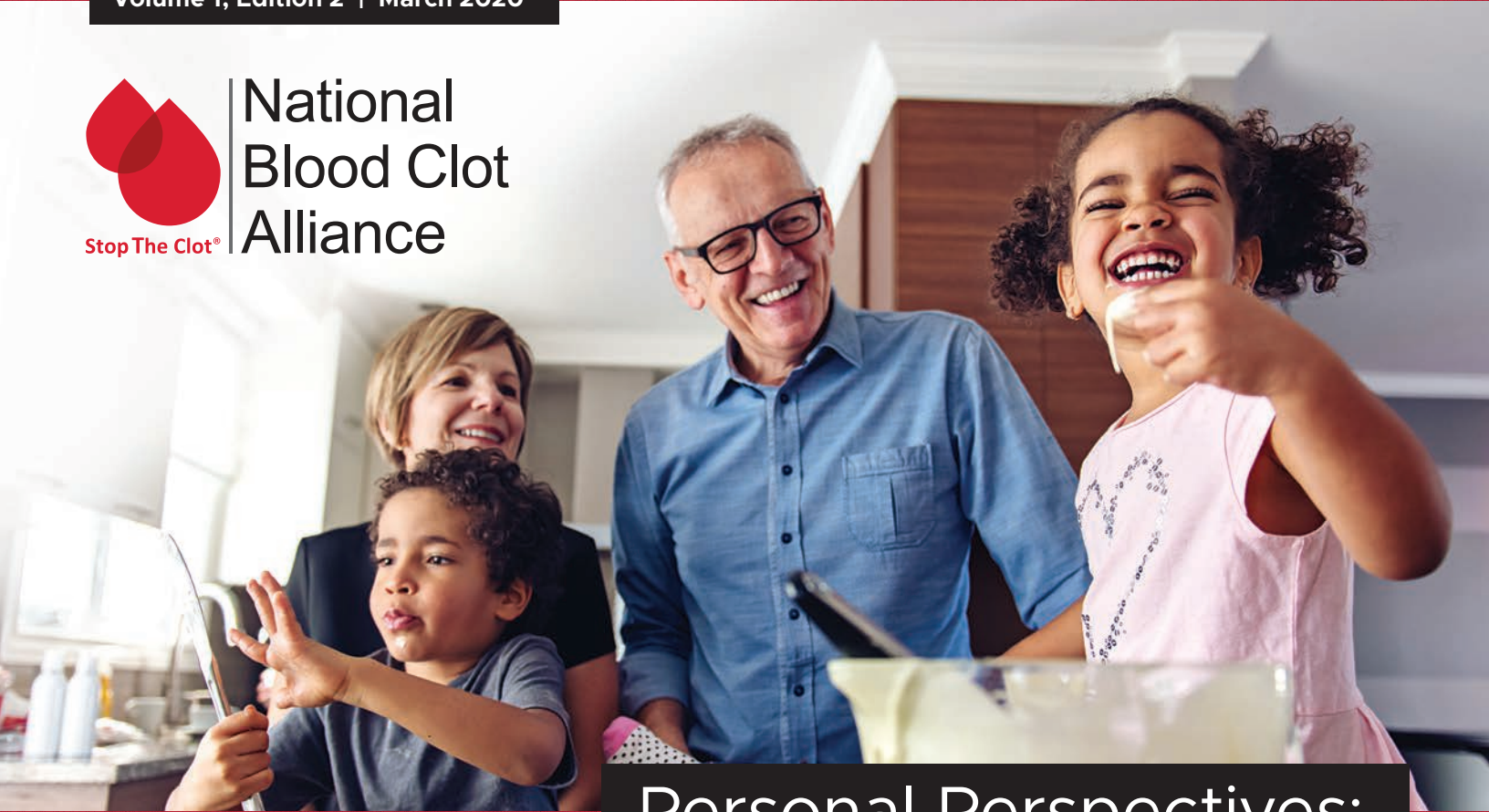


Volume 1, Edition 2 | March 2020



National
Blood Clot
Alliance



Personal Perspectives: My Blood Clot, My Life



Blood Clots: The Young and Old of it All

See the story on page 4



WELCOME

A Second Edition, A Second Opportunity to Focus on Recovery Issues

With this, the Second Annual Edition of our e-Magazine, *Personal Perspectives: My Blood Clot, My Life*, the National Blood Clot Alliance (NBCA)—its Board of Directors, Medical and Scientific Advisory Board, and Staff—extends its gratitude to the larger clotting and clotting disorders community for supporting this important undertaking and the overall mission of our organization.

This e-Magazine is dedicated to the memory of those we have lost to blood clots, and also to those individuals who have survived following a blood clot experience. The stories of these individuals inspire the work of NBCA on a daily basis, and provide the narrative for much of the outreach work we do to help people address the multitude of questions and information needs they encounter following a blood clot diagnosis. Their stories and their voices provide the rich and diverse threads that NBCA weaves as it serves as the *Community Connection* for all people affected by clots and clotting disorders in the United States.

While each voice in our community is unique, collectively our voices tell a similar story of strength, determination, and support. We hope that the stories

and information that we share here reflect your interests, and also resonate and provide important support to you, your family, and your friends.

NBCA also wishes to extend its appreciation to the generous corporate sponsors—the Bristol-Myers Squibb-Pfizer Alliance and Grifols—whose support, in part, made the production of this issue of NBCA's recovery focused e-Magazine possible this year.

The National Blood Clot Alliance is a 501(c)(3), non-profit, voluntary health organization dedicated to advancing the prevention, early diagnosis and successful treatment of life-threatening blood clots, such as deep vein thrombosis, pulmonary embolism, and clot-provoked stroke. NBCA works on behalf of people who may be susceptible to blood clots, including, but not limited to, people with clotting disorders, atrial fibrillation, cancer, traumatic injury, and risks related to surgery, lengthy immobility, pregnancy/childbirth, and hormonal birth control. NBCA accomplishes its mission through programs that build public awareness, educate patients and healthcare professionals, and promote supportive public and private sector policy.



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Communication:

A PRESCRIPTION FOR RECOVERY

If you or someone you know has been diagnosed with a blood clot, you may be feeling overwhelmed, scared, or even unsure of the future. It may feel like you have no idea what to expect in the coming days, weeks, or months. It is normal to feel this way, and it is normal to wonder what might happen as you consider your diagnosis, treatment, and recovery. You may be wondering if you will ever get better, or if you will ever be able to return to the life and activities that you enjoy.

