My Blood Clot Journey

Leslie Lake
Pulmonary Embolism Survivor
Patient Advocate
Volunteer President, National Blood Clot Alliance

www.stoptheclot.org
Symptoms

- June 2018, I experienced extreme shortness of breath-the kind of shortness where you think you are having a heart attack
- I eventually ended up in the Emergency Room of a major NYC hospital
- I presented with shortness of breath, elevated heart rate, and a heavy period
- Despite some typical blood clots symptoms, I never had a d-dimer test
- I did have 3 gynecological exams and was told I had fibroids and that was the cause of my shortness of breath
- Prior to being discharged it was decided to do a scan of my lungs. During the scan they discovered blood clots in my lungs, otherwise known as a pulmonary embolism. I was then admitted to the ICU.

The Disconnect

- I received almost no information about what had happened to me while in the ICU and spoke with a pulmonologist for 10 minutes.
  - I left the hospital with a prescription for Eliquis and began educating myself about blood clots.
- Think about this-I left a hospital in NYC in 2018 with absolutely no resources to educate me about blood clots. Not what it is, nothing about my medication, diet, exercise, or who my healthcare team would be.
- I am a lucky person. I suffered from something that kills 100,000 people each year.... And I have great contacts in NYC so I transitioned to a different hospital and ran both hospitals on parallel paths for 6 months while I did my own homework.

www.stoptheclot.org
NBCA’s Role

- That homework led me to the National Blood Clot Alliance (www.stoptheclot.org) which gave me the tools I needed to get my life back in order. They educated me on what a blood clot is, different medication, and gave me the questions to ask my doctors that were most meaningful to my situation. They also gave me access to other patients which was invaluable-to learn from others that had gone through something similar and who encouraged me along my recovery.

- At the end of 6 months, I asked my two teams what the extended protocol would be, for me as an unprovoked PE patient.
  - The first group told me anticoagulants for 6 months then transition to aspirin, go to the ER if I had chest pains.
  - The second group told me, because I was unprovoked, I would stay on anticoagulants possibly for life to avoid a reoccurrence. I chose this option; with a 30% recurrence rate after 10 years-this was the best protocol for me.

- I learned a tremendous amount about blood clots during my recovery and I am forever thankful for the resources the National Blood Clot Alliance provided to me. They were there for me when I needed someone the most.

- I also learned that I had the ability to advocate for myself and navigate a complex health care system but I was disheartened at how many people cannot and how many people experience blood clots which probably could have been avoided. I decided I didn’t want anyone to go through what I did-and so I joined the National Blood Clot Alliance Board of Directors and eventually became their Volunteer President.

www.stoptheclot.org
Talking About Blood Clots

A guide to provide standardized facts and talking points to assist in sharing public information about blood clots and NBCA.

StopTheClot.org
info@stoptheclot.org
You and your audience can learn more about NBCA in this informational video.
www.youtube.com/watch?v=8jjL1R7shi4&t=4s

The National Blood Clot Alliance (NBCA) 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 and pulmonary embolism.

KEY ASPECTS ABOUT NBCA:

• NBCA is patient-led.

• NBCA’s Medical and Scientific Advisory Board (MASAB) includes nationally recognized experts in thrombosis and thrombophilia.

• NBCA accomplishes its mission through programs that build public awareness, educate patients and healthcare professionals, and promote supportive public and private sector policy.

• NBCA programs include patient education and professional training about the signs, symptoms, and prevention of blood clots and clotting disorders.

• Since 2003, NBCA has partnered with the Centers for Disease Control and Prevention (CDC). Through a cooperative agreement with the CDC, NBCA has produced many educational programs and materials.

• NBCA’s website is www.StopTheClot.org

Learn more about blood clots at StopTheClot.org
NBCA’s Reach

• Hundreds of millions of people have been reached via our signature Stop the Clot, Spread the Word® initiative since its inception in 2015.

• 3 million people annually come to our website, www.stoptheclot.org.

