Clot Connect Program Report

September 2010 – May 2013

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Terms used in this document

**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 abdomen, and the brain.

**Deep Vein Thrombosis (DVT):** a clot that has formed in the deep veins of the body, also called Deep Vein Thrombosis, often referred to as DVT for short. While DVT can occur anywhere in the body, it is most common in the leg.

**Pulmonary Embolism (PE):** a clot in the pulmonary vessels, often referred to as PE. A pulmonary embolism occurs when a blood clot breaks off from a DVT, travels through the blood stream and lodges in the lung. It can be a potentially life-threatening complication of DVT.

**Venous Thromboembolism (VTE):** DVT + PE are collectively known as VTE
Program History

Clot Connect (clotconnect.org) is an outreach initiative in the Hemophilia and Thrombosis Center of the University of North Carolina at Chapel Hill, which has a long leadership history in the area of thrombosis care. As a thrombosis center, UNC is able to offer a multi-disciplinary team of health care specialists, clinical research programs, as well as outreach and education.

Clot Connect initiatives are targeted at:

- Persons who have experienced venous thromboembolism (VTE)
- Persons at high risk for developing VTE
- Health care professionals who care for patients at risk for VTE or who have experienced VTE

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 within the McAllister Heart Institute.

Clot Connect emerged in September 2010 from the observation that venous thromboembolism 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. Patients 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 venous thrombosis and thrombophilia. In addition, it was known that although blood clots are a common health condition, there exists low public awareness.

Our Mission

To increase knowledge of venous thrombosis, thrombophilia and anticoagulation by connecting patients and health care professionals to educational and support resources.

Our Vision

To become the premier resource for information on venous thrombosis, thrombophilia and anticoagulation by addressing what patients and health care professionals have on their minds and want to know about thrombosis, thrombophilia and anticoagulation.
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

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
Promoting blood clot awareness

Clot Connect utilizes a “Be Clot Aware” campaign to encourage people to be proactive about blood clots by knowing their risk factors as well as the symptoms of DVT and PE.

Clot Connect also conducts targeted awareness activities each March, which is National Blood Clot Awareness Month.

Collaboration on national clot prevention initiatives

Clot Connect engages public health agencies, hospitals, community providers and nonprofits to facilitate VTE education in both the patient and healthcare professional communities. We have collaborated on key initiatives with:

- Centers for Disease Control and Prevention (CDC)
- US Department of Health and Human Services (HHS) and the Center for Medicare and Medicaid Innovation (CMS), Partnership for Patients
- North Carolina Center for Hospital Quality and Patient Safety
- National Quality Forum-National Priorities Partnership

Outreach supporting enhanced VTE education and prevention

NASCAR driver Brian Vickers, a blood clot survivor, partners with Clot Connect to promote awareness through multiple race and media activities.

Corinne Guillen, a high school senior from Mebane, NC, chose as her volunteer graduation project to increase awareness of the Factor V Leiden mutation and thrombophilia with resources from Clot Connect.

Dr. Stephan Moll, Clot Connect Medical Director, encouraged wider VTE education at the CDC’s National Blood Disorders in Public Health Conference.

Beth Waldron, Clot Connect Program Director, engaged healthcare professionals at the NC Center for Hospital Quality and Patient Safety Conference.
Resource Utilization

Since its start in September 2010, Clot Connect’s online outreach has steadily expanded, as our capacity has evolved to reach more patients and health care professionals. The program’s website, clotconnect.org, receives around 30,000 unique visitors each month.

**Unique website visitors**

Definition: Unique visitors are measured according to their unique IP addresses, which are like online fingerprints, and unique visitors are counted only once no matter how many times they visit the site.

**Average Daily Page Views**

Definition: A page view is the accessing of a web page by a visitor. It is used as a measurement of audience engagement for a website.
Where are clotconnect.org website visitors from?

Since September 2010, nearly 400,000 people in over 190 countries have been connected to information on the diagnosis, treatment and prevention of deep vein thrombosis and pulmonary embolism.

<table>
<thead>
<tr>
<th>United States</th>
<th>73%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other countries</td>
<td>27%</td>
</tr>
</tbody>
</table>

*Within the US:*
- California  9.2%
- New York  8.6%
- North Carolina  7.6%
- Texas  6.0%
- Florida  5.8%
- Illinois  4.8%
- Pennsylvania  4.5%
- Michigan  4.1%
- Ohio  3.6%
- New Jersey  3.2%

What educational topics are audiences interested in?

- Symptoms of DVT and PE
- How long to treat with anticoagulant following DVT or PE
- How to manage the new oral anticoagulants

Creating Online Community

<table>
<thead>
<tr>
<th>Community</th>
<th>Subscribers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newsletter</td>
<td>1,037</td>
</tr>
<tr>
<td>Facebook</td>
<td>535</td>
</tr>
<tr>
<td>Twitter</td>
<td>421</td>
</tr>
<tr>
<td>Patient Blog</td>
<td>525</td>
</tr>
<tr>
<td>HCP Blog</td>
<td>620</td>
</tr>
<tr>
<td>Support Forum</td>
<td>543 comments</td>
</tr>
<tr>
<td>YouTube</td>
<td>9,350 views</td>
</tr>
</tbody>
</table>

To engage our audience on an ongoing basis, Clot Connect works to create a ‘thrombosis community’ within social media, online forums and other electronic methods.

Subscribers = persons who have opted to ‘join’ or ‘subscribe’ to an online community or receive regular updates of educational information.

Snapshot on May 28, 2013
**Funding and Expenditures**

*Clot Connect* was launched in September 2010 utilizing a grant from the Centers for Disease Control (CDC) for thrombosis centers. The grant funded one full-time staff person and provided 10% salary support for the Medical Director for program development and medical content development. The CDC grant expired June 2012.

