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Our Mission
To increase knowledge of blood clots and clotting disorders by providing education and support resources for patients and health care professionals.

Our Vision
For our educational resources to address what patients and health care professionals have on their minds and want to know about blood clots and clotting disorders.
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 of 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. UNC is one of five thrombosis centers funded by the Centers for Disease Control and Prevention (CDC) to find out how best to provide treatment and preventative care to people with thrombosis and thrombophilia. 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.

**Leadership**

*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

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.

*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.

**Our Mission**

*To increase knowledge of blood clots and clotting disorders by providing education and support resources for patients and health care professionals.*
Program Activities

Clot Connect outreach activities include:

A. **Website** providing connection to educational resources

B. **Education materials**

   Do you know the symptoms of a blood clot?

   Deep Vein Thrombosis (DVT)
   
   A DVT can happen to anyone at any age. Symptoms range from mild to severe, may involve the foot, ankle, calf, leg, or arm:
   
   - Pain
   - Swelling
   - Discoloration (bluish or red)
   - Warmth

   Pulmonary Embolism:
   
   A blood clot in the lung:
   
   - Shortness of breath
   - Chest pain (may be sharp or achy)
   - Unexplained cough (may cough up blood)
   - Unexplained rapid heart rate

   If you have any of these symptoms, get medical help right away!

   www.ClotConnect.org

C. **Two educational blogs** (one for patients and one for health care professionals) providing answers to commonly asked questions and reviewing the latest research

D. **Online Patient Support Forum**

E. **Newsletter**

See Attachment at the end of this report entitled “3 Year Strategic Plan” for detailed information about specific outreach initiatives, current status and future plans.
Resource Utilization and Persons Served

Since its start in September 2010, Clot Connect’s outreach has steadily expanded, as our capacity has evolved to reach more patients and health care professionals. Our core online outreach tools are a website, patient education blog and health care professional (HCP) education blog:

![Average Daily Page Views](image)

**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.

Creating Community

To engage our audience on an ongoing basis, Clot Connect is actively creating a ‘thrombosis community’ within social media, forums and other electronic networks.

<table>
<thead>
<tr>
<th>Community</th>
<th>Subscribers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newsletter</td>
<td>556</td>
</tr>
<tr>
<td>Facebook</td>
<td>348</td>
</tr>
<tr>
<td>Twitter</td>
<td>184</td>
</tr>
<tr>
<td>Patient Blog</td>
<td>274</td>
</tr>
<tr>
<td>HCP Blog</td>
<td>349</td>
</tr>
<tr>
<td>Support Forum</td>
<td>112</td>
</tr>
</tbody>
</table>

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

Where are website visitors from?

Top 10 states and percentage of total website traffic:

<table>
<thead>
<tr>
<th>State</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Carolina</td>
<td>16%</td>
</tr>
<tr>
<td>California</td>
<td>8%</td>
</tr>
<tr>
<td>New York</td>
<td>6%</td>
</tr>
<tr>
<td>Texas</td>
<td>5%</td>
</tr>
<tr>
<td>Florida</td>
<td>5%</td>
</tr>
<tr>
<td>Michigan</td>
<td>5%</td>
</tr>
<tr>
<td>Illinois</td>
<td>5%</td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>4%</td>
</tr>
<tr>
<td>New Jersey</td>
<td>4%</td>
</tr>
<tr>
<td>Ohio</td>
<td>3%</td>
</tr>
</tbody>
</table>

The greatest percentage of visitors to the clotconnect.org website are from North Carolina. The largest audience concentration is in the eastern half of the US.

What educational topics are visitors accessing most?

On the patient blog,

- Anticoagulation: 31%
- Symptoms and Diagnosis: 13%
- Complications of VTE: 5%

On the health care professional blog,

- Anticoagulation: 26%
- Clinical care guidelines: 8%
- Vascular anatomy: 3%
Program and Educational Message Promotion

Being a new program, part of our efforts over the past year has been to inform both patients and health care professionals of the existence and availability of Clot Connect resources, to encourage their utilization. Additionally, there have been opportunities for Clot Connect to promote public blood clot awareness and prevention messages via media interviews, community events, and special promotion activities. We have also partnered with health care organizations to disseminate education materials.