A blood clot can be a life-changing diagnosis for many people, and the path to healing is different for everyone. While most people recover from blood clots and are able to return to the activities they enjoy, everyone recovers at their own pace. There is no right or wrong way to heal. While the majority of people affected by blood clots do recover without long-term complications, it can take weeks, months, or even years to get better. Other people may face long-term consequences due to blood clots, or require lifelong management of underlying conditions, such as inherited or acquired clotting disorders, also known as thrombophilias. No matter how significant your blood clot is, it can take work—and patience—to deal with what you have been through, follow your treatment plan, and eventually recover.

“After a blood clot diagnosis, it can be overwhelming to think about where your life might be once you have recovered. In fact, I was in denial about taking better care of myself for many years after my clot. Don’t be afraid to confront and talk through these feelings with those who support you, and know that you might now enjoy or appreciate life even more, and even try new and exciting things. Being proactive about my wellness has empowered me and given me a positive outlook about my health and future. I wish I had done it sooner.”

— Joe Harouni, blood clot survivor and NBCA Board Member

Blood Clots: The Young and Old of it All

Healthcare professionals and advocacy organizations alike stress again and again that blood clots do not discriminate. They affect people of all ages. No doubt, this is true. However, there are important facts to understand about the incidence and impact of blood clots at both ends of the spectrum: Young and Old.

Blood Clots in Children

The incidence of blood clots in children, in general, is very low. About 1 in 10,000 children develop problems with blood clots each year. However, blood clots are seen much more frequently in children who are hospitalized. About 1 in 200 children who are hospitalized will develop blood clots.

According to the American Society of Hematology, children are one of the most challenging patient populations to treat because blood clots in these very young patients usually occur with another serious illness that also must be treated.

Historically, the limited amount of research on blood clots in children led healthcare professionals to draw upon what they know about treating blood clots in adults to help them navigate the treatment of blood clots in children. In recent years, however, great progress has been made in pediatric blood clotting research, including clinical trials.

Blood Clots: The Young and Old of it All continues on page 16

Whether you are newly diagnosed with blood clots, have been following your treatment plan for quite some time, or are learning to live your new normal after blood clots, communication is a tool that can play a central role in your healing and eventual return to health. It is important that when communicating with your doctor or other healthcare provider, your friends and family—or even yourself—that you create and maintain an open, honest dialogue focused on how you are doing and feeling.

Healthy exchange relative to all of the touch points for communication we explore here—self-talk, family and friends, your medical team—also provides an opportunity for you to receive and, equally important, share words of hope and encouragement. No doubt, recovery after a blood clot can be difficult, but living your best life after a blood clot is possible.

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Your story as a blood clot survivor is already one of success.

Whether your recovery is short or long, easy or difficult, you have a success story to share if you choose, and by sharing your story you can lift up not only yourself, but also inspire others who might face struggles similar to your own.



Self-Talk: Be Your Own Best Friend

How you communicate with yourself—or your self-talk during recovery—is more important than most people realize. If you have experienced a blood clot, you may be feeling angry, anxious, or even depressed. You might feel like your body let you down or that you could have done something different to prevent blood clots. You may even blame yourself for what you are experiencing now. However, sometimes there is nothing you can do to prevent a blood clot, and sometimes, blood clots just happen even when you take steps to prevent them.

The important thing to remember is that now you are receiving treatment, and you are doing all that you can to take care of yourself and to feel better. It is important to be patient with your recovery—and with yourself—as your body heals. Whether it takes weeks or months to feel better, your body is making progress each day, even if it doesn't seem like it to you. Be kind to yourself, and give yourself credit during the healing process. Your body and mind have

been through a lot, and it may take a lot of time and energy to heal from your experience.

Going to your doctor's appointments, taking your medication, exercising when you are able to, eating a nutritional diet, and getting plenty of rest are all things you can do to take care of yourself while you are healing from blood clots. It is also important to care for yourself emotionally and to find healthy ways to manage stress and anxiety. For example, you could go for a walk, read a book, listen to music, or learn a new skill or hobby.

Don't "beat yourself up" or get bogged down in all the negatives. Recognize and embrace that you have experienced something that is crucially very important—life-changing for some—and celebrate the path you are on now. You are moving forward. You are a blood clot survivor. Your best life is in front of you and all about what you make of it. 🍓



Self-Care Tips

- 1 Attend regular follow-up appointments with your medical team.
- 2 Take your medication as prescribed, and let your doctor or pharmacist know about any changes that concern you.
- 3 Exercise or spend time moving, even if you just walk around the block, when you are feeling well.
- 4 Eat a nutritional diet, and talk to your doctor about any changes that you may need to make with regard to your anticoagulant medication or health goals.
- 5 Get plenty of rest while you are healing.
- 6 Talk to your doctor or mental health professional about ways to manage stress and anxiety.



To Share or Not to Share: Family and Friends

It can be difficult for friends and family to understand what you are going through, and it also can be difficult to explain your situation and feelings, especially if you are overwhelmed yourself. Being open and honest about your recovery with the people you care about is as important as being open and honest with your healthcare team and yourself. If you need help preparing meals, cleaning your home, caring for kids or pets, or running errands, let someone know, or reach out to your local community assistance programs. In most communities, you can dial 2-1-1 on your phone or visit www.211.org to be connected to resources near you.

Many people find it very helpful—even therapeutic—to talk with other people about what they have been through. Sharing your feelings by “talking things out” can help if you are struggling with anxiety and depression. You should always be able to share your feelings with a trusted healthcare professional, friend, or family member. You also can look into different safe and supportive groups, such as the National Blood Clot Alliance peer-to-peer *Stop the Clot® Online Support Group and Discussion Community*, powered

by Inspire (www.stoptheclot.org/peer-support), where you can connect with peers who also have been diagnosed with a blood clot.

Often times, it may seem easy to tell your family or friends about how you are feeling, but other times, you may not want to share anything, either because it is too personal or you may not want to answer a lot of questions. Both situations are okay. Set boundaries with your friends and family, and if you don’t want to share information about your journey, you don’t have to. It can be as simple as redirecting the conversation to another topic, or indicating that you don’t wish to discuss the particulars of your health.

Whether you choose to share details about your personal recovery journey with others or not, when it comes to your family, it is important to share your health history. Clotting disorders, as well as a family history of blood clots, can increase a person’s risk for blood clots. Some people are born with thrombophilia, so it is always important to share your family’s health history. ❤️

“I felt so alone and alienated until I was able to connect with other people through NBCA’s online support group. It really helped with my anxiety, and the connections I’ve made online there have been so helpful and have given me so much support and so many great resources. It’s been a real lifeline for me.”

— Michelle E, blood clot survivor



Your Healthcare Provider is Your Best Resource

From diagnosis to treatment to recovery, you probably have a number of medical questions that you need answered. No matter how simple or complex your questions may be, it's important that you get the answers you are seeking.