• 37,000 followers on Facebook.

• 5,500 followers on Instagram.

• 6,000 followers on Twitter.

• 2,000 subscribers on YouTube.

• 9,500 followers on Inspire, our patient support community.

NBCA Online Channels

Facebook
@StopTheClot
@TeamStopTheClot

Pinterest
@StopTheClot

Twitter
@StopTheClot
@WomenAndClots
@TeamStopTheClot

LinkedIn
National-Blood-Clot-Alliance

Instagram
@StopTheClot
@WomenAndClots
@TeamStopTheClot

YouTube
StopTheClot

info@stoptheclot.org | StopTheClot.org
NBCA Websites

www.StopTheClot.org

www.WomenAndBloodClots.org
NBCA Programs and Community Engagement
Stop the Clot, Spread the Word®

NBCA’s signature Stop the Clot, Spread the Word® awareness campaign—developed in collaboration with the CDC—has reached hundreds of millions of people since it was launched in 2015. The campaign, which offers potentially life-saving information about blood clots, utilizes a variety of integrated digital communications tools to encourage targeted audiences to ask themselves one potentially life-saving question: Could I be at risk for a blood clot?

Stop the Clot® – What Every Healthcare Professional Needs to Know

NBCA’s online curriculum for healthcare professionals – Stop the Clot® – What Every Healthcare Professional Needs to Know – is a self-paced, online course providing the most current foundational information and clinical considerations to assess and treat patients with blood clots and clotting disorders, or those at risk of blood clots. The target audience for this accredited curriculum—developed in collaboration with the CDC—includes physicians, physician assistants, pharmacists, nurses, nurse practitioners, and other healthcare professionals. Over 16,000 health care professionals have completed the curriculum.

Covid-19 and Blood Clots

NBCA, in partnership with the University of Oklahoma, received an award through an Association of University Centers on Disabilities-Centers for Disease Control cooperative agreement to facilitate and advance research into blood clots as a complication of COVID-19. The award is also funding efforts to raise awareness among certain high-risk populations, including how COVID-19 blood clot complications affect African Americans and pediatric patients.
Women and Blood Clots

NBCA has developed a unique web-based information portal (womenandbloodclots.org), focused singularly on the risk of blood clots among women. Women are at unique risk at various life stages: when making decisions on birth control and family planning, pregnancy and childbirth, and the treatment of menopause symptoms. The campaign also features a multi-part video series, as well as a striking companion infographic.

Download our women and blood clots risk assessment tool

Sports and Wellness Institute

In 2020, NBCA launched a Sports and Wellness Institute, a comprehensive online community and resource designed specifically for amateur athletes and others striving to return to healthy, active lifestyles after surviving blood clots. The NBCA Sports & Wellness Institute is dedicated to the concept of TEAM: focused on Togetherness, Education, Awareness, and Motivation. Athletes across the country raise blood clot awareness by participating in races as Team Stop The Clot®. Katie Hoff, Olympic swimmer and three-time Olympic medalist, is the official ambassador for the National Blood Clot Alliance Sports & Wellness Institute.

Patient Support Community

NBCA offers a supportive environment for patients, providing the opportunity to share their story and learn from the experience of others. NBCA provides an online Stop the Clot® Support Community, powered by Inspire, which provides a safe and supportive space where people affected by blood clots and clotting disorders can gather to share information and interact with others who share the same experience.

PEP Talk: Patients Educating Patients

NBCA hosts a monthly PEP Talk (Patients Educating Patients). This virtual support group focuses on a different topic each month to help guide patients through their blood clot diagnosis and recovery journey.
NBCA Thrombassadors

NBCA is building a grassroots network of thrombosis ambassadors—thrombassadors—who are patients, caregivers, and family members from across the nation who are professionally trained to promote NBCA’s blood clot awareness mission. They connect with people and organizations in their community to share information about NBCA and blood clots. Outreach is conducted via churches, schools, civic clubs, sports teams, employers, and local press.

