What you can do to increase awareness

Talking points to help teach others about blood clots

Clot Connect

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Purpose:

If you have experienced deep vein thrombosis or pulmonary embolism, your personal story can be a powerful example to educate those around you. This document provides facts about blood clots you can use when sharing your experience with others. Additional information is available online at www.ClotConnect.org.

This document is intended to provide general information about blood clots and clotting disorders so you can help educate others. It is not intended to be medical advice and is not a substitute for seeing a physician. If you or someone you know show signs and symptoms of a blood clot, please seek medical attention right away.
Section One: How You and Others Can Get Involved

People often ask: What can be done to increase awareness? Here are some ideas:

1. **Talk about it**

   Simply talking about blood clots to those around you creates a powerful message. Starting a conversation might not be easy, but it may save a life if you inspire a friend or family member to not ignore symptoms of a blood clot and to get medical help right away. Talk to people you know about blood clots and encourage others to do the same.

   ➢ Use the ‘talking points’ found in Section Two (page 5) of this document to find facts you can use about blood clots, the symptoms, and tips on prevention.

2. **Share Clot Connect resources**

   **Know someone who has experienced a blood clot?** Make them aware of the resources and support available at [www.clotconnect.org](http://www.clotconnect.org) which can help them be more proactive in their care. Tell them about the ‘Newly diagnosed with DVT or PE’ educational brochure’, available at [www.clotconnect.org](http://www.clotconnect.org) which answers many common questions.

   **Know someone at risk for developing a blood clot?** (And that covers just about everyone at some point in their lives!) Make sure they know the symptoms of DVT/PE and what to do if they arise. Symptoms can be found on page 6 of this document or at: [http://www.clotconnect.org/patients/symptoms-and-risk-factors](http://www.clotconnect.org/patients/symptoms-and-risk-factors)

3. **Use social media**

   Do you do Facebook, Twitter, MySpace or other social media? Use your social media network to spread the word about blood clots. Post a status update with a link to www.ClotConnect.org. Ask others to repost to their networks. Talk about the symptoms of blood clots. Encourage your friends to learn more to educate themselves.

   *Don’t have any ideas for a post? Here’s a few suggestions:*

   Example 1: I had a blood clot. It can happen to anyone, at any age. Know the symptoms. Visit www.ClotConnect.org to learn more.

   Example 2: Do you know the symptoms of a blood clot? Visit www.ClotConnect.org to learn more.

   Example 3: One person is diagnosed with a blood clot every minute. Are you at risk? Visit www.ClotConnect.org to find out.
4. **Promote awareness through your community and workplace groups.**

Many organizations have a newsletter, bulletin, or place to post flyers. Look for opportunities to share your own personal experience with blood clots and educate others. Church bulletins, community homeowners newsletters, online local club forums... all can be opportunities to create awareness about blood clots.

**Flyers:** Distribute a flyer about the symptoms of blood clots. Many offices and public places have a space for community flyers. Print copies of Clot Connect's 'Blood Clot Symptoms flyer' listing the symptoms and risk factors for deep vein thrombosis and pulmonary embolism. (This flyer is found at the end of this document and on www.ClotConnect.org). Ask permission to post them in community centers, physician offices, coffee shops and other public places where such a post might be appropriate. Please only post flyers where you have permission to do so.

5. **Hold a fundraiser.**

*Clot Connect* is supported entirely through grants and charitable donations. We currently receive no direct federal, state, or university financial assistance.

Educating people about blood clots and clotting disorders requires funds for many uses: for printing educational materials, for maintaining the website and support forums, for developing research and education collaborations with patients and physicians, for hiring staff to answer patient and physician questions.

- Simply put, *Clot Connect* cannot achieve its mission to connect patients and healthcare professionals to reliable information on the diagnosis, treatment and prevention of blood clots without adequate resources.

From creating a public event in your community to hosting a dinner party in your home, there are many creative ways to raise funds to benefit *Clot Connect*.

Encourage your friends and colleagues to support blood clot awareness by making a donation either via the www.ClotConnect.org website or by sending a check made payable to: **Medical Foundation of NC DVT Fund #91388**, and mailed to: Medical Foundation of NC, 880 Martin Luther King Jr Blvd, Chapel Hill, NC 27514.
Section Two: Talking Points….facts to use when teaching others

1. What is a blood clot? Terms and definitions

Thrombosis is the medical term for a blood clot that forms within a vessel. Blood clots can happen anywhere in the body.

Arteries are the blood vessels that carry blood away from the heart, to the extremities, the abdomen, and the brain. Blood clots which form in arteries lead to heart attack and stroke.

