National Blood Clot Alliance

New Patient Guide

"We know the patient because we are the patient."

StopTheClot.org
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@StopTheClot

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Welcome to the NBCA Community

You have been diagnosed with a blood clot. This life-changing experience can be both upsetting and confusing at times. You may be asking yourself: *What is a blood clot? How did this happen to me? Will I be okay? Will my life ever be the same?* These are important questions that deserve to be answered.

The National Blood Clot Alliance (NBCA) developed this guide for newly diagnosed patients and their caregivers to help answer common questions and provide the resources to help you navigate life, post-diagnosis. Blood clots can be deadly, but you are a survivor and that makes you a thriver.

Welcome to the NBCA community. Please know that you are seen and heard by NBCA. We are here to help you every step of your blood clot journey.

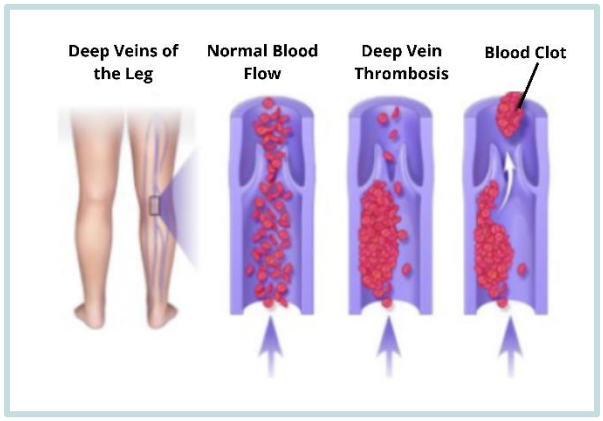
> "I came out of the doctor's office with my head spinning, full of anxiety, and found the National Blood Clot Alliance. I am not alone! Thank you!"
>
> - Paul in North Carolina

It is important to note that this new patient guide does not replace medical advice. Please consult your physician should you have any medical questions.

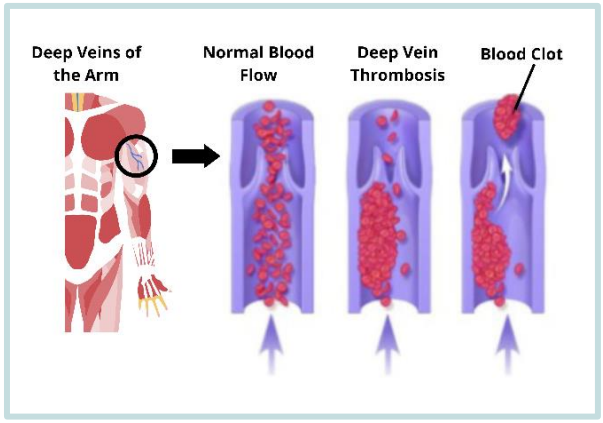
What is a Blood Clot?

This may be the initial question that you want answered. Blood clots are gel-like clumps of blood, which are beneficial when they form in response to an injury or cut. But they can also form when they aren't needed and cause serious medical problems, such as deep vein thrombosis (DVT), pulmonary embolism (PE), and cerebral venous sinus thrombosis (CVST). A DVT is a blood clot that forms in the large veins of the arms or legs. These types of blood clots can block the flow of blood and can cause swelling, pain, and red or purplish discoloration. If a DVT is not treated, it can move or break off and travel to the lungs, which can cause a PE. A PE can be life-threatening and requires immediate medical attention. A CVST is a rare form of stroke and happens when a blood clot forms in the brain's venous sinuses. This is a serious medical condition and requires attention right away.

