

National
Blood Clot
Alliance

MEDIA KIT



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

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ABOUT the National Blood Clot Alliance (NBCA)



Advance the prevention, early diagnosis, and successful treatment of life-threatening blood clots.

You and your audience can learn more about NBCA in this informational video.

www.youtube.com/watch?v=8ljL1R7shi4&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.stopthecлот.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



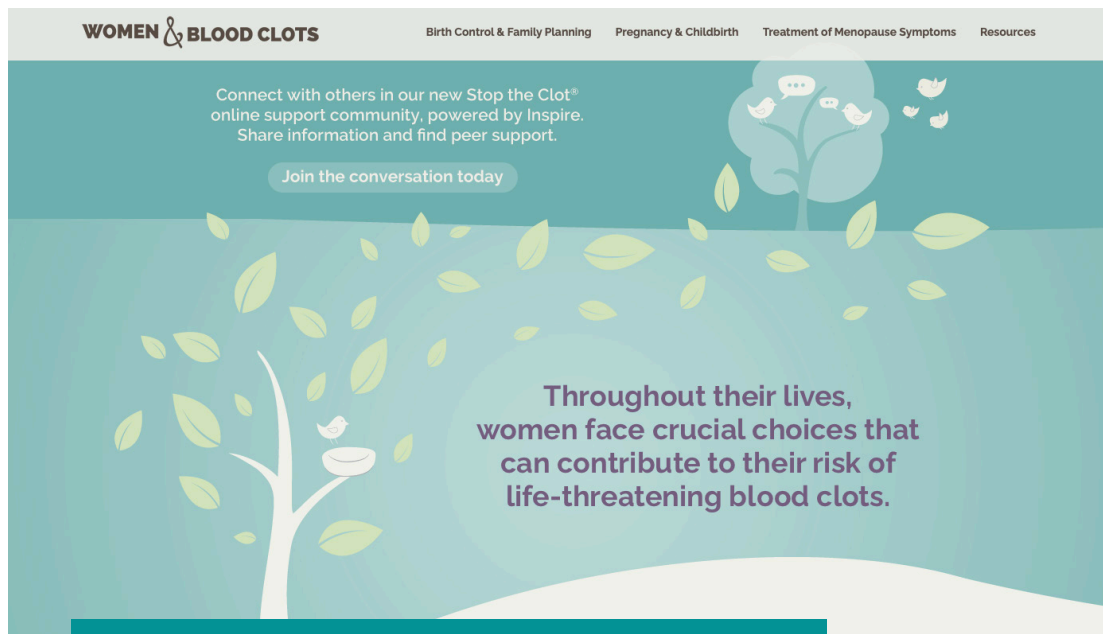
YouTube

StopTheClot

NBCA Websites



www.StopTheClot.org

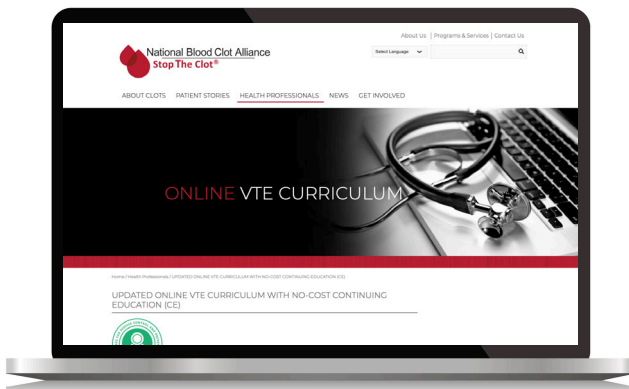


www.WomenAndBloodClots.org

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?



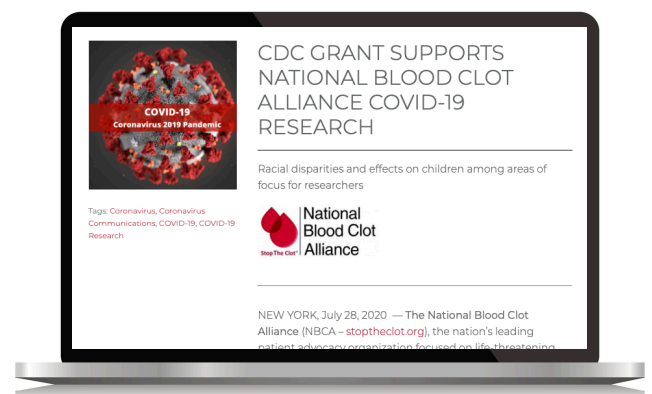
Take the course!

