SPECIAL ANNIVERSARY ISSUE

The Bleeding Disorders Magazine Mational Hemophilia Foundation Themaware.org

# Celebrating 75 Years

THE RED THREAD: HONORING HISTORY, HOPE, AND PROGRESS



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LEARN ABOUT ALPROLIX

# WHAT'S A CoRe MANAGER?

Sanofi Community Relations and Education Managers (CoRes) have years of experience working with patients on ALPROLIX and can provide you with helpful resources and education.

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CoRe Managers are dedicated to providing education and empowering those within the community.

# **UNDERSTANDING**

CoRe Managers are driven professionals with decades of combined experience who understand and appreciate the community's needs.

# ACCESSIBLE

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# INSIDE



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The National Hemophilia Foundation is grateful to the sponsor of this special 75th anniversary issue.

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# hemaware.org

Search #NHF75 on social media to learn more about this historic year on your favorite social platform.



This is an amazing moment to not only reflect on NHF's impact over our 75-year history, but to also look forward.

# 75 Years of Research, Education, and Advocacy

The National Hemophilia Foundation began in 1948 as one couple's pursuit of a better quality of life for their child with a bleeding disorder.

Today, an astonishing number of people contribute to the cause and greatly expand the foundation's reach. But at the core, our values remain unchanged — to find cures for inheritable blood disorders and to address and prevent the complications of these disorders through research, education, and advocacy, enabling people to thrive.

As we celebrate our 75th anniversary, we commemorate the researchers whose groundbreaking discoveries helped us first to recognize blood and bleeding disorders and then to understand more about them. We appreciate the medical experts who advise on treatment guidelines.

We recognize the professionals and volunteers at our chapters and treatment centers throughout the U.S. and Puerto Rico. We applaud their hard work and dedication to treat, educate, and support the bleeding disorders community at a local level.

We have grown our community to include people with blood and bleeding disorders besides hemophilia, such as von Willebrand disease and rare factor deficiencies.

I'm particularly proud of the work we've done to be more inclusive in our communities, especially among women and people of color, and to expand their access to care.

This is an amazing moment to not only reflect on NHF's impact over our 75-year history, but to also look forward to the organization's next chapter. The more inclusive we become for all bleeding and blood disorders, the more progress we can make in creating an equitable health care system for our community's vocal and passionate advocates.

With this goal in mind, we're taking a bold step into the future by changing our organization's name. Turn to Page 11 to find out more.

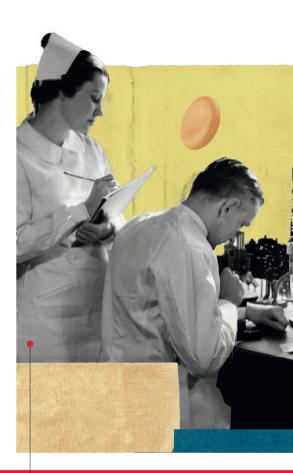
Throughout this yearlong campaign, which we call "The Red Thread," I have enjoyed looking back on our organization's first 75 years and envisioning what lies ahead for all of us. I hope you'll enjoy it, too.

Sincerely,

Leonard A. Valentino, M.D. President and CEO

# THE RED THREAD





# 1948

NHF is founded as The Hemophilia Foundation Inc. by Robert Lee Henry, whose son was diagnosed with hemophilia in 1942 when he was just 14 months old.



# CHAPTERS BRING EDUCATION AND ADVOCACY TO THE LOCAL LEVEL

Since its founding in 1948, NHF has been dedicated to research, education, and advocacy so people within the bleeding disorders community can thrive. NHF chapters have been instrumental in driving the organization's initiatives at the local level. A network that began with one chapter in 1949 is now 52 chapters strong.

Through the years, NHF has worked with its chapters to aid in their capacity and staff development, train advocates, and identify issues around accessing care. Chapters, in turn, provide vital programs that connect people within their local bleeding disorders communities through state advocacy days, educational retreats, summer camps, scholarships, and financial assistance.

# 1949

NHF's Midwest Chapter (now the Bleeding Disorders Alliance Illinois) is formed in Chicago. Over the years, more of these local organizations form throughout the U.S. and in Puerto Rico to provide education and services to people with bleeding disorders. Today, NHF has 52 established local chapters.

# 1954

NHF founder Robert Lee Henry establishes the Medical Advisory Council (now the Medical and Scientific Advisory Council, or MASAC) to advise on treatment standards, research, and other general health concerns for the bleeding disorders community.

