



NORTH AMERICAN THROMBOSIS FORUM



**NATF**

North American Thrombosis Forum

**NATF**

**WORK PLAN SUMMER 2008 - SPRING 2011**





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# Executive Summary

The North American Thrombosis Forum (NATF) was founded on May 11, 2006 with the goal of focusing on the unmet needs and issues related to thrombosis and cardiovascular diseases such as deep vein thrombosis, pulmonary embolism, myocardial infarction, peripheral arterial occlusive disease, and stroke. NATF's five areas of major focus are: 1) basic translational research; 2) clinical research, especially diagnosis and therapy; 3) prevention and education; 4) public policy; and 5) advocacy.

Since its inception, NATF has demonstrated its important role in the field of thrombosis. As NATF begins its third year, the organization is positioned to set in motion the transition from a start-up non-profit agency to an established agency. This maturation is consistent with the organization's productivity and success over the past two years.

NATF's new phase will be marked by expansion and programmatic growth that continue to reflect the organization's mission as a multi-disciplinary forum. Efforts will continue to reflect NATF's membership: 80% medical professionals (researchers, physicians, nurses, pharmacists, and pharmacologists) and 20% thrombosis patients and advocates.

For the next 3 years, four areas of concentration have been identified:

- 1) Membership expansion
- 2) Committee involvement
- 3) Fundraising
- 4) Timely consensus meetings on issues related to thrombosis prevention, diagnosis, and treatment

Keys to a successful outcome in each of these identified areas are:

- 1) Advocacy/Awareness
- 2) Collaboration
- 3) Outreach
- 4) Public visibility and professional impact

This Work Plan, which will be revised and will evolve as novel circumstances arise, will guide NATF's work over the next three years. It should be noted that the actual work includes the summer and fall of 2008. This reflects a change in NATF staffing and allows future work plans to be synchronized with NATF's fiscal year.

A calendar of scheduled events is listed below:

September 26, 2008:	VIP Closed Thrombosis Working Group
September 27, 2008:	Thrombosis Summit
November 9, 2008:	Educational Dinner at AHA
April 4, 2009:	Proactive Thrombosis Prevention Forum
July 11, 2009:	Educational Dinner at ISTH



# North American Thrombosis Forum

## MISSION STATEMENT

The goal of the North American Thrombosis Forum (NATF) is to focus on unmet needs and issues related to thrombosis and cardiovascular diseases such as deep vein thrombosis, pulmonary embolism, myocardial infarction, peripheral arterial occlusive disease, and stroke.

NATF's five areas of major focus are:

- 1) Basic translational research
- 2) Clinical research, especially diagnosis and therapy
- 3) Prevention and education
- 4) Public policy
- 5) Advocacy

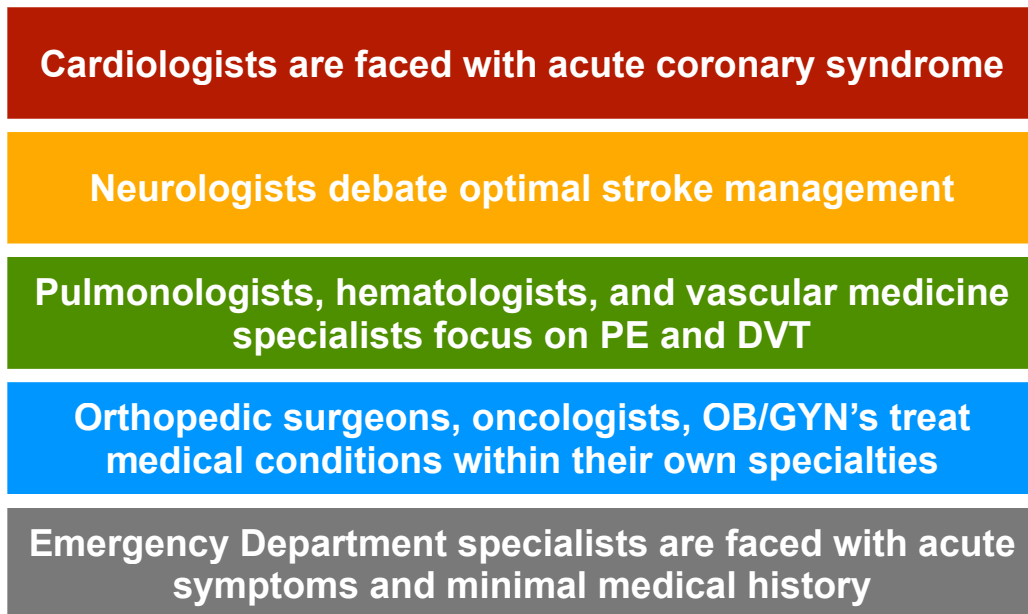
## VISION STATEMENT

NATF's vision is to improve patient care, outcomes, and public health by utilizing a multi-disciplinary approach to advance thrombosis research and education. NATF's legacy will be the improvement of patient care, outcomes, and public health by supporting thrombosis-related programs, such as novel research projects, innovative educational programs, public policy initiatives, regulatory issues, and advocacy. NATF also seeks to broaden training opportunities for physicians, scientists, and other health professionals.

## BACKGROUND

NATF was incorporated by the Commonwealth of Massachusetts on May 11, 2006 and received 501(c)(3) nonprofit status on June 27, 2007. The organization was conceptualized to complement existing thrombosis-related organizations and provide a forum for those interested in venous thromboembolism and other thrombotic disorders to focus their efforts. As such, NATF was founded with the objective of eliminating communication gaps between the medical disciplines with regard to the prevention, diagnosis, and treatment of thrombosis and cardiovascular disease (Figure 1). Fractured communication or "silos" also exist on a global level, with disconnects between scientific researchers, health care providers, government offices/policy makers, and patients (Figure 2). It is envisioned that a forum for an all-inclusive dialog will have a positive impact on prevention and treatment of thrombosis and cardiovascular disease. NATF's programmatic efforts are designed to encourage communication and collaboration among the "silos". Similar to regional thrombosis organizations in Europe, Asia, and Latin America, NATF provides a structure to coordinate and address all aspects of the thrombosis challenge. This multi-disciplinary approach provides a common forum for the "silos" as well as for agencies with missions that address specific aspects of thrombosis awareness, advocacy, and care (Table 6, pages 25-26). Key to this comprehensive approach is the need to communicate and work collaboratively with congruent agencies. NATF's promotion of synergy will lead to greater awareness of thrombotic disease and ultimately to better outcomes.

**FIGURE 1: THE HEALTH PROFESSIONAL “SILO”**



*This segmented strategy fails to undertake a broad based, inclusive approach.*

**FIGURE 2: THE GLOBAL “SILO”**



*The Global “Silo” also contributes to failure of undertaking a broad-based inclusive approach.*

## PAST AND PRESENT

Since its inception in the spring of 2006, NATF's accomplishments demonstrate the important role the organization plays in the field of thrombosis. The organization's mission and areas of focus are reflected in the programmatic efforts. The multi-disciplinary approach to thrombotic disease enhances education, awareness, advocacy, research, prevention, and diagnosis.

### NATFonline Website

Launching of the NATFonline website [www.NATFonline.org](http://www.NATFonline.org), was an organizational milestone.

The website content provides up-to-date information on:

- ▶ Educational opportunities for both clinicians and patients, including those sponsored by NATF and other organizations involved in thrombosis
- ▶ Research related to clinical treatment of thromboembolism
- ▶ Advances in public policy that will have impact on thrombosis advocacy, awareness, and treatment
- ▶ NATF-sponsored Traveling Fellowship program
- ▶ NATF as an organization and the supporting infrastructure
- ▶ Opportunities to support NATF either as a volunteer, as an NATF member, or both
- ▶ Links to other thrombosis-related websites

Paid e-advertising on Google and Yahoo was initiated to help increase traffic to the site. Table 1 is an example of monthly website traffic.

<b>Table 1: NATFonline Web Profile, 2007</b>	
<b>Site Visits</b>	<b>31,912</b>
<b>Total Hits</b>	<b>61491</b>
<b>Average Number of Page Views Per Visit</b>	<b>1.93</b>
<b>Average Per Day Visitors</b>	<b>120</b>

### eThrombosis

eThrombosis, housed at [www.NATFonline.org](http://www.NATFonline.org), is NATF's online journal. Leaders in the thrombosis field are invited to author the content articles. The journal is updated monthly with articles related to NATF's five areas of focus (basic translational research, clinical research, prevention and education, public policy, and advocacy). eThrombosis Editor-in-Chief is Debra A. Hoppensteadt, PhD.

## **Thrombosis Working Group Discussion**

The Thrombosis Working Group Discussion is held in conjunction with the Thrombosis Summit. This is a closed event that NATF has specially convened for leaders in the field. The Working Group provides an opportunity for specially invited attendees to discuss problems and challenges in thrombosis research, clinical practice, prevention, education, public policy, and advocacy. The next VIP Working Group meeting will be held in Boston, MA on Friday, September 26, 2008.

## **Thrombosis Summit**

NATF's first Thrombosis Summit was held in Boston, MA in September 2007; a second summit will be held on September 27, 2008. National and international leaders in the field of thrombosis are invited to present papers at this 1-day symposium. The program provides a concise state-of-the-art overview of prophylaxis measures and critical developments in the diagnosis, treatment, and prevention of thrombotic disorders.

The Thrombosis Summit is CME accredited for physicians, nurses, and pharmacists, reflecting NATF's multi-disciplinary approach. Summit content is documented and available either through the NATF website and/or CD-ROM obtainable through NATF.

## **Proactive Thrombosis Prevention Forums**

To date, NATF has sponsored two Proactive Thrombosis Prevention Forums, in March 2007 and March 2008. Both programs were held in Boston, MA. The next Forum will be convened on April 4, 2009 in Boston MA. The Forum's objective is to improve patient care through the advancement of thrombosis education. The approach is multi-disciplinary, targeting patients, advocates, office-based physicians, hospitalists, nurse practitioners, nurses, pharmacists, physician assistants, and hospital administrators. The Proactive Thrombosis Prevention Forum provides a unique educational experience, allowing patients and their families to interact with the professionals who carry out research, provide clinical care, or work on public policy or advocacy issues related to thrombosis.

Like the Thrombosis Summit, the Proactive Thrombosis Prevention Forum is CME accredited for physicians, nurses, and pharmacists. Content of the forums is preserved; the enduring materials are available through the NATF website and a CD-ROM that is available on request.

## **Traveling Fellowship**

The NATF Traveling Fellowship Program is an annual scientific exchange opportunity for physicians (either Junior Faculty or physicians-in-training), scientists, nurses, or pharmacists. The goal of the Fellowship is to provide recipients the opportunity to explore the cross-disciplinary diagnosis, treatment, education, and research related to thrombosis. Fellows benefit from the program as it fosters an exchange of scientific information, stimulates research, and develops friendships among leaders in thrombosis research and treatment. The Traveling Fellowship serves as a bridge that will be used to forge the future leadership in thrombosis treatment and

prevention. The Program provides a stimulus for junior faculty deemed to be “on the fast track” with much potential for academic leadership in the field of thrombosis.

NATF awarded its first Traveling Fellowship of \$5,000 in the summer of 2007. The recipient was Ousama Dabbagh, MD, Assistant Professor of Clinical Medicine and Associate Fellowship Program Director, Division of Pulmonary, Critical Care and Environmental Medicine at University of Missouri. Under the specification of the award, the Fellow had the opportunity to visit a North American thrombosis research and education center of his choice. Dr. Dabbagh chose to spend a two-week period with the Venous Thromboembolism Research Group located at the Brigham and Women’s Hospital in Boston, MA and led by Samuel Z. Goldhaber, MD. The visit enabled Dr. Dabbagh to work side-by-side with Dr. Goldhaber and learn more about the research projects being conducted within the Venous Thromboembolism Research Group. As a result of the fellowship experience, Dr. Dabbagh strengthened his commitment to continue his career in academic medicine and clinical research related to thrombosis.

### **Public Policy and Advocacy**

Members of NATF Board of Directors are actively involved in increasing thrombosis awareness and changing public policy related to thrombotic disease. In May 2006, Dr. Goldhaber, NATF’s President, planned and co-chaired the two-day Surgeon General’s Workshop on DVT that was co-sponsored by NHLBI. This groundbreaking 2-day meeting included panel discussions on epidemiology, high-risk groups, diagnosis, treatment, awareness and best practices, prevention, and translation and application. Five workshops were also held, including Dr. Goldhaber’s discussion on Primary Prevention. The presented material was documented and is available on the Internet ([www.surgeongeneral.gov/topics/deepvein/workshop/agenda.htm](http://www.surgeongeneral.gov/topics/deepvein/workshop/agenda.htm) or [www.surgeongeneral.gov](http://www.surgeongeneral.gov)).

The workshop concluded with a decision by the then Surgeon General, Dr. Richard Carmona, to develop a Call to Action targeted to both health care professionals and the lay public. Unfortunately, the Call to Action has been delayed. Despite this delay, prior advocacy efforts resulted in the United States Senate Resolution in 2005 proclaiming March as National DVT Awareness Month.

Dr. Goldhaber has also been active at the state level. Through his efforts, Massachusetts Governor Deval Patrick declared as a one-time only proclamation that November 2007 is Thrombosis Awareness Month in the Commonwealth of Massachusetts. The Massachusetts House and Senate subsequently enacted a law making November permanently Thrombosis Awareness Month in the Commonwealth of Massachusetts.

### **Membership**

In Spring 2008, NATF initiated a membership drive. Free membership is available online through the NATFonline website. All members receive a NATF membership card and preferred registration with a 25% discount for all NATF-sponsored events.

It is anticipated that membership will reflect NATF’s programmatic efforts, of which 80% are geared for medical professionals (scientific researchers, physicians, nurses, and pharmacologists) and 20% for thrombosis patients and advocates.



# Thrombosis

## THE DISEASE

Thrombosis is the formation of a blood clot within a blood vessel causing a partial or total occlusion and preventing blood from flowing normally through the circulatory system. Propensity to hypercoagulability (caused by genetic, environmental, or unknown factors), endothelial cell injury of the vessel wall (exacerbated by infection or trauma), and static blood flow contribute to the formation of blood clots.

Partial or complete detachment of the thrombus from the blood vessel wall permits the clot to embolize to vital organs such as the brain, heart, lungs, or leg arteries. The free-flowing embolus lodges within the vasculature and obstructs blood flow. Life threatening pathological conditions ensue, such as stroke, heart attack, pulmonary embolism, or limb-threatening gangrene.

Risk factors that contribute to DVT are varied and include:

- ▶ Immobilization
- ▶ Hypercoagulability
- ▶ Vessel wall damage
- ▶ Previous History of DVT/PE
- ▶ Age
- ▶ Surgery
- ▶ Cancer
- ▶ Heredity (including the Factor V Leiden genetic mutation)
- ▶ Pregnancy
- ▶ Increased estrogen levels (oral contraception, HRT)
- ▶ Obesity
- ▶ Smoking
- ▶ Crohn's Disease

Arterial thrombosis within the coronary arteries leads to myocardial infarction, while occlusion of the cerebral vasculature causes stroke. Of note is that venous and arterial thromboses share many of the same risk factors, including cigarette smoking, hypertension, and diabetes mellitus.

Deep vein thrombosis is the most common form of venous thrombosis. Post-Thrombotic Syndrome (PTS) develops in at least half of patients with a DVT. Chronic leg swelling, calf pain, calf heaviness/fatigue, skin discoloration, and/or venous ulcers in the affected limb characterize PTS. Quality of life is significantly impaired in patients with PTS.

Pulmonary embolism (PE) results from DVT. Symptoms and signs of PE include shortness of breath, chest pain, hemoptysis, fast or irregular heart rate, and/or lightheadedness. An acute, massive PE can lead to cardiac arrest.

## **The Frequency of Thromboembolism**

Stroke and myocardial infarction are major causes of death. It is estimated that every 45 seconds, someone in the United States suffers from a stroke. Annually, approximately 700,000 people experience a new or recurrent stroke; about 500,000 of these are first attacks, and

200,000 are recurrent attacks. The estimated frequency of a heart attack is even greater. Each year, approximately 1,200,000 people living in the United States will suffer from a new or recurrent myocardial infarction. In addition, it is estimated that there are 175,000 silent first heart attacks each year.

Venous thromboembolism (VTE) is the term used to encompass both DVT and PE. The precise number of cases of VTE is uncertain because the diagnosis is often obscure or the disease may be asymptomatic or mimic other diseases. In the United States, estimates range from about 900,000 to 2,000,000 VTE cases per year. About two-thirds are DVT alone and about one-third are DVT plus PE or PE alone. The number of deaths is uncertain. Estimates of death rates per year vary from 50,000 to 300,000.

Annually, more individuals probably die from DVT complications than from the combination of AIDS, breast cancer, and motor vehicle accidents. Fatal PE caused by DVT may be the most common preventable cause of hospital death in the United States. Yet, only one-third of hospitalized patients with risk factors for venous blood clots receive preventive measures.

## **Public Awareness**

Large-scale marketing campaigns have successfully increased public awareness of arterial disease as a risk factor of stroke and myocardial infarction. Yet, unlike stroke and myocardial infarction and diseases such as AIDS, diabetes, Alzheimer's, breast cancer, the public is not attuned to the severity of vascular thrombosis. In fact, vascular thrombosis is considered the "silent disease" reflecting, at least in part, the limited public awareness. The high frequency of vascular thrombosis and the potential of a devastating or fatal outcome make thromboembolism a public health risk. Despite the severity of the disease, the public does not know enough about prevention, treatment, or the potential of the devastating or even possibly fatal outcome of thrombosis and thromboembolism.

## **Prevention of Venous Thrombosis**

Prophylaxis of venous thrombosis is most frequently undertaken with an anticoagulant such as heparin, low molecular weight heparin, fondaparinux, or warfarin. Safe and effective use of warfarin requires regular laboratory monitoring of coagulation using the International Normalized Ratio (INR) to help achieve the target dose. Several novel agents in development are currently undergoing late-stage, Phase III clinical trials.

## Heparin and Low Molecular Weight Heparin Safety

NATF has emphasized the importance of anticoagulant drug safety, especially as related to heparin and low molecular weight heparin. NATF has cautioned against premature approval of untested generic drugs and has favored development of a standardized policy for testing of complex molecules.

Recently, heparin contamination attributed to unsafe manufacturing processes in certain Chinese factories and has caused hundreds of severe allergic reactions and many dozens of deaths. The FDA certainly has the challenge of ensuring the safety of imported pharmaceuticals (Schweitzer SO. *NEJM* 2008; 358: 1773). However, as stated by Alastair Wood, MD: “It is easier to attack the FDA than to assume one’s own share of responsibility.”—cited in *NEJM* 2008; 358: 1774. Oversulfated chondroitin sulfate has been implicated as a contaminant in heparin that is associated with adverse clinical events (Guerrini M, et al. *Nature Biotechnology* 2008; ePub April 23). Heparin and related products should remain in continual surveillance for other contaminants as well. One putative mechanism of action is activation of the contact system (Kishimoto TK, et al. *NEJM* 2008; epub April 23).





# Work Plan: Summer 2008 - Spring 2011

## OVERVIEW

Though a new nonprofit organization, NATF within two years has established itself as an important voice in the field of thrombosis. NATF is well positioned for its next phase, one of programmatic growth. Expansion of the organization will continue to reflect its mission as a multi-disciplinary forum for issues related to thrombosis and cardiovascular diseases such as deep vein thrombosis, pulmonary embolism, myocardial infarction, peripheral arterial occlusive disease, and stroke. Support of the five identified areas of focus (basic translational research; clinical research; prevention and education; public policy, and advocacy) will continue. NATF activity in all five of these areas differentiates NATF from other nonprofit organizations working in the thrombosis area.

As NATF matures, efforts to expand membership, committee involvement, fundraising, and timely consensus meetings on issues related to thrombosis prevention, diagnosis and treatment will enhance NATF to secure a robust future. Consistent with these areas of growth will be the emphasis of NATF's unique multi-disciplinary approach, reflected through programmatic efforts as well as the organizational structure.

The Board of Directors will periodically review committee membership.

## NATF: THE ORGANIZATION

### Infrastructure

NATF current infrastructure consists of 5 elements with the following general responsibilities:

- 1) Board of Directors – responsible for oversight of goals and vision of the organization
- 2) A Scientific Advisory Committee – responsibilities outlined in Table 2
- 3) An Advocacy Committee – responsibilities outlined in Table 2
- 4) An International Advisory Committee – responsibilities to be defined prior to ISTH 2009
- 5) An Executive Director – responsible for day-to-day operations required to carry-out the organization's mission

Engaging committee members in meaningful work is a challenge to any organization. The approach will be to use regularly scheduled conversations (teleconference, email, or personal conversations; 1-3 calls/quarter) as a means of connecting and eliciting involvement of members of Advocacy and Scientific Advisory Committees. Specific issues/tasks have been defined for both of these committees for implementation (Table 2). Members of the committees will determine the approach to the work.

**TABLE 2: RESPONSIBILITIES OF SCIENTIFIC ADVISORY COMMITTEE AND ADVOCACY COMMITTEE**

SCIENTIFIC ADVISORY COMMITTEE	ADVOCACY COMMITTEE
<ol style="list-style-type: none"> <li>1. Participate in the selection of NATF's Traveling Fellow</li> <li>2. Co-author 2 eThrombosis articles per year</li> <li>3. Contribute at least 1 comment per month, for 9 out of 12 months, on the eThrombosis conversation thread</li> <li>4. Speak at a minimum of 1 Grand Rounds per year at a local community hospital, pro bono</li> <li>5. Attend North American Thrombosis Summit and Thrombosis Working Group Session</li> <li>6. Attend Proactive Thrombosis Prevention Forum</li> <li>7. Participate in at least 9 out of 12 monthly NATF Scientific Advisory Committee teleconferences</li> <li>8. Register as NATF member</li> </ol>	<ol style="list-style-type: none"> <li>1. Co-monitor 3 months/year NATF's website conversation threads</li> <li>2. Contribute at least 1 comment per month on each of the NATF website conversation threads</li> <li>3. Provide 4 topics per year for the Advocacy conversation thread</li> <li>4. Author 2 website articles per year</li> <li>5. Attend North American Thrombosis Summit and Thrombosis Working Group Session</li> <li>6. Attend Proactive Thrombosis Prevention Forum</li> <li>7. Participate in at least 9 out of 12 monthly NATF Advocacy Committee teleconferences</li> <li>8. Register as NATF member</li> </ol>

Currently, the International Advisory Committee is comprised of six members with representation from England, Germany, Israel, and Switzerland. The role of this committee has not yet been clearly defined. With an emphasis of engaging members in a more meaningful way, a job description for members of the International Advisory Committee members will be created prior to July 2009, when ISTH will be held in Boston. At that time, the committee will be expanded to include representation from other areas of the globe.

Changes or additions to the organizational structure may be needed to support NATF's growing membership and programmatic efforts. This effort will be initiated during the summer of 2009. Changes that may be considered are electing a Vice President and creating a financial committee to oversee NATF's fundraising efforts and expenditures.

The agreed upon changes to the NATF infrastructure, together with an updated work plan, will be the basis of creating a Business Plan for NATF.

### **General Organization**

As a new organization, NATF has not been able to provide fringe benefits to employees. As the organization grows and matures, additional staff will be required to support NATF's efforts. In order to be competitive in the hiring process, NATF will need to create a benefits package that includes: medical and dental insurance, a retirement plan including employer contribution and disability insurance.

## THE WORK PLAN: GENERAL APPROACH

This Work Plan is a statement of objectives to guide NATF's work over the next 3 years. The plan outlined below is subject to fine-tuning based on outcome and feedback from members of the NATF community. At the same time, additional programs will be added as necessary, particularly in response to changes in public policy, and depending upon financial and personnel resources.

### Awareness/Advocacy

Currently, the low public awareness of vascular thrombosis risk factors and symptoms is inversely proportional to its high prevalence and severity. A large-scale publicity campaign is necessary to increase awareness of thromboembolism to a level appropriate to its frequency and equivalent to other diseases. Increased awareness will have implications in terms of NATF's other areas of focus, including research, prevention, treatment, and public policy. Greater awareness and concern is also linked to successful fundraising.

## THE WORK PLAN: PROGRAMMATIC EFFORTS

### WORK PRIORITIZATION

Prioritization of the efforts described within this work plan is as follows:

- 1) NATF Website
- 2) NATF-Sponsored Courses and Symposia
- 3) NATF Traveling Fellowship
- 4) NATF Membership
- 5) Fundraising
- 6) New Educational Initiatives
- 7) Collaboration and Outreach



### PRIORITY #1: NATF WEBSITE

#### NATFonline Website

Our top priority is maintaining an outstanding state-of-the-art Internet presence through the NATFonline website.

*Goals: diagnosis and therapy, fundraising, membership, participation, prevention and education, public policy, research*

*Responsibilities: Advocacy Committee, Staff*

During the summer of 2008, the NATFonline website will undergo an upgrade in functionality. The anticipated changes will enhance navigation, provide an interactive forum for discussions of thrombosis-related issues, enable online meeting registration and traveling fellowship/career development award applications, and allow for secure online donations.

The website will include three sections: 1) general; 2) health professionals (including translational and clinical researchers), and 3) patients/advocates. Where appropriate, the information will be technologically linked.

### 1) GENERAL SECTION

This section will contain general information about NATF and its multi-disciplinary approach to enhancing prevention, diagnosis, and treatment of thromboembolism. The synergistic impact of removing both the “Health Professional Silo” (Figure 1) and the “Global Silo” (Figure 2) will be highlighted.

### 2) HEALTH PROFESSIONALS SECTION/ TRANSLATIONAL AND CLINICAL RESEARCHER SECTION

The health professionals’ section/ translational and clinical researcher section will include educational opportunities, NATF-sponsored programs, and programs sponsored by other agencies. Highlights from NATF-sponsored events will be available. Online registration for upcoming NATF programs will be included in the health professionals/ translational and clinical researcher section as well as online applications for the NATF traveling fellowship or career development awards. eThrombosis will continue to be posted within this section of the website.

### 3) PATIENT/ADVOCATE SECTION

Three subsections will be housed within the patient/advocate section: 1) Thrombosis Prevention, 2) Recently Diagnosed, and 3) Living with Thrombosis. Content to be included are:

- ▶ Brochure on DVT (*linked as appropriate*)
- ▶ Frequently Asked Questions
- ▶ Educational opportunities (*linked as appropriate*)
- ▶ Glossary (*linked as appropriate*)
- ▶ Links to other organizations related to thrombosis
- ▶ Stories of patients who survived an acute episode of thrombosis and continue to live with the disease
- ▶ Support group opportunities (*linked as appropriate*)

The website will include the opportunity for visiting members to participate in moderated conversation threads. Each month there will be two simultaneous conversation streams. One conversation will be related to an issue of concern for patients/advocates. The second conversation stream will be connected to the highlighted topic in eThrombosis. The latter online conversation will be introduced by a lay summary.

NATF membership will be required for participation in the conversation threads.

## **eThrombosis**

*Goals: diagnosis and therapy, membership, participation, prevention and education, public policy, research*

*Responsibilities: Scientific Advisory Committee, International Scientific Advisory Committee, eThrombosis Editor-in-Chief, Staff*

eThrombosis is NATF's online journal containing the most-up-to-date information on thromboembolism. A three-year plan will position eThrombosis as an interactive and education forum for hot topics in thrombosis. The first step in the change process is the creation of an online conversation that allows website visitors to post input, comments/questions, on the journal article. The author's name and work institution will accompany all postings. NATF membership will be required for participation. Monthly eThrombosis articles, and accompanying comments will be archived in a searchable format.

In Year 2, each month eThrombosis will include two papers on the designated hot topic of the month. The articles will present opposing opinions on the topic. The online forum will continue to allow readers to voice their opinions. Year 3 will expand the forum further by inclusion of a commentary of the presented arguments written by a third party.

The Scientific Advisory Committee will be charged with the content of eThrombosis. The committee will determine the monthly hot topics and be responsible for soliciting contributors. The Committee will encourage members of NATF's International Advisory Committee to author journal articles. Dr. Debra Hoppensteadt will continue as Editor-in-Chief.

## **PRIORITY #2: NATF-SPONSORED COURSES AND SYMPOSIA**

### **Thrombosis Leadership VIP Closed Working Group Discussions**

*Goals: advocacy diagnosis and therapy, participation, prevention and education, public policy, research*

*Responsibilities: Board, Scientific Advisory Committee, Advocacy Committee, Staff*

A closed, VIP Thrombosis Leadership Working Group Discussions will be held in conjunction with the North American Thrombosis Summit. (See Table 3 for meeting agenda.) These leadership discussions serve as a consensus meeting and are viewed as an important part of NATF's role as a forum to address and discuss all aspects of the thrombosis challenge.

The list of invitees will reflect NATF's multi-disciplinary approach for providing tools to break down and integrate traditional "silos." As such, well-known representatives from various "silos" will be invited, including: clinical and research physicians, scientists, nurses, pharmacists, patients, and policy makers. Representatives within the various areas of medicine (including: cardiology, gynecology/obstetrics, hematology, neurology, oncology, orthopedic surgery, etc.) will be invited. Delegates of the various agencies engaged in the thrombosis challenge will also be invited.

Discussion group attendees will be asked to discuss unresolved issues and propose action steps in the area of thromboembolism. The chosen topics will be specific questions related to NATF's five areas of focus: basic translational research; clinical research (especially prevention, diagnosis, and therapy), prevention strategies and education; public policy, and advocacy. The multi-disciplinary dialog will enable participants to learn from each other while creating a collaborative action plan to address the unmet needs and issues related to thrombosis.

**Table 3: Thrombosis Leadership VIP Closed Working Group Discussions 2008 Meeting Agenda**

<b>12:30 PM</b>	<b>1:45 PM</b>	Informal Lunch and Registration
<b>1:45 PM</b>	<b>2:00 PM</b>	Seating
<b>2:00 PM</b>	<b>2:15 PM</b>	Introduction: NATF—Past, Present, and Future
<b>2:15 PM</b>	<b>2:30 PM</b>	<b>Workshop Objectives/Questions – Samuel Z. Goldhaber, MD</b>
<p><b>“Thrombosis Outreach: NATF Top 10”</b></p> <p>Discussants will divide into 5 Discussion Groups based on NATF's 5 main areas of focus: 1) Translational Research, 2) Clinical Research, 3) Prevention and Education, 4) Public Policy, and 5) Advocacy. Each group will identify the "Top 2" areas of need within their respective focus area. From these discussions, the Thrombosis Outreach "Top 10" will be developed.</p> <p>At the conclusion of the evening, discussants will place their vote for the most urgent of the two in each category. The top 5 areas of need will become NATF action items for 2009.</p>		
<b>2:30 PM</b>	<b>2:45 PM</b>	<b>Seating in Breakout Sessions</b>
<b>2:45 PM</b>	<b>4:45 PM</b>	<b>Breakout Sessions</b>
<b>4:45 PM</b>	<b>5:00 PM</b>	<b>Return to Plenary Session</b>
<b>5:00 PM</b>	<b>6:15 PM</b>	<b>Group Presentations</b>
5:00 PM 5:15 PM 5:30 PM 5:45 PM 6:00 PM	5:15 PM 5:30 PM 5:45 PM 6:00 PM 6:15 PM	Group I: Translational Research Group II: Clinical Research Group III: Prevention and Education Group IV: Public Policy Group V: Advocacy
6:15 PM	7:00 PM	Closing Remarks, Adjourn

**North American Thrombosis Summit**

*Goals: advocacy diagnosis and therapy, fundraising, membership, participation, prevention and education, public policy, research*

*Responsibilities: Board of Directors, Staff*

The format of the annual North American Thrombosis Summit will continue. (Table 4 outlines the 2008 program agenda.) Consistent with NATF's multi-disciplinary approach to thrombotic

disease, the program content will be broadened so as to encourage participation of a diverse health care professional constituency. In addition, scientists involved in basic research of thrombotic diseases or diagnoses will be invited to present papers as a means of facilitating dialog between clinicians and basic researchers.

Advertising for the North American Thrombosis Summit will be expanded, reflecting the goal of broadening the agenda and participation. Print and online advertisements in strategic medical/ research journals will be used. Other thrombosis-related organizations will be asked to include information about the Summit on their website.

**Thrombosis Summit 2008 Course Syllabus.**

NORTH AMERICAN THROMBOSIS FORUM  
**THROMBOSIS SUMMIT**  
SATURDAY, SEPTEMBER 29, 2007 BOSTON, MASSACHUSETTS

**COURSE DIRECTORS**  
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Jawed Fareed, PhD  
Arthur A. Sasahara, MD

**COURSE FACULTY**  
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Melanie Bloom  
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Geno Merli, MD  
Ruth B. Morrison, RN, BSN, CVN  
Thomas L. Ortel, MD, PhD  
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CME Credit for this program is  
Provided by

**Brigham and Women's Hospital**  
Department of Medicine  
and **Harvard Medical School**  
Department of Continuing Education



**Table 4: North America Thrombosis Summit on Saturday, September 27, 2008  
Program Agenda**

6:45 AM	8:00 AM	Registration and Breakfast, Seating
8:00 AM	8:15 AM	<b>Welcome and Opening Remarks</b> – <i>Samuel Z. Goldhaber, MD, Jawed Fareed, PhD, and Arthur A. Sasahara, MD</i>
<b>TRANSLATIONAL RESEARCH</b>		
8:15 AM	8:40 AM	<b>Pharmacogenomics of Warfarin: Are the Promises Justified?</b> ..... <i>Brian F. Gage, MD, MSc</i>
8:40 AM	9:05 AM	<b>HIT: Controversies and Updates</b> ..... <i>Jeanine M. Walenga, PhD</i>
9:05 AM	9:30 AM	<b>Controversies Surrounding the Optimal Therapy of Extensive Leg DVT</b> ..... <i>Suresh Vedantham, MD</i>
9:30 AM	9:55 AM	<b>Bar-Coding Inpatient Medications to Improve Patient Safety</b> ..... <i>John Fanikos, RPh, MBA</i>
9:55 AM	10:10 AM	Morning Break
10:35 AM	11:00 AM	<b>Estrogen and Thrombosis: A Women’s Health Issue</b> ..... <i>JoAnn E. Manson, MD</i>
<b>CLINICAL RESEARCH</b>		
11:00 AM	11:10 AM	<b>NATF Traveling Fellowship Awards 2008</b> ..... <i>Arthur A. Sasahara, MD</i>
<b>KEYNOTE SPEAKER</b>		
11:10 AM	12:00 PM	<b>“The 10 Most Important Advances in Thrombosis Understanding During the Last 50 Years”...with apologies to David Letterman</b> ..... <i>Joseph S. Alpert, MD</i>
12:00 PM	1:10 PM	Lunch (provided)
<b>PREVENTION AND EDUCATION</b>		
1:10 PM	1:35 PM	<b>Anticoagulation Management &amp; Warfarin Safety: A Systems Approach</b> ..... <i>Allen Kachalia, MD</i>
1:35 PM	2:00 PM	<b>Anticoagulation Bridging: Hope or Hype</b> ..... <i>Samuel Z. Goldhaber, MD</i>
2:00 PM	2:25 PM	<b>Prevention of Stroke</b> ..... <i>Mary Amatangelo, RN, MS, APRN-BC, CCRN</i>
2:25 PM	2:50 PM	<b>Prevention of VTE: Can Computers Help?</b> ..... <i>Karen Fiumara, PharmD</i>
2:50 PM	3:15 PM	<b>Thrombosis and Cancer</b> ..... <i>Craig M. Kessler, MD</i>
3:15 PM	3:30 PM	Afternoon Break
3:30 PM	4:00 PM	<b>Policies to Prevent and Minimize the Burden of CHD</b> ..... <i>Deepack Bhatt, MD</i>
4:00 PM	4:30 PM	<b>The National Heart, Lung and Blood Institute</b> ..... <i>Susan B. Shurin, MD</i>
4:30 PM	5:00 PM	<b>Concluding Comments, Future Plans, Wrap-Up</b> ..... <i>NATF Directors</i>

## Proactive Thrombosis Prevention Forum

*Goals: advocacy, diagnosis and therapy, membership, participation, prevention and education*

*Responsibilities: Board of Directors, Scientific Advisory Committee, Traveling Fellows, Advocacy Committee, Staff*

The format of the Proactive Thrombosis Prevention Forum will remain as in previous years while continuing to broaden the program content to include areas of vascular thrombosis beyond DVT. Table 5 outlines the Proactive Thrombosis Prevention Forum 2008 program agenda. The next Forum will be held in Boston, MA on April 4, 2009.

In addition to the annual Boston Proactive Thrombosis Prevention Forum, similar programs will be offered in other locations, thus expanding the conversation beyond the northeastern region of the United States. Members of the Scientific Advisory Committee and the Advocacy Committee will be responsible for creating connections with medical institutions to host a Proactive Thrombosis Prevention Forum at their site. Recipients of the Traveling Fellowship award will also be asked to host a Forum at their institution.

**Table 5: Proactive Thrombosis Prevention 2008 Program Agenda**

8:45 AM	9:00 AM	Welcome and Opening Remarks
<b>9:00 AM</b>	<b>9:25 AM</b>	<b>Stroke Update</b> – <i>Farzaneh A. Sorund, MD, PhD</i>
<b>9:25 AM</b>	<b>9:50 AM</b>	<b>Coronary Stent Thrombosis</b> – <i>Federic S. Resnic, MD, MSc</i>
<b>9:50 AM</b>	<b>10:15 AM</b>	<b>Peripheral Arterial Disease and Update</b> – <i>Marie Gerhard-Herman, MD</i>
<b>10:15 AM</b>	<b>10:40 AM</b>	<b>Pulmonary Embolism Diagnosis</b> – <i>Paul D. Stein, MD</i>
10:40 AM	11:00 AM	Coffee Break
<b>11:00 AM</b>	<b>11:25 AM</b>	<b>HIT Education Programs</b> – <i>Steven Baroletti, PharmD, MBA</i>
<b>11:25 AM</b>	<b>11:50 AM</b>	<b>Generic vs. Brand Name Drugs</b> – <i>Jawed Fareed, PhD</i>
11:50 AM	1:05 PM	Lunch
<b>1:05 PM</b>	<b>1:30 PM</b>	<b>Electronic Alerts to Prevent DVT</b> – <i>Karen Fiumara, PharmD</i>
<b>1:30 PM</b>	<b>1:55 PM</b>	<b>Novel Anticoagulants</b> – <i>John Fanikos, RPh, MDA</i>
<b>1:55 PM</b>	<b>2:20 PM</b>	<b>Anticoagulation Update</b> – <i>Samuel Z. Goldhaber, MD</i>
2:20 PM	2:40 PM	Afternoon Break
<b>2:40 PM</b>	<b>3:05 PM</b>	<b>Patient Education and Patient Compliance</b> – <i>Rita M. Morrison, RN</i>
<b>3:05 PM</b>	<b>3:30 PM</b>	<b>Point-of-Care, INR Testing</b> – <i>Jack E. Ansell, MD</i>
<b>3:30 PM</b>	<b>3:55 PM</b>	<b>Patient Advocacy</b> – <i>Kelly Clark, NATF Patient Advocate</i>
3:55 PM	4:30 PM	General Discussion and Questions, Adjourn

## PRIORITY #3: NATF TRAVELING FELLOWSHIP

### **NATF Traveling Fellowship**

*Goals: advocacy, diagnosis and therapy, membership, participation, prevention and education, research*

*Responsibilities: Board of Directors, Scientific Advisory Committee, Staff*

Beginning in July 2008, the NATF Traveling Fellowship Program will be expanded both in terms of offerings and scope. The number of traveling fellowships offered per year will be increased from one to two. With the goal of having Fellows representing a greater spectrum of professionals involved in thrombosis research and treatment, further increase in the numbers of Fellows per year, as many as four per year, will be considered.

The first traveling fellowship (2007) was offered only to Junior Faculty and Fellow/Trainee physicians. In 2008, research scientists, nurses, and pharmacists will be included in the application pool. In addition, projects related to cross-disciplinary diagnosis, treatment, education, and research related to thrombosis will be encouraged.

The goals of the Fellowship have also been expanded. Traveling Fellows will be asked to:

- ▶ Work on a joint project with the hosting center
- ▶ Contribute to the development of a cross-disciplinary approach for research, diagnosis, treatment, or education in the field of thrombosis
- ▶ Tour research facilities and clinical sites to observe innovations in thrombosis diagnosis, treatment, and prevention methods
- ▶ Participate in scientific symposia with members of the NATF Board of Directors and Scientific Advisory Committee
- ▶ Participate in the NATF's North American Thrombosis Summit
- ▶ Summarize learnings in a written format and submit this report to eThrombosis
- ▶ Present learnings gained through NATF Traveling Fellowship at the NATF Working Group Discussion
- ▶ Serve as an NATF Ambassador

Members of the Board of Directors and the Scientific Advisory Committee will continue to evaluate the Fellowship applicants and be responsible for assigning the awards.

Applications for the Traveling Fellowship Award will be available through the NATFonline website, via distribution at meetings, and distribution by members of the Scientific Advisory Committee. Other thrombosis-related organizations will be asked to include information about the Traveling Fellowship on their websites. In addition, the Fellowship will be advertised in strategic medical/research journals (e.g., Blood and Circulation).



## **PRIORITY #4: NATF MEMBERSHIP**

### **NATF Membership Drive**

*Goals: advocacy, diagnosis and therapy, membership, participation, prevention and education, research*

*Responsibilities: Board, Staff*

During the next three years, NATF will continue to provide free membership. The 3-year goals for membership are diversification and expansion in numbers. Membership numbers will be increased through the ability to participate in specific NATF-sponsored programs such as posting on any of the online conversation threads, eThrombosis, and the patient/advocates discussions. Outreach and collaboration with other medical and scientific communities as well as the expansion of NATF's programmatic efforts are designed to create a diverse membership. The enlarged membership will continue to reflect NATF's emphasis on reaching out to medical professionals.

Contact with NATF members will also increase. Members will receive monthly email updates of NATF programs and, as appropriate, timely notification of advances in thrombosis. A link to the NATFonline Website will be attached.

## **PRIORITY #5: NATF FUNDRAISING**

### **Fundraising Efforts**

*Goals: advocacy, diagnosis and therapy, fundraising, prevention and education, research*

*Responsibilities: Board, Scientific Advisory Committee, Advocacy Committee, Staff*

An extensive work plan is proposed; accomplishing any of this work requires financial resources. A comprehensive fundraising campaign will be created to support NATF's work. Funds will be sought from government agencies, industry (particularly pharmaceutical companies and possibly airlines and compression stocking manufacturers/retailers), philanthropic foundations, and individual donors. The Board of Directors, Scientific Advisory Committee, and Advocacy Committee will be engaged in the fundraising effort with a defined division of efforts. Relationships already exist between the Board of Directors members and Scientific Advisory Committee with key representatives of both government agencies (NHLBI and CDC) and the pharmaceutical and device-manufacturing companies. Therefore, these two organizational bodies will be responsible for fundraising in these areas.

The 2008, American Heart Association will be used to begin expanding fundraising efforts within the pharmaceutical industry. NATF will host a dinner on Sunday, November 9, 2008, at the American Heart Association in New Orleans to connect with health care professionals, philanthropists, and industry representatives who can be influential in providing financial backing to support NATF's efforts. This event will also serve as a means of educating industry members about NATF.

Hearing directly from patients about their individual stories of survival is a moving experience. Therefore, the Advocacy Committee will take the lead on cultivation and solicitation of individual donors. A member of the Advocacy Committee will lead this fundraising effort.

Grant writing is generally required for seeking funds from philanthropic foundations. This is a time-consuming process, raising the possibility of hiring a part-time grant writer.

In addition to raising funds to support the proposed efforts, funds for an endowment fund will also be sought. An endowment fund provides a continuous stream of revenue and will position NATF for a long and productive future. Naming opportunities within NATF's programmatic efforts will be identified. Examples include the Traveling Fellowship and Career Development Awards. NATF will encourage donations in the form of Estate Planning as well.

A capital campaign for endowment will not be initiated until a successful annual campaign is established.

### **Other Income Sources**

Currently, there is no charge for NATF membership. Asking members to make a voluntary donation to NATF will be included in the registration process. Changing the policy of free NATF membership will also be considered in the future.

A nominal registration fee is being required for attendance at the fall of 2009 North American Thrombosis Summit. Currently, there is no charge for other NATF-sponsored programs. A change in this policy will be considered in the future.

## **PRIORITY #6: NEW EDUCATIONAL INITIATIVES**

### **Satellite Conferences**

*Goals: advocacy, diagnosis and therapy, membership, participation, prevention and education*  
*Responsibilities: Board of Directors, Advocacy Committee, Staff*

Satellite conferences at already-organized and well-attended medical society meetings will be used to expand awareness and interest in vascular thrombotic disease. These conferences will spur greater concern about thromboembolism, encouraging attendees to participate in NATF's Web-Based Conferences.

Satellite conferences will be arranged through the creation of mutually beneficial relationships with the medical societies that represent the medical disciplines as outlined in the "Outreach" section. The three-year plan will include hosting 1-3 satellite conferences each year.

Our inaugural satellite meeting will be held in Boston at the 2009 ISTH meeting. NATF will be hosting an educational dinner on July 11, 2009.

## Grand Rounds

*Goals: advocacy, diagnosis and therapy, membership, participation, prevention and education*

*Responsibilities: Board of Directors, Scientific Advisory Committee, Traveling Fellows, Advocacy Committee, Staff*

NATF-sponsored Grand Rounds at medical institutions throughout North America will expand the dialog about thrombosis and thromboembolism, both geographically and within the various medical disciplines. An additional advantage of Grand Rounds is that medical students are frequently in attendance. As such, this educational forum will enable the conversation to expand into the next generation of physicians.

Scheduling of Grand Rounds will increase over the course of the 3-year work plan, with an emphasis on National and State-wide Thrombosis Awareness Months. Currently, for example, 3 of the 6 New England States (Connecticut, Maine, and Massachusetts) have designated November as a special Thrombosis Awareness Month. The geographic location of Grand Rounds will also expand over the course of the 3-year plan. Members of the Scientific Advisory Committee and the Advocacy Committee will be responsible for creating connections with medical institutions to host Grand Rounds at their sites. Recipients of the Traveling Fellowship award will also be asked to arrange