Understanding the Impact of Blood Disorders

Blood disorders affect millions of Americans, but we don't yet have an accurate picture of the real impact of these conditions. We do know that more than 20,000 people live with hemophilia. Sickle cell disease affects 90,000 to 100,000 Americans. As many as 1% of women in the United States may have a bleeding disorder and many are unaware of their condition. And we know that half a million or more Americans experience a new deep vein thrombosis (blood clot) each year; that at least 1 in 10 die—many without ever being diagnosed.

We evaluate multiple approaches for tracking the number of people who have blood disorders, like hemophilia and blood clots. This will help us target prevention efforts and identify where awareness of risk factors, signs, and symptoms needs to be raised. We know that it makes a difference when doctors and practitioners use health care recommendations, and that with early and accurate diagnosis and management, we can prevent and reduce the burden of blood disorders.

Blood disorders are a serious public health problem. CDC is uniquely positioned to reduce the public health burden resulting from these conditions by contributing to a better understanding of blood disorders and their complications. We ensure that prevention programs are developed, implemented, and evaluated, and that information is accessible to consumers and health care providers. We encourage action that improves the quality of life for people living with or affected by these conditions.

Mary's Story

My name is Mary Campise, and I would like to share my personal experience with blood clots, also known as deep vein thrombosis (DVT). I have been an avid runner and biker, and enjoyed good health my entire life. However, just before my 48th birthday, I began to experience shortness of breath. I found that I couldn't keep up running with my husband and friends. I began to struggle for breath just walking up stairs and finally decided to see a doctor. I was told that the shortness of breath could be the result of exercise-induced asthma or possibly an allergy. While I was trying to find an answer, my shortness of breath persisted.

Two weeks later I woke up to find that my left leg was twice the size of my right leg. My husband drove me straight to Texas Health Presbyterian Hospital of Dallas, where doctors told me that I had DVT. One thinks of a blood clot as being small. However, my sonogram showed a blockage that ran from my abdomen to my ankle, and I was told that no blood was moving up or going down. In the hospital I also learned that I had a complication of DVT—pulmonary embolism (PE). A PE occurs when the clot breaks off, travels to the heart and lodges in the lung. Most concerning to me, I learned that a PE can be fatal if not treated in time.

While I was in the hospital, a CT scan was conducted and the pulmonologist described my lungs as "being showered in blood clots." An interventional radiologist talked with me that evening and explained that I needed a thrombectomy, an emergency procedure in which blood clots are surgically removed. After I was made aware of the risks and the necessity of this surgery, my husband and best friend convinced me that I needed to proceed in order to regain normal use of my leg. The very next morning I underwent a successful thrombectomy. I also had a special filter, called an inferior vena cava filter, inserted into that vein to prevent any more blood clots from moving into my lungs.

The best news for me was that when I came out of surgery my leg was once again normal in size and I could stand up on my legs with no problem! Doctors told me that it was very likely that my blood clot was caused by May-Thurner syndrome, a condition in which a vein on the left side is compressed by an artery on the right. I now take blood thinners, known also as anticoagulants, to manage my condition.

I am sharing my story because my experience with DVT is so similar to other people's stories—mainly that I did not recognize a warning sign, which for me was unexplained shortness of breath. My advice for other people is simple: be aware of your own body. If you experience a symptom such as unexplained shortness of breath, take this seriously and seek medical care immediately. Be your own advocate for your health and respond quickly to any symptoms that are not normal for you!