# EXPERTS IN ADVANCING MEDICINE

The foundation began as an organization that brought doctors and researchers together at a time when little was known about treatments for bleeding disorders. It makes sense, then, that soon after incorporation, founder Robert Lee Henry established the Medical Advisory Council, which later became the Medical and Scientific Advisory Council, or MASAC.

Over the years, MASAC — made up of experts in research, patient care, and public health — has issued more than 400 communications, including standard treatment guidelines covering a wide range of medical issues.

# **TIMELINE:** 1948 - 1969



#### Here are a few noteworthy advisories:

• MASAC created the standards and criteria for the care of people with congenital bleeding disorders. The regularly updated document includes lists of services that hemophilia treatment centers should provide.

• The council issued recommendations for prophylaxis treatment for people with hemophilia A or B.

• Noting that inherited bleeding disorders often go unrecognized among girls and women, MASAC made recommendations regarding the diagnosis and management of bleeding disorders in that group.

.....

• MASAC developed guidelines for emergency departments to give appropriate, expeditious care to people with bleeding disorders.

• The council detailed products that health care providers and physicians should use to treat people with bleeding disorders. MASAC also made recommendations to the manufacturers of those products and to the U.S. Food and Drug Administration regarding regulation.



The Hemophilia Foundation Inc. changes its name to the National Hemophilia Foundation. Later in the year, NHF hands over business functions from volunteers to official staff and maintains its headquarters in New York City.

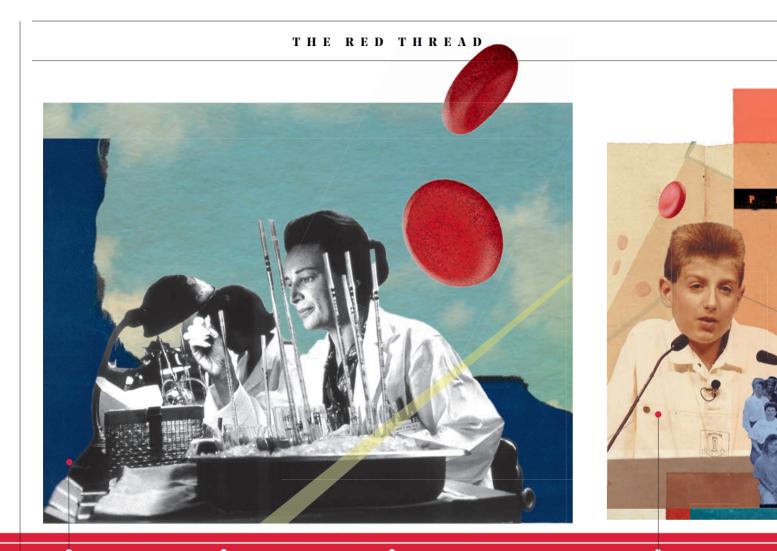
#### 1962

At an NHF luncheon, Congressman John Fogarty spoke of his support for hemophilia research and treatment: "That is why I urge you to join me in telling the people in your organization, in the areas where you have a voice, how important it is that nothing interfere with the rising tide of medical research in this nation." Two months later, he asks Congress to increase funding for the disorder.

#### 1969

Summer camps begin at Camp Bold Eagle in Michigan, providing children with bleeding disorders a typical camp experience under the caring watch of counselors and staff.

In 2006, with support from NHF, a committee of camp directors and health care professionals created a set of health and safety guidelines for camp personnel.



# 1972

The Judith Graham Pool Postdoctoral Research Fellowship program is established. Named after the pioneering researcher who discovered a method for extracting clotting factor from human plasma to create cryoprecipitate, the fellowship provides funding to postdoctoral scientists who go on to produce vital insights into hemophilia and other bleeding disorders.

# RESEARCH PIONEER JUDITH GRAHAM POOL, PH.D. (1919–1975)

Judith Graham Pool is best known for discovering a method to extract clotting factor from human plasma to create cryoprecipitate. This 1965 breakthrough made it possible for people to have concentrated factor transfusions that were shorter, safer, and less expensive.

Pool spent most of her career at Stanford University and founded the Professional Women of Stanford University Medical School organization.

In 1972, NHF established the Judith Graham Pool Postdoctoral Research Fellowship in her honor, which over the past 50 years has awarded more than \$16.5 million in research funding and supported more than 100 research projects focused on bleeding disorders.

