS**
- BioMarin Pharmaceutical
- Genentech, Inc.
- Novo Nordisk, Inc.
- Takeda

**PLATINUM EXHIBITORS**
- Bayer
- Sanofi Genzyme

**GOLD EXHIBITORS**
- CSL Behring
- Pfizer

**BRONZE EXHIBITORS**
- Grifols USA, LLC
- HEMA Biologics
- Kedrion Biopharma
- Medexus
- Octapharma
- Spark Therapeutics
- uniQure
Other Exhibitors

Accredo
ARJ Infusion Services
BioMarin Pharmaceutical Inc. Medical Affairs
Cottrill’s SP
CVS Specialty
Diplomat Specialty Infusion Group
Drugco Health
Fidelis Specialty Pharmacy
Genentech’s HemWork
Hemophilia Alliance
Hope Charities
My Drugco

National Hemophilia Foundation
Option Care Health
Paragon Healthcare Specialty
Plasma Protein Therapeutics Association
Rare Patient Voice LLC
Save One Life, Inc.
Sigilon Therapeutics, Inc.
Soleo Health
The Alliance Pharmacy
The Coalition For Hemophilia B
Tremeau Pharmaceuticals, Inc.
World Federation of Hemophilia

Member Organization Booths

This year’s virtual platform will allow more “room” for booths in our Exhibit Hall, so we are pleased to welcome the following Member Organizations from throughout the country. Visit their booths to learn more about how they are serving the bleeding disorders community in their area.

Bleeding Disorders Alliance of North Dakota
Central California Hemophilia Foundation
Connecticut Hemophilia Society
Florida Hemophilia Association
Gateway Hemophilia Association
Hemophilia Association of the Capital Area
Hemophilia Foundation of Michigan
Hemophilia of North Carolina
Hemophilia of South Carolina
Lone Star Bleeding Disorders Foundation
Midwest Hemophilia Association

New England Hemophilia Association
New York City Hemophilia Chapter
Northern Ohio Hemophilia Foundation
Pacific Northwest Bleeding Disorders
United Hemophilia Foundation
Virginia Hemophilia Foundation
Western Pennsylvania Chapter of NHF

*Participating organizations are subject to change. Please visit the Exhibit Hall Aug.24-29 to see all exhibitors.
Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information in a way you can understand.

Let’s explore gene therapy together at HemDifferently.com

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.
When it comes to your hemophilia A treatment

Move beyond the threshold

Esperoct® can give you high factor levels for longer.

Safety Proven across 5 studies, the largest and longest EHL clinical trial program

Switching made easy
with a standard 50 IU/kg dose every 4 days
-50% fewer infusions if you previously infused every other day
-40% fewer infusions if you previously infused 3x a week

High factor levels
At or above 3% for 100% of the time\(^a\,^e\)
At or above 5% for 90% of the time\(^a\,^f\)

Flexible on the go
The ONLY extended half-life product that can be stored up to 104°F\(^g\)
Please see Brief Summary for complete storage instructions.

What is Esperoct®?
Esperoct® [antihemophilic factor (recombinant), glycopegylated-exel] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A. Your healthcare provider may give you Esperoct® when you have surgery

- Esperoct® is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

Who should not use Esperoct®?
- You should not use Esperoct® if you are allergic to factor VIII or any of the other ingredients of Esperoct® or if you are allergic to hamster proteins

What is the most important information I need to know about Esperoct®?
- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center
- Call your healthcare provider right away or go to the emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

What should I tell my healthcare provider before using Esperoct®?
- Before taking Esperoct®, 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 Esperoct®, which may stop Esperoct® from working properly.

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

What are the possible side effects of Esperoct®?
- Common side effects of Esperoct® include rash or itching, and swelling, pain, rash or redness at the location of infusion

Please see Brief Summary of Prescribing Information on the following page.

Discover more at Esperoct.com.
You may infuse ESPEROCT® 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 hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member. Your healthcare provider will tell you how much ESPEROCT® to use based on your weight, the severity of your hemophilia A, and where you are bleeding. Your dose will be calculated in international units, IU. Call your healthcare provider right away if your bleeding does not stop after taking ESPEROCT®.

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 ESPEROCT® or even a different product to control bleeding. Do not increase the total dose of ESPEROCT® to control your bleeding without consulting your healthcare provider.

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

If you forget to use ESPEROCT®
If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next doses as scheduled and continue as advised by your healthcare provider.

