

BLOOD CLOT AWARENESS, ACTION, AND ADVOCACY: THE TOOLKIT

PROVIDED BY
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MESSAGE FROM CONGRESSWOMAN LISA BLUNT ROCHESTER



Millions of Americans are impacted by deep vein thrombosis (DVT)/pulmonary embolism (PE). Despite longstanding efforts by stakeholders to mitigate the distressing impacts of blood clots, Americans continue to face disability, suffer serious illness, and risk death due to these conditions. This serious public health issue necessitates a whole-of-society response. In 2023, I, along with my colleagues, Larry Bucshon, M.D. (R-IN), Michael Burgess, M.D. (R-TX), and Paul Tonko (D-NY), introduced the bipartisan **Charles Rochester Blood Clot Prevention and Treatment Act (H.R. 5699)**, named after my late husband who passed away suddenly from this illness.

This bill is deeply personal to me. My husband, Charles Rochester, tore his Achilles tendon playing a game of pickup basketball before a business meeting. Blood clots traveled to his heart and lungs and, at the age of 52, he died. The grief and pain that followed his passing were unbearable. But I knew Charles would not want me to give up; he would want me to go on. I turned my pain into purpose by deciding to run for Congress where I am helping lead the charge to save lives through **awareness, action, and advocacy of DVT/PE**.

In total, the Centers for Disease Control and Prevention (CDC) estimates that about 900,000 people suffer from DVT/PE per year, and of those, nearly 100,000 die, which is roughly the same number of people who die from drug overdoses and diabetes annually. But the CDC also recognizes that the exact number of people affected by DVT/PE is unknown, due to the lack of adequate data collection. Given that the number one cause of death for the most severe PE is diagnostic failure, it is alarming that DVT/PE continues to be underdiagnosed. Americans still do not understand the gravity of this condition and more must be done to raise awareness among the public.

I do this work each day with Charles's memory as my guiding light, with the hope of saving lives both in Delaware and across the nation. I urge you to join me in this effort.

AWARENESS

UNDERSTANDING BLOOD CLOTS

WHAT IS A BLOOD CLOT?

A **blood clot** is a gel-like clump of blood that can form in your arteries and veins. Blood clots can help control bleeding by plugging injured blood vessels, but they may also cause serious medical issues, including deep vein thrombosis (DVT) and pulmonary embolism (PE).

Deep vein thrombosis (DVT) is a medical condition that occurs when a blood clot forms in a deep vein, usually in the lower leg, thigh, or pelvis, and less commonly in the arm. These blood clots can partially or completely block blood flow in the vein back to the heart. When a DVT is left untreated, a part of the clot can break off and travel to the lungs, causing a blockage known as a **pulmonary embolism (PE)**. DVT and PE are collectively known as **venous thromboembolism (VTE)**.

It is important to know that these conditions can happen to anybody, and can also lead to serious illness, disability, and in some cases, death. Even if an individual does not develop a PE, there are instances where blood clots in the legs can harden over time and cause chronic problems, including ulcers and amputation. The good news is that DVT and PE are highly preventable and treatable if discovered early.

WHAT ARE THE SIGNS AND SYMPTOMS?

Common signs and symptoms of a **DVT** include:

- Swelling of the affected area
- Pain
- Tenderness
- Redness of the skin

Common signs and symptoms of a **PE** include:

- Difficulty breathing
- Faster than normal or irregular heartbeat
- Coughing up blood
- Very low blood pressure, lightheadedness, or fainting



Seek medical attention right away if you experience any of these signs or symptoms.

UNDERSTANDING BLOOD CLOTS

WHAT FACTORS PUT YOU MORE AT RISK?



Hospitalization and Surgery

One-half of blood clots occur during or soon after a hospital stay or surgery.



Being Immobile

Not moving for long periods of time (for example, extended bed rest or extended travel).