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

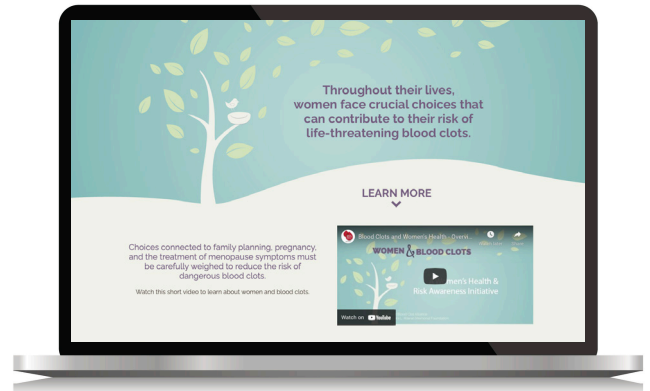
NBCA, in partnership with the University of Oklahoma, **received an award** through an Association of University Centers on Disabilities-Centers for Disease Control cooperative agreement to facilitate and advance research into blood clots as a complication of COVID-19. The award is also funding efforts 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



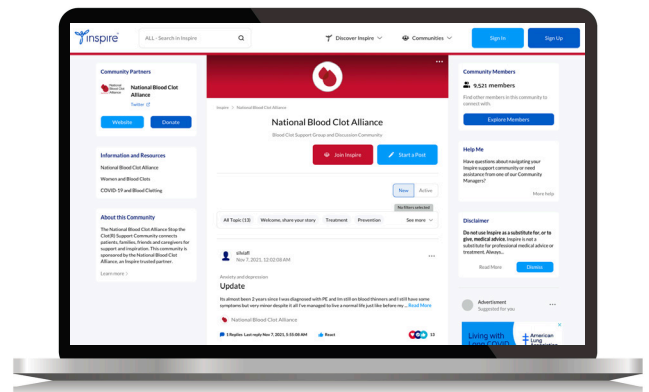
Sports and Wellness Institute

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's Monthly Patient to Patient Virtual Support Group for DVT and PE Survivors



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.



Thrombassador

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.

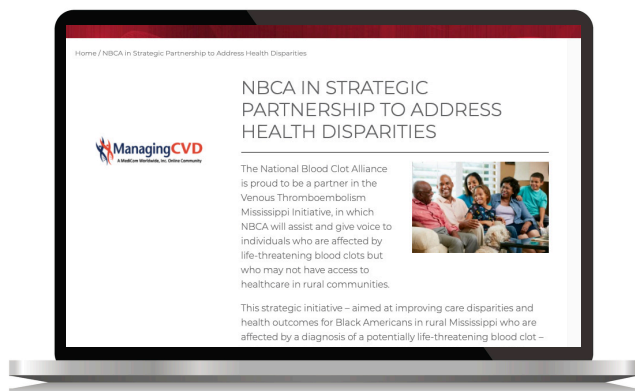
Lunch and Learn

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.



Tags: CLUES, Mental Health, Survey

THE CLUES BLOOD CLOT STUDY

The CLUES Blood Clot Study

A Critical Look at Understanding the Emotional Suffering of Blood Clot Survivors

Calling all blood clot survivors, we have heard you!

We know the physical toll that blood clots can take on your body, but you have also told us of the psychological impact and we want to learn more. What are the emotional issues it has caused you? Have you experienced anxiety or post-traumatic stress after having your clot? You are the expert and we want to learn from you.

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 innovative method for preventing post-thrombotic syndrome.
- A Patient-Centered Outcomes Research Institute (PCORI) project on imple-

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

StopTheClot.org

NBCA Leadership



Board of
Directors

Medical and
Scientific
Advisory

Professional
Staff

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

80%

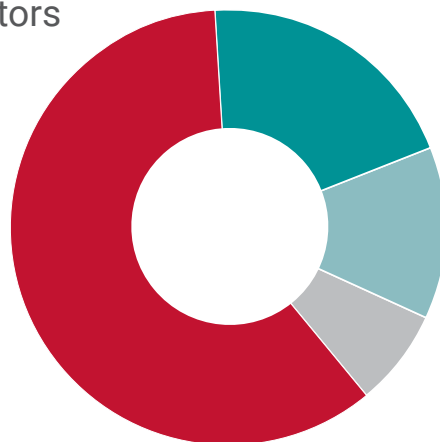
of the NBCA Board of Directors is either a patient or a family member of a patient.