If you stop using ESPEROCT®
Do not stop using ESPEROCT® without consulting your healthcare provider. If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much ESPEROCT®?
Always take ESPEROCT® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more ESPEROCT® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of ESPEROCT®?
Common Side Effects Include:
- rash or itching
- swelling, pain, rash or redness at the location of infusion
Other Possible Side Effects:
You could have an allergic reaction to coagulation Factor VIII products. Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called “inhibitors” against ESPEROCT®, which may stop ESPEROCT® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time. These are not all of the possible side effects from ESPEROCT®. 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 ESPEROCT® dosage strengths?
ESPEROCT® comes in five 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 five different strengths are as follows:

- 500 IU per vial
- 1000 IU per vial
- 1500 IU per vial
- 2000 IU per vial
- 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 healthcare provider.

How should I store ESPEROCT®?
Prior to Reconstitution (mixing the dry powder in the vial with the diluent):
- Protect from light. Do not freeze ESPEROCT®.
- ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months until the expiration date stated on the label. During the 30 month shelf life, ESPEROCT® may be kept at room temperature (not to exceed 86°F/30°C) for up to 12 months, or up to 104°F (40°C) for no longer than 3 months.
- If you choose to store ESPEROCT® at room temperature:  
  - Record the date when the product was removed from the refrigerator.
  - 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 stated 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:
The reconstituted (the final product once the powder is mixed with the diluent) ESPEROCT® should appear clear and colorless without visible particles. The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°C).

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

What else should I know about ESPEROCT® and hemophilia A?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use ESPEROCT® for a condition for which it is not prescribed. Do not share ESPEROCT® with other people, even if they have the same symptoms that you have.

Revised: 10/2019

ESPEROCT® is a trademark of Novo Nordisk Health Care AG.

More detailed information is available upon request. Available by prescription only.
Manufactured by:
Novo Nordisk A/S
Novo Allé
DK-2880 Bagsvaerd, Denmark
For information about ESPEROCT® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA
1-800-727-6500
© 2019 Novo Nordisk
US19ESP00168  December 2019

Your body can also make antibodies called “inhibitors” against ESPEROCT®, which may stop ESPEROCT® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time. These are not all of the possible side effects from ESPEROCT®. 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 possible side effects of ESPEROCT®?
Common Side Effects Include:
- rash or itching
- swelling, pain, rash or redness at the location of infusion
Other Possible Side Effects:
You could have an allergic reaction to coagulation Factor VIII products. Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called “inhibitors” against ESPEROCT®, which may stop ESPEROCT® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time. These are not all of the possible side effects from ESPEROCT®. 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 ESPEROCT® dosage strengths?
ESPEROCT® comes in five 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 five different strengths are as follows:

- 500 IU per vial
- 1000 IU per vial
- 1500 IU per vial
- 2000 IU per vial
- 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 healthcare provider.

How should I store ESPEROCT®?
Prior to Reconstitution (mixing the dry powder in the vial with the diluent):
- Protect from light. Do not freeze ESPEROCT®.
- ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months until the expiration date stated on the label. During the 30 month shelf life, ESPEROCT® may be kept at room temperature (not to exceed 86°F/30°C) for up to 12 months, or up to 104°F (40°C) for no longer than 3 months.
- If you choose to store ESPEROCT® at room temperature:
  - Record the date when the product was removed from the refrigerator.
  - 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 stated 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:
The reconstituted (the final product once the powder is mixed with the diluent) ESPEROCT® should appear clear and colorless without visible particles. The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°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 ESPEROCT® and hemophilia A?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use ESPEROCT® for a condition for which it is not prescribed. Do not share ESPEROCT® with other people, even if they have the same symptoms that you have.

Revised: 10/2019

ESPEROCT® is a trademark of Novo Nordisk Health Care AG.

More detailed information is available upon request. Available by prescription only.
Manufactured by:
Novo Nordisk A/S
Novo Allé
DK-2880 Bagsvaerd, Denmark
For information about ESPEROCT® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA
1-800-727-6500
© 2019 Novo Nordisk
US19ESP00168  December 2019
No matter where you are on your bleeding disorder journey, we’re there for you.

EVERY MILE OF THE JOURNEY.

MAKE TAKEDA YOUR FIRST DESTINATION AT HFA!

Check out our Educational Session!
Be inspired by members of the Bleeding Disorders Community through our educational symposium.

JOIN US AT OUR VIRTUAL BOOTH!
Learn about new product information and learn how Takeda can support you throughout your Bleeding Disorders Journey.