Other Risk Factors

- Older age
- Being overweight or obese
- Family history of venous thromboembolism (VTE)
- Recent or recurrent cancer
- During and just after pregnancy
- Estrogen-based medicine such as hormonal birth control or hormone replacement therapy
- Injury and trauma

WHAT CAN YOU DO TO PREVENT DEATH OR COMPLICATIONS FROM A BLOOD CLOT?

- Know your risks and recognize symptoms.
- If you have any symptoms, see your doctor as soon as possible. Blood clots can be safely treated by your doctor.
- Before any surgery, talk with your doctor about blood clots.
- Tell your doctor if you have risk factors for blood clots.

STATISTICS ON BLOOD CLOTS

Only 6% of the American population knows what deep vein thrombosis is.

3 in 10 people who have a blood clot will have another episode within 10 years.

Black Americans are at higher risk of venous thromboembolism than other races.

One third of people who have had deep vein thrombosis will have long-term complications, such as swelling, pain, and discoloration in the affected area.

Pregnant women are 5 times more likely to experience a blood clot than women who are not pregnant.

Pulmonary embolism is the 3rd most frequent cause of cardiovascular-related death in the United States.

Pulmonary embolism is the leading cause of death in people with cancer, after the cancer itself.

Blood clots are a leading cause of preventable hospital death in the United States.

ACTION

THE CHARLES ROCHESTER BLOOD CLOT PREVENTION AND TREATMENT ACT H.R. 5699

THE PROBLEM

The severe health complications associated with deep vein thrombosis (DE) and pulmonary embolism (PE) are among the most significant threats to public health in America. **One American dies of a blood clot every six minutes** and **one in four PE victims die suddenly and without warning**. The economic impacts of blood clots are also significant, with direct and indirect **costs surpassing \$10 billion annually**. Timely diagnosis of blood clots is crucial in preventing PE, but far too few Americans recognize the risk factors, understand the symptoms of blood clots, or are aware of available treatment options.

THE 3-STEP SOLUTION

A proactive approach **centered on education, collaboration, and data collection** is crucial. This bill would improve patient awareness of blood clot risks; improve surveillance, detection, and treatment of patients who may be at a higher risk of forming blood clots; and ultimately save lives. More information about the main goals of the bipartisan **Charles Rochester Blood Clot Prevention and Treatment Act (H.R. 5699)** can be found below:

1 EDUCATION

Increase public awareness of blood clot signs and symptoms, and **educate health care providers and hospitals** on the signs, symptoms, and treatments of blood clots **by requiring the CDC to conduct a nationwide public awareness campaign**.

2 COLLABORATION

Establish an advisory committee to provide advice, information, and recommendations to the Secretary of HHS regarding **programs, policies, and research to promote the diagnosis, treatment, and prevention** of blood clots and pulmonary embolisms.

3 DATA COLLECTION

Improve our understanding of who and how many Americans are impacted by blood clots **by requiring the CDC to conduct a study on novel ways of detecting and monitoring blood clots** at the national level.

A CLOSER LOOK AT H.R. 5699

Below you can find a detailed explanation of the sections of the The Charles Rochester Blood Clot Prevention and Treatment Act (H.R. 5699):

FINDINGS

Congress finds that:

- DVT occurs when blood clots form in the legs, pelvis, or arms, and the most serious complications occur when a part of the clot breaks off and travels to the lungs, causing a blockage called PE.
- 1 American dies every 6 minutes as a result of a blood clot, and 1 in 4 people who have a PE die without warning.
- The CDC has estimated that about 900,000 people suffer from DVT/PE per year and 100,000 people die each year from blood clots, but also recognizes that the precise number of people affected by DVT/PE is unknown.
- These numbers are estimated because currently there is no systematic collection of DVT/PE-related morbidity or mortality data in the United States.
- Blood clots can affect anyone, but certain risk factors make certain individuals more susceptible, including pregnancy, cancer, hospitalizations, obesity, older age, and being a Black American.
- The overall incidence of DVT and PE is 30 to 60 percent higher in Black Americans, who also have a higher rate of 30-day mortality compared with White Americans.
- The direct and indirect cost of blood clots is more than \$10,000,000,000 annually.
- Early diagnosis of a DVT is one of the most important factors in preventing a PE.