40%

of professional staff are also blood clot patients.

NBCA Board of Directors

60%
Patients



20%
Family and Caregivers

13%
VTE Professionals

7%
Layperson

Board of Directors

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Professional Staff

Leslie Lake,
President

Tarin Patrikis,
Deputy Director

Bill Robertson,
Program Director

Julia Thompson, *Development and
Community Outreach Associate*

NBCA Medical and Scientific Advisory Board

The NBCA Board and professional staff are guided by a Medical and Scientific Advisory Board comprised of clinical experts in thrombosis and thrombophilia.

MASAB CHAIR

Alok A. Khorana, MD, FACP, FASCO, Professor of Medicine, Cleveland Clinic Lerner College of Medicine, Case Western Reserve University, the Sondra and Stephen Hardis Chair in Oncology Research, Vice-Chair for Clinical Services of the Taussig Cancer Institute and Director of the Gastrointestinal Malignancies Program at the Cleveland Clinic

MASAB MEMBERS

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Carrie Eichberg, PsyD, Boise, ID

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MASAB MEMBERS, continued from previous page

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Suresh Vendantham, MD, *Professor of Radiology and Surgery, Mallinckrodt Institute of Radiology, Washington University, St. Louis, MO*

Jeffery Weitz, MD, *Professor of Medicine and Biochemistry at McMaster University, Henderson Regional Cancer Centre, Hamilton, Ontario, Canada*

Diane L. Wirth MS ANP-BC CACP, *Provider Health Services*

Daniel M. Witt, Pharm D, FCCP, BCPS *Professor and Chair of the Department of Pharmacotherapy at the University of Utah College of Pharmacy*

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.

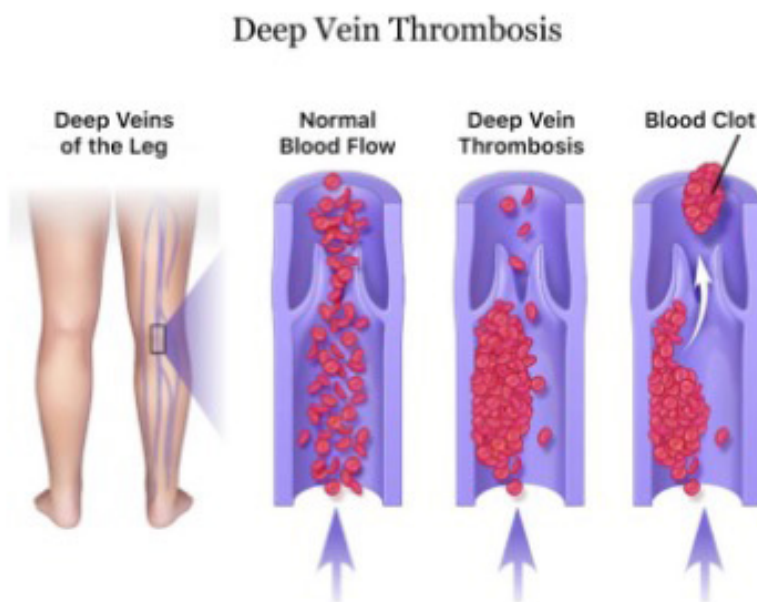
Pulmonary Embolism (PE): A potentially life-threatening complication of deep vein thrombosis (DVT) is pulmonary embolism, often referred to as PE. A pulmonary embolism occurs when a blood clot breaks off, travels through the blood stream and lodges in the lung.

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.