#### 1973-1975

The Hemophilia Act of 1973 is introduced — and passes two years later — to establish a national network of federally funded hemophilia treatment centers. HTCs provide comprehensive care for people with bleeding disorders in one convenient location.

# 1984

Ryan White, a 13-year-old with hemophilia, receives an AIDS diagnosis after a contaminated factor infusion and becomes the face of the HIV crisis for the bleeding disorders community. Four years later, more than 60% of America's 20,000 people with hemophilia had contracted HIV, and NHF continues its efforts to improve the safety of the nation's blood supply.

### 1989

The Women's Outreach Network of the NHF (WONN) is founded to educate and support women in the bleeding disorders community during the HIV/AIDS crisis.

# TIMELINE: 1972 - 1996



# RESEARCH PIONEER KENNETH BRINKHOUS, M.D. (1908–2000)

Kenneth Brinkhous, M.D., began his career by studying the coagulation properties of blood, and, along with his colleagues in the Department of Pathology at the University of North Carolina at Chapel Hill, he made numerous discoveries to advance bleeding disorders care.

In 1953, he led a team of researchers to develop a diagnostic tool for identifying suspected clotting factor deficiencies. In 1955, he and two other pathologists developed IV infusions of factor VIII. Brinkhous' work paralleled NHF's in the 1940s and '50s. When the foundation's Medical and Scientific Advisory Council was formed in 1954 to advise on treatment and research for the bleeding disorders community, Brinkhous was the unanimous choice to serve as its first chair, a position he held for 19 years.

NHF honored his many contributions to the bleeding disorders community in 1991 by establishing the Kenneth M. Brinkhous Award for Excellence in Clinical Research.

# 1991

A companion to the WONN women's group, the Men's Advocacy Network of the NHF (MANN) launches to educate and offer peer support to men in the bleeding disorders community.

#### 1991

In response to the HIV/ AIDS crisis, NHF establishes HANDI (Hemophilia and AIDS/HIV Network for the Dissemination of Information) to be a trusted source of educational and informational resources for the bleeding disorders community.

### 1996

NHF hosts the first Washington Days in the District of Columbia. The annual three-day event brings hundreds of advocates from all over the country together to receive advocacy training and meet with legislators on Capitol Hill to discuss issues important to the NHF community.

#### 1996

NHF publishes its first issue of *HemAware*. The twice-yearly magazine provides in-depth information about blood and bleeding disorders.

# THE RED THREAD



#### 1996

NHF creates a publication — retitled "Playing it Safe" in 2005 and revised in 2017 that encourages children to enjoy the benefits of physical activity while explaining how to do so safely with blood and bleeding disorders.

#### 1998

The Women with Bleeding Disorders Task Force convenes to focus on the needs of women in the bleeding disorders community.

#### 1998

The Ricky Ray Hemophilia Relief Fund Act becomes law. NHF lobbyist Val D. Bias is instrumental in the passage and funding of the legislation, which compensates people with bleeding disorders who contracted HIV from contaminated blood products. Bias becomes NHF's CEO in 2008 and leads the foundation for 12 years.

#### 2000

The Career Development Award is created to fund innovative bleeding disorders research projects and foster the careers of researchers in the field.

#### 2002

The National Youth Leadership Institute is launched to provide leadership opportunities for young adults (ages 18 to 24) in the bleeding disorders community and to encourage personal growth, effect change, and positively influence others.

# 2003

NHF launches a clinical fellowship program that provides new physicians an opportunity to receive training from mentors at designated university centers. Many of the 43 physicians trained through the program are leaders of hemophilia treatment centers today.

#### 2008

To build NHF's capacity to achieve and maintain access to care for the entire bleeding disorders community, the foundation launches the ACT Initiative (Access to Care Today, Achieving Cures for Tomorrow). Goals include a united network of chapters, major funding of research for better treatments, and effective national advocacy.

#### 2011

The Steps for Living website launches, providing comprehensive information on bleeding disorders for young children, adolescents, adults, parents, and health educators to promote healthy living through all life stages.

#### 2012

The State-Based Advocacy Coalition begins with five states to respond to advocacy challenges affecting access to care for the bleeding disorders community.

#### 2014

NHF conducts a summit meeting of stakeholders on von Willebrand disease in Washington, D.C. The purpose is to discuss and develop a strategic

# TIMELINE: 1996 - 2020



approach for raising awareness of VWD and improving patients' access to care.