Among the education promotions and partnerships:

- Fox Business
- CNN
- Forbes
- Pain Pathways Magazine
- Cardio Brief
- Cardio Exchange
- Brian Vickers, Prelude to the Dream race televised on HBO
- CDC Expert Panel on the Prevention of Hospital Acquired Venous Thromboembolism
- Hemostasis and Thrombosis Research Society
- Anticoagulation Forum
- Community Free Clinic of Newport News
- NC Cancer Hospital, Chapel Hill, NC
- NC Center for Hospital Quality and Patient Safety- Safe Surgery Initiative
- Partnership for Patients
- The 2nd National Conference on Blood Disorders and Public Health
- Numerous medical education talks and conference presentations
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 funds one full-time staff person and provides 10% salary support for the Medical Director for program development and medical content development. The CDC grant expires June 2012.

While housed at the University of North Carolina at Chapel Hill, Clot Connect receives no direct state or university funds. The program is entirely supported through grants and donations.

Funds during the start-up year of the program were utilized primarily to support one full-time staff person, 10% time of the Medical Director and to develop internet and print outreach resources.
**Program Needs and Goals**

*Clot Connect* has evolved dramatically in its first year. We are proud that a great deal has been accomplished in such a short time, utilizing modest resources. Yet, there is far more to do.

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.

As an outreach program, our ability to directly engage patients and health care professionals is dependent upon available staff and resources, which is a direct reflection of the availability of funding. *The demand for education and support services from both patients and health care professionals exceeds our current organizational capacity.*

The *Clot Connect* Program has two immediate needs:

**Need A: Secure Funding**

The program’s start-up grant funding provides for a full-time program director and 10% support of a medical director until June 2012. Continuing the program after this date will necessitate securing donations to compensate for the loss of these grant funds.

However, it is clear from our first year that the need for blood clot education is so great, that we desire to secure funds to not only maintain the program as it exists today, but to grow the program to better meet the needs of those whom we desire to serve.

**Need B: Increase Organization Capacity**

We desire to engage our audiences in a direct and meaningful way to ensure they are connected to accurate and appropriate information about thrombosis, thrombophilia and anticoagulation. Doing so requires time and attention on the part of both staff and volunteers. There are several ways we envision increasing our organizational capacity.

1. **Increase Medical Direction**

First, to create and coordinate medical content of our educational outreach and to engage patients and health care professionals in clinically relevant discussion, it is necessary to increase physician availability for the program and, thus, funding for medical direction from its current 10% allocation to at least 50%. The ability to have a medical professional provide accurate and timely medical information is critical to the success and credibility of *Clot Connect*. 
2. **Add a Blood Clot Educator**

In addition, we would like to add one full-time position, a Blood Clot Educator who would be tasked with conducting hands-on blood clot research dissemination, education and outreach. We anticipate the Blood Clot Educator to:

a. Provide medical leadership to the patient support forums, facilitate volunteer engagement, answer inquiries from patients and health care professionals
b. Produce medical content to support creation of educational handouts, blog posts, and other education dissemination tools for both patients and health care professionals
c. Oversee creation of support groups for persons who have experienced a blood clot
d. Engage in blood clot prevention initiatives

**Budget Requirements: Fundraising Goal**

Increasing organizational capacity from 1.1 fully funded positions to 2.5 positions (as outlined above) and implementing outreach initiatives (outlined in the attachment following this document) will require an estimated annual program budget of $275,000 to $300,000. We have therefore set an annual fundraising goal of $300,000.

**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 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
Future vision

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 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*
Addendum

Clot Connect – 3 year Strategic Plan
September 2011

Initiative 1: ClotConnect.org website

Goal: To serve as online portal to connect audiences to information and support
Aim: To increase usage with target of 15,000 visitors by December 2011; 75,000 by December 2012; 150,000 by December 2013
Status: 10,356 visitors representing 25,824 page views as of 9/01/11
Milestones: Base site implemented 11/2010
Major design enhancement 4/2011
Addition of patient support discussion forum 5/2011
Next steps:
- Optimization for search engine results
- Promotion via online channel, social media, print media
- Optimization of Clot Connect’s educational blogs so they can be indexed/searched from the clotconnect.org site
- Addition of links/clearinghouse education materials to deepen content and connect people to existing resources in addition to Clot Connect produced materials

Initiative 2: Patient education blog

Goal: To educate patients who have experienced a blood clot
Aim: To increase usage with target of 100,000 page views by December 2011; 250,000 by December 2012; 400,000 by December 2013.
Status: 61,155 page views as of 9/01/2011; 154 email subscribers
Milestones: Patient education blog implemented 11/2010
Next steps:
- Make topics easier to find; improve index
- Integrate content more fully with ClotConnect.org website portal
- Greater promotion
- Increase content
- Pursuit wider range of authors and professional perspectives
- Develop solution for managing comments and questions from readers
- Evaluation of usefulness of content
**Initiative 3: Health care professional education blog**

**Goal:** To educate health care professionals who care for patients who have experienced a blood clot

**Aim:** To increase usage with target of 50,000 page views by December 2011; 100,000 by December 2012; 250,000 by December 2013. Secondary aim: To increase email subscriptions of updates by health care providers.

