





INTRODUCTION: BLOOD & OUR HEALTH

Properly functioning blood is the foundation of good health. From fighting infections to transporting oxygen throughout the body to vital organs and the brain, blood is quite literally the body's most important tissue. It is critical for us to know whether our blood is healthy, as well as understand the many signs and symptoms that indicate when something is wrong.

OUR HEALTH—OR PROBLEMS WITH OUR HEALTH—CAN OFTEN BE DETERMINED WITH ONE DROP OF BLOOD.

Unlike other parts of the human body, blood is connected with every organ, every tissue, and every part of our bodies. Many of the most common health problems—heart attack, stroke, anemia—are closely tied to blood functions. Blood-related illnesses and conditions affect a wide range of people, from infants to older adults, including people from all ethnic backgrounds and both genders. Everyone can benefit from understanding blood health, knowing risk factors and symptoms of problems, talking with their doctors, and getting more information.

ABOUT THIS DISCUSSION GUIDE

To help people understand the relationship between blood and their overall health, the American Society of Hematology (ASH) has launched a public awareness campaign and Web site, "Blood: The Vital Connection" (*www.BloodTheVitalConnection.org*). As part of this campaign, ASH, along with the groups below, supported an hour-long documentary, "Blood Detectives," produced by award-winning filmmaker, Joseph Lovett:

- National Heart, Lung, and Blood Institute
- National Institute for Diabetes and Digestive and Kidney Diseases
- National Cancer Institute
- National Center for Research Resources

The Institutes and Center listed above are part of the:

National Institutes of Health U.S. Department of Health and Human Services

This film shows the connection between blood and many of our most serious health conditions, including anemia, bleeding disorders, blood clots, and blood cancers.

This discussion guide is designed to be used in formal or informal screenings or showings of "Blood Detectives" to guide discussions and raise awareness about topics related to blood health.

HOSTING A SCREENING & LEADING A DISCUSSION

The "Blood Detectives" DVD and discussion guide can be used in an educational setting, a community-group setting, or with patient organizations interested in informing the public about blood-related conditions. In large and small groups, we encourage you to play the video first, and then lead a conversation using the suggested discussion topics below.

"Blood Detectives" is an hour-long documentary that details the secrets and mysteries of human blood and follows the highly specialized medical professionals—hematologists—who unravel these medical mysteries to save lives. The film delves into the lives of patients who are affected by some of the most common, and sometimes deadliest, blood disorders—from six-year-old Ezra, who suffers from severe life-threatening anemia, to Rebecca, the young mother whose life and that of her baby are at risk because of a disorder that causes dangerous blood clots. This hour-long show follows prominent hematologists as they race against time to find treatments for conditions, from leukemia to bleeding disorders and more.

"Blood Detectives," executive-produced by award-winning filmmaker, Joseph Lovett, debuted on the Discovery Health Channel in December 2008. The film will also be aired on a number of local PBS stations in 2009 and 2010.

To request a DVD of the film to use in non-commercial screenings, please visit *www.BloodDetectives.org*.



DISCUSSION TOPICS

After showing the film to a group, follow these suggested discussion topics to lead a conversation. Questions are included for each topic, along with the full information needed to lead the discussion and help answer the posed questions. Consumer health groups and patient groups might want to consider focusing on the specific topics that deal with their particular interests.

BLOOD & OUR HEALTH

What are some of the ways that blood is central to our health?

Blood is our largest organ—it fights infection and carries oxygen to every part of our bodies. Each drop of blood provides evidence about how healthy we are—or what is going wrong. In fact, doctors can sometimes give an immediate diagnosis just by looking under a microscope at the shape of blood cells and how they are behaving. Other times, the clues provided in a drop of blood merely serve as pieces of the puzzle that help identify a more serious underlying condition.

Why should people know about blood conditions?

When something is wrong with our blood, it can affect our overall health. That is why it is important to know about some of the common blood disorders that can affect us. Many people are affected by blood conditions and cancers, and millions of cases go undiagnosed until a crisis happens. Learning about the risk factors, the signs, and symptoms of common blood disorders can help people be proactive about seeking appropriate medical care.