Sometimes, it may feel like healthcare professionals don't fully understand or appreciate the personal impact of a blood clot diagnosis and subsequent recovery. This is often due to the fact that recovery from blood clots, and each individual's own treatment plans, can vary from person to person. Your situation may not be the same as the next person's, and some situations are more complicated than others, which means your doctor may not know to what extent you need guidance and reassurance during your recovery from blood clots until you let them know.

Whether your situation is complicated or not, you need to have clear conversations with your doctor or healthcare provider during your treatment. To make good decisions about your care, you need to have good information. If you have questions about your treatment and recovery, make

sure you ask your doctor, and let them know what information you need. Also, take time to share your family's health history with your doctor, particularly a history of blood clots. Write down your questions and take them to your follow-up appointments or call your doctor's office and ask if you cannot wait for an appointment. It may also help to take someone with you to your initial appointments, to support you and ask any additional questions you may have forgotten. Don't be afraid to ask the questions you have to get the answers you need.

If your doctor is not answering your questions, or if you feel like you do not consider your doctor a partner in your treatment and recovery, find another doctor or seek another opinion. Sometimes, it may take seeing more than one doctor to find one who can offer you the support and guidance that you need. It can also be helpful to see a specialist, like a hematologist, if you aren't getting the answers you need from a family doctor or primary care physician. A hematologist, or other specialist, can often answer specific questions that a primary care physician may not be able to address fully or in great detail for you. 🍷

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FOR Patients**

Our mission is clear — we discover, develop and deliver transformational medicines that help people prevail over serious diseases. Our sense of urgency is real — we work every day to push the boundaries of scientific discovery and to make a meaningful difference in the lives of patients.
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Questions to Ask Your Doctor

- 1 What will my treatment plan consist of and for how long? How do we determine which anticoagulant is best for me? What side effects should I be aware of?
- 2 Do I need to have follow-up appointments with you, and if so, how often?
- 3 Do I need to meet with specialists, like a hematologist, to help determine the cause of my blood clot? If so, how do I go about setting that up?
- 4 What can I expect my recovery to be like physically? How long will it take?
- 5 Is it normal for me to feel anxious or overwhelmed after a blood clot?
- 6 Do I need to be aware of any changes that may occur? How do I know if I need to call the doctor or go to the hospital?
- 7 Do I need to take time off from work? If so, how do I know when I am ready to go back?
- 8 When can I resume activities I enjoy, such as travel and exercise again?
- 9 How might my blood clot experience impact future decisions I make (i.e., about birth control, pregnancy, surgery and hospitalization, etc.)?
- 10 What preventive measures can I take to reduce my risk of another blood clot? How likely is that to occur in my situation?

Understanding Clinical Trials

When people think of clinical trials, they often think of them as a potential treatment option of last resort for individuals who are very ill or facing a life-threatening disease, but clinical trials can offer different opportunities to many different types of individuals. For example, clinical trials can provide access to people who may not be responding well or optimally to currently available therapies, and many trials actually seek out healthy volunteers to participate in research studies. In the field of venous thromboembolism, or in clinical trials



studying deep vein thrombosis (DVT) and pulmonary embolism (PE), there are literally hundreds and hundreds of studies taking place throughout the United States and around the globe. If you're interested in participat-

ing in a clinical trial, your first step should be to learn more about clinical trials—how they are conducted, how they enroll and work with patients, and what you can expect if you find yourself part of a clinical trial.

What is a Clinical Trial?

Clinical trials are used in medical research to help evaluate and determine the safety and effectiveness of new drugs or new treatments, and to compare different treatments or approaches to treatment. Some clinical trials also explore the use of new diagnostic tools and medical devices, while others might look at the development or progression of disease in certain patient populations.

Carefully designed clinical trials are the safest and quickest way to find treatments that work. Ideas for clinical trials usually come from researchers who first test new therapies or procedures in the laboratory and get promising results prior to planning clinical trials or research that will involve human subjects or patients. New therapies are tested

on people only after laboratory and animal studies show that they are generally safe and may offer some promising results.

Clinical trials are sponsored or carried out by government agencies, such as the National Institutes of Health, pharmaceutical companies, healthcare organizations, such as hospitals or health maintenance organizations, individual physicians or researchers, and companies that research and develop other medical products such as diagnostic tests, medical devices, and medical or surgical equipment.

Clinical trials can take place in a number of locations, including doctors' offices, community health centers or clinics, hospitals, and universities.

More detailed information about clinical trials can be found at www.clinicaltrials.gov

All clinical trials have guidelines or criteria that identify who can and cannot participate in a research program. There are inclusion criteria that state clearly

who the study subjects are intended to be, while exclusion criteria indicate who should not be included, or who should be excluded from the study. These criteria are not meant to reject people personally. Rather, the criteria are used to identify appropriate participants and to make sure that they are kept safe and also enable researchers to get the information or answers about the medication they plan to study.

These guidelines may be based on an assortment of factors, including, for example: Age, type of disease, medical history, and current medical condition.

Before you join a clinical trial, you must qualify for the study. Some research studies seek volunteers with illnesses or conditions to be studied in the clinical trial, while others need healthy volunteers.

There are strict government guidelines in place to ensure that people who participate in clinical trials remain safe. All planned clinical trials that are designed for implementation in the United States must be reviewed, approved, and monitored by an Institutional Review Board (IRB) made up of physicians, patient advocates, research and statistical experts, and other stakeholders who can help ensure that the study is ethical and that the rights and safety of the participants are protected. Federal regulations require that all institutions that conduct or support medical research involving human subjects have an IRB that initially approves and periodically reviews the research.

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Questions to Consider When Evaluating a Clinical Trial

- Why is this research being done and what is the purpose of this study?
- Who is sponsoring the study?
- What happens to my treatment if I'm in the placebo group?
- Who has reviewed and approved this study?
- Why does the research team think the treatment, drug, or medical device will work?
- If I do not qualify for this clinical trial, are there others?
- Where is the study site?
- What kinds of therapies, procedures, and/or tests will I have during the trial?
- Will they hurt? If so, for how long?
- How will the tests in the study compare to tests I would have outside the study?
- How long will the study last?
- How often will I have to go to the study site?
- Who will provide my medical care after the study ends?
- Will I be able to take my medications during the trial?
- What medications, procedures, or treatments must I avoid while in the study?
- What are my responsibilities during the study?
- Will I have to be in the hospital during the study?
- Will the study researchers work with my doctor while I am in the study?
- Can anyone find out that I am participating in a study?

Questions to Consider About Benefits and Risks of Clinical Trials

- How do the possible risks and benefits of the study compare with approved treatments for me?
- What are the possible immediate and long-term side effects?
- What other treatment options do I have?
- Will I have to pay anything to participate in the study?
- What are the charges likely to be?
- Is my insurance likely to cover those expenses?



