CAMC Hemophilia Center

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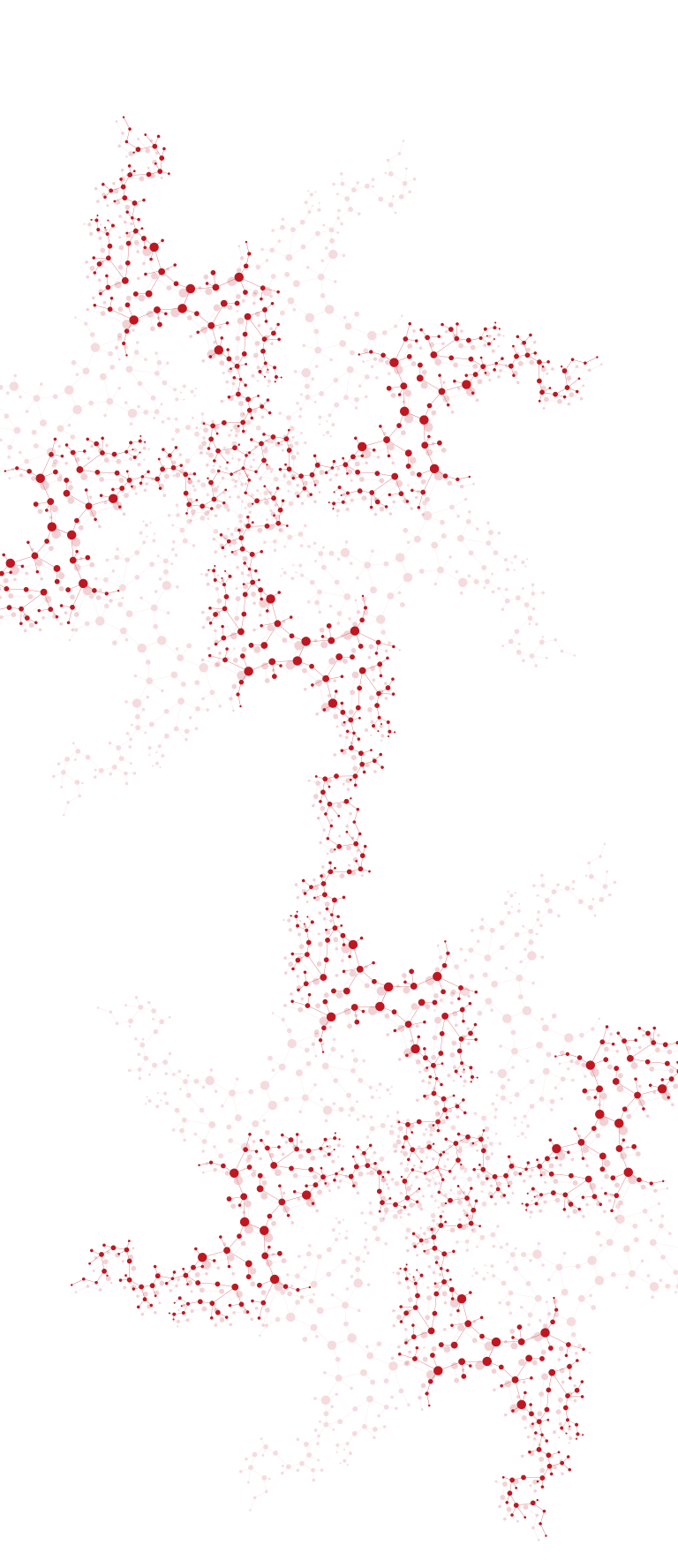

What is hemophilia?

Hemophilia is an inherited disorder of the blood. Because of an abnormality in one of several plasma proteins necessary for clotting, the blood does not coagulate (clot) properly. This genetic blood clotting disorder affects about 20,000 Americans, almost exclusively male. There is no cure and people with hemophilia require lifelong treatment.

A person with hemophilia has either an inactive or an inadequate supply of one of several clotting factors needed for blood to clot normally. Often bleeding is internal, into joints and results in arthritis or crippling.

Types of hemophilia

There are two major types of hemophilia. Depending on the level of these factors in the blood, hemophilia can be mild, moderate or severe.

- **Hemophilia A (classic hemophilia):** Caused by an abnormality in clotting factor VIII
- **Hemophilia B (Christmas disease):** Caused by an abnormality in clotting factor IX

Types of bleeding

The severity of hemophilia is established at birth and does not change throughout life. Some patients with hemophilia experience occasional bleeding, while others suffer frequent and severe bleeding episodes.

Spontaneous bleeding may occur as often as once a week in a person severely affected. This bleeding is usually internal and may occur in any muscle tissue or organ. However, most internal bleeding tends to affect the joints – primarily the ankles, knees, elbows and shoulders.

The accumulation of blood in

internal tissues causes swelling, pain and extended rehabilitation if not treated. It also eventually may cause destruction of the joint itself and/or damage to nerve fibers and muscles.

Since people with hemophilia do have normally functioning platelets and other factors that help to promote blood clotting, small cuts and bruises usually will stop bleeding without problems. It is a common misunderstanding that patients with hemophilia will bleed to death from small cuts. People with hemophilia do not bleed any faster than others – they just continue to bleed until it is controlled through proper treatment.

Genetic factors

In hemophilia, a clotting factor is missing or abnormal because genetic instructions for its formation have been passed on incorrectly by a defective gene. Hemophilia A and B are linked to gender. The defective gene for Hemophilia A and B appear on the X-chromosome. Females have two X-chromosomes and males have one X-chromosome. If the defective gene is present on the single X-chromosome of the male, he will have hemophilia. If the gene is present on one of the X-chromosomes of a female, she will be a carrier.