How is medical research related to the treatment of common conditions and medical events, like heart attack, stroke, and anemia?

Research in the field of hematology—as well as other related medical fields—is crucial to making discoveries that improve the treatment of common conditions such as heart attacks, stroke, anemia, and many other ailments.



Over the past 50 years, great progress been made in the study and treatment of blood-related conditions, including these notable examples:

- Animal research using the zebrafish has led to an improved understanding of anemia and clotting disorders, which are often implicated in heart attacks and strokes.
- Research on stem cell transplantation has led to improved survival rates for a number of blood-related conditions, including leukemia and other bone marrow disorders, as well as autoimmune disorders such as systemic lupus erythematosus, which is associated with several hematologic conditions (thrombotic thrombocytopenic purpura, idiopathic thrombocytopenic purpura, neutropenia, and autoimmune hemolytic anemia) along with arthritis, kidney failure, and several other problems.
- Research in the treatment of many types of leukemia and lymphoma has led to a number of "targeted therapies," which are increasing remission and survival rates.

ANEMIA

What is anemia? What are some of the common signs and symptoms?

Anemia is caused by a shortage of red blood cells, which are important in the transportation of oxygen throughout the body, leading to weakness and other symptoms that range in severity. In the film, we learned about Ezra, a young boy who suffered from a disorder called hereditary spherocytosis in which defects in the red blood cell membranes cause them to lose their flexibility and become sphere-shaped. This results in their destruction in small blood vessels in the spleen because the body identifies them as damaged cells. This condition causes severe anemia. Through his story, we learned how anemia affects the body and how important it is to treat it. Anemia can cause serious health problems and often goes undiagnosed.

Signs and symptoms include:

- Weakness
- Shortness of breath
- Dizziness
- Fast or irregular heartbeat
- Pounding or "whooshing" in your ears
- Headache
- Cold hands or feet
- Pale or yellow skin
- Chest pain

In addition, people with any of the following chronic conditions might be at greater risk for developing anemia:

- Rheumatoid arthritis or other autoimmune diseases
- Kidney disease
- Cancer
- Liver disease
- Thyroid disease
- Inflammatory bowel disease (Crohn disease or ulcerative colitis)

How can anemia be treated?

While anemia can sometimes be the result of poor nutrition, it can also be a sign of a more serious underlying medical condition, such as hereditary spherocytosis, as we saw in the film. The treatment for anemia will depend on what is causing it; therefore, it is important to consult with a doctor to first determine the cause.

Many forms of anemia can be easily treated by eating foods rich in iron (such as dark green leafy vegetables, red meat, fortified cereals, eggs, and peanuts) and/or taking dietary supplements.

Anemia is common in pregnant women and should be monitored by a doctor. A nutritious diet that includes foods rich in iron and dietary suppliments (iron and folic acid) are the primary tools used to ward off anemia in pregnancy.

What is sickle cell anemia and how is it treated?

In the film, we learned about Alexandria, who suffered from a "silent stroke" because of her sickle cell anemia. This type of anemia is an inherited form caused by abnormally shaped red blood cells that can get stuck in blood vessels, blocking the flow of blood and delivery of oxygen to vital organs and leading to pain and other complications. Early diagnosis and treatment is crucial; in the United States, all newborns are tested for sickle cell anemia.

Signs and symptoms include:

- Anemia
- Dark urine
- Hand-foot syndrome, which causes your hands and feet to swell
- Frequent pain episodes
- Stunted growth
- Vision problems
- Stroke



Patients with sickle cell disease are being treated with a range of methods, including blood transfusions, as in Alexandria's case; bone marrow transplants; drugs such as pain medications and hydroxyurea; and even stem cell transplants.

Patients should talk with their doctors about different treatment options and clinical trials. More information about clinical trials can be found on page 19 of this guide.

BLEEDING DISORDERS

What are bleeding disorders?

In the film, we learned about bleeding disorders through the stories of Jerry, who was diagnosed with hemophilia, a rare bleeding disorder, and Anne, who has von Willebrand disease, a relatively common condition. Both of these illnesses are considered bleeding disorders, a group of conditions that result when the blood cannot clot properly because certain "clotting factors" or platelets are missing. Many of these disorders are inherited.