Lunch and Learn

NBCA offers ‘Lunch and Learn’ blood clot education presentations to businesses, schools, clubs, or other civic groups. These virtual and in-person blood clot education talks are designed to increase awareness, teach the signs and symptoms, and encourage prevention. Talks are given jointly by NBCA staff, patients, and nationally recognized experts in thrombosis and thrombophilia.

Health Disparities Initiative

NBCA is committed to reducing disparities in the prevention, diagnosis, and treatment of blood clots. NBCA is participating in a quality improvement project led by MediCom Worldwide and in partnership with the Mississippi State Medical Association, Mississippi Hospital Association, and the Mississippi Business Group on Health. The project is aimed at reducing health disparities and improving health outcomes among African Americans affected by blood clots in rural Mississippi.

The CLUES Blood Clot Study

Recognizing that blood clots have an emotional as well as physical impact, NBCA conducted the largest study of its kind in Fall 2021 examining the emotional well-being of blood clot survivors. Published results are forthcoming and will inform future NBCA programs.

info@stoptheclot.org | StopTheClot.org
Emerging Researchers Board

NBCA Council of Emerging Researchers, chaired by Dr. Rushad Patell and Dr. Dana Angelini, will work under the leadership of NBCA’s Medical and Scientific Advisory Board (MASAB), which is comprised of the nation’s foremost experts on blood clots and blood clotting disorders. NBCA’s Council of Emerging Researchers will participate in various clinical research projects on behalf of NBCA and lead efforts to facilitate data analysis and dissemination on NBCA’s existing five year cooperative agreement with the CDC.

Health Equity Institute

The National Blood Clot Alliance (NBCA) has established an advisory council consisting of Black VTE patients, Black VTE patient caregivers and Black health care providers to identify and address the gaps associated with VTE treatment, incidence, and mortality within the Black community by conducting research among patients, patient caregivers, health care providers, and potential partners.

We are the patient voice...

NBCA advocates on behalf of patients impacted by blood clots and blood clotting disorders by promoting increased funding, awareness, and supportive public and private sector policy.

Throughout the year, NBCA represents the patient perspective on numerous workgroups such as:

- The C-TRACT Study (Chronic Venous Thrombosis: Relief with Adjunctive Catheter-Directed Therapy) which examines an innovate method for preventing post-thrombotic syndrome.

- A Patient-Centered Outcomes Research Institute (PCORI) project on implementing best-practice, patient-centered VTE prevention.

For the additional information on current NBCA programs and community outreach, visit our website at StopTheClot.org
NBCA Leadership

NBCA is patient-led with guidance from nationally recognized experts in thrombosis and thrombophilia.

80% of the NBCA Board of Directors is either a patient or a family member of a patient. 40% of professional staff are also blood clot patients.

NBCA Board of Directors

- 60% Patients
- 20% Family and Caregivers
- 13% VTE Professionals
- 7% Layperson
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Jeff Zwicker, MD, Associate Professor of Medicine at Harvard Medical School and Chief, Section of Benign Hematology at Beth Israel Deaconess Medical Center, Boston, MA
Terms

Definitions you may find useful:

Thrombosis: The medical term for a blood clot that forms within a vessel.

Thrombophilia: The medical term for a blood clotting disorder.

Veins: The blood vessels that carry blood back to the heart from the extremities (the legs and the arms), the abdomen, and the brain.

Arteries: The blood vessels which carry blood away from the heart to the extremities (the legs and the arms), the abdomen, and the brain.

Deep Vein Thrombosis (DVT): When a clot forms in the deep veins of the body, it is called Deep Vein Thrombosis, often referred to as DVT for short. DVT occurs most commonly in the leg; although it can occur anywhere in the body, such as the veins in the arm, abdomen, or around the brain.

Pulmonary Embolism (PE): A potentially life-threatening complication of deep vein thrombosis (DVT) is pulmonary embolism, often referred to as PE. A pulmonary embolism occurs when a blood clot breaks off, travels through the blood stream and lodges in the lung.