While housed at the University of North Carolina at Chapel Hill, *Clot Connect* receives no direct federal, state or university financial assistance.

The program is entirely supported through grants and donations.

Funds support one full-time staff person, internet and print outreach.
Clot Connect’s Plan for the Future

Clot Connect has evolved dramatically since its creation in late 2010. While a great deal has been accomplished in a short time, utilizing modest resources, there is far more to do.

One person each minute is diagnosed with DVT in the United States. An estimated 300,000-600,000 people in the US develop a blood clot (deep vein thrombosis and pulmonary embolism) each year. Nearly 40% of patients develop post-thrombotic syndrome. These patients and the health care professionals who care for them need information and support to manage the effects of clotting and to prevent future clots.

Over the next year, we desire:

To continue to achieve our Mission
To increase knowledge of venous thrombosis, thrombophilia and anticoagulation by connecting patients and health care professionals to educational and support resources.

To achieve results consistent with our Vision
To become the premier resource for information on venous thrombosis, thrombophilia and anticoagulation by addressing what patients and health care professionals have on their minds and want to know about thrombosis, thrombophilia and anticoagulation.

To achieve our Goals
- To educate and support patients who have experienced venous thromboembolism (VTE)
- To educate patients who are at-risk for developing VTE
- To educate health care professionals who look after patients who have experienced VTE and those who are at-risk for VTE

We will do this by utilizing the following Strategies
- To identify and evaluate existing educational materials and create new materials to fill gaps identified.
- To create and maintain an online portal where patients and health care professionals can access educational and support resources.
- To reach patients and health care professionals via innovative technology-based communication methods which reflect how people access information used for decision making.
To engage the media, public health agencies, nonprofits and community groups to facilitate greater education of patients and health care professionals about VTE.

To serve as a knowledge resource to support local and national VTE education and prevention initiatives.

To serve as a model for patient and health care professional engagement by sharing experiences and advising local and national health initiatives.

We will monitor our Performance and Evaluation through the following indicators

- To track materials and resource utilization to determine depth and breadth of program reach.
- To survey end-users (subgroups of patients, health care professionals, administrators) to determine if there is meaningful utilization of resources...ie if a specific resource meets the educational need and then to identify areas where needs remain unmet.

We will achieve our mission in the following Organizational context

- Medical Director: heads the program’s leadership, providing medical content input and institutional administration. This position is embedded within the UNC Hemophilia and Thrombosis Center and Division of Hematology/Oncology.
- Program Director: coordinates the day-to-day program administration and activities. Reports to the Medical Director and is housed within the UNC McAllister Heart Institute and the UNC Hemophilia and Thrombosis Center.
- Volunteers: help with social media and discussion board facilitation, share their patient and professional experiences, facilitate community engagement and outreach dissemination.
- Funding: To identify new public and private funding sources which will allow the program to grow to meet demand. The demand for education and support services exceeds current organizational capacity. Immediate needs:
  - Secure funding: The program’s start-up CDC grant expired in June 2012. To achieve our mission, a long-term and sustainable funding model must be identified which reduces reliance upon short-term grants.
  - Increase outreach capacity: Protected time for medical direction to create and oversee content is highly desirable, as well as involvement of additional clinicians in the education delivery. Additional support for administrative and development tasks is also desirable to allow more focused time on program direction and audience outreach.
**Budget requirements**

To maintain the Clot Connect program, as it today, requires an annual budget of $100,000.

To increase outreach capacity to achieve the goals listed on the previous page, would require increasing the annual program budget to an estimated level of $275,000 to $300,000.

*Clot Connect’s current program budget can be found on page 8.*

**Donations**

The Medical Foundation of North Carolina, a 501(c)(3) charitable not-for-profit organization, is the fiduciary agent for UNC School of Medicine affiliated programs like Clot Connect.

A fund has been established with the Medical Foundation, DVT Fund #91388, in which donations to Clot Connect can be made.

**Donations are tax-deductible.**

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**To Make a Donation**

Donations can be made online via the [clotconnect.org](http://clotconnect.org) website or by mail.

**Make checks payable to:**

The Medical Foundation of NC-DVT Fund 91388

**And mail to:**

The Medical Foundation of North Carolina, Inc.
880 MLK Jr. Blvd.
Chapel Hill, NC 27514

*If you have questions concerning your gift or would like further information on giving opportunities which will support Clot Connect, please contact:*

The Medical Foundation of North Carolina,
(919) 966-1201
Looking forward

Our goal with Clot Connect’s educational outreach is to reduce the occurrence of and complications from venous thromboembolism. Improving clinical outcomes requires a multifaceted approach.

For patients, it means empowering them with knowledge about their condition and treatment so they can be active partners in their health care, resulting in better and safer treatment, greater satisfaction and an improved quality of life.

For health care professionals, it means providing them with the information and resources they need to confidently and consistently provide quality care to patients who have experienced venous thromboembolism.

It is an exciting time in the history of thrombosis education and outreach. Clot Connect presents a unique opportunity to address an unmet need. As we move forward, it will be critical that we keep focused on our core mission and established project plan while we remain open to new opportunities, diversify our funding sources to ensure long-term sustainability and cultivate meaningful collaborative relationships.

Providing medical information and support is only the beginning. Next comes evaluating the impact of our activities. With the information gained, we can then determine future content and direction of our program.

We are passionate about the work we are undertaking and are confident that with adequate resources and commitment, Clot Connect can continue to successfully achieve its mission.

We are grateful to those who have helped us arrive at this point in our development. We have benefited from the dedication and generosity of numerous volunteers, supporters and donors. Quite sincerely, thank you.

Beth Waldron
Program Director, Clot Connect

Stephan Moll, MD
Medical Director, Clot Connect