What are the symptoms?

In "Blood Detectives," Anne suffered from life-long serious nosebleeds and hemorrhaged during the birth of her baby, which provided important clues about her von Willebrand disease. In fact, this disorder often goes undetected.

Symptoms of bleeding disorders like hemophilia and von Willebrand disease include:

- Easy bruising
- Bleeding gums
- Heavy bleeding from small cuts or dental work
- Unexplained nosebleeds
- Heavy menstrual bleeding

How are bleeding disorders treated?

Although bleeding disorders are often undiagnosed, it is very important to recognize and treat these conditions because they always carry a risk for excessive bleeding in the case of an injury, during surgical procedures, or even from internal bleeding that can damage joints, organs, and tissues in the body over time. A range of treatments are available—from avoiding particular medications, such as aspirin or ibuprofen, that aggravate bleeding; to taking drugs that help the blood to clot; to receiving transfusions containing synthetic blood clotting proteins (called "factors") that are lacking in those with the disease. Patients should work with their doctors for individualized treatment.

BLOOD CLOTS

Why are blood clots dangerous?

In "Blood Detectives," we learned about several stories dealing with blood clots and their complications, including Aamir's travel-related blood clot, Rebecca's pregnancy-related clotting condition, and Luis' heart attack caused by a blood clot. Although blood clotting is a natural process in which blood platelets stick together to prevent excessive bleeding when a blood vessel is damaged, it can also cause serious complications when clots form unnecessarily or do not dissolve naturally. In fact, blood clots in arteries are often factors in two of our most devastating health conditions—heart attack and stroke. A heart attack death occurs every minute in the United States, and stroke is the number one cause of long-term disability in this country.

Genetics and certain risk factors can predispose a person to blood clots. These risk factors include:

- Obesity
- Pregnancy
- Immobility

(including prolonged inactivity, long trips by plane or car)

- Smoking
- Oral contraceptives
- Certain cancers
- Trauma

- Certain surgeries
- Age (increased risk for people over age 60)
- Inherited clotting disorders

(family members who have had clots)

Chronic inflammatory diseases

Hereditary and lifestyle risk factors can be modified through changes in diet and behavior, including not smoking, maintaining a healthy diet, and remaining active.

How are blood clots treated?

The treatment of blood clots depends on the severity, the location of the clot (in an artery or a vein), and the patient's individual characteristics.



Treatment options include:

- Anticoagulants—medicine that prevents clots from forming
- Antiplatelet agents—medications such as aspirin that prevent platelets from sticking to blood vessels
- Clot busters—medicine that dissolves blood clots
- Catheter-directed thrombolysis—a procedure in which a long tube, called a catheter, is surgically inserted and directed toward the blood clot where it delivers clot-dissolving medication
- Thrombectomy—surgical removal of a clot

What developments have been made in the treatment of heart disease?

Research in hematology and other medical fields has led to substantial developments in the treatment of heart disease because of greater understanding about how and why blood clots form.

For example, new developments show that young heart attack patients have one or more small genetic changes that cause their blood to clot abnormally. Years ago, young people with heart attacks often presented confusing cases to doctors. Now, hematologists can identify what the issues are and then properly diagnose and provide the right treatment.

Why are pregnant women at higher risk, and what can be done?



During pregnancy, blood naturally tends to clot more easily. Sometimes pregnant women can form clots in the deep veins of the legs or in the pelvic area. This condition is known as deep-vein thrombosis (DVT). Pulmonary embolism (PE) is a life-threatening event that occurs when a clot from elsewhere in the body breaks off and travels to the lungs.

Additionally, one particular blood-clotting condition—antiphospholipid antibody syndrome (APS)—causes one in four early miscarriages. Like

Rebecca from the film, these patients need to be tested and treated throughout pregnancy. In fact, 33 percent of all strokes in people under age 50 are due to APS. The main treatment for APS during pregnancy and after delivery is blood thinners, which should always be given under close supervision by a hematologist.

Blood Cancers (Leukemia, Lymphoma, Myeloma)

What are blood cancers and who is affected?