Venous Thromboembolism (VTE): DVT + PE are collectively known as VTE, also as venous blood clots.

The National Blood Clot Alliance (NBCA) focuses upon venous blood clots which form in the deep veins of the body (DVT and PE). In this document, use of the term ‘blood clot’ refers to blood clots in the veins, DVT and PE.
What is a Blood Clot?

- A blood clot is a clump of blood that has changed from a liquid to a gel-like or semisolid state.

- Blood clotting is a normal, complex process that prevents excessive bleeding when a blood vessel is injured.

- Sometimes clots can form abnormally.

- Clots can occur in both arteries and veins, but their causes and effects are different. Their treatments are also different.

- Arterial clots include stroke and heart attack.

- Venous clots include deep vein thrombosis (DVT), pulmonary embolism (PE), cerebral vein thrombosis (CVT) and portal vein thrombosis (PVT).

- Venous blood clots occur most commonly in the leg; although it can occur anywhere in the body, such as the veins in the arm, abdomen, or around the brain.

Clots can occur in both arteries and veins. However, their causes and treatments are different. DVT and PE are vein clots.
Symptoms and Risk Factors

When a clot forms in the deep veins of the body, it is called deep vein thrombosis, often referred to as DVT for short. DVT occurs most commonly in the leg; although it can occur anywhere in the body, such as the veins in the arm, abdomen, or brain.

Deep Vein Thrombosis (DVT) Symptoms:
- Pain
- Swelling
- Discoloration (bluish, purplish or reddish skin color)
- Warmth

A potentially life-threatening complication of deep vein thrombosis (DVT) is pulmonary embolism, often referred to as PE for short. A PE occurs when a blood clot breaks off, travels through the blood stream and lodges in the lung.

Pulmonary Embolism (PE) Symptoms:
- Shortness of breath
- Chest pain (which may be worse with deep breath)
- Unexplained cough (may cough blood)
- Unexplained rapid heart rate

Seek medical attention if you experience these signs or symptoms.

STOP CLOT is an acronym created by NBCA to help you remember the signs and symptoms.

Symptoms can range widely from mild and barely noticeable to severe.

Blood clot symptoms can sometimes be confused with other medical conditions, leading to a delayed diagnosis.

DVT may be confused with a pulled muscle or “charley horse.”

PE may be misinterpreted as a respiratory infection or inflammation of the ribs.

STOP THE CLOT®
BLOOD CLOT AWARENESS: KNOW THE SIGNS & SYMPTOMS

Swelling
in the leg

Chest pain
back pain when breathing

Tenderness
leg cramps

Leg discoloration
(red/blue hue)

Out of breath

Overdrive
racing heart

Pass out
lightheaded

Time
call for help 911
What Causes Venous Blood Clots?

Blood clots may form when either the flow of blood in a vein slows, damage to a vein occurs, or the blood is more clottable. Many factors can increase a person’s risk for developing a blood clot in a vein.

**Common risk factors for developing a blood clot include:**

**Immobility:**
- Hospitalization
- Prolonged Sitting

**Surgery and Trauma:**
- Major surgery (pelvis, abdomen, hip, knee)
- Bone fracture or cast
- Catheter in a big vein (PICC line, central venous catheter, port)

**Increased estrogen:**
- Birth control pills, patches, rings
- Pregnancy, for up to 6 weeks after giving birth
- Estrogen + progestin hormone therapy

**Medical conditions:**
- Cancer and its treatment
- Heart failure
- Inflammatory disorders (lupus, rheumatoid arthritis, inflammatory bowel disease)
- Nephrotic syndrome

**Other risk factors:**
- Previous blood clot
- Family history of clots
- Clotting disorder (thrombophilia)
- Obesity
- Smoking
- Older age
- Varicose veins
Clot Statistics

The following facts about blood clots may be useful when discussing blood clots. They are from reputable sources, which have been cited at the end of this document.