#### 2016

March is designated Bleeding Disorders Awareness Month on the National Health Observances calendar, making it easier for NHF advocates to elevate awareness among elected officials and present solutions to them on how to better serve the community.

#### 2017

NHF introduces the Guias Culturales (cultural guides) program, in which trained volunteers provide education and empowerment to the Spanish-speaking bleeding disorders community.

#### 2018

For its 70th anniversary, NHF rebrands its annual meeting as the Bleeding Disorders Conference.

#### 2019

NHF launches MyBDC later renamed Community Voices in Research — as a community-powered registry for people with bleeding disorders to help researchers understand what it means to live with the condition.

# 2020

Puerto Rico's bleeding disorders chapter, Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado, is chartered by NHF, expanding the ways the foundation can support people on the island.

#### STAR-STUDDED SUPPORTER

Alex Borstein, Emmy award winner and star of *The Marvelous Mrs. Maisel*, has a brother and uncle with hemophilia and has been a longtime supporter of the foundation. She has contributed to many NHF initiatives, including an awareness campaign for von Willebrand disease. "I have seen how it literally 'bleeds' into every aspect of your life," she says. "Not only from my family, but through my work with the bleeding disorders community. I have learned how these conditions have an emotional component that needs to be addressed, too."





## RESEARCH PIONEER JEANNE LUSHER, M.D.

# (1935–2016)

Jeanne Lusher, M.D., a researcher and clinician in pediatric hematology, made groundbreaking contributions to the bleeding disorders community. In 1966, she and a colleague were the first to identify inhibitors as antibodies to factor VIII.

Two years later, she began two appointments: as an assistant professor of pediatrics at Wayne State University School of Medicine, where she later became the Marion Barnhart hemostasis research professor and a distinguished professor of pediatrics, and as a pediatric hematologist/ oncologist at Children's Hospital of Michigan, where she later became chief of hematology/oncology.

Lusher received NHF's Outstanding Research Award in 1984 and the Kenneth M. Brinkhous Award for Excellence in Clinical Research in 1990.

Because of her leadership in bleeding disorders research, in 1994 Lusher was named chair of NHF's Medical and Scientific Advisory Council. She was the first woman to hold the position.

In 2021, the Jeanne Marie Lusher Diversity Fellowship was established in her honor to support new clinicians and researchers who are people of color.

# 2020

In response to recalls and product safety notifications issued in 2019, NHF and the Hemophilia Federation of America (HFA) convene a Safety Summit in Washington, D.C., to discuss how to improve education on drug safety standards and communications to people who use those therapies.

#### 2020

NHF creates a national online forum exclusively for Black and African American members of the bleeding disorders community, along with their families and caregivers, to connect and share experiences. In 2022, the platform transitions to a Facebook group.

### 2021

NHF refocuses its mission statement to reflect a renewed emphasis on research. It also expands the scope to include inheritable blood disorders such as sickle cell disease and platelet disorders in addition to bleeding disorders such as hemophilia and von Willebrand disease.

### 2021

The Jeanne Marie Lusher Diversity Fellowship is established in honor of a distinguished clinician and researcher who had a tremendous effect on the bleeding disorders community. The fellowship is open to people of color.

# TIMELINE: 2020 - 2023



## ADVOCACY: FIGHTING FOR CHANGE

Advocacy has been a critical part of NHF's mission. In 1948, Robert Lee Henry and his wife, Betty Jane, founded NHF to support their son, who was diagnosed with hemophilia at 14 months old, and to give others living with bleeding disorders a collective voice that would be heard by legislators and government agencies.

# 2021

NHF holds a virtual State of the Science Research Summit to design and implement the National Research Blueprint — to be released in 2023 — that will shape the future of bleeding disorders research, putting people with inherited bleeding disorders, as well as their families and caregivers, front and center.

#### 2021

Keri Norris, Ph.D., becomes vice president of health equity, diversity, and inclusion, a new position at NHF, to create a framework for the foundation's programs that addresses disparities in health outcomes within the bleeding disorders community.

# 2023

At the 75th annual Bleeding Disorders Conference, NHF unveils a rebrand, including an organizational name change and an aesthetic update. The new name, National Blood Disorders Foundation (NBDF), reflects the many blood and bleeding disorders represented by this community. Individuals and families looking for answers for all blood and bleeding disorders and conditions have a place to receive research and educational information and representation on public policy and health care issues.