Veins are the blood vessels that carry blood back to the heart from the extremities, the abdomen, and the brain. Blood clots which form in the deep (main) veins of the body lead to Deep Vein Thrombosis and Pulmonary Embolism.

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 and PE are collectively known as VTE

Thrombophilia: The medical term for a blood clotting disorder

Clot Connect’s educational focus is on 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.
2. Symptoms and Risk Factors for blood clots

What are the symptoms of a blood clot?

Deep Vein Thrombosis (DVT):
A clot that typically is in one leg (can also occur in unusual sites, such as veins in the arm, abdomen or around the brain). Symptoms range from mild to severe; may involve the foot, ankle, calf, whole leg or arm.
- Pain
- Swelling
- Discoloration (bluish or reddish)
- Warmth

Pulmonary Embolism (PE):
A blood clot in the lungs
- Shortness of breath
- Chest pain (may be worse with deep breath)
- Unexplained cough (may cough up blood)
- Unexplained rapid heart rate

Symptoms may be mild to severe or there may be none noticeable at all. There can be a wide range of presentations and one does not need to have all symptoms to have a blood clot.

Symptoms of blood clots may also be subtle and easily confused with other medical conditions.

- Deep vein thrombosis (DVT) may be confused with sprained ankle, ‘Charley horse’, or pulled muscle.
- Pulmonary embolism (PE) may be attributed as ‘a touch of pneumonia’, new onset of asthma, respiratory infection, inflammation of the joints of the breast bone or ribs.

Because symptoms of DVT and PE can mimic these conditions, a wrong or delayed diagnosis can occur in patients who eventually get diagnosed with DVT or PE.
What are the risk factors for developing a blood clot?

Factors that increase risk:

Immobility:
- Hospitalization
- Being paralyzed
- 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, or 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 chemotherapy
- Heart failure
- Inflammatory disorders (lupus, rheumatoid arthritis, inflammatory bowel disease)
- The kidney disorder called nephrotic syndrome

Other risk factors:
- Previous blood clot
- Family history of clots
- Clotting disorder
- Obesity
- Smoking
- Older age
3. How many people are affected by blood clots?

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

• **One person each minute will be diagnosed** with deep vein thrombosis in the United States

• **One person every six minutes will die** from pulmonary embolism

• Pulmonary embolism is the sixth most common cause of death in the United States

• Two-thirds (2/3) of all vein clots are associated with hospitalization (*Deep Vein Thrombosis* + *Pulmonary Embolism*) --- they occur either in the hospital or within a few weeks after discharge.

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**Additional information from the Centers for Disease Control and Prevention (CDC):**

• The precise number of people **affected** by DVT/PE is unknown, but estimates by the CDC range from **300,000 to 600,000** each year in the United States

• Estimates suggest that **60,000-100,000 Americans die** of DVT and PE.
  • 10 to 30% of people will die within one month of diagnosis.
  • Sudden death is the first symptom in about one-quarter (25%) of people who have a PE.
  • **Many deaths from blood clots are preventable**
4. What are the affects of clots for survivors?

- Among people who have had a DVT, one-third will have long-term complications (post-thrombotic syndrome) such as swelling, pain, discoloration, heaviness and tiredness or itching, dryness and scaling in the affected limb.

- One-third (about 33%) of people with DVT/PE will have a recurrence within 10 years.

- Blood clot survivors face many challenges including:
  - Risks associated with the use of blood thinners (anticoagulants), foremost bleeding.
  - Development of post-clotting disorder 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.
  - Increased risk for a future blood clot.
  - Costly outpatient medical care and inpatient hospitalizations.

5. Low public awareness. Little support available for patients.

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

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

Despite being a common health condition, there are few support groups and educational programs for patients and their families.
6. How can you be a proactive person about blood clots?

**Family history**

Know your family medical history. Learn if anyone in your family has experienced deep vein thrombosis or pulmonary embolism. A family history increases risk. Make your physicians aware of this family history.

**Diagnosis**

Blood clots are often misdiagnosed or diagnosed after a delay. Be aware that other medical conditions can also mimic the symptoms of a blood clot, making it difficult to diagnosis and treat in a timely manner. Symptoms can sometimes be subtle or there may be none at all.

**Don't delay going to the doctor**

If you have symptoms of a blood clot, go get checked out by a physician. Don't delay going to the doctor. Early treatment can prevent many complications, including death.

**Ask questions**

It is OK to ask your doctor, "Could this be a blood clot?" Be proactive. Make sure your doctor is screening you for blood clots.

**Move**

Immobility increases the risk of developing clots. Move your legs frequently when on long trips--such as when traveling by plane, bus, or car. If you've been sitting for a long period of time, stop and take a break to stretch your legs. Be active. Activity improves circulation.