PUBLIC EDUCATION, AWARENESS, AND DIAGNOSIS OF DVT/PE

This provision requires the Secretary of HHS, acting through the Director of CDC, to carry out projects to increase education, awareness, or diagnosis of DVT or PE, and to reduce the incidence of morbidity and mortality caused by blood clots. The Secretary may carry out these projects directly or via awards of grants/contracts to public or non-profit private entities. The grants may prioritize entities targeting individuals who are at greater risk for DVT/PE, including women, seniors, cancer patients, hospitalized patients, pregnant and postpartum women, Black Americans, and those in rural areas.

The projects may include the implementation of public information and education programs, and surveillance of the prevalence and incidence of DVT/PE to improve patient outcomes.

A CLOSER LOOK AT H.R. 5699

Below you can find a detailed explanation of the sections of the The Charles Rochester Blood Clot Prevention and Treatment Act (H.R. 5699):

ADVISORY COMMITTEE FOR DVT/PE PREVENTION

This provision requires the Secretary of HHS to establish an advisory committee that will:

- identify the aggregate number of individuals in the U.S. who experience DVT/PE annually;
- identify how data is collected regarding DVT/PE and the adverse outcomes associated with such conditions;
- identify how DVT/PE impacts the lives of individuals in the U.S.;
- identify the standard of care for DVT/PE surveillance, detection, and treatment;
- identify emerging treatments, therapies, and research relating to DVT/PE;
- develop recommendations to help health care providers identify patients who may be at higher risk of forming DVT/PE in health care facilities;
- develop recommendations to help improve patient awareness of DVT/PE;
- develop recommendations with respect to the standard of care for patients at risk of forming DVT/PE;
- develop recommendations relating to providing patients and their families with written notice of increased risks of forming DVT/PE; and
- identify the estimated level of Federal funding needed for DVT/PE service to meet the needs of high-risk populations.

The advisory committee will be composed of members from a variety of backgrounds; and they will create a report to Congress summarizing their findings, and making recommendations for legislative or administrative action to improve DVT/PE prevention, treatment, and diagnosis.

DVT/PE SURVEILLANCE STUDY AND REPORT

This provision requires the Secretary of HHS to conduct or support a study on the establishment of a National VTE surveillance system. Without a national VTE surveillance system that can systematically collect representative data on VTE, the precise number of people affected by VTE within the U.S. is difficult to estimate.

The model systems of DVT/PE surveillance may include the use of electronic medical record-based methods of detecting DVT and PE International Classification of Disease codes or other population-based surveillance. The Secretary shall submit a report detailing the results of the study.

CONGRESSIONAL CO-LEADS



“ The Charles Rochester Blood Clot Prevention and Treatment Act recognizes the critical importance of increasing awareness of blood clot signs and symptoms. As a physician, I have seen the challenges and consequences imposed on patients and families dealing with this issue. This legislation will save lives by providing education and support, while helping to streamline diagnosis and treatment. I am honored to work across the aisle with my colleague Rep. Lisa Blunt Rochester on this legislation honoring her late husband.

Congressman Larry Bucshon, M.D. (R-IN) ”

“ I am honored to work with Rep. Blunt Rochester in introducing the Charles Rochester Blood Clot Prevention and Treatment Act, named in memory of her late husband. This vital legislation aims to increase awareness of the warning signs associated with deep vein thrombosis and pulmonary embolisms. By doing so, we aspire to bolster prevention efforts and enhance treatment options for the benefit of all Americans who may experience the distressing impact of deep vein thrombosis or pulmonary embolisms.

