Media Kit

March 2013 Edition

Clot Connect

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Purpose:

This is intended to be a guide for members of the media doing research on blood clots and the Clot Connect project. It contains facts which can be utilized for public use.
1. What is a blood clot? Terms and definitions

Terms you may encounter:

**Thrombosis**: the medical term for a blood clot that forms within a vessel

**Thrombophilia**: the medical term for a blood clotting disorder

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

**Arteries** are 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

*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 Causes/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 around the brain.

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.

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

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

Symptoms can range widely from mild and barely noticeable to severe. They can sometimes be confused with other medical conditions, leading to a missed or 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.

What causes 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 clotable. 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:

<table>
<thead>
<tr>
<th>Immobility:</th>
<th>Medical conditions:</th>
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</thead>
<tbody>
<tr>
<td>Hospitalization</td>
<td>Cancer and its treatment</td>
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<tr>
<td>Prolonged sitting</td>
<td>Heart failure</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Surgery and Trauma:</th>
<th>Inflammatory disorders (lupus, rheumatoid arthritis, inflammatory bowel disease)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major surgery (pelvis, abdomen, hip, knee)</td>
<td>Nephrotic syndrome</td>
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<td>Bone fracture or cast</td>
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<tr>
<td>Catheter in a big vein (PICC line, central venous catheter, port)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Increased estrogen:</th>
<th>Other risk factors:</th>
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<tbody>
<tr>
<td>Birth control pills, patches, rings</td>
<td>Previous blood clot</td>
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<tr>
<td>Pregnancy, for up to 6 weeks after giving birth</td>
<td>Family history of clots</td>
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<tr>
<td>Estrogen + progestin hormone therapy</td>
<td>Clotting disorder (thrombophilia)</td>
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<tr>
<td></td>
<td>Obesity</td>
</tr>
<tr>
<td></td>
<td>Smoking</td>
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<tr>
<td></td>
<td>Older age</td>
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<td></td>
<td>Varicose veins</td>
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Blood clots are a common health condition. They can happen to anyone, at any age.

Incidence figures:
- The precise number of people affected by DVT/PE is unknown because there is currently no national surveillance for VTE, but estimates by the Centers for Disease Control and Prevention (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.
  - Between 10 to 30% of people with a blood clot 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

- Blood clots (DVT and PE) are a leading cause of preventable hospital death in the United States. Approximately 40% of clots are associated with hospitalization, occurring either in the hospital or shortly after discharge.

- Blood clots (DVT and PE) are the leading cause of maternal death in the United States. Pregnancy increases clot risk (due to increased estrogen) and that risk remains elevated for up to 6 weeks after giving birth.

- Blood clots contribute to an estimated $10 billion in medical costs each year in the US.

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.
4. What are the effects for blood clot survivors?

- Among people who have had a DVT, **40-50% 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 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.

- High levels of anxiety, depression, and stress have been reported among blood clot patients.

5. How can 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 long-distance travel), 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. *(The risk factors are listed on page 4 of this document)*

- 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 called ‘DVT prophylaxis’. 
6. 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.

**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, MA is the Program Director of Clot Connect at the UNC Hemophilia and Thrombosis Center.

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 clots.

**Clot Connect’s Mission**

The mission of Clot Connect is to increase knowledge of thrombosis, thrombophilia and anticoagulation by providing connection to education and support resources for patients and health care professionals.

A key role of Clot Connect is to serve as the go-to clearinghouse for reliable, clinically relevant thrombosis and anticoagulation information.
Clot Connect outreach activities include...

- A website: www.ClotConnect.org, which serves as the hub for the online clearinghouse
- Online support forum
- Two education blogs answering common questions—one for patients, one for health care professionals
- Education materials, videos, webinars
- Easy access to clinical care guidelines
- Monthly newsletter
- Support and partnership with local and national blood clot prevention initiatives
**Clot Connect’s Funding**

Although housed at the University of North Carolina at Chapel Hill, *Clot Connect* receives no direct state or university funds. The program and project are entirely supported through a combination of grants and donations.

*Clot Connect* was initially launched in September 2010 utilizing a CDC pilot thrombosis center grant which expired in June 2012.

Details about our budget and program activities can be found in *Clot Connect’s* Annual Report, available on our website.

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**How to make a donation**

*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
7. Want to learn more?

Visit 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 patients who have experienced DVT and PE, Clot Connect has a comprehensive guide, available on our website. This will answer many of the most common questions of patients.

8. Main takeaway audience 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

9. Contact information

For questions about blood clots or Clot Connect, contact:

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*If you are on a deadline*: The quickest way to connect 7 days a week is via email: bwaldron@med.unc.edu Email is checked frequently, even when away from the office.  
Or by Twitter, direct message @clotconnect