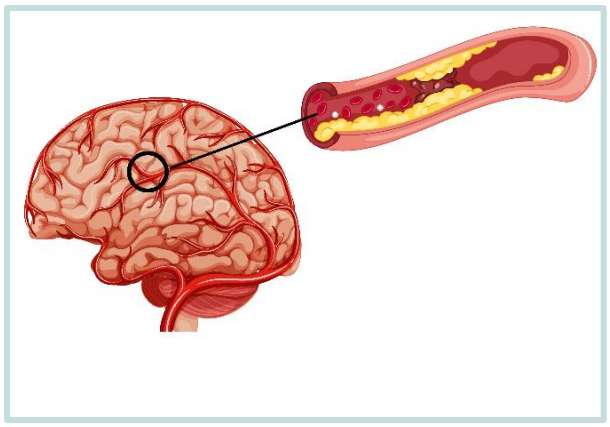
Deep Vein Thrombosis (DVT) in the Leg



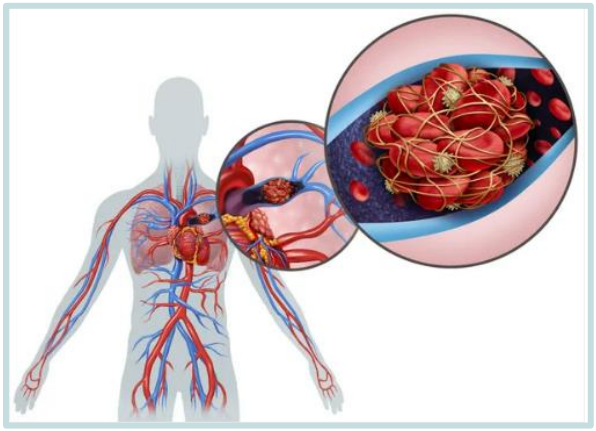
Deep Vein Thrombosis (DVT) in the Arm



Cerebral Venous Sinus Thrombosis (CVST)



Pulmonary Embolism (PE)



Blood clots can either be “provoked” or “unprovoked.” Provoked blood clots are clots that have an identifiable trigger, such as a hospital stay. An unprovoked blood clot has no identifiable cause. It’s important to know the difference in these terms in case you hear them, as it can impact your treatment protocol.

Some of the most common risk factors for blood clots include:

- Hospitalization for illness or surgery
- Severe trauma, such as a car accident
- Sitting too long, especially with legs crossed
- Injury to a vein maybe caused by a broken bone or severe muscle injury
- Being overweight
- Confinement to a bed or wheelchair
- Family history of blood clots
- The use of hormone therapy that contains estrogen
- Hip or knee replacement surgery
- Pregnancy, including up to three months after the baby is born
- Cancer and cancer treatments
- Use of oral contraceptives that contain estrogen, such as the pill, ring, or patch
- Smoking and/or vaping
- Age 55 or older
- Long-term diseases including diabetes, heart, or lung conditions
- Dehydration
- Covid-19

Know your risk. Talk to your healthcare provider about your risk for future blood clots and use these risk assessment tools as your guide:

General Risk Assessment Tool

Women’s Risk Assessment Tool

Blood Clotting Disorders (Thrombophilia)

Thrombophilia (also known as hypercoagulation or hypercoagulability) is a predisposition to developing blood clots. You can either acquire or inherit your thrombophilia during your lifetime.

You can acquire or develop a thrombophilia from abnormalities of the blood, such as too many red blood cells (polycythemia), too many platelets (thrombocytosis or thrombocythemia), placement of a mechanical heart valve, the development of abnormal proteins or antibodies, or diseases of the kidney or liver, or HIV infection.

Inherited thrombophilia is due to an inherited genetic predisposition and can either be heterozygous (meaning you inherited one copy of the gene mutation from one parent) or homozygous (meaning you inherited two copies of the gene mutation from both parents). The risk for developing a blood clot is greater for homozygous individuals versus heterozygous.

The presence of thrombophilia can be suspected when unexplained blood clotting occurs, blood clots occur in younger individuals, blood clots occur in an unusual area of the body (i.e., brain or abdomen), or having a history of multiple pregnancy losses.

The most common inherited thrombophilias include:

- Factor V Leiden
- Prothrombin G20210A
- Protein C Deficiency
- Protein S Deficiency
- Hereditary Antithrombin Deficiency

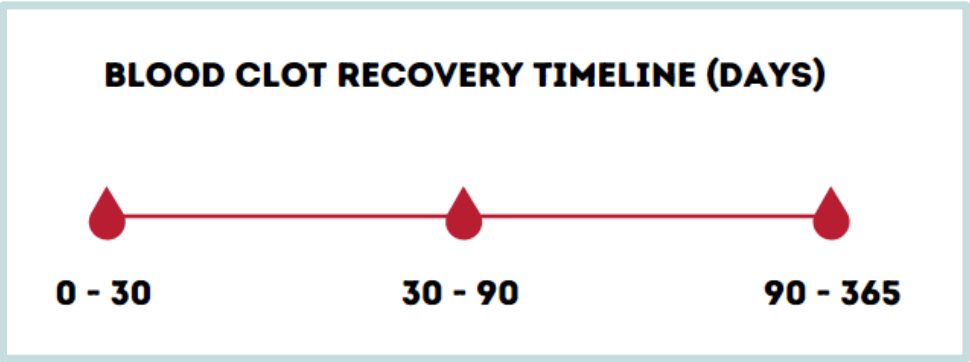
Learn more about thrombophilia:

Genetic Testing for Thrombophilia

There is no definite right or wrong answer when it comes to genetic testing for thrombophilia. There are many complexities— understanding your risk, dealing with emotional responses to this information, and determining if there is benefit to genetic evaluation. It is important to discuss these issues with a knowledgeable healthcare provider, who can make recommendations regarding thrombophilia testing for your situation. Genetic counselors are healthcare professionals who have experience and expertise in helping individuals and families with these issues.

Find a genetic counselor:

Blood Clot Recovery Timeline



Time is important in your blood clot journey. The first year can be filled with a range of emotions. It is normal to feel confused, anxious, and angry in those first few days and months post-diagnosis. However, NBCA hopes that patients will eventually discover a renewed sense of strength as they begin to learn more about blood clots, their risk factors, and develop strategies for a healthy recovery.

- **0-30 Days:** The first 30 days are very important. The highest risk of recurrence for a blood clot is in the first 30 days post-diagnosis. This time will be filled with activity – learning new information, more medical appointments than usual with new providers, and taking new medications which could result in potential side effects that might be unfamiliar to you. Please attend all your medical appointments, take your medication as prescribed, and be sure to take time to rest.

- **30-90 Days:** The dosage of your medication could change as you begin to heal, so try to adhere to any dosage modifications. This can still be a period of gathering information as you may be learning who should be on your new medical team, and understanding more about blood clots, your diagnosis, and your blood clot risk factors. This can lead to increased feelings of anxiety, which is completely normal.

- **90-365 Days:** This can be a period of adjustment and figuring out your "new normal." Consider resuming physical activity and/or other activities that you engaged in before your diagnosis. At this stage, your medical appointments will primarily be follow-up appointments. These are still important appointments to maintain as you try to keep all the providers on your medical team informed about what is happening with your treatment and recovery. If you were unprovoked or have a genetic clotting disorder, your timeline will likely go beyond 365 days. This will involve a discussion between you and your healthcare provider.

Medical Team

A blood clot can affect various parts of your body which means that you may need to meet with medical specialists, some of whom may be new to you and can treat the affected area. Each provider plays an important role in your care and should work with your other providers to ensure your optimal health.

Primary Care (PC) Doctor: A primary care doctor is a physician that treats individuals with undiagnosed health conditions and provides continuing care for various medical conditions. PC physicians also provide referrals to specialists. Your PC may be the first to suspect a blood clot and can refer you to a specialist or to the emergency room for an ultrasound or CT scan to check if there is a clot. Make sure to keep your PC informed about what is happening when you visit other providers, provide them with copies of test results, and let them know the medications that you are taking. You may already have a PC, but if you don't have a one, now is an important time to find a PC who can help monitor your overall health.

Hematologist: A hematologist is an internal medicine doctor who specializes in blood disorders, bone marrow, and the lymphatic system. A hematologist may be one of the first physicians that you visit post-diagnosis. These providers may prescribe anticoagulants (blood thinners), to aid your treatment as well as schedule additional imaging tests to monitor your recovery.

Pulmonologist: A pulmonologist is a doctor that specializes in lung conditions. If a blood clot is not treated, it can travel to the lungs and cause a pulmonary embolism (PE). It's important to see a pulmonologist for treatment if a blood clot has affected your lungs.

Cardiologist: A cardiologist is a doctor with specific skills and training in finding, treating, and preventing diseases of the heart. A blood clot can damage your heart and the vessels or valves of the heart. Cardiologists can assess any potential damage to your heart caused by the blood clot and can help develop a treatment plan.

Interventional Radiologist: Interventional Radiologists are doctors who use medical imaging to guide minimally invasive surgical procedures, which are used when more aggressive treatment is necessary. For example, when a DVT is very large, blocks major veins, or produces severe pain and swelling of the limb. These treatments can also be

used if you're diagnosed with a DVT but do not respond well to anticoagulants or compression socks.

Pharmacist: Pharmacists are a key part of your healthcare team and a valuable resource to patients. In addition to dispensing your medication, pharmacists can help educate and counsel you on how to take your medications safely and appropriately. They protect patient safety by ensuring that the medications and doses are correct, and routinely check for any drug interactions.