Congressman Michael Burgess, M.D. (R-TX) ”



“ This issue came to my attention thanks to the dedication and advocacy of the family of Jennifer Luft, a constituent who lost her life in 2022 due to her condition of deep vein thrombosis (DVT) and pulmonary embolism (PE) being misdiagnosed. These deadly but preventable blood clots take lives every day, but raising awareness about the signs can make all the difference. I'm proud to join my friend and colleague, Congresswoman Blunt Rochester, in introducing this legislation that honors the memory of her late husband and will save lives.

Congressman Paul Tonko (D-NY) ”



ENDORSEMENTS

The bipartisan Charles Rochester Blood Clot Prevention and Treatment Act is supported by the following organizations:

- American College of Cardiology
- American College of Chest Physicians (CHEST)
- American Heart Association
- American Thrombosis and Hemostasis Network
- American Venous Forum
- Anticoagulation Forum
- Association of Black Cardiologists
- Coalition for National Trauma Research
- Foundation for Women and Girls with Blood Disorders
- International Society for Laboratory Hematology
- International Society on Thrombosis and Hemostasis
- Minority Health Institute
- National Bleeding Disorders Foundation
- National Blood Clot Alliance
- National Health Council
- North American Thrombosis Forum
- SANO Health ARM (Advocacy Research Mentoring)
- Society of Interventional Radiology
- Temple University Health System/Temple Lung Center
- The PERT Consortium™

ENDORSEMENTS

WHAT THE EXPERTS ARE SAYING

“As the nation’s leading patient advocacy organization focused on the prevention, early diagnosis, and treatment of life-threatening blood clots such as deep vein thrombosis and pulmonary embolism, the National Blood Clot Alliance “NBCA” unequivocally supports the passage of the Charles Rochester Blood Clot Prevention and Treatment Act. As a pulmonary embolism survivor, and as the president of NBCA, I have witnessed first-hand the unnecessary death and devastation caused by blood clots. NBCA calls on Congress to protect the American public from this silent killer by supporting the Charles Rochester Blood Clot Prevention and Treatment Act. Together, we can #StoptheClot.”

-Leslie Lake, President, National Blood Clot Alliance

“When blood clots reach the heart or brain, the resulting heart attack or stroke can be deadly. Many of these deaths can be prevented through appropriate prevention, diagnosis, and treatment. The American Heart Association is grateful to Rep. Blunt Rochester for turning her personal loss into action by sharing the story of her husband Charles’ death to raise awareness of blood clot symptoms. The Charles Rochester Blood Clot Prevention and Treatment Act would call on the Centers for Disease Control and Prevention to launch a national education campaign to help the public better recognize the warning signs of a blood clot, respond effectively, and help save lives.”

-Mark Schoeberl, Executive Vice President of Advocacy, American Heart Association

“Blood clots are a significant health care issue that disproportionately impact people with chronic diseases and disabilities. This is especially true for people from marginalized communities. Blood clots can also cause other chronic conditions. The National Health Council supports the Charles Rochester Blood Clot Prevention and Treatment Act as a tool to educate patients, increase health equity, and help providers understand the public health effects of this all-too-common condition.”

-Randall Rutta, Chief Executive Officer, National Health Council

“VTE is a major cause of avoidable patient harm in the US and efforts to increase public awareness, improve the quality of clinical care, and advance national surveillance are critical. The Anticoagulation Forum strongly supports the Charles Rochester Blood Clot Prevention and Treatment Act as an important step in addressing this growing national health concern.”

-Allison Burnett, PharmD, President, Anticoagulation Forum

ENDORSEMENTS

WHAT THE EXPERTS ARE SAYING

“We firmly believe that the implementation of the Charles Rochester Blood Clot Prevention and Treatment Act will contribute significantly to enhancing public awareness, improving patient outcomes, and reducing the economic burden associated with blood clots. The International Society on Thrombosis and Hemostasis pledges its support in advocating for the swift passage of this crucial legislation.”