How many People are Affected by Blood Clots?

- Venous blood clots (DVT and PE) occur in an estimated 900,000 Americans each year.¹
- The precise number of people affected by it is unknown because there is currently no national surveillance for venous blood clots.
- 3 in 10 people (30%) who have a venous blood clot will have another venous blood clot within 10 years.¹
- Approximately 100,000 Americans die each year of venous blood clots.¹
- Venous clots kill more people than AIDS, breast cancer, prostate cancer and motor vehicle crashes combined.¹³
- A blood clot death can happen without warning: Sudden death is the first symptom in about one-quarter (25%) of people who have a PE.¹

Many blood clot deaths are preventable.

1 PERSON EVERY MINUTE will be diagnosed with deep vein thrombosis in the United States.¹

1 PERSON EVERY SIX MINUTES will die from pulmonary embolism in the United States.¹
What are the Effects for Blood Clot Survivors?

Blood clot survivors face many challenges including:

- Risks associated with the use of anticoagulants, or blood thinners, foremost bleeding.
- Development of post-thrombotic syndrome after a DVT, which causes pain and swelling of an extremity.
- Development of chronic lung damage (pulmonary hypertension) after a pulmonary embolism, which causes chronic shortness of breath.
- Costly outpatient medical care and inpatient hospitalizations.
- High levels of anxiety, depression, and stress have been reported among blood clot patients.
- Half of VTE patients experience ongoing psychological distress related to their blood clot.\(^\text{10}\)

Complications of DVT and PE

Most blood clot patients recover completely within several weeks to months without significant complications or long-term adverse effects. However, ongoing problems can occur in some patients, such as:

**Post-thrombotic syndrome:** Around half of patients with DVT will have some degree of chronic discomfort, and approximately 15% will experience moderate to severe chronic swelling and pain known as post-thrombotic syndrome.\(^\text{2}\)

**Pulmonary hypertension or chronic thromboembolic pulmonary hypertension, CTPH:** Around 2% to 4% of patients with PE will have chronic damage to the lungs known as pulmonary hypertension (chronic thromboembolic pulmonary hypertension, CTPH), which is characterized by shortness of breath and decreased exercise ability.\(^\text{2}\)
Hospitalization is a major risk factor for developing a blood clot. If you are hospitalized or planning for surgery, talk to your doctor about blood clot prevention.
Estrogen increases blood clot risk. The level of clot risk varies throughout a woman’s life and is associated primarily with underlying hormonal exposure. Estrogen levels are increased during pregnancy (and up to 6 weeks postpartum) or when taking certain birth control or hormone replacement therapy.

**Pregnancy**

- Venous blood clots are a leading cause of death in a woman during pregnancy or just after having a baby.\(^1\)
- Clot risk is increased during all trimesters, but is highest during the postpartum period. Risk remains elevated for up to 12 weeks following delivery.\(^4\)
- In pregnancy, the risk of VTE is increased 5 times greater than in non-pregnancy.\(^4\)

**Why?**
The increased risk associated with pregnancy is thought to be due to a combination of a) slower blood flow in the lower body (venous stasis of the lower extremities), b) blood vessel damage (endothelial injury) and c) the increase of estrogen (creates a hypercoagulable state that occurs during pregnancy).\(^3\)

**Women on Birth Control Pills**

- Use of birth control pills—combined hormonal contraception—doubles the venous clot risk.\(^5\)

**2X**

**Women on Hormone Replacement Therapy (HRT)**

- Use of hormone replacement therapy (HRT) increases VTE risk by 2 to 4 times.\(^5\)

**2 to 4X**
Blood clots are a common complication in cancer patients and the leading cause of death in people with cancer after the cancer itself.\(^6\)

- A cancer patient’s risk of developing a venous blood clot is 4 to 7 times greater than that of a person without cancer.\(^7\) Risks vary by location of a tumor and a patient’s additional risk factors for clotting, such as immobilization, obesity or presence of a thrombophilia (clotting disorder).\(^7\)

- Among people with cancer, survival rates are lower for people who also have blood clots.\(^6\)

- The risk of a blood clot is greatest in the first few months after cancer diagnosis, the time when treatment generally occurs.\(^6\)

**Why?**
Both active cancer and some cancer treatments increase clot risk.

A cancer patient’s risk of developing a venous blood clot is **4 to 7X** greater than a person without cancer.