# NATIONAL BLOOD DISORDERS FOUNDATION

To see more moments throughout NHF's 75-year history, visit hemophilia.org/75

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# Hemophilia on your terms.

Everyone's hemophilia needs are different. We're here to help meet those needs simply—with education and support options that can help inspire the new normal that's just right for you.



Discover how we can help.

RedefiningHemophilia.com

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# sanofi





# Sanofi's Ongoing Commitment to Improving the Lives of People With Rare Blood Disorders

# BLAZING A TRAIL FOR RARE BLOOD DISORDERS

At Sanofi, we chase the miracles of science to improve people's lives and challenge the status quo for rare blood disorder treatments. Patients and science are at the center of everything we do, and we are steadfast in our commitment to find, research, and develop treatments where there are unmet needs. Our approach to scientific innovation is foundational to our ability to serve the rare blood disorder community and offer hope now, and in the future. By focusing on first-in-class and best-in-class treatments and vaccines, Sanofi aims to change the practice of medicine for the better.

# SCIENTIFIC INNOVATION TO DEVELOP BREAKTHROUGH THERAPIES

In 2014, we launched the first extended half-life factor replacement therapies for people with hemophilia A and B. These products were the first innovations in hemophilia management in 20 years. More recently, we pioneered a high-sustained factor VIII replacement therapy class that is elevating treatment expectations for people with hemophilia A, regardless of age. Sanofi's quest to push the boundaries of scientific innovation continues as we explore potential treatments for hemophilia A and B with or without inhibitors. Continuing to build on our legacy of innovation for patients with limited

Sanofi is dedicated to developing transformative therapies that evolve treatment expectations and empower people living with rare blood disorders to better manage their health.

Jeff Schaffnit, Head of US Rare Blood Disorders at Sanofi

treatment options, Sanofi launched the first and only FDA-approved treatments for acquired thrombotic thrombocytopenic purpura (aTTP) and cold agglutinin disease (CAD). We are also exploring new treatment approaches in immune thrombocytopenia (ITP). We never stop innovating and are determined to transform the standard of care for people affected by rare blood disorders.

# AMPLIFYING PATIENT AND CARE PARTNER VOICES TO UNCOVER UNMET NEEDS

At Sanofi, our passion is to prevent and treat illness and disease throughout life. Our goal is to bring visibility to the sometimes invisible and, most importantly, listen and learn from external stakeholders about what patients and their families need and deserve. We are proud to participate in National Research Blueprint efforts to help shape the future of research for people with inheritable bleeding disorders (IBDs). This communitydriven collaboration will help shed light on the most pressing issues challenging people and families with IBDs.

# MAKING THE FUTURE OF HEMOPHILIA CARE MORE ACCESSIBLE AND SUSTAINABLE

We believe that every person should have the opportunity to be as healthy as possible and receive the care that they deserve. Our mission is to accelerate health equity, so that all patients have access to transformative medicines. Through our partnership with the National Hemophilia Foundation's Health Diversity, Equity & Inclusion Initiative, we work together to advocate for underrepresented communities.



# SUPPORTING MENTAL HEALTH AMONG PEOPLE WITH BLEEDING DISORDERS

In an effort to engage a more holistic approach to healthcare, Sanofi supported a **mental health documentary that presents the perspectives of people with rare blood disorders** produced by Believe Limited, called *Let's Talk*. The film was developed to help address an unmet need for mental health resources, and to spark conversation, increase awareness, and decrease stigma.

At the 2023 Annual Bleeding Disorders Conference, Sanofi unveiled a new documentary produced by Believe Limited, titled *Elite Athletes With Hemophilia*. The film **chronicles the experiences of 6 athletes with bleeding disorders who have managed to overcome adversity** and pursue their passion for athletic competition. At the meeting, Sanofi will also be releasing an album with 7 songs that were inspired by the journeys of 7 individuals living with hemophilia.



# Sanofi Rare Blood Disorders at a Glance: Our Past, Present, Future

# Sanofi has also introduced 2 programs to address health equity challenges with out-of-the-box solutions:

# Annual Health Equity Accelerator

Awards that support the efforts of US advocacy groups to address specific challenges impacting underserved populations. The 2023 winners will be announced this fall, so please keep an eye on Sanofi US social channels for more information.

# **Health Equity Acceleration Community**

of Practice provides a space that brings



together 150+ USbased advocacy leaders across all therapeutic areas in which Sanofi engages to make connections, inspire learning, and share best practices.