-Thomas Reiser, Executive Director, International Society on Thrombosis and Hemostasis

“As the Executive Director of the North American Thrombosis Forum, I wholeheartedly endorse the Charles Rochester Blood Clot Prevention and Treatment Act. This legislation addresses a critical gap in public health by prioritizing education, early intervention, and data collection related to blood clots and pulmonary embolisms. By increasing awareness, enhancing surveillance, and fostering research, this bill not only saves lives but also alleviates the immense economic burden caused by these conditions. It is a crucial step toward empowering patients, health care providers, and policymakers in our collective effort to combat this preventable yet significant health threat.”

-Kathryn Mikkelsen, Executive Director, North American Thrombosis Forum

“The Society of Interventional Radiology (SIR) physicians regularly care for patients suffering from pulmonary embolism (PE) and deep vein thrombosis (DVT) using minimally invasive, image guided therapies. SIR supports the Charles Rochester Blood Clot Prevention and Treatment Act (H.R. 5699), which seeks funding for a national public awareness campaign, to improve the treatment and prevention of pulmonary embolism and deep vein thrombosis. SIR compliments and thanks Representative Blount Rochester for her leadership addressing this important health care matter.”

-Society of Interventional Radiology

“The PERT Consortium™, the single largest pulmonary embolism (PE) specific organization in the world whose mission is to increase awareness of treatment options available to patients with PE, to reduce the worldwide incidence of PE, and to further scientific discovery in the realm of PE research, believes that The Charles Rochester Blood Clot Prevention and Treatment Act will decrease the morbidity and mortality associated with PE in the US, and we not only strongly support this bill, but also have several innovative projects underway that are in line with this bill and address important clinical questions that will lead to changes in the care of PE patients and their outcomes.”

-Rachel Rosovsky, M.D., President, The PERT Consortium™

ENDORSEMENTS

WHAT THE EXPERTS ARE SAYING

“Deaths from deep venous thromboembolism (DVT) can be prevented when the signs and symptoms of a potentially deadly blood clot are recognized early. The Association of Black Cardiologists (ABC) thanks Congresswoman Blunt Rochester for her extraordinary and deeply personal commitment to raising awareness about DVT, as well as identifying approaches and increased funding resources that will lead to improved prevention, screening, detection and diagnosis. The ABC is proud to endorse the Charles Rochester Blood Clot Prevention and Treatment Act and calls for the bill’s passage this year.”

-Anekwe Onwuanyi, M.D., FACC, President, Association of Black Cardiologists

“Venous Thromboembolism (VTE) represents a significant and preventable factor contributing to patient morbidity and mortality across the United States. At Temple Health/Temple Lung Center, we recognize the urgent need to elevate public understanding, enhance standards of care, and bolster national tracking mechanisms to combat this issue effectively. We wholeheartedly endorse the Charles Rochester Blood Clot Prevention and Treatment Act, viewing it as a vital measure in tackling this escalating healthcare challenge. Such legislative action is crucial for safeguarding public health and advancing the fight against VTE.”

-Parth Rali, M.D., FCCP Associate Professor, Director, TUHS PERT Program, Temple University Hospital, Philadelphia

“The Minority Health Institute wholeheartedly endorses the Charles Rochester Blood Clot Prevention and Treatment Act (H.R. 5699) and commends the Congresswoman’s efforts on this vital piece of legislation. By prioritizing public awareness, healthcare provider education, and innovative research, we can take significant strides toward reducing the burden of blood clots on individuals and our healthcare system as a whole.”

