AIDS (Acquired Immunodeficiency Syndrome)—a disease caused by the human immunodeficiency virus (HIV), which attacks the body's immune system, making it more prone to certain infections and rare cancers.

Anemia—a condition in which the blood is deficient in red blood cells, in hemoglobin (the iron-carrying component) or in total volume from loss of blood.

Antifibrinolytics - agents that inhibit the breakdown of fibrin, such as aminocaproic acid or tranexamic acid.

aPTT - Activated partial thromboplastin time. aPTT is defined as the time needed for a fibrin clot to form in plasma to which calcium and a phospholipid reagent have been added. aPTT is used to evaluate the intrinsic clotting system.

Arthritis - Damage to the structures of the joint including the synovium, cartilage, and underlying bone which often results from repeated bleeding episodes and leads to pain, stiffness, and limitation in function.

Arthropathy - Arthropathy is a term used to describe a joint affected by a disease, such as seen in hemophilia

Bethesda Unit—a laboratory measurement of an antibody, called an inhibitor. Values above 5 are considered high; the inhibitor weakens the effect of clotting factor.

Biopsy—a procedure in which samples of tissues, cells or fluid are removed for examination. Liver biopsies reveal the extent of damage from cirrhosis, or scarring.

Biosimilars—new versions of existing drugs, created once the current patent expires.

Bleeding Disorders—several chronic health conditions in which the blood does not clot properly, resulting in excessive or lengthy bleeding.

Breakthrough Bleed—bleeding between infusions of factor product.

Bypassing factor products - Coagulation factor products, which are commonly used in hemophiliacs who have inhibitors, to activate clotting though using other routes in the coagulation pathway. These products supply activated or partially activated forms of coagulation factors such as X, VII, and IX.

Carrier—a person who has the gene for a condition, but does not necessarily display the symptoms.

Asymptomatic Carrier—a person without symptoms of a condition, but carries the gene for that condition.

Symptomatic Carrier—a carrier of a genetic condition that displays symptoms of that condition. In hemophilia, a symptomatic carrier is one that has bleeding symptoms due to low factor levels, without formally carrying the diagnosis of hemophilia.

CBC - Complete blood count. CBC measures the number of blood cells in the blood including red blood cells, white blood cells, and platelets.

CDC—U.S. Centers for Disease Control and Prevention. It supports the HTC network. Through the Universal Data Collection (UDC), it monitors blood safety and conducts research on the bleeding disorders community.

Central Venous Access Device (CVAD)—a small, flexible tube placed in a vein for patients who need regular infusions.

Chromosome—structures in the cell's nucleus that contain genetic information in the form of DNA.

Cirrhosis—deterioration of the liver from excessive scarring.

Clotting Cascade—a series of steps that occur in the formation of a clot, involving the clotting proteins and other substances.

Clotting Disorders—conditions in which there is an increased tendency toward excessive clotting.

Clotting Factors—proteins in the blood that act in sequence to stop bleeding and form a clot.

Coagulation—the process of forming a blood clot.

Coagulation Disorders—several chronic health conditions in which the body does not clot properly, resulting in excessive or lengthy bleeding.

Co-Infection—having two viral infections at the same time, particularly HIV and hepatitis C virus (HCV).

Compartment syndrome - A limb-threatening complication of hemophilia resulting from a soft tissue injury or hemorrhage into a compartment such as the forearm or calf. Compartment syndrome may manifest with swelling, pain, and paresthesias.

Creutzfeldt-Jakob Disease (CJD)—an incurable degenerative brain disease that is fatal. It is caused by a prion, a protein particle that causes infectious diseases of the nervous system.

Variant Creutzfeldt-Jakob Disease (vCJD)—the human form of CJD, or “mad cow disease.”

Cryoprecipitate—human plasma-derived product rich in factor VIII and von Willebrand factor (vWF). Cryoprecipitate is formed after frozen human plasma is thawed and the liquid supernatant removed.

DDAVP—desmopressin acetate, a synthetic hormone used to treat some patients with mild hemophilia or von Willebrand disease.

Deep Vein Thrombosis (DVT)—a blood clot in a vein deep in the body, usually in the lower leg or thigh.

Desmopressin Acetate (also DDAVP or Stimate®)—a synthetic hormone used to treat some patients with mild hemophilia or von Willebrand disease.

DNA (Deoxyribonucleic Acid)—the molecular basis of heredity. The order of the four bases that compose DNA—adenine, cytosine, guanine and thymine—provides information on cell activity.

Ecchymosis - purplish discoloration of the skin. Ecchymosis is the result of extravasation of blood under the skin and is usually larger than petechiae.

End-Stage Liver Disease—irreversible damage to the liver that can end in liver failure. It is caused by chronic cirrhosis.

Factor Assay—a lab test that determines the level of circulating factor in the body. The results are reported as a percentage of normal levels.

Factor Product—treatment that is infused to replace the body’s missing clotting proteins. It is made from plasma or recombinant products.

Factor Deficiencies—bleeding disorders identified by the missing clotting factor. They include factors I, II, V, VII, VIII, IX, X, XI, XII and XIII.

