



Managing Life with Hemophilia

A RESOURCE FOR PARENTS,
FAMILIES AND CAREGIVERS

AcariaHealth[™]
Specialty Pharmacy

Transforming Lives With Compassionate Care



What is Hemophilia?

Hemophilia is a rare disorder in which blood doesn't clot normally. One study shows that as many as 33,000 males in the US are living with the disorder.*

Hemophilia Type A is the most common type. Patients with Hemophilia A have low levels of a blood-clotting substance called factor 8. They may bleed for longer periods of time after an injury. The biggest risk involves bleeding into joints and other vital areas such as the result of a head injury. Hemophilia A affects 1 in 5,000 male births. About 400 babies are born with Hemophilia A each year.

Hemophilia Type B is caused by a deficiency of factor 9. Hemophilia B is also referred to as "Christmas Disease" after Stephen Christmas, the first patient diagnosed with factor 9 deficiency. Hemophilia B affects around 1 in 25,000 male births.

* pubmed.ncbi.nlm.nih.gov/9840909/

What are the Symptoms?

Symptoms of Hemophilia can include:

- > ***Excessive and unexplained bleeding from cuts or injuries, or after surgery or dental work***
- > ***Many large or deep bruises***
- > ***Unusual bleeding after vaccinations***
- > ***Pain, swelling or tightness in joints***
- > ***Blood in urine or stool***
- > ***Nosebleeds without a known cause***

Treatment of Hemophilia

Fortunately, Hemophilia treatments keep improving. It is now possible for people with Hemophilia to live a relatively normal life, despite challenges.

Replacement therapy is one of the treatments for Hemophilia used to help replace missing or low clotting factors. These include concentrates of either clotting factor 8 (for Hemophilia A) or clotting factor 9 (for Hemophilia B), which are injected into the patient's veins. There is also one subcutaneous treatment for Hemophilia A that is in a whole new therapy class. New emerging gene therapies are on the horizon showing promising results.

Hemophilia Treatment Centers

Hemophilia Treatment Centers (HTCs) are an important resource available to patients and their families. HTCs are specialized health care centers that bring together doctors, nurses, and other health professionals experienced in treating people with Hemophilia. Many of the 141 HTCs across the US are at major university medical and research centers. Patients treated at HTCs generally experience fewer bleeding complications and hospitalizations. They are more likely to have a better quality of life due to the centers' comprehensive care model.

Importance of Nutrition

While a special diet isn't always needed for a patient with Hemophilia, eating properly and being a healthy weight is critical. Extra pounds put more stress on joints and increase the amount of factor 8 replacement therapy needed to treat or prevent a bleed. Eating a healthy diet and keeping an ideal weight can also decrease the risk for chronic illnesses like diabetes and high blood pressure. Children with Hemophilia A should eat a vitamin and mineral rich diet, as it's crucial for their growth and development.

Importance of Exercise

Regular exercise is vital for patients with Hemophilia because building muscle helps protect joints. Regular exercise also helps improve mental health and lowers the chance of being overweight, which can add stress on joints.

Sports and physical activity used to be discouraged for people with a bleeding disorder such as Hemophilia. New treatments allow both children and adults to engage in low-impact physical activity and low-contact sports. These activities are now encouraged for patients, despite their bleeding condition. Talk with your doctor about their recommendations for physical activities.

Teenagers and Young Adults with Hemophilia

Teenagers and young adults with Hemophilia face added challenges related to maturity, personal responsibility, and increased individuality at this age. These patients also tend to be wary about when and with whom to share information about their condition. They may have little awareness of educational and financial resources and may place a low value on regular hematology care.


Further, many young adults worry about building relationships, starting a career and finding medical insurance. Help navigating these challenges requires understanding the needs of this specific population.

Know Your Insurance

Make sure you are aware of your insurance coverage and also what patient assistance programs are available to you. For more information on assistance and reimbursement programs, patients and caregivers are encouraged to check out all of the national organizations listed on the last page.

Our Focus on Supporting Hemophilia Patients

At AcariaHealth, our Hemophilia Care Management Program is designed to meet the specialized needs of people living with Hemophilia. We understand that bleeding disorders affect a person emotionally, as well as physically. We care about our patients' welfare, which is why we do much more than just fill a factor prescription.

A young man wearing a bright yellow hoodie, dark pants, and white sneakers with teal accents is sitting on a green park bench. He is wearing large white headphones and looking down thoughtfully. The background is a sunlit park with trees and fallen yellow leaves on the ground.

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We provide individualized support and services designed to empower our patients – not only to manage their treatment, but to be healthy, active, and thriving. It all starts with the simple premise: the patient comes first.

Experience and Expertise

Our team of experts provides educational resources, helps navigate insurance benefits and provides information on financial assistance programs. We take pride in the timely coordination and follow-up of these services, which are key to successful treatment. Our services include:

Pharmacy Services

- > *All factor products delivered to your door*
- > *IV, injectable and oral medications available*
- > *Emergency same-day delivery available*
- > *Pharmacist available 24/7*
- > *Multilingual staff*
- > *Coordination of nursing services*
- > *Drug recall alert program to ensure immediate notification of recalls*
- > *Assay management*

Education

- > *IV and injectable drug therapy training to promote independence*
- > *Catheter/port care training*
- > *Adherence training*
- > *Reinforcement of Hemophilia Treatment Center treatment plan*

Reimbursement Services

- > *Comprehensive benefits investigation*
- > *Collaboration with Hemophilia Treatment Centers on prior authorization process*
- > *Monitoring lifetime maximums*
- > *Assistance in finding alternate sources of coverage (i.e., Medicare, high risk insurance pools, COBRA)*

Patient Advocacy

- > *Partner with non-profit organizations to provide current information on regional and national Hemophilia conferences, workshops and support groups*
- > *Facilitate access to manufacturer-sponsored copay assistance programs*




Download Our Hemophilia Factor Chart



ahrx.co/FactorGuide

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Bleeding Disorder Helpful Resources

National and World Organizations

hemophilia.org

hemophiliafed.org

hopeforhemophilia.com

kelleycom.com

Insurance Assistance and Premium Assistance

healthcare.gov

panfoundation.org