**Status:** 33,555 page views as of 9/01/11; 207 enrolled email-subscribers

**Milestones:** Health care professional blog implemented 11/2010

**Next steps:**
- Make topics easier to find; improve index
- Integrate content more fully with ClotConnect.org website portal
- Greater promotion via professional associations, at medical meetings, in medical publications
- Increase content
- Encourage range of authors and professional perspectives
- Develop solution for managing comments and questions from readers
- Evaluation of usefulness of content
- Tie content more clearly to “what you can do for your patients”

**Initiative 4: Education handouts**

**Goal:** To create handout materials on a wide variety of thrombosis, thrombophilia and anticoagulation topics to be available for online download and in print.

**Aim:** To produce three patient handouts in 2011; four additional in 2012; five additional in 2013

**Status:** Two patient handout completed as of 9/01/11; third-fifth in initial development/drafting stage

**Next steps:**
- Pursue collaborations to write, edit and design next topics
- Identify distribution channels
- Identify method to produce medical illustrations
- Secure funding to cover costs
- Evaluate usage, impact, and usefulness

**Desired expansion:**
To create a series of materials aimed at health care professionals. Not currently planned or budgeted.
**Initiative 5: Education bookmark**

**Goal:** To provide at-risk patients with an easy-to-remember reminder of the signs, symptoms, and risk factors of deep vein thrombosis and pulmonary embolism.

**Aim:** To form collaborations for use of the bookmark by health care professionals and organizations, with target of 5 health care organizations by December 2011; 10 by 2012; 20 by 2013.

**Status:** 5 health care organizations using the bookmark as of 9/01/11

**Challenges:** No program funding is available for mass print and distribution of the bookmarks. All costs must be absorbed by the end-user organization. A strategy of co-branding is being utilized to encourage health care organization participation.

**Next steps:**
- Reach out to greater numbers of health care professionals and organizations
- Secure funding to print the bookmark and distribute to organizations which lack sufficient funds to do it themselves
- Evaluate impact

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**Initiative 6: Focus on a high-risk population for targeted education - Cancer patients**

**Goal:** To provide targeted education to cancer patients.

**Notes:** Initiative stems from a grant from the NC Cancer Hospital Endowment Fund to educate cancer patients about blood clots. Cancer patients are four times more likely to develop a blood clot compared with the general population, and 15% of patients with cancer will have a clot during the course of treatment.

**Aim:** To provide online and print materials to cancer patients with target deliverables by December 2011 of a. education brochure b. education bookmark c. online resources d. education webinar

**Status:** As of 9/01/11:
- Needs assessment underway by graduate students at UNC School of Nursing
- Education bookmark developed and being distributed at UNC Cancer Hospital and community clinic
- Website enhanced to provide greater outreach capabilities
- Online patient support forum started 5/2011 with special section for cancer patients

**Next steps:**
- Develop and distribute brochure on topic of ‘Cancer and Clotting’
- Develop and implement education webinar
- Enhance ‘Cancer and Clotting’ topic information on ClotConnect.org website
- Promote resources to the cancer communities
- Identify next target population to targeted education; ie hospitalized patients, pregnant women, people who have previously had a clot
Initiative 7: Webinars

Goal: To provide education via online webinars
Aim: To develop first webinar November 2011
Status: Development
Next steps:
- Development of slide set and narrative for webinar
- Development of evaluation measure
- Coordinate webinar technical mechanism; hosting and registration

Initiative 8: Patient support

Goal: To develop model of patient support
Aim: To develop pilot support project in 2012
Status: In-person support not currently in development; online support added 5/2011
Next steps:
- To find health care professionals willing to support development of a pilot patient support group
- To secure funding for support group development and materials

Additional activities: Ad hoc projects

In addition to above initiatives, Clot Connect provides on an ongoing ad hoc basis:
- media interviews
- presentations to groups
- community engagement
- participation in public events
- consultation with health care professionals
- partnership with health advocacy groups and public health agencies

In the next three years, these types of activities will remain important engagement tools to advance the mission of the program and we anticipate new initiatives emerging from these activities.

We anticipate playing an active role in venous thromboembolism reduction initiatives both within North Carolina and nationally.