SIGN UP. STAY INFORMED. FIND YOUR DRIVE.
Go to www.hematologyoptin.com and sign up to receive the latest Takeda Bleeding Disorders Community News.
"I was diagnosed when I was three weeks old—the first in my family. No family history whatsoever."
–Ryan Moulton, Guest Speaker

WHEN:
Saturday, August 29
5–6:30pm ET

HOW TO ATTEND:
Log in to the HFA Symposium virtual lobby and navigate to the “Auditorium.”

HOST:
Tiago Dias,
Director of Marketing, Bayer

SPEAKERS:
Ryan Moulton, Patient
Juan Pablo Lopez Padilla, Patient
Stacey Mollinet, Mom

Join us for a virtual My Journey to Jivi event.

Special guest speakers from the community will share stories about their life experiences and transition to Jivi – a treatment option from Bayer.

You’ll also learn more about the science behind Jivi including results from our extension study.

Visit MyJourneyToJivi.com to hear more inspiring and relatable stories through our new series of videos, and to find out about additional upcoming programs.
You are why.
At Sanofi Genzyme, we are deeply connected to the rare blood disorders community. From innovative research to personal support, you inspire our efforts to make more possible for you and the people you love.

Visit our virtual booth to learn more.
WE WILL MISS SEEING YOU IN BALTIMORE
BUT HOPE TO SEE YOU AT
CSL BEHRING’S VIRTUAL BOOTH
AUGUST 24 TO 29, 2020

PLEASE JOIN US TO LEARN ABOUT MANAGING YOUR
BLEEDING DISORDER, CONNECT WITH MEMBERS
OF THE CSL BEHRING TEAM, AND ENTER TO WIN
A RAFFLE PRIZE.

Learn more at www.hemophiliafed.org/Symposium
HFAexhibitors@hemophiliafed.org
At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you’ve shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team
Get updates from the Takeda Bleeding Disorders Community.

Scan the QR code and sign up to receive the latest Takeda Bleeding Disorders Community News.
FIND YOUR DRIVE.
Now it’s easier than ever to make a difference.

Help make IXINITY® available to individuals in the United States who can’t afford to be without it. It’s easy. Just visit signthe9.com and fill out a brief form. When you do, 9 IU of IXINITY will be donated in your name. While you’re there, build your own one-of-a-kind 9. Add your name, share your 9 on social media…and watch the support grow!

Visit signthe9.com today!
Help make IXINITY® available to individuals in the United States who can’t afford to be without it. It’s easy. Just visit signthe9.com and fill out a brief form. When you do, 9 IU of IXINITY will be donated in your name.

While you’re there, build your own one-of-a-kind 9. Add your name, share your 9 on social media…and watch the support grow!

Visit signthe9.com today!

BRINGING GENE THERAPY TO LIFE

Leon, hemophilia B patient in AMT-060 gene therapy clinical trial.

Learn more about our focus on the rare bleeding disorder community

Visit hemabio.com

TALK TO YOUR DOCTOR TO LEARN MORE ABOUT KOĀTE.

KOĀTE® [Antihemophilic Factor (Human)]

Discover more, including additional resources, financial assistance programs, and community support, at mykoate.com

Koate is a registered trademark of Kedrion Biopharma Inc. ©2019 Kedrion Biopharma Inc. All rights reserved. September 2019 KT-0698-00-2019A
At this year’s Hemophilia Federation of America symposium...

DISCOVER WHAT THESE PEOPLE HAVE IN COMMON

- Hemophilia A high-volume patient
- Hemophilia A patient with inhibitor
- Previously untreated hemophilia A patient
- Patient with von Willebrand disease requiring surgery

VISIT THE GRIFOLS BOOTH TO FIND OUT!

Grifols

© 2020 Grifols
All rights reserved
US-A8-2000053
© 2020 Grifols
July 2020

Get to know Octapharma better.
Visit: www.octapharmausa.com

BE INFORMED.
FEEL EMPOWERED.
ADVANCE YOUR KNOWLEDGE OF GENE THERAPY.

Explore the science of gene therapy research at HemophiliaForward.com.

Hemophilia Forward

© 2020 SparkTherapeutics, Inc. N-HEM-US-420091

Thank you to our 2020 Virtual Symposium Sponsors!
Virtual Symposium Participant
Code of Conduct

HFA’s Virtual Symposium is a new experience for HFA and our community. It is intended to be a fun and safe learning environment designed to provide the same educational opportunity as our in-person conference, increase interaction and engagement among the community, and foster a sense of connectivity and collaboration among participants.