> "I don't know what I would have done had it not been for the NBCA... They treat me like family and helped me with questions to ask my hematologist."
>
> -Tina in Florida

Mental Health Professional: A mental health professional, including a psychologist, psychiatrist, or counselor, can help you to deal with feelings of anxiety, depression, or other issues that may interfere with your daily life due to your diagnosis. A blood clot diagnosis can be scary and can come out of nowhere. Don't feel ashamed if you need to speak with a mental health professional to help you develop the tools to manage these emotions and a healthy mindset moving forward.

Caregivers: Even though caregivers are not an "official" part of your medical team, they play a critical role in your recovery. Caregivers provide an additional layer of support and can help advocate for your care. Consider asking your caregiver to accompany you to doctor's appointments. They may think of additional questions to ask your medical provider, can assist with notetaking during appointments, identify potential care gaps, and can help you rehabilitate at home. Caregivers play a valuable role and can help you heal, both physically and mentally.

Blood Clot Treatment

Treatment for blood clots depends on where the blood clot occurs in the body and the severity of the clot. The primary treatment for blood clots is known as anticoagulants or "blood thinners." Anticoagulants increase the time it takes for the blood to clot, stop new blood clots from forming, and keeps existing clots from growing. Please keep in mind that

anticoagulants do not dissolve a clot – our body's own clot busting system dissolves existing clots. Anticoagulants may be taken orally, by injection, or intravenously.

Some common anticoagulants include:

- Coumadin (Warfarin): This medication requires regular INR testing. (See page 11)
- Lovenox (Enoxaparin) This medication is typically given to pregnant women.
- Savaysa (Edoxaban)
- Pradaxa (Dabigatran)
- Eliquis (Apixaban)
- Xarelto (Rivaroxaban)

Please take your medication **as prescribed**. Skipping doses or stopping medication can cause those on anticoagulants to be at an increased risk of a life-threatening blood clot. Taking more medication than prescribed can also be extremely dangerous and can cause bleeding problems. Some people experience side effects while taking anticoagulants which can vary from person to person. If you have any problems with your medication, please consult your physician.

Taking an anticoagulant may pose financial challenges. Several pharmaceutical companies have financial assistance programs to help patients cover the cost of medication.

- Janssen: If you are prescribed Xarelto, Janssen Carepath is a financial assistance program that aids patients in finding the resources that they need to stay on track for their treatment. This program helps patients who have commercial insurance, government coverage, and the uninsured.

- Eliquis: If you are prescribed Eliquis, Eliquis 360 Support is a program that helps patients understand their prescription coverage and learn about ways to save on out-of-pocket costs.

- Savaysa: Savaysa helps eligible patients who are not enrolled in a state or federally funded prescription benefit program (such as Medicare Part D or Medicaid) pay as little as $4 a month with their savings card. Eligibility for this program varies.

- Pradaxa: Pradaxa has a savings card for patients who are currently taking this prescription, or who have just received a prescription. This program helps patients who have commercial insurance, government coverage, and the uninsured.

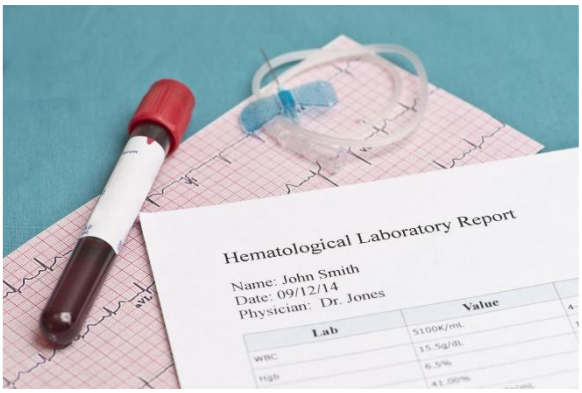
- Patient Advocate Foundation: This organization has a patient financial resources directory that contains a list of potential organizations that provide financial assistance, including copayment and medication assistance, to patients with a variety of conditions. Eligibility for these programs vary.

In addition to anticoagulants, you may require other interventions, including surgical procedures, implantable devices, or other medications and products.