Informed-consent

Another crucial aspect of clinical trials that helps to safeguard patients involves informed consent, or the process a patient or study subject goes through to learn about a clinical trial before they decide whether or not to participate.



Before consenting to participate in a clinical trial, an informed consent document should explain in some detail, for example: The goals or reasons for the research, the procedures and timeline the study will employ, the potential risks study subjects may encounter in the trial, the benefits they may realize, other treatment op-

tions that might be available, and the patient's right to leave the trial at any time. Participating in a clinical trial is a major decision, and you should ask your doctor or the research staff any questions you have before you make a decision or sign the consent form.

If you are interested in participating in a clinical trial, talk to your doctor or healthcare provider to determine if they are familiar with any trials that might be a good match for you. Your doctor also can help you determine if studies you might research on your own represent a good opportunity for you, or perhaps pose unnecessary risks.

However, it's important to understand that informed consent is a process that continues after you sign the document of the same name. Informed consent continues throughout the duration of the study, and you should ask your doctor or the research staff questions before, during, and after the study.

There are currently more than 325,000 studies based in the U.S. and other countries, listed on www.clinicaltrials.gov. The data on www.clinicaltrials.gov change daily. New studies are published on the web site and existing studies are updated daily. To ensure that you are accessing the most up-to-date and accurate information, take some time to familiarize yourself with how searches are done effectively on the site, and then do your search in real time to ensure you are seeing the latest search results. Most importantly, work with your medical team to make sure that any clinical trials you might pursue are compatible with your health history and clinical needs. 🍷

CLINICAL TRIAL STUDY SEARCH TOOLS

There are tools available online to facilitate your research into clinical trials connected to blood clots. One of the most popular and easy-to-use tools is available at www.clinicaltrials.gov. At this site, you can access thousands of clinical trials, including many trials involving diagnosis, treatment, and longer-term management of deep vein thrombosis and pulmonary embolism.

To find a specific study or to narrow your search of studies of interest to you, you can simply enter specific search terms—such as deep vein thrombosis, pulmonary embolism, or post thrombotic syndrome, for example—at the top of the www.clinicaltrials.gov home page.

A screenshot of the "Find a study" search interface on the ClinicalTrials.gov website. The interface is titled "Find a study (all fields optional)". It features several search filters: "Status" with radio buttons for "Recruiting and not yet recruiting studies" and "All studies" (selected); "Condition or disease" with a text input field and a clear button (X); "Other terms" with a text input field and a clear button (X); and "Country" with a dropdown menu and a clear button (X). At the bottom, there are two buttons: "Search" and "Advanced Search".

As shown here, you simply enter your search terms into the data fields, then click on the "search" button. You will then be taken to a page that shows the studies that correspond with your search terms, if they exist.

Caught Off Guard: Olanna's Story



March 2015 was the start of a health journey that would impact the rest of my life. Earlier that month, I was experiencing a slight, nagging pain in the back of my calf. After a few weeks of dealing with the symptoms, I made an appointment with my primary care doctor. Later that afternoon, I ventured to the local hospital for an ultrasound of my leg. The results revealed no signs of anything abnormal with my leg.

A few weeks later, I started experiencing a minor pain in my lower bicep and tightness in the middle of my left forearm. The discomfort increased as the month of April went on. I remember one night I packed a small suitcase, which sat next to the sofa in my living room in the event anything happened. Eventually, I decided to visit my doctor again toward the end of April. During the visit, we discussed how I had recently moved a few boxes around my place and a recommendation of physical therapy was given, as my symptoms appeared to be a muscle strain. As I waited for approval to proceed with scheduling physical therapy sessions, my symptoms grew worse.

The first week of May, I was attending a graduation ceremony. I noticed some numbness of my fingers and rubbed my arm all day in hope that the discomfort would ease a little bit. While in attendance at the event, I lost feeling in my fingers. Fifteen minutes later, I arrived at the hospital, where tests were swiftly done on my heart and left arm. Within a matter of minutes, the nurse returned to my room and delivered the news that a blood clot was

found in my arm. More specifically, it was a deep vein thrombosis, or DVT, in the basilic vein or the large superficial vein of the upper arm. This caught me off guard and little did I know I would be contacting a colleague to grab the small suitcase sitting in my living room. Diagnosis of the blood clot would lead to ongoing blood tests, different medical treatments, monitoring by specialists, unexplained loss of strength in my arms and fingers, and tightness in my arm.

“Within a matter of minutes, the nurse returned to my room and delivered the news that a blood clot was found in my arm.”

Today, I am blood clot free and no known cause was ever found. I continue my research about blood clots and share my experience with others. My passion for this topic is not only based on my own experience, but also due to the loss of a beloved sorority sister who suffered from a blood clot in her lung in October 2009. Also, other members of my sorority have traveled this journey with their family members and friends. I am sharing with other people to continue yearly medical checkups, know your body, and do not be afraid to share your story. 💖

Sharing My Story, My Final Step in Healing:

Shelley's Story

At 23 years old, I never thought I would be lying in a hospital bed surrounded by doctors who were baffled by one of the youngest cases of blood clots in the lung that they had ever seen.

It was the summer of 2014, and my husband and I had just bought our first home and we were trying to figure out the whole “new homeowner thing.” I was young and felt healthier than I ever had before. Aside from all the house work, I was exercising at the gym and going for morning runs with my dog. I started having pains in both of my legs and calves. I assumed I gave myself shin splints because that seemed normal with all the exercise and activity I was doing. I complained for days, but didn't think much of it, and assumed I was just out of shape.

One weekend, I decided to get a quick workout in before working on the house again, but little did I know what was happening to my body, or the warning signs it was trying to give me. In the midst of my run, I started to feel a sharp pain in my left rib cage. Thinking I was maybe still “out of shape,” I shrugged it off and continued my run. Shortly after, I noticed each breath I took became more strenuous than the last, and the pain seemed to be getting worse. I stopped for a minute to try and catch my breath, hoping to ease the pain, but nothing seemed to help.

When I got home, I tried my best to hide from my husband the great discomfort I was feeling, and spent three days in excruciating pain. I was up in the middle of the night crying in the living room in silence so my husband wouldn't hear me. I was afraid to see a doctor about it, which seems so silly to me now. With being new homeowners, I knew I couldn't afford to skip work, let alone be stuck in a hospital bed, but the pain was too much for my body to handle. I couldn't sit or lay down without being in pain. My chest felt tight, and I felt like I was being suffocated while having to slowly gasp for air. After the pain became too much for my body to handle, my husband had enough and drove me to the emergency room. I was rushed back for a CT scan where they found

I had a bilateral pulmonary embolism, or blood clots in both of my lungs, which would leave me in the hospital for a week, and in recovery for over a year after being discharged.