Cancer patients should discuss their blood clot risk with their oncologist.
Economic Impact

- Blood clots (DVT and PE) contribute to an estimated $10 billion in incremental medical costs each year in the US.\(^8\)

- Treatment can be as much as $15,000 to $20,000 per person and often results in a hospital stay.\(^8\)

- The total economic impact of DVT and PE, including the value of lost economic output due to premature mortality, are as high as $69 billion per year.\(^12\)

- DVT and PE are significant sources of disability and lost productivity.\(^12\)

“Deep vein thrombosis and pulmonary embolism (DVT/PE) represent a major public health problem, exacting a significant human and economic toll on the Nation.”

- The US Surgeon General’s Call to Action to Prevent DVT and PE\(^9\)

Awareness

- Despite being a common health condition, there is low public awareness.

- Only about six percent of Americans know what DVT (deep vein thrombosis) is and how it can be prevented.\(^9\)
Prevention

How can venous blood clots be prevented?

- Stay active. Immobility increases the risk of developing clots. If you’ve been sitting for a long period of time (such as during long-distance travel, playing video games, when sick or even working at your desk) stop and take a break to stretch your legs.

- Maintain an ideal body weight.

- Know your risk factors for developing a clot and discuss these with your doctor.

- Know your family medical history. Make sure your doctor knows about any history of blood clots.

- If you are hospitalized or planning for surgery, ask your doctor: What will be done to prevent blood clots? You may be given a blood-thinning medication (anticoagulant) or special stockings designed to prevent blood clots. These blood clot prevention measures are called ‘DVT prophylaxis.’

- Stay hydrated. Drink plenty of fluids. Dehydration may increase clot risk.¹¹

Many blood clots can be prevented. Talk to your doctor about ways to reduce your blood clot risk.

Handout Material

NBCA has a helpful handout you can download and print to share with your audience, so they remember the signs and symptoms of blood clots.

[Link to handout]

STOP THE CLOT®
BLOOD CLOT AWARENESS: KNOW THE SIGNS & SYMPTOMS

Swelling in the leg

Chest pain back pain when breathing

Tenderness leg cramps

Leg discoloration (red/blue hue)

Out of breath

Overdrive racing heart

Pass out lightheaded

Time call for help 911

Learn more about blood clots here

info@stoptheclot.org | StopTheClot.org
Key Messages

• Blood clots can happen to anyone, at any age.
• They are often preventable.
• Early diagnosis is critical to prevent complications, including death.
• If you suspect a clot, don’t delay getting medical help.

Audience Asks

Ask the audience to take a particular action. Such as:

• Take action now to educate yourself about blood clots. Know your risk factors and how clots can be prevented. Know the symptoms of DVT and PE and take action if you suspect you have a venous blood clot. Time matters.
• Talk with your doctor about your individual risk for blood clots and what you can do to reduce risk.
• Share your knowledge of blood clots with others.
• Visit StopTheClot.org for resources to help you.
REFERENCES

1 CDC VTE Data and Statistics https://www.cdc.gov/ncbddd/dvt/data.html


3 CDC HA-VTE Data and Statistics https://www.cdc.gov/ncbddd/dvt/ha-vte-data.html


6 CDC https://www.cdc.gov/ncbddd/dvt/cancer.html


8 CDC Economic impact VTE https://www.cdc.gov/ncbddd/dvt/infographic-impact.html

9 Surgeon General’s Call to Acton on DVT/PE https://www.ncbi.nlm.nih.gov/books/NBK44188/