Factor I Deficiency—a rare bleeding disorder caused by deficient or defective fibrinogen.

Factor II Deficiency—an extremely rare bleeding disorder caused by a deficiency of prothrombin.

Factor V Deficiency—a rare bleeding disorder caused by a deficiency of factor V protein.

Factor VII Deficiency—the most common rare bleeding disorder, caused by a deficiency of factor VII protein. It is usually severe.

Factor VIII Deficiency—also called hemophilia A, most common form of hemophilia.

Factor IX Deficiency—also called hemophilia B, second most common form of hemophilia.

Factor X Deficiency—a rare bleeding disorder caused by a deficiency of factor X protein, which activates enzymes that help form a clot.

Factor XI Deficiency—also called hemophilia C.

Factor XII Deficiency—not a bleeding disorder. Factor XII deficiency causes abnormal coagulation laboratory screening tests, but people who have it do not experience bleeds.

Factor XIII Deficiency—the rarest bleeding disorder, caused by the deficiency of factor XIII protein, which stabilizes the clot.

Fibrosis—the accumulation of tough, fibrous scar tissue in the liver. It is measured by stages or grades.

Fresh Frozen Plasma—the liquid portion of the blood. It is used to treat bleeding in patients with rare factor deficiencies, such as factors II, V, VII, IX, X and XI.

Gene—a sequence of DNA that occupies a specific location on a chromosome and determines a particular characteristic.

Gene Therapy—replacing, manipulating or supplementing a dysfunctional gene with a functional one.

Half-Life—the time it takes for half the quantity of factor or factor product to be eliminated from blood plasma.

Hemarthrosis—bleeding into a joint.

Hematologist—a physician specializing in disorders of the blood.

Hematoma - a mass of clotted or partially clotted blood that is localized and confined within a space or organ

Hemoglobin—the protein in red blood cells that contains iron and carries oxygen and carbon dioxide.

Hemophilia—a bleeding disorder in which a clotting factor protein, such as factor VIII or IX, is completely or partially lacking or does not function normally.

Hemophilia A—a deficiency or absence of factor VIII. The most common form of hemophilia, also called “classic hemophilia.”

Hemophilia B—a deficiency or absence of factor IX. Also called “Christmas disease” after the first family diagnosed with the condition.

Hemophilia C—also called factor XI deficiency. Patients are deficient in or lack factor XI protein.

Mild Hemophilia—a factor VIII or IX level ranging from 5% up to 40% of normal blood levels.

Moderate Hemophilia—a factor VIII or IX level ranging from 1% up to 5% of normal blood levels.

Severe Hemophilia—a factor VIII or IX level below 1% of normal blood levels.

Hemophilia Treatment Centers (HTCs)—a group of federally funded medical treatment centers that specialize in treating patients with bleeding disorders.

Hemorrhage—rapid, uncontrollable bleeding.

Hemostasis—the process by which the body stops bleeding.

Hepatitis—inflammation of the liver. It can be caused by infection from several hepatitis viruses, including hepatitis A, B or C.

Hepatitis A—inflammation of the liver caused by the hepatitis A virus. There is a vaccine to prevent it.

Hepatitis B—inflammation of the liver caused by the hepatitis B virus. There is a vaccine to prevent it.

Hepatitis C—inflammation of the liver caused by the hepatitis C virus. There is no vaccine against it.

Hereditary Disease—a condition that is genetically passed down to offspring.

HIV (Human Immunodeficiency Virus)—the virus that causes AIDS.

Infusion—delivering clotting factor concentrate directly into a vein.

Continuous Infusion—steadily infusing clotting factor concentrate; often used during surgery.

Inheritance—the biological process of transmitting certain characteristics or conditions from parents to offspring.

Inhibitor—an antibody to infused clotting factor concentrates, making standard treatments ineffective.

Intracranial Hemorrhage—a bleed into the brain.

Immune tolerance induction - See ITI.

ITI - immune tolerance induction. Immune tolerance induction is a program of care designed to reduce or eliminate inhibitors in patients with hemophilia. A variety of immune tolerance induction protocols exist, but usually include chronic exposure to the deficient factor against which the inhibitor is directed, plus/minus immunomodulating agents such as IVIG and rituximab.

ITP - immune thrombocytopenic purpura. A condition characterized by thrombocytopenia, ecchymoses, and hemorrhage from mucosal membranes which may mimic some types of inherited bleeding disorders. ITP is an antibody mediated process, which results in removal of platelets by the reticuloendothelial system.

Joint Fusion—surgery to combine one or more bones in a joint. Most commonly used in joints where replacement surgery is not recommended, such as the ankle.

Joint Replacement—using artificial components in a joint, such as the knee or elbow, to replace those that are damaged from wear and tear or chronic bleeds.

Lifetime Cap—a spending limit on insurance benefits. Once it is reached, the policy no longer provides coverage.

Medical and Scientific Advisory Council (MASAC)—NHF's medical board that issues recommendations and advisories to the bleeding disorders community.

Menorrhagia—prolonged, heavy bleeding during menstruation. Can be a symptom of a bleeding disorder, such as VWD.