I was diagnosed with heterozygous prothrombin G20210A mutation, also called factor II, which means people like me produce more prothrombin protein than needed, which can increase a person's risk for blood clots. I inherited two of these mutated genes—one from each parent—which leaves me at a greater risk for recurrent clots, even being on an anticoagulant or blood thinner, which I will take for the rest of my life.

I was told that if I had waited another day, I would have died. While I feel so lucky to be alive, I have struggled with severe depression along the way. Something changes when you go through something like this that I can't explain, and no one who hasn't been through it understands. I had thoughts of how I wasn't ready to “leave” yet, fear of falling asleep and never waking up again, and regret for not showing or telling my husband or my family and friends that I loved them more often than I already did.

Don't get me wrong, I'm beyond blessed and thank God every day for giving me a second chance at life, but this journey hasn't been easy. It doesn't just happen and then go away. There are countless appointments, endless bills, numerous scans, and doctors to see. At times, it is so overwhelming, but I know I have a huge support system behind me made up of people who encourage me and push me to be strong still to this day.

I'm so grateful to be able to share my story with the hope that I can help others know the signs before it's too late. I hope reading my story encourages other people to write their own story too. It took me years after finding the National Blood Clot Alliance to get the courage to write my story, but I believe this was my final step in my journey of healing. 🍷



Blood Clots: The Young and Old of it All

continued from page 4

Illness Underlies Pediatric Blood Clots

Most young children who experience blood clots are very ill, and their blood clot risk is most commonly connected to an acute or chronic illness, such as a severe infection, cancer, an abnormal heart structure, or disorders of the immune system. In these young children, clots occur due to poor blood circulation in the veins, which can happen when children are confined to bed, for example.

Also, damage to the inner lining of veins, caused by central venous lines, or the long, flexible tubes that may be inserted through a young child's veins (e.g., a port or PICC line), are a major cause of clots in children. Damage to the veins can also occur when certain drugs or toxins circulate in the blood.

Teens and Blood Clots

Blood clots in children span a wide age range from newborns through 18 years old. While blood clots in children are commonly seen among those who are

younger and very sick, dangerous blood clots also affect teenagers.

In teenagers in particular, with the hormonal changes that come with puberty that mildly increase the risk of blood clots, an underlying inherited clotting disorder (or genetic thrombophilia) can become unmasked, combining to cause a blood clot that is either spontaneous or triggered by an additional factor like immobility, severe illness, or taking estrogen-containing birth control.

Most genetic thrombophilias are characterized by the lack of adequate amounts of properly-functioning natural anti-clotting proteins in the body, or by genetic changes that cause other parts of the body's clotting system to be resistant to these natural anti-clotting proteins. These conditions are either inherited genetically from one or both parents, or acquired as the result of injury, illness, or surgery.

Hereditary or Inherited Thrombophilia

Certain genetic mutations correspond with specific inherited thrombophilias. Some mutations, such as those underlying factor V Leiden and prothrombin

 Hereditary
CLOTTING disorders

Take the first step, know your risk

Did you know some blood-clotting disorders are inherited?

Some blood-clotting disorders are passed down from your parents. You may never know if you have one of these conditions until you develop a blood clot or another serious complication. If a rare genetic clotting disorder runs in your family, it is important to get tested to find out if you have it, too.

Talk with your doctor about getting tested

A blood test is the only way to find out if you may have a serious hereditary condition. If you think you or someone in your family may be at risk for a genetic clotting disorder, don't wait—talk with your doctor about getting tested today.

To learn more about genetic blood-clotting disorders, please visit www.hereditaryclottingdisorders.com

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G20210A, are relatively common, affecting one to five percent of the general population. Others, such as hereditary antithrombin deficiency, and also those responsible for protein C and protein S deficiencies, are less common, affecting less than one percent of people.

Many individuals with thrombophilia may never have a clotting problem, while others may experience a life-threatening clot or even a series of them. The good news is that close to 90 percent of all people with thrombophilia never develop a blood clot. In fact, they may live their whole lives without even knowing they have this risk. Unfortunately, however, certain types of thrombophilia do carry much higher risks.

“I’m a true testament to the fact that a blood clot can affect anyone. As a healthy teenage boy, blood clots never even crossed my mind...until I was diagnosed with one. This life-changing experience taught me to be thankful for my health. If you sense something is wrong, trust your instincts and tell someone or get it checked out. It could save your life.”

— Wheeler M., blood clot survivor, diagnosed at age 14

Families with a history of clotting should talk to their doctors, and their children’s pediatrician and pediatric hematologist, about their clotting risks and the ways they can develop a blood clot prevention plan suited to their short- and longer-term needs. Make sure your child’s pediatrician and pediatric hematologist know about any clotting risk that may have been identified in the family, and check that this information becomes part of the child’s health history records as they grow and are seen by other doctors. Today, electronic medical records are

increasingly helpful in transferring important medical information seamlessly as people move, travel within a health network, or work with different healthcare professionals over time.

Estrogen-Based Contraception

Teenage girls who are prescribed estrogen-based birth control may be at increased risk for a blood clot, particularly if they have a family history of clotting or genetic clotting disorders. While estrogen-containing birth control pills are safe and effective for many individuals who don’t have blood clotting risk factors like smoking, obesity, and a family history or prior personal history of blood clots, experts do caution that birth control with estrogen, including the pill, patch, or ring, can pose serious risks, including dangerous blood clots in the legs or arms, and deadly blood clots in the lungs.



As they mature and might be considering their birth control options, teenage girls should talk to their doctors about their blood clot risks and use a health risk assessment tool, such as the small example of one shown below, to work with their healthcare provider as they explore their contraceptive options.

Visit www.womenandbloodclots.org/resources to download this risk assessment tool.

Hormonal Contraception Screening Guide & Risk Assessment Tool	
Use this questionnaire when considering birth control options that contain the hormone estrogen, which may include the birth control pill, patch, or ring. This questionnaire will help you and your healthcare provider determine if you are a good candidate for hormonal contraception. Share the results of this questionnaire with your healthcare provider before taking hormonal birth control. Your healthcare provider will use your answers to the questions below to help you determine if you are a good candidate for hormonal contraception or if you should consider different birth control options that do not contain hormones.	
Name _____	Healthcare Provider's Name _____ Date _____
Date of Birth _____	Age _____ Weight _____ What was the date of your last women's health clinical visit? _____
Any Allergies to Medications? Circle One: Yes / No If yes, list them here: _____	
1	What was the first date of your last menstrual period? (month/day/year) _____ / _____ / _____
2	Do you think you might be pregnant now? Yes <input type="checkbox"/> No <input type="checkbox"/>

“Children who survive following a blood clot diagnosis are at increased risk of developing another clot later in life or as they mature, and it’s important for this to be recognized and discussed with all of the child’s healthcare providers.”