**Weight loss and smoking**

Obesity is a risk factor for clots---lose weight if you are overweight. Smoking is a mild risk factor—don’t smoke.

**If you are hospitalized or planning a surgical procedure...**

Hospitalization greatly increases blood clot risk. If you are hospitalized or planning for surgery, ask your doctor:

- Am I at risk for blood clots?
- Should I be on a medication to prevent blood clots? (You may hear such blood clot prevention measures called 'DVT prophylaxis' by your doctor.)
  - If yes, then: How long should I be on this medication? Only while I'm hospitalized or also after I go home?
**Hormones**

If you are a woman and you are on hormone replacement therapy, ask your doctor whether you still need to be on the hormones. If your doctor plans to start you on hormones—or osteoporosis or other reasons—ask whether there are alternatives.

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**7. What is Clot Connect?**

*Clot Connect (clotconnect.org)* is an outreach initiative housed within the Hemophilia and Thrombosis Center of the University of North Carolina at Chapel Hill.

*Clot Connect* initiatives are targeted at:

- Persons who have experienced a blood clot
- Health care professionals
- Persons at high risk for developing a blood clot
- The General Public

**Leadership**

Stephan Moll, MD is the Medical Director of *Clot Connect*. Dr. Moll is Associate Professor in the Department of Medicine and Division of Hematology-Oncology at the University of North Carolina at Chapel Hill, NC.

Beth Waldron is the Program Director of *Clot Connect* at the UNC Hemophilia and Thrombosis Center, McAllister Heart Institute.

*Clot Connect* emerged in September 2010 from the observation that blood clot survivors face many unique challenges including risks associated with anticoagulant use (blood thinners), the development of post-thrombotic disorders and increased risks for future clots. Blood clot survivors and their families need information and support to manage the effects of a blood clot and to prevent future clots. It was also recognized that health care professionals need easier access to the latest treatment options and scientific research related to the diagnosis, care and management of patients with blood clots and clotting disorders. In addition, it was known that although blood clots are a common health condition, there exists low public awareness.

**Clot Connect’s Mission**

*To increase knowledge of blood clots and clotting disorders by providing connection to education and support resources for patients and health care professionals.*
Clot Connect’s Program Activities

For Patients...

- Education materials, videos, webinars, website
- Education blog answering common questions and concerns
- Online support forum to connect with other patients
- Monthly newsletter

ClotConnect.org website

For Healthcare Professionals...

- Clinical care VTE prophylaxis and treatment guidelines
- VTE reduction strategy development resources
- Patient education materials
- Healthcare professional’s education blog to assist with clinical care and anticoagulation management
- Monthly newsletter to keep informed of latest resources and clinical care guidelines

Patient educational materials
Clot Connect’s Funding and How to Make a Donation

Although housed at the University of North Carolina at Chapel Hill, the UNC Blood Clot Outreach Program and Clot Connect project receive no direct state or university funds. The program and project are entirely supported through grants and donations.

The Clot Connect project was initially launched in September 2010 utilizing a CDC pilot thrombosis center grant which expired in June 2012. Budget and program details can be found in our program report at: http://www.clotconnect.org/about-clot-connect/annual-report

Instructions for persons wishing to make a tax-deductible contribution towards the program:

Online donations are accepted thru the website at www.ClotConnect.org

or by mail:

Make checks payable to:
Medical Foundation of NC - DVT Fund 91388

And mail to:
Medical Foundation of NC
880 MLK Jr Blvd.
Chapel Hill, NC 27514
8. How to learn more about blood clots

Visit ClotConnect.org.

There is a wealth of resources available at www.ClotConnect.org

A good starting place to learn more about blood clots is under the “What do I need to know” and “DVT and PE Video Series” under the “For Patients” menu.

For persons newly diagnosed with deep vein thrombosis or pulmonary embolism, the brochure “Newly Diagnosed with DVT or PE” answers many of the most common questions.
http://www.clotconnect.org/patients/resources/brochures

9. Main takeaway messages

In sum, the main messages to provide an audience are:

- Blood clots are a common medical condition.
- Blood clots can happen to anyone, at any age.
- Be aware of the risk factors for blood clots.
- Know the symptoms of blood clots.
- Take action if you suspect you have a blood clot. Don’t delay seeking medical care.
- If you are concerned about blood clots, talk with your doctor about your individual risk factors and what you can do to reduce your risk.
- Talk with your doctor about clots before any surgery or hospitalization.
- For more information about blood clots, visit www.ClotConnect.org

Thank you for helping increase awareness of blood clots and clotting disorders!
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If you have any of these symptoms, get medical help right away!

Factors that increase blood clot risk

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- Cancer and its treatment
- Heart failure
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