If a female carries the gene for hemophilia, there are five possible outcomes with each pregnancy:

- **A daughter who is a carrier**
- **A daughter who is not a carrier**
- **A son who has hemophilia**
- **A son who does not have hemophilia**
- **Rarely, a daughter who has hemophilia**

If a male has hemophilia, all of his sons will be free from hemophilia and all of his daughters will be carriers. Although a family history of

the disease is frequently reported, 25% of new cases report no known family incidence.

All races and socioeconomic groups are equally affected. There are more than 200 people in West Virginia with hemophilia.

Treatment

The type of treatment needed for hemophilia depends on the type that is diagnosed. The primary treatment for hemophilia is called factor replacement therapy, which involves receiving replacement of the specific clotting factor that you need through an IV. This type of therapy can treat a bleeding episode in progress or can be given on a regular schedule at home to prevent episodes. Replacement clotting factor can be made from donated blood or manufactured in a laboratory. Most factor is recombinant (man-made).

Other types of therapies include:

- **Desmopressin:** A hormone that can be injected into a vein or taken through the nose to stimulate your body to release more clotting factor
- **Clot-preserving medications:** Medicines that help prevent clots from breaking down
- **Physical therapy:** Eases signs and symptoms of internal bleeding
- **Hemlibra®:** Prescription antibody medication given subcutaneously to treat Factor VIII patients to prevent or reduce the frequency of bleeding episodes

Our commitment to patients

The Hemophilia Center at CAMC has four goals:

- **To treat patients with hemophilia with the most advanced technology available**
- **To educate patients in all**

aspects of their disease so they may play an active role in their treatment

- **To assist patients in carrying out their medical plan so they may develop confidence in their own knowledge and judgment, and become informed patients in their own medical care**
- **To support patients in their pursuit of a normal life and achievement of a normal life expectancy**

Effective treatment of patients requires a comprehensive care approach. We focus our care on the individual and on the family. Our comprehensive health care team includes specialist in orthopedics, hematology, dentistry, behavioral health, registered nurses, social workers, physical therapists and ultrasound evaluations are offered.

The CAMC Hemophilia Center also treats patients with other bleeding disorders, including von Willebrand's Disease – a genetic condition. It affects both men and women and is characterized by a deficiency of a plasma-clotting factor and by mucosal and petechial bleeding due to abnormal blood vessels.

Our team

Medical Director:
Steven J. Jubelirer, MD

Pediatric Hematologist:
Mohamad Badawi, MD

Nurse Coordinator:
Donna Arden, RN

Contact us

For more information about the CAMC Hemophilia Center, please call **(304) 388-8896** or visit ***camc.org/services/hemophilia-care***.

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HEMOPHILIA CENTER

Charleston Area Medical Center

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3200 MacCorkle Ave. SE
Charleston, WV 25304

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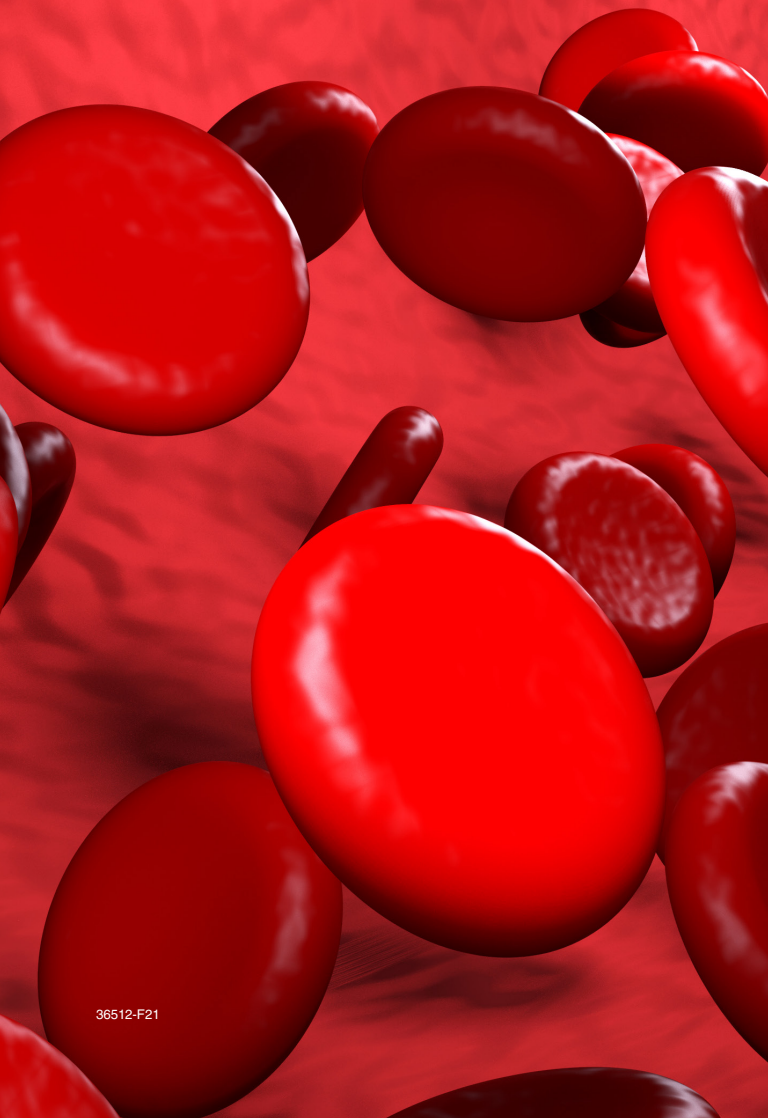

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