— Neil Goldenberg, MD, PhD, Professor of Pediatrics and Medicine, Johns Hopkins University, and NBCA Medical & Scientific Advisory Board Member





Advancing Age, Increased Clotting Risk

It is an unfortunate fact that blood clot risks escalate as we age. Although blood clots can affect anyone, they are much more likely to occur in people older than 60 and recur in patients older than 65 who have already had an initial clot.

Advanced age is an independent risk factor for blood clots for multiple reasons. First, the body works less efficiently as it gets older. These age-related deficits have been associated with activation of both inflammation and coagulation processes in the circulatory system that play a role in blood clot formation. Likewise, older individuals are more likely to have plaque buildup on the walls of their blood vessels (a condition known as atherosclerosis) that also can be a contributing factor to the formation of blood clots.

Older people are also more likely to experience other health problems—and require related medical treatments—that further increase the odds for a blood clot. These are considered associated blood clot risk factors, and include:

Hospitalization

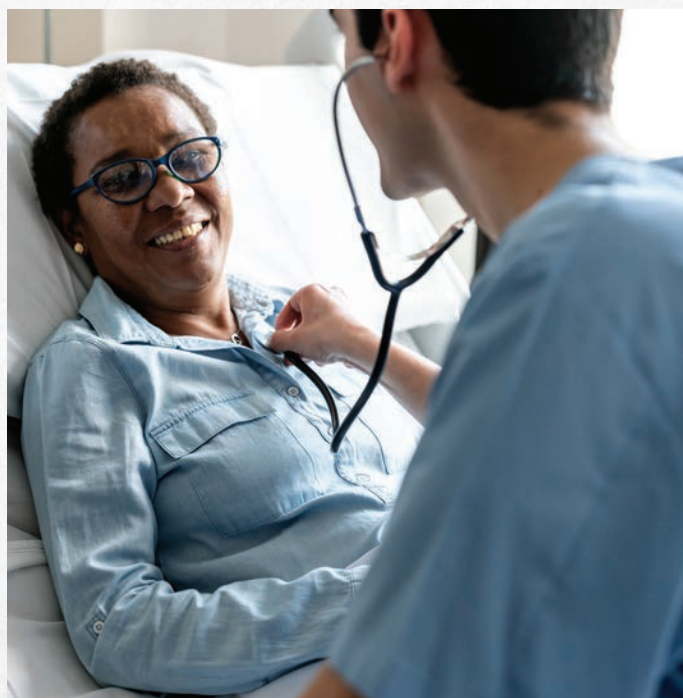
The older you are, the more likely it is that you will be admitted to a hospital. In fact, people older than 65 are twice as likely to have brief or extended stays in a medical facility than those between the ages of 44 and 65 (15.3% vs. 7.4%, respectively). Hospitalized patients have 10 times the risk of developing a blood

clot compared to non-hospitalized individuals. In fact, hospitalization is a leading risk factor for blood clots:

Nearly half of all new blood clot cases occur during or within 90 days of hospital admission.

Surgery

Surgery—especially total knee replacement (TKA) and total hip replacement (THA)—presents significant risk for blood clots in older patients.



Approximately one out of every 100 individuals between the ages of 65 and 84 undergoes a TKA or THA each year. Nearly 40% of those not medicated with blood thinners will experience a blood clot within two weeks of the procedure. For surgical patients with congestive heart failure, a common cardiovascular illness in seniors, the risk is even higher.

A significant percentage of surgery-related VTE episodes are asymptomatic—or without clear signs and symptoms—and are, therefore, not easily diagnosed. This makes it critical for TKA and THA patients to understand the blood clot risks of surgery and to discuss effective preventive strategies with their physician in advance of any operation.





Cancer

According to The National Cancer Institute, “Advancing age is the most important risk factor for cancer.” In fact, one quarter of all new cancer cases are diagnosed in people between the ages of 65 and 74.

discuss your blood clot risks with your cancer doctor, and be vigilant too about the signs and symptoms (outlined on next page) of blood clots in your limbs and lungs.

Weight Gain/Obesity:

Excess weight increases the odds of blood clot formation. This is particularly concerning for older adults because people tend to gain weight as they age. There are several reasons for this trend. First, body composition gradually shifts with age. The proportion of muscle decreases and the proportion of fat increases. These changes slow down metabolism, making it easier to put on pounds.

In addition, people become less physically active as they get older, so they burn fewer calories.



Blood clots are a particular danger for cancer patients. By some estimates, the risk for a blood clot is 50 times higher following a cancer diagnosis and the death rate among people with cancer who experience a blood clot is also 50-fold higher than mortality rates in the general population. Overall, blood clots are the second-leading cause of death in people with cancer.

If you are being admitted to the hospital, or scheduled for surgery, it’s important to have a blood clot prevention plan in place. If you are diagnosed with cancer, or being treated for cancer, be sure to



To reduce your chances of developing a dangerous blood clot, it is important to maintain a healthy

weight, particularly if you have other risk factors. Exercise is one of the fundamental habits that can help you offset age-related weight increases. Discuss a suitable exercise program with your doctor that takes into account your general health and any medical conditions that may limit activity.

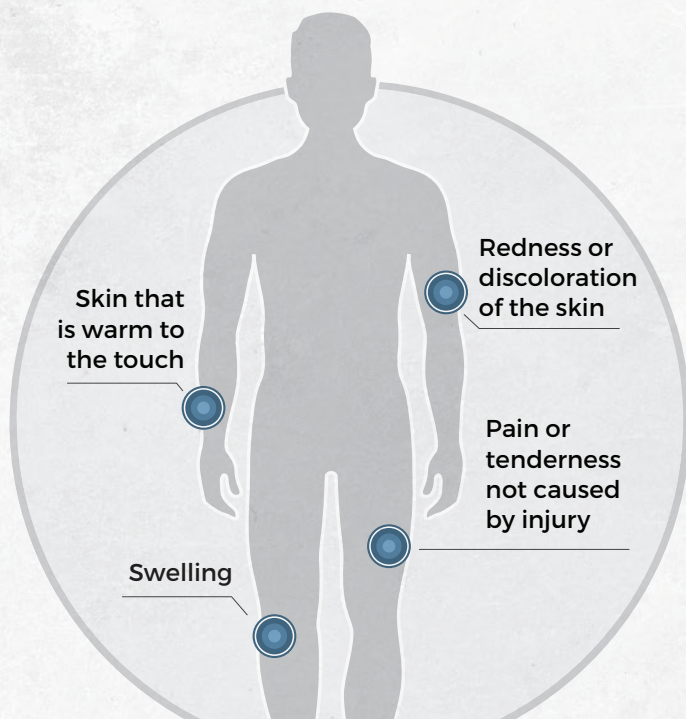
“The reason for my blood clot was generally unknown, but it’s suspected to have been connected to my weight. Since my blood clot, I have been vigilant about my health and nutrition, losing more than 60 pounds following my diagnosis.”