Blood cancers are usually known by their specific names—leukemia, lymphoma, and myeloma. Blood cancers affect the production and function of your blood cells. Most of these cancers start in the bone marrow where blood is produced or in the lymph nodes where lymphocytes—important parts of your immune system—grow and mature. Cancerous cells multiply and divide, spreading to other organs if untreated. Blood cancers can strike anyone.

What kinds of advances have been made in the treatment of blood cancers?

Research in hematology and other medical fields has vastly improved the effectiveness of treatment options for blood cancers. In the film, we heard the story of Doug, who was diagnosed with a blood cancer known as chronic myeloid leukemia (CML). He was treated with an experimental "targeted therapy" that stopped the action of a particular protein that was signaling the production of too many white blood cells.

Advances in research are leading to greater understanding of the causes and treatment of blood cancers on a daily basis. Targeted therapies and stem cell transplants are important developments in the treatment of blood cancers like leukemia.

Patients should ask their doctors about the latest approved treatments, as well as clinical trials involving treatments that are still being studied.

FINDING NEW TREATMENTS Zebrafish Research

What is the relationship between zebrafish and a patient with anemia?

Research involving a small fish with zebra stripes is leading to some important developments in the treatment of conditions related to blood disorders. The zebrafish is very close to humans in terms of its blood development; zebrafish and humans actually make blood in the same way. By studying zebrafish who have spherocytosis—a hereditary type of anemia also found in humans—researchers hope to find chemicals that can alter spherocytosis, which will lead to better understanding of the disease and possibly new treatments.



How can zebrafish research help in the study of human illnesses?

Research focused on the blood of the zebrafish is also important in the study and treatment of other inherited blood conditions, including von Willebrand disease, which is the most common bleeding disorder in the United States. By studying the way clotting occurs in the zebrafish, researchers can gain valuable insight into all types of clotting disorders, which are often the root of some very serious medical conditions, including heart attack and stroke.

CLINICAL TRIALS

What is a clinical trial and why are clinical trials so important to advancing the field of medicine?

A clinical trial is a research study involving human volunteers to evaluate new ways to prevent, diagnose, or treat diseases. Clinical trials help determine if experimental treatments are safe, effective, or better in some way than standard treatments.

What are the benefits of participating in a clinical trial?

Patients who are already being treated for blood-related conditions might be interested in learning more about clinical trials. By participating in a trial, a patient may have access to a treatment that is new or better than the standard treatment. By participating in a trial, you are also helping others who may benefit from the findings in the future. Some patients also receive free medical care or are paid for their participation. Talk with your doctor to find out if joining a clinical trial is right for you.

How can patients find out about clinical trials?

There are many Web sites that list current clinical trials for a variety of diseases and conditions, including the following:

www.clinicaltrials.gov www.cancer.gov/clinicaltrials www.centerwatch.com For more information about clinical trials, please visit *www.BloodTheVitalConnection.org*, click on "Patients," and scroll to "A Guide to Clinical Trials."

TALKING WITH YOUR DOCTOR

If you believe you are at risk for a blood condition, be sure you are prepared to talk with your doctor about it. A doctor's office is usually busy, so make the most of your visit by preparing in advance.

Before Your Visit

- Prepare questions to discuss.
- Make a list of your symptoms and health concerns.
- Make a list of medications you are currently taking.

During Your Visit

- Bring someone with you for moral support such as a friend or family member.
- Arrive in plenty of time to fill out any medical and insurance forms. Answer all health- and family history-related questions honestly.
- Do not withhold any information from your doctor.
- When speaking with your doctor, make sure you understand the diagnosis and the next steps you should take.
- If there is a word or phrase you do not understand, ask your doctor to explain it in a way that will make sense to you.
- Do not be afraid or embarrassed to ask about symptoms or concerns.
- Prior to leaving the doctor's office, make sure you understand the follow-up plan or arrangements.

After Your Visit

• Call your doctor's office with any additional questions you did not get to ask or that may have occurred to you after the visit.







FOR MORE INFORMATION

For more information about health and conditions, please visit: www.BloodTheVitalConnection.org

REQUEST A DVD

To Request a DVD of "Blood Detectives," please visit: www.BloodDetectives.org