# **OUR VISION FOR THE FUTURE**

As we look toward the future, we are inspired by the resilience of our patients and are strengthened by our heritage. We will continue to forge close relationships with physician, patient, care partner, and advocacy communities. Sanofi is committed to working on new ways to fight chronic, complex, and rare diseases with medicines that offer hope for the future of healthcare.

# Scan the QR code or visit rareblooddisorders.com

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# sanofi

# Our all, for you.

You inspire us to break new ground in treatment, expand access to education and support, and help to redefine hemophilia for this incredible community.



# See our dedication in action.

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# [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion proteinehtl] for intravenous use after reconstitution only

# Single-dose vial

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

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

Do not attempt to give yourself an injection 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 injecting ALTUVIIIO so that your treatment will work best for you.

# What is ALTUVIIIO?

ALTUVIIIO is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIO when you have surgery.

# Who should not use ALTUVIIIO?

You should not use ALTUVIIIO if you had an allergic reaction to it in the past.

## What should I tell my healthcare provider before using ALTUVIIIO? Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ALTUVIIIO may harm your unborn baby.
- Breastfeeding. It is not known if ALTUVIIIO passes into the milk and if it can harm your baby.

# How should I use ALTUVIIIO?

You get ALTUVIIIO as an injection into your vein. Your healthcare provider will instruct you on how to do injections on your own, and may watch you give yourself the first dose of ALTUVIIIO.

Contact your healthcare provider right away if bleeding is not controlled after using ALTUVIIIO.

# What are the possible side effects of ALTUVIIIO?

You can have an allergic reaction to ALTUVIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

# What are the ALTUVIIIO dosage strengths?

ALTUVIIIO comes in seven different dosage strengths with 3 mL sterile water for injection (sWFI). The actual number of international units (IU) of Factor VIII activity in the vial will be imprinted on the label and on the box. The seven different strengths are as follows:

Strength	Cap Color
250 IU	Yellow
500 IU	Red
750 IU	Garnet
1000 IU	Green

(continued)	
Strength	Cap Color
2000 IU	Royal Blue
3000 IU	Mist Grey
4000 IU	Orange

(continued)

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 ALTUVIIIO?** 

- Keep ALTUVIIIO in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated 2°C to 8°C (36°F to 46°F) up to 48 months or at room temperature [not to exceed 30°C (86°F)], for a single period up to 6 months. Do not use ALTUVIIIO after the expiration date printed on the label and carton of each vial.
- When storing at room temperature:
  - Note on the carton the date on which the product is removed from refrigeration.
  - Use the product before the end of this 6-month period or discard it.
- Do not return the product to the refrigerator.

# After mixing with the diluent:

- Do not use ALTUVIIIO if the mixed solution is not clear and colorless to slightly yellowish.
- Use mixed product as soon as possible.
- You may store mixed ALTUVIIIO at room temperature, not to exceed 30°C (86°F), for up to 3 hours. Protect the mixed ALTUVIIIO from direct sunlight. Discard any mixed ALTUVIIIO not used within 3 hours.

# What else should I know about ALTUVIIIO?

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

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AHF-PPI-SL-FEB23

A NEW CLASS OF ONCE-WEEKLY INFUSION



# FACTOR UP with ALTUVIIIO TM

Higher-for-longer Factor VIII levels in the near-normal to normal range (over 40%) for most of the week



# **HIGHER FACTOR** LEVELS FOR LONGER Above 40% for most of the week (near-normal to normal range).\*†



ALTUVIIIO offered adults the longest half-life of any Factor VIII therapy.



# **BLEEDS PER YEAR<sup>‡</sup>**

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.<sup>†</sup>

\*Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

<sup>1</sup>159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1, and switched to ALTUVIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients. <sup>‡</sup>Data based on treated bleeds.

# **INDICATION**

ALTUVIIIO<sup>™</sup> [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIO when you have surgery.

# **IMPORTANT SAFETY INFORMATION**

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

Do not attempt to give yourself an injection 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 injecting ALTUVIIIO so that your treatment will work best for you.

# Who should not use ALTUVIIIO?

You should not use ALTUVIIIO if you have had an allergic reaction to it in the past.

# What should I tell my healthcare provider before using ALTUVIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

# What are the possible side effects of ALTUVIIIO?

You can have an allergic reaction to ALTUVIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

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Please see brief summary of Patient Information on the previous page.

# Connect with your CoRe today

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