— Leslie Lake, blood clot survivor and NBCA Board Chair

Word to the Wise

As we age, it’s important to understand our potential risks for blood clots, and work with our healthcare providers to ensure that we are taking steps to remain healthy and reduce those risks whenever possible. As the saying goes, “with age comes wisdom.” As people age, they can put that wisdom to work for themselves, their families, and their health. A better understanding of blood clot risks, as well as signs and symptoms, can help to prevent clotting... among the young, the old, and all ages in between.

RECOGNIZE THE SIGNS AND SYMPTOMS OF A BLOOD CLOT

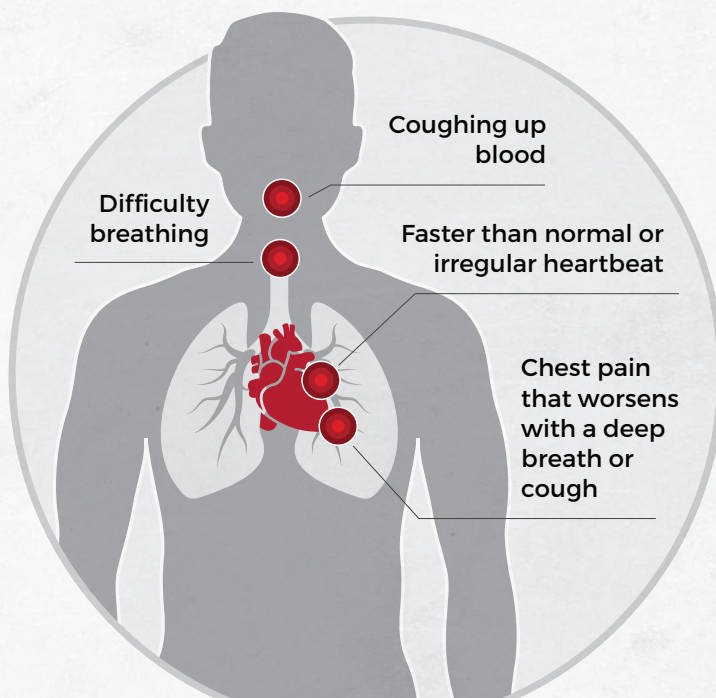


Deep Vein Thrombosis (DVT)

Signs and Symptoms

BLOOD CLOT IN THE LEG OR ARM

Contact your doctor if you experience any of these symptoms



Pulmonary Embolism (PE)

Signs and Symptoms

BLOOD CLOT IN THE LUNG

Call 911 or seek immediate medical attention if you experience any of these symptoms

My Blood Clot Life: Health Hacks

When it comes to managing life following a blood clot diagnosis, there are plenty of challenges you might encounter. To help manage these issues, below are some important health hacks specific to the real life challenges many blood clot survivors encounter. If you have any *Blood Clot Life Health Hacks* you might want NBCA to share with others, drop a note to us at info@stoptheclot.org and we will surely spread the word.

Managing Anticoagulant Medication When Medical Procedures Are Planned

When used properly, anticoagulation medications or “blood thinners” can safely and effectively prevent blood clots. As with all prescription medications, they also can cause side effects. The most common side effect or complication of all anticoagulation medications is bleeding.

Bleeding risks with anticoagulation therapy can be minor, such as when you nick yourself while shaving, scrape your knee, or undergo a dental cleaning or procedure like a tooth extraction. Bleeding risks with anticoagulation therapy can be major or life threatening, such as internal bleeding that can occur if you have an accident, serious injury, or major surgery.

Effective anticoagulation management requires the successful balance between the prevention of blood clotting and the potential risk of bleeding that is a complication of all anticoagulation therapies. You should always talk to your doctor or healthcare team about your anticoagulation management when you have surgery or any other medical or dental procedure planned.



Take These Four Steps

STEP 1

Before Your Surgery or Medical or Dental Procedure

Work with your doctor to schedule your medical procedure, and make sure your doctor and healthcare team are aware of all of the medications you are taking, as well as your existing risk for blood clots and prescribed anticoagulation treatment.

STEP 2

When Your Surgery or Procedure is Scheduled

Follow all of your doctor's instructions before and after your surgery or medical procedure. If you do not follow your doctor's instructions, you run greater risks for bleeding and clotting and your surgery or procedure may need to be postponed.

STEP 3

General Guidelines for Anticoagulation Management & What You Can Expect

Everyone is different, and you will have different risks. Your healthcare provider will give you instructions for when to stop taking your anticoagulant prior to your surgery or medical procedure. Depending on your specific health history and the type of anticoagulant medication you take, they also will let you know if there is any other medication or steps you need to take prior to your surgery or medical procedure. Follow these instructions very carefully. Prior to your surgery or medical procedure, make sure to let your doctor or healthcare provider know if you have any questions, or if you were unable to follow their directions or to stop taking your anticoagulant as instructed.

STEP 4

After Your Surgery or Procedure

Follow-up with your doctor for specific instructions to restart anticoagulant medication. This will vary based on your clotting and bleeding risks, the type of anticoagulant you are taking, and the type of procedure that was performed.



The Nuisance of Nosebleeds

The risk for nosebleeds increases while taking an anticoagulant, and over-the-counter gels and sprays or room humidifiers can help moisten the nose to prevent nosebleeds. If you experience a nosebleed, here is what you can do:

- Stay calm
- Pinch your nostrils at the bridge of the nose and below the bone
- Bend your head forward (chin to neck) while pinching the nose to control bleeding
- Breathe through your mouth
- Contact your doctor if the nosebleed is very heavy or goes on for more than 30 minutes
- Record the frequency of your nosebleeds to inform your healthcare provider
- Talk to physician or pharmacist about over-the-counter remedies that could be helpful to you



Passport to Safety

If you are making plans to get away, always make sure to add blood clot prevention to your itinerary. Whether traveling by plane, train, car, or bus, take steps to protect yourself when you are traveling or immobile for more than four hours.

- Raise your heels with your toes on the floor
- Raise your toes with your heels on the floor
- Get out of your seat and walk every hour or so
- Drink plenty of fluids, especially water
- Avoid alcohol and caffeine
- Wear loose clothing
- Do not cross your legs
- Avoid sleeping pills or long rest periods
- If you are driving, stop the car and walk around for a few minutes every hour

If you are confined to your seat or immobilized for extended periods of time, you can do the following exercises and stretches.