Learn more about other treatment options:

INR Testing

Patients taking warfarin are required to undergo routine INR (International Normalized Ratio) blood tests – at least once a month and sometimes as frequently as twice weekly – to make sure the dose is correct. The target INR range is between 2 and 3. If the INR is below the target range, there is an increased risk of developing a blood clot, and if the INR is above range, there is an increased risk of bleeding. This is important for your doctor to monitor so that your medication dosage can be adjusted accordingly.



Some patients are eligible for INR self-testing to avoid frequent trips to the lab. If you are interested in doing INR self-testing at home, you should talk to your physician about the pros and cons, and carefully consider your individual medical history, diagnosis, current situation, treatment plan, and long-term goals as you make your decision in consultation with your healthcare team.

A patient's guide to INR self-testing with warfarin:

How to Prevent a Recurrence

Even though you have been diagnosed and treated for a blood clot, there is still a risk of recurrence. 3 in 10 people who have a blood clot will have another episode within 10 years. This risk can be decreased significantly by taking your medication as prescribed. However, it is important to learn how to recognize the signs and symptoms of a blood clot in case of a recurrence.

Signs and symptoms:

- **S**welling in the arm or leg
- **T**enderness or leg cramps
- **O**ut of breath
- **P**ass out or feeling lightheaded
- **C**hest pain or back pain when breathing
- **L**eg discoloration
- **O**verdrive or a racing heart
- **T**ime to call for help! Dial 911 if you are experiencing any of these symptoms

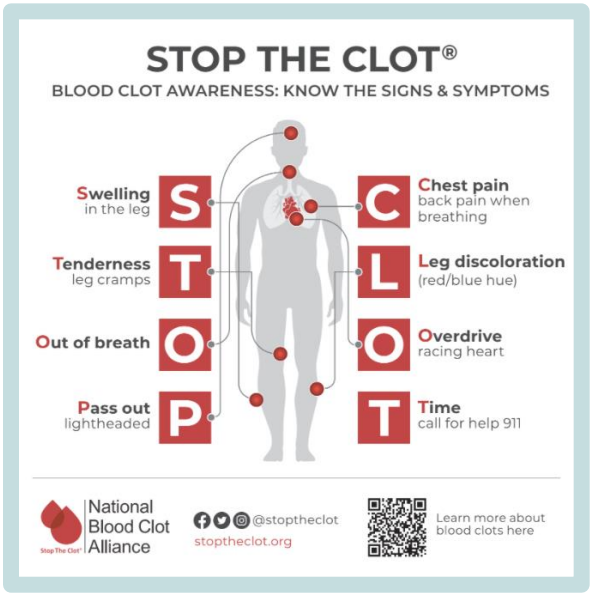
DVT specific symptoms include:

- Swelling in the arm or leg; pain or tenderness not caused by an injury; skin that is warm to the touch, with swelling or pain; redness of the skin, with swelling or pain.

PE specific symptoms include:

- Difficulty breathing; chest pains that worsen with a deep breath; coughing up blood; faster than normal or irregular heartbeat.

If you experience any of these symptoms, please contact your medical provider. If these symptoms persist, please go to the emergency room.



Blood Clot Complications

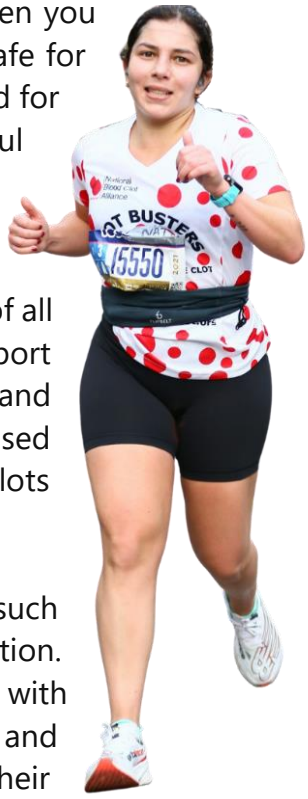
Most patients do not develop long-term complications and will recover completely. However, some people develop long-term complications including:

- Post-thrombotic syndrome: persistent swelling, pain, and skin discoloration in the affected arm or leg
- Chronic lung damage: 2-4% of PE patients will develop this condition
- Additional clotting episodes
- Anxiety and/or depression

Please contact your healthcare provider if your symptoms don't improve.

Healthy Lifestyle

Maintaining a healthy lifestyle is important. You may be wondering when you can resume physical activity. The amount and type of exercise that is safe for you is a decision that you should make with your doctor. Exercise is good for you physically and mentally. Diet is also a key component to a successful recovery and for overall health. Try to maintain a healthy weight, as being overweight is linked to an increased risk for blood clots.