We value the involvement of each participant and endeavor to deliver an enjoyable and fulfilling experience. Participants are expected to conduct themselves with integrity, courtesy and respect for others at all sessions and activities.

All participants are asked to do their part to ensure that Virtual Symposium discussions are conducted in a respectful manner, and to allow all participants the opportunity to take part. All participants are required to observe the following Code of Conduct:

• HFA will not tolerate harassment in any form and is dedicated to providing a safe and welcoming experience for all participants regardless of gender, sexual orientation, disability, physical appearance, race or religion. All participants must conduct themselves in a manner that is appropriate for and inclusive of people of diverse backgrounds and cultures. Sexual or derogatory language and imagery is not appropriate.

• Do not insult or defame participants, speakers or exhibitors. Participants violating these rules will be asked to leave the program.

• Some discussions over the course of Virtual Symposium may include disclosure of an individual’s personal information (e.g., health or financial information). All participants are asked to help protect the integrity of Symposium, and to keep confidential any such information discussed.

• All participants are also reminded to refrain from steering conversation in the direction of bleeding disorders business (to or away from specific companies, products, and/or providers).

Thank you for helping to make this a welcoming event for all!

Please contact symposium@hemophiliafed.org for more information or to report misconduct.
We’ll miss seeing you in person, but help us
create new memories in this virtual setting.
COMMUNITY AWARDS
Presented Live During Awards Ceremony
Tuesday, Aug. 25 • 7:30 to 8:30 p.m. ET
Each year, we recognize the service of special individuals who have gone above and beyond to serve the bleeding disorders community.

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

Charles Stanley Hamilton Legacy Award
For extraordinary lifetime service that encompasses national volunteerism, professionalism and leadership.

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

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

Terry Lamb Health and Wellness Award
For exceptional commitment to supporting HFA in its national efforts to encourage health, nutrition and wellness behaviors in the bleeding disorders community.

Member Organization Spotlight Award
Recognizing an HFA Member Organization with a true passion for service to their community, this award honors an organization who has created an environment within their membership that engages members, continually promotes education and consistently encourages self-advocacy.

Special Service Recognition
An award chosen by HFA staff in recognition of special behind-the-scenes volunteer work.

*Not all awards are given annually.
BOARD, STAFF & VOLUNTEERS

HFA Board of Directors & Member Organizations
HFA recognizes our Board Members, representing 50 Member Organizations for the bleeding disorders community. Our board is purposefully designed to ensure each Member Organization has a voice at the national level.

Executive Board
Josh Hemann .................................. Chair
Lianne Lapiere ................................. Vice Chair
Stephen Long .................................. Secretary, Hemophilia Association of the Capital Area
Clyde Brawner ................................. Treasurer, Oklahoma Hemophilia Foundation
Carletha Gates ................................. Member at Large, United Hemophilia Foundation
Ashley Gregory ................................. Member at Large, Hemophilia Foundation of Northern California
Daniel Warren ................................. Member at Large, Virginia Hemophilia Foundation
Tracy Cleghorn ................................. Past Board Chair
Board Members

John Palmatier ..................................... Alaska Hemophilia Association
Monica Diaz ........................................ Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado
Allison Ritcey ......................................... Bleeding Disorder Foundation of Washington
Lily Schwartz ......................................... Bleeding Disorders Alliance Illinois
Carson Ouellette ..................................... Bleeding Disorders Alliance of North Dakota
Michael Deeb ......................................... Bleeding Disorders Association of Northeastern New York
Cheri Wakeham ....................................... Bleeding Disorders Association of the Southern Tier
Jeffery Watkins ...................................... Blood Bond Bleeding Disorder Network
Sean Hubbert ......................................... Central California Hemophilia Foundation
Meagan Rhyanedd Murray ........................... Connecticut Hemophilia Society
Bernadette Fox .................................... Eastern Pennsylvania Hemophilia Foundation
Maria Rubin ........................................... Florida Hemophilia Association
Anne Parrott ......................................... Gateway Hemophilia Association
Thomas Beaudet ..................................... Hemophilia Alliance of Maine
Joseph Markowitz .................................. Hemophilia Association of New Jersey
Tyshawn Constantine ............................... Hemophilia Association of New York Inc.
Austin Holland ..................................... Hemophilia Foundation of Arkansas
Natasha Burroughs .................................. Hemophilia Foundation of Maryland
Shari Luckey ......................................... Hemophilia Foundation of Michigan
Kris Manns ............................................ Hemophilia Foundation of Minnesota / Dakotas
Ron Staake ............................................ Hemophilia Foundation of Southern California
Kasey Shade .......................................... Hemophilia of Indiana
Estefana Monge-Sotelo ............................ Hemophilia of Oregon
Gillian Schultz ....................................... Hemophilia of North Carolina
Renita Johnson ........................................ Hemophilia of South Carolina
Jesus Escobedo-Soto ................................ Hemophilia Outreach of El Paso
Laura Portales ....................................... Lone Star Hemophilia Chapter
Erica Simpson ....................................... Louisiana Hemophilia Foundation
Lindsay Hooper ...................................... Mary M. Gooley Hemophilia Center
Angela Brown ........................................ Midwest Hemophilia Association
Britnee Vieira ....................................... New England Hemophilia Association
Alice Araphsian ..................................... New York City Hemophilia Chapter
Tanya Ricchi ......................................... Northern Ohio Hemophilia Foundation
Maria Chavez ........................................ Sangre de Oro Inc., Bleeding Disorders Foundation of New Mexico
Dena Shepard ........................................ Southwestern Ohio Hemophilia Foundation
Anne-Louise Wirthlin ............................... Tennessee Hemophilia and Bleeding Disorder Foundation
Taha Amir ............................................. Texas Central Hemophilia Association
Scott Muir ............................................ Utah Hemophilia Foundation
Stephanie Mancusi .................................. Wisconsin Bleeding Disorders Network
Scott Domowicz ..................................... Western Pennsylvania Chapter of NHF