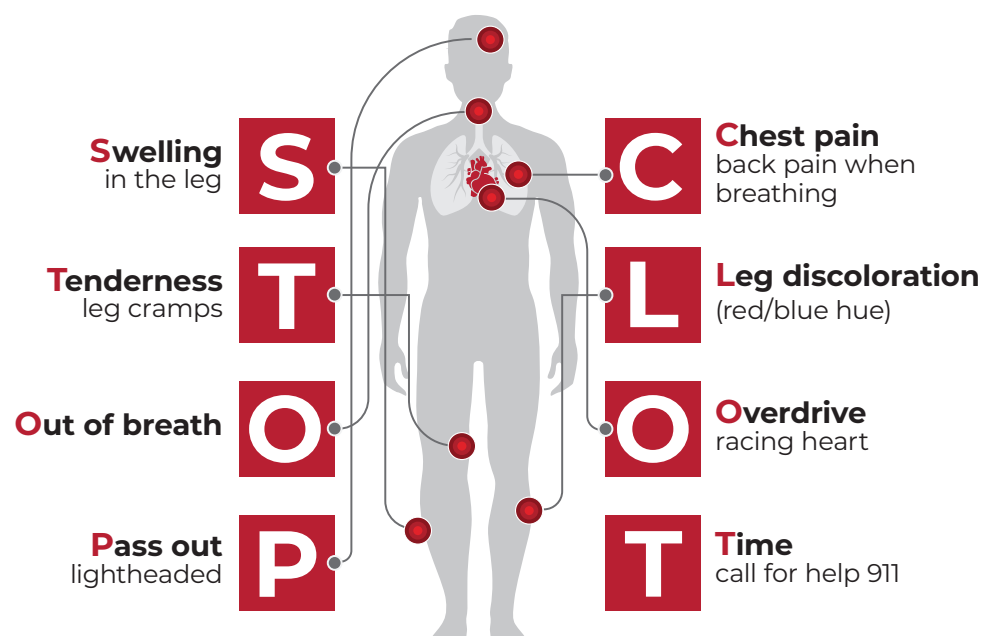
Blood clot symptoms can sometimes be confused with other medical conditions, leading to a delayed diagnosis.

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



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.

Blood clots are a common health condition. They can happen to anyone, at any age.

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.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.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.²

Statistics for Specific Patient Populations

HOSPITAL PATIENTS

- Blood clots (DVT and PE) are a leading cause of preventable hospital death in the United States.³
- Approximately 40% of clots are associated with hospitalization, occurring either in the hospital or shortly after discharge.³
- As many as 70% of DVT and PE in hospitalized patients are preventable through prevention measures, such as use of anticoagulants (medication which help prevent blood from clotting), or use of compression stockings.³
 - Yet fewer than half of hospital patients receive these measures.³



Why are hospitalized patients at high-risk for blood clots?

Hospitalized patients can have multiple factors which increase their clot risk:

- Prolonged immobility.
- Physical trauma or surgery.
 - Hip, knee, abdomen, pelvis surgeries are considered higher risk for clot development.
- Medical conditions and procedures which increase risk.
 - Catheter, bone fracture, pregnancy, cancer, inflammatory disorders, heart failure are higher risk.

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.

WOMEN

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

Pregnancy increases clot risk and that risk remains elevated for up to 12 weeks after giving birth.

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

CANCER

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

\$10
BILLION
in incremental
medical costs
each year in the US

“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 PE⁹

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

<6%
of Americans
KNOW
what DVT is

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.

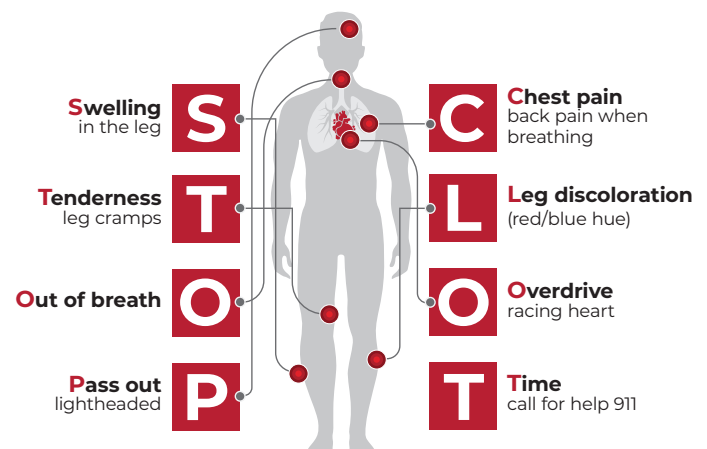
Handout Material

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.

www.stopthecLOT.org/wp-content/uploads/2021/08/NBCA_Blood-Clot-Awareness.pdf

STOP THE CLOT®

BLOOD CLOT AWARENESS: KNOW THE SIGNS & SYMPTOMS



National
Blood Clot
Alliance

[@stopthecLOT](https://www.stopthecLOT.org)
[stopthecLOT.org](https://www.stopthecLOT.org)



Learn more about
blood clots here

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.

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