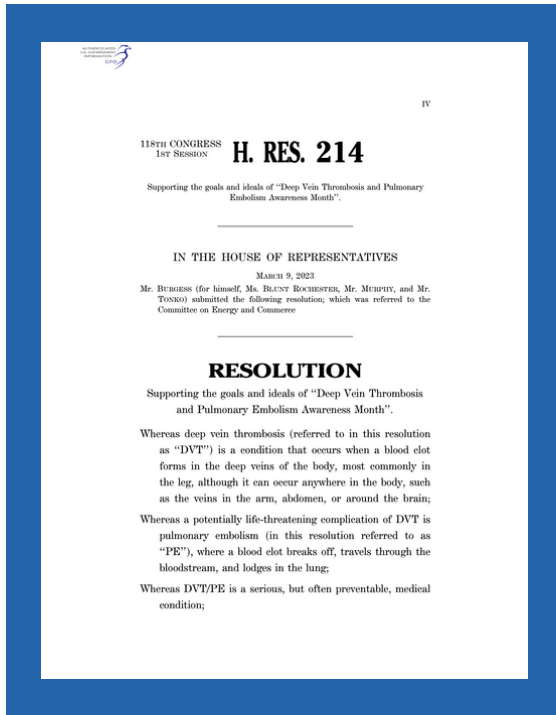
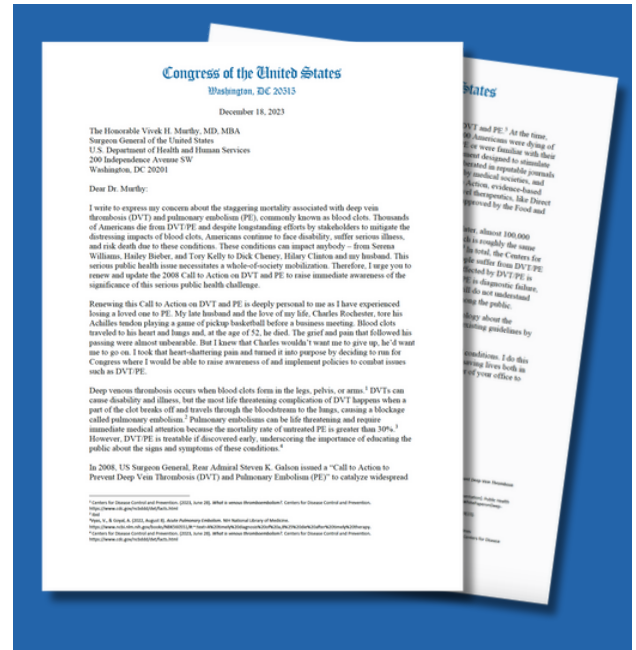
-Richard Allen Williams, M.D., FACC, FAHA, FACP, DHL, DSC (Hon), President and CEO, Minority Health Institute

“In the time it takes you to read this, someone will likely have died of a blood clot. While there are risk factors that make someone more likely to experience a blood clot, this dangerous condition can happen to anyone. Fortunately, blood clots are often preventable, but early diagnosis and treatment is key when they do occur. The ACC thanks Rep. Blunt Rochester, a longtime advocate for cardiovascular health, for recognizing the importance of education and awareness, and introducing The Charles Rochester Blood Clot Prevention and Treatment Act. It will save lives.”

-B. Hadley Wilson, M.D., FACC, President, American College of Cardiology

ADDITIONAL SUPPORT FROM REP. BLUNT ROCHESTER

LETTER TO SURGEON GENERAL ON DVT AND PE



H.RES.214 - TO SUPPORT THE GOALS AND IDEALS OF "DEEP VEIN THROMBOSIS AND PULMONARY EMBOLISM AWARENESS MONTH"

LETTER TO HOUSE APPROPRIATIONS COMMITTEE ON FUNDING A BLOOD CLOT AWARENESS CAMPAIGN



ADVOCACY

ADVOCATING FOR YOURSELF

To get the care you need and deserve, you may have to act as your own advocate. Here are some methods to become an active participant in your own care so that you can ensure the most optimal outcome:

- **ASK QUESTIONS:** Don't hesitate to ask your healthcare providers questions about your condition, treatment plan, and any concerns you may have. You can find sample questions [here](#). Request explanations in plain language so you can fully understand your care.
- **STAY INFORMED:** Research your medical condition and the treatments you are receiving. This knowledge can help you ask informed questions and make decisions about your care.
- **SPEAK UP:** If you notice any unusual symptoms, discomfort, or changes in your condition, inform your healthcare team immediately. Early intervention can be critical in preventing complications.
- **INVOLVE A TRUSTED ADVOCATE:** If possible, have a family member or friend with you during medical visits to act as an advocate. They can help ensure your concerns are heard, take notes, and help make decisions if you are unable to do so.
- **BE SAFE WITH MEDICATIONS:** Double-check the medications you are given. Ask about each medication's purpose, dosage, and potential side effects. Ensure that your healthcare providers are aware of any allergies or adverse reactions you have had in the past.
- **ASK FOR A SECOND OPINION:** If you have concerns about a diagnosis or treatment plan, consider seeking a second opinion from another healthcare provider.
- **KNOW YOUR RIGHTS:** Familiarize yourself with your patient rights and responsibilities, including the right to informed consent and the right to refuse treatment.
- **DOCUMENT EVERYTHING:** Keep a record of your medical history, symptoms, medications, and interactions with healthcare providers. This can help you keep track of your care and communicate effectively.
- **FOLLOW UP:** After discharge, continue to monitor your health and follow your healthcare provider's instructions. Attend follow-up appointments and report any lingering symptoms or concerns.

SOCIAL MEDIA TOOLKIT

HASHTAGS

#AwarenessActionAdvocacy
#StopTheClot
#BloodClotToolkit
#BloodClot
#DVT
#PE

ACCOUNTS TO TAG

@RepLBR
@RepLarryBucshon
@MichaelCBurgess
@RepPaulTonko

GRAPHICS



[Click here for graphics.](#)

SAMPLE POSTS

- One American dies of a blood clot every six minutes. @RepLBR's Charles Rochester Blood Clot Prevention and Treatment Act will work to increase awareness about this potentially life-threatening condition.
- It is estimated that 900,000 people suffer from blood clots each year, and of those, nearly 100,000 die. However, the exact number is unknown due to inadequate data collection methods. Support the Charles Rochester Blood Clot Prevention and Treatment Act, which works to enhance our understanding of blood clots and the magnitude of their impact.
- You are at higher risk for blood clots if you are older, have cancer, are pregnant, suffered an injury or trauma, or have a family history of blood clots. The Charles Rochester Blood Clot Prevention and Treatment Act would increase awareness of blood clot signs and symptoms.
- I'm proud to support @RepLBR's Charles Rochester Blood Clot Prevention and Treatment Act - important, bipartisan legislation to raise awareness, establish an advisory committee, and enhance data collection surrounding blood clots.
- The Charles Rochester Blood Clot Prevention and Treatment Act, led by @RepLBR, will save lives by prioritizing patient education to enable early intervention that will lead to reduced deaths, diseases, and health care costs associated with blood clots.
- Direct and indirect costs of blood clots surpasses \$10 billion annually. The Charles Rochester Blood Clot Prevention and Treatment Act is a proactive, bipartisan approach centered on education, awareness, and data collection.
- Incidents of blood clots are 30-60% higher in Black Americans. The Charles Rochester Blood Clot Prevention and Treatment Act works to protect the communities most vulnerable to the condition.

ACRONYM & DEFINITION GUIDE

ACRONYMS

CDC - Centers for Disease Control and Prevention

DVT - Deep Vein Thrombosis

HHS - U.S. Department of Health and Human Services

PE - Pulmonary Embolism

VTE - Venous Thromboembolism

DEFINITIONS

Arteries: The blood vessels which carry blood away from the heart to the extremities (e.g., legs, 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.

Thrombosis: A blood clot that forms within a vessel.

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

Venous Thromboembolism (VTE): DVT and PE are collectively known as VTE.

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