The following organizations have an open seat on the board: Hemophilia of Iowa, Rocky Mountain Hemophilia and Bleeding Disorders Association, Snake River Hemophilia and Bleeding Disorders, Arizona Bleeding Disorders Association, and Great Lakes Hemophilia Foundation.
HFA Staff & Consultants
Dr. Sharon Meyers ...........President / CEO
Pat Brown ...................Vice President, Meetings
Michelle Burg ..............Vice President, Operations
Ann LeWalk ...............Vice President, Education
Sonji Wilkes .............Senior Director, Policy, Advocacy & Government Relations
Janet Chupka ............Director, Research
Dr. Mabel Crescioni ....Director, Public Health & Outcomes Projects
Matt Landseadel .........Director, Technology
Lori Long .................Director, HFA Institute
Miriam Goldstein ......Director, Policy/Principal Legal Counsel
Carrie Koenig ..........Director, Programs
Kyle McKendall ..........Director, Advancement
Lauren Black ............Associate Director, Services
Michael DeGrandpre ....Associate Director, Communications
Emily Roush-Bobolz ......Associate Director, Communications
Kimberly Ramseur .......Senior Manager, Policy & Advocacy
Mark Hobraczk ..........Senior Manager, Policy
Dr. DeBran Tarver ........Senior Analyst
Angela Burton ..........Grants Manager
Martha Boria Negron ...Programs Manager
Allison Harrison .......Programs Manager
Renee Waller ............Board Liaison and Special Projects Manager
Athena Harrison ........Meetings Manager
Andy Anderson ........Program Coordinator
Eric Burgeson ..........Program Coordinator
Tatiana Pacheco Parés ....Program Coordinator
Michael Bishop ........Web Specialist
Ashley Smith ..........Development Coordinator
Alexander Butler ........Data Coordinator
Serina Tabisola ........Project Coordinator

Consultants
Meredith Clark ............Program Coordinator
Heather Case ...............Program Coordinator
Sarah Tarver ............Helping Hands Coordinator
Whitney Armijo ..........Research Coordinator
Chad Stevens ............Project Coordinator
Kristin Mitchell ..........Graphic Designer
Ashley Williams ..........Graphic Designer
Gina Richards, Kevin Daniels ....Photography
Chiuminatto Accounting Services

SPECIAL THANKS
Our sincere thanks to those who helped make Symposium possible!
The time, skills and enthusiasm you’ve invested are invaluable.

Symposium Planning Committee
Tracy Cleghorn, Committee Chair
Cristina Barnes
Natasha Burroughs
Tyshawn Constatine
Monica Díaz Mattei
Danielle Flores
Carleatha Gates
Ashley Gregory
Josh Hemann
Renita Johnson
Lianne Lapierre
Stephanie Mancusi
Emma Miller
Laura Portales
Maria Rubin
Britnee Vieira

HFA Volunteers
To the many volunteers, activists and advocates that work with us through the year, we honor and appreciate you.
Hemophilia Federation of America is a national nonprofit organization which assists, educates and advocates for the bleeding disorders community.

THANK YOU FOR JOINING US!
SEE YOU NEXT YEAR!