Mild hemophilia - classification used for patients with hemophilia who have factor levels of 5% to around 40%. Patients with mild hemophilia bleed infrequently, usually only after some type of injury/trauma or surgical intervention. The exact percentage of patients with mild hemophilia may be underestimated due to lack of identification of the entire population, but it is estimated that mild hemophilia represents about 15% to 20% of the total population.

Moderate hemophilia - classification used for patients with hemophilia who have factor levels of 1% to 5% of normal. Moderate hemophilia represents about 15% of patients with hemophilia A and about 30% of patients with hemophilia B. Patients with moderate hemophilia have a higher risk of bleeding than those with mild hemophilia, but usually do not experience frequent spontaneous bleeds.

Mutation—a change in the DNA of a cell, due to such causes as exposure to radiation or viruses, or during cell division. Hemophilia is caused by cell mutation.

On-demand therapy - administration of replacement factor in response to a bleeding episode.

Parvovirus B19—an infectious virus that can potentially be transmitted through plasma-derived blood products.

Pegylated Interferon—a drug made from human proteins, called interferons, used to treat chronic hepatitis C. Usually paired with ribavirin.

Petechiae - small reddish or purple hemorrhagic spots appearing on the skin. Petechiae are much smaller than ecchymoses.

Plasma—yellow-colored, protein-rich portion of the blood, which carries the red blood cells, white blood cells and platelets.

Platelets—tiny platelike components of blood that help seal injured blood vessels and stop bleeding.

Primary prophylaxis - administration of replacement factor on a regular schedule to prevent bleeding episodes and their subsequent sequelae usually initiated in young patients with severe hemophilia.

Port—a device that delivers intravenous drugs. It is usually implanted under the skin in the chest.

Pre-Existing Condition—a health condition that existed prior to obtaining health insurance.

Prophylaxis—a treatment regimen to prevent bleeds.

Primary Prophylaxis—regularly scheduled factor product treatments to prevent bleeding episodes. Usually begun in childhood and performed two to three times weekly.

PT - prothrombin time. PT is defined as the time needed for a clot to form in blood after the addition of thromboplastin and calcium. PT is used to evaluate the extrinsic clotting system.

PTT - partial thromboplastin time. PTT was the precursor of aPTT. It was used to detect abnormalities in the intrinsic clotting system but was relatively insensitive to heparin.

Secondary Prophylaxis—regularly scheduled factor product treatments begun after a pattern of bleeding occurs or to treat a target joint.

Spontaneous Mutation—a genetic change that occurs without a triggering agent, usually due to a malfunctioning cell enzyme.

Recombinant Product—genetically engineered factor product made without human blood products, decreasing the risk of transmission of bloodborne infections.

Replacement factor - coagulation factor products (either human plasma-derived or recombinant) used for prophylaxis or treatment of bleeding episodes in patients with hemophilia or related bleeding disorders.

Ribavirin—an antiviral drug used with peg-interferon to treat chronic hepatitis C infection. It can have serious, severe side effects.

RICE - an acronym for rest, ice, compression, and elevation. These measures are recommended as adjunctive therapy to factor replacement for bleeding episodes. RICE may be used alone for chronic hemophilic arthropathy without acute bleeding or for small subcutaneous hematomas not requiring replacement factor. The goal of RICE therapy is to prevent or limit musculoskeletal damage.

Ristocetin - an antibiotic used in the in vitro assay of von Willebrand factor (vWF). Ristocetin induces vWF binding to glycoprotein Ib receptors on platelets.

Secondary prophylaxis - administration of factor replacement to prevent bleeding in patients who have early arthropathy as a result of previous severe joint bleeds. Secondary prophylaxis may be administered in order to interrupt a bleeding episode or to rest a joint experiencing repeated bleeding.

Severe hemophilia - classification used for patients with hemophilia A or B who have factor levels of less than 1% of normal. Severe hemophilia represents about 60% of patients with hemophilia A and about 50% of patients with hemophilia B. Patients with severe hemophilia are at high risk for spontaneous bleeding, especially into the joints and muscles. These patients are also at a higher risk for life-threatening bleeds, such as CNS hemorrhage.

Standards of Care—state legislation to protect patient access to HTCs and the full range of products and services.

Sustained Viral Response—indicator that hepatitis C virus has been cleared from the bloodstream.

Synovitis—inflammation of the synovial membrane, which surrounds joints. Can be caused by repeat bleeding into the same joint.

Target Joint—a joint that has had repeated bleeds, or at least four bleeds within a six-month period.

Thrombophilia—several distinct conditions in which there is an increased tendency toward excessive clotting.

Thrombosis—the formation of a blood clot.

Titer—a measure of the concentration of antibodies, called inhibitors, in the blood.

UDC (Universal Data Collection System)—a CDC program that monitors the safety of the US blood supply and the occurrence of joint complications.

Von Willebrand Disease (VWD)—a bleeding disorder in which von Willebrand factor (VWF), a blood protein, is either deficient or defective.

Von Willebrand Factor (VWF)—a blood protein that helps platelets plug injured blood vessel walls by causing them to stick together. It is also a carrier for factor VIII.