Seated Exercises:

- **Ankle Circles:** Lift your feet off the floor and twirl your feet as if you're drawing circles with your toes. Continue this for 15 seconds, then reverse direction. Repeat as desired.
- **Foot Pumps:** Keep your heels on the floor and lift the front of your feet toward you as high as possible. Hold for a second or two, then flatten your feet and lift your heels as high as possible, keeping the balls of your feet on the floor. Continue for 30 seconds, and repeat as desired.
- **Knee Lifts:** Keeping your leg bent, lift your knee up to your chest. Bring back to normal position and repeat with your other leg. Repeat 20 to 30 times for each leg.
- **Shoulder Roll:** Lift your shoulders upward, then pull them backward, downward, and forward, creating a gentle circular motion. Continue for 30 seconds. Then reverse direction if desired.
- **Arm Curl:** Start with arms on chair rests, bent at a 90-degree angle. Raise one hand up to your chest and back down. Alternate hands and continue for 30 seconds. Repeat as desired.

Seated Stretches:

- **Knee to Chest:** With both hands clasped around your right knee, bend forward slightly and pull your knee to your chest. Hold the stretch for 15 seconds; then slowly let your knee down. Repeat the same stretch with your left knee. Perform 10 stretches for each leg.
- **Forward Flex:** Keep both feet on the floor and slowly bend forward, reaching for your ankles. Hold the stretch for 15 seconds and slowly return to a normal seated position.
- **Overhead Stretch:** Raise both hands straight up over your head. Use one hand to grab the wrist of the opposite hand and gently pull to one side. Hold the stretch for 15 seconds, and repeat with the other arm.
- **Shoulder Stretch:** Bring your right hand over your left shoulder. Then place your left hand behind your right elbow and gently pull your elbow toward your body. Hold the stretch for 15 seconds and repeat with the other arm.
- **Neck Roll:** Relax your neck and shoulders. Then drop your right ear to your right shoulder and gently roll your head forward and to the other side, holding each position about 5 seconds. Repeat 5 times.





Blood Clots and Travel: American Society of Hematology Recommendations

In 2019, the American Society of Hematology (ASH) set forth its recommendations for the prevention of blood clots in long-distance travelers. These ASH recommendations address several key questions and, as documented by ASH, these questions include:

Who is at increased risk?

The following factors place people at an increased risk for developing blood clots:

- Recent surgery
- Prior blood clot
- Postpartum women
- Active malignancy
- Equal or greater than 2 factors, including combinations of the above with hormonal replacement therapy, obesity, or pregnancy


How long is long distance?

Long-distance travel is defined as travel longer than four hours in duration.

Who should wear graduated compression stockings or take low molecular weight heparin (LMWH) or aspirin for blood clot prevention?

In long distance travelers without risk factors for blood clots, the ASH guideline panel suggests not using these measures. However, the ASH guidelines panel suggests using graduated compression stockings or preventive LMWH for long-distance travelers who are at substantially increased risk for blood clots.

What if a patient cannot wear graduated compression stockings or take LMWH?

For long-distance travelers who are at an increased risk of blood clots but who are unable or unwilling to use LMWH or graduated compression stockings (due to resource constraints or aversion to other indicated anticoagulants), the ASH guidelines panel suggests using aspirin rather than no blood clot prevention. 

Source: Schünemann, HJ, Cushman M, Burnett AE, et al. American Society of Hematology 2018 guidelines for management of venous thromboembolism prophylaxis for hospitalized and non-hospitalized medical patients. *Blood Adv.* 2018;2:3198-225.

Making a Full Recovery: Paul's Story

One year ago, I was diagnosed with a massive blood clot in my lung. It occurred when I was away for the long Martin Luther King Jr. weekend on a ski trip in New York. Early that weekend, on a Saturday, I had a minor fall getting off of the lifts. I injured both of my knees and spent the rest of that day lying around resting, and the next day watching football.

The following Monday, as I was getting ready to leave and check out of the hotel, I began to feel a little dizzy. My wife, who was there with me in our hotel room, saw me sliding off the bed. I appeared to be unconscious. We called ski patrol, who took my vitals, and thought it would be okay for me to seek treatment when we got home since we were leaving soon. While walking to the car, I felt dizzy again and passed out. I was then taken by ambulance to a local hospital, where I was diagnosed with a bilateral pulmonary embolism, or blood clot in my lung, and enlarged right ventricle of my heart.

The following day, I underwent a procedure to help dissolve the blood clot. It was a procedure that was part of a research study. The doctors had asked me if I wanted to be part of this research and I agreed. After the procedure, I spent four days in the hospital and took a month off from work. I didn't realize that recovery would take so long, and found myself often trying to do things sooner than I should have. I have been on a new oral anticoagulant or blood thinning medication, which I may remain on indefinitely,



since several of my doctors are concerned about how quickly my clot seemed to have formed following my injury.

While they did find some blood clots below my right knee when an ultrasound scan of my legs was performed, my doctors and I were not able to identify any common risk factors for blood clots in my case, like long flights or traveling long distances in a car. I have since been tested for any genetic clotting disorders and, again, nothing was found.

Today, I feel like I have no side effects and can do almost anything I could do before. I don't have any difficulty breathing and no pain in my lungs. I feel that my doctor's quick actions and the surgical procedure I had are the main reasons I have fully recovered. I hope that in sharing my experience I can give hope to others who are going through or who have gone through a similar experience. ❤️

NBCA RESOURCES

Life-Saving Resources You Can Share

Below is a list of resources you can use to learn more about blood clots, share life-saving information with the people that you know, and connect with the National Blood Clot Alliance (NBCA).

NBCA Website Resources

Visit NBCA's website for more information about blood clots, blood clot treatment, help finding a doctor, and personal stories. Also, visit our website for the latest news and information about blood clots, plus learn more about our signature public awareness programs.

www.stoptheclot.org

www.stoptheclot.org/spreadtheword

www.womenandbloodclots.org

Online Peer Support

Join NBCA's online Stop the Clot® Peer-to-Peer Support Group and Discussion Community, powered by Inspire and moderated by NBCA. With more than 5,000 members, there is always someone available here who understands what you are going through.

www.stoptheclot.org/peer-support

Connect with NBCA on Social Media

Make a connection with us on social media and get daily updates, information, and news important to our community. Using NBCA's handle @stoptheclot, connect with NBCA on Facebook, Twitter, and Instagram.

NBCA Programs & Services

To get more information about NBCA's educational resources, read more about our programs and services at www.stoptheclot.org/programs-services.

Get Involved with NBCA

To help support NBCA's mission, make a donation, or volunteer, read more about how you can get involved at www.stoptheclot.org/how-to-help.

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