The NBCA has launched a Sports and Wellness Institute to help athletes of all abilities understand and manage their blood clot diagnosis, help support them with the resources and tools needed to get back in the game, and regain strength and confidence as an athlete. People are often surprised when athletes or sports enthusiasts experience blood clots, but blood clots do not discriminate. Anyone can get a blood clot at any time.

Athletes may have unique blood clot risk factors and contributing factors such as previous injury, height, immobilization, dehydration, and repetitive motion. The Institute provides athletes, and anyone with an interest in sports, with resources and tools to resume their lives in a healthy way with strength and confidence. The Institute ensures that people who regularly listen to their bodies have information about early blood clot prevention and detection.

Learn more about the Sports and Wellness Institute:

Questions to Ask Your Doctor

Below are some, but not all, of the important questions that you might want to ask your medical team when you are in the hospital, or at one of your follow up appointments. Pick the questions from the list below that are the most important to you and go through them with someone on your healthcare team. You can also check out a full comprehensive list of questions to ask on our website. If your current doctor cannot answer any of the questions you ask, make sure they help you find someone who can. Remember, you are your best health advocate, and if you feel like you aren't being heard – get a second opinion and find a doctor who makes you feel comfortable.

Blood Clots

- What caused my blood clot? Why did I have a blood clot?
- What are my chances of a recurrence?
- Will there be any long-term damage to my body?
- What are they checking for in my blood tests?

Pulmonary Embolism Specific Questions

- Will I have any lung damage?
- Will you be giving me a lung function test?
- How can I strengthen my lungs?
- Will I always have shortness of breath and/or lung pain?
- Will I need to monitor any of my vitals?
- Is it normal to cough up blood after a PE?
- Can the blood clot in my lung travel anywhere else in my lung or body?
- How will my environment (climate, altitude, etc.) affect my lungs after a blood clot?
- Can I see the scans of my lungs that were taken? Will you explain these to me?
- Will I need to get another scan to see if my blood clot is gone?

Anticoagulants

- What if I miss a dose of my anticoagulant?
- Will I need regular blood testing?
- Do I need to change my diet on my medication?
- Are there any side effects of anticoagulants?
- What are signs of "hidden" bleeding?
- Should I wear a medical alert ID bracelet?
- Will my anticoagulant interact with other medications I take?
- How safe are herbal medicines?

Recovery

- How long will it take for me to recover?
- What can I expect to feel emotionally and physically in the next weeks/months?
- Should I use a heating pad or ice on the affected area?
- Should I wear compression stockings?
- Should I elevate my legs when I sleep?
- Will I need to get a follow-up scan to check the status of the blood clot?
- What types of over-the-counter pain reliever medication can I take?

Lifestyle

- Do I need to make any lifestyle changes? (Smoking, diet, exercise, etc.)
- Can I drive, take a long road trip for work, or fly in a plane?
- Will my clot affect my home and work life?
- Will this affect my sex life?
- Does this diagnosis impact any of my current medications? (i.e., birth control)
- What risks are involved with pregnancy and childbirth?
- Will this affect my periods?
- Can I have a glass of wine or drink other alcohol on the prescribed anticoagulant?
- Can I get a massage, a tattoo, or use a hot tub?

Download the full list of questions to ask your doctor on our website:

Frequently Asked Questions

Do you have additional questions surrounding your blood clot diagnosis? Check out our website and find answers to some frequently asked patient questions.

NBCA Resources

NBCA is here for you. We answer every email that we receive. Please visit our website www.stoptheclot.org where you can learn about the latest in blood clot resources, research, upcoming NBCA activities, and ways to get involved. If you have any questions, please do not hesitate to send an email to info@stoptheclot.org. You can also connect with NBCA on Facebook, Twitter, Instagram, LinkedIn, Pinterest, and YouTube.

> "Team Stop the Clot and The National Blood Clot Alliance have been instrumental in my mental and physical recovery."
>
> - Jennifer in Texas

You can still live life to the fullest and be your best self after a blood clots diagnosis. Join our NBCA Facebook Support Group or register for our monthly virtual patient support group, PEP Talk: Patients Educating Patients to learn how.

PEP Talk

Facebook Support Group

Thank You and Welcome to the NBCA Community!

"We know the patient because we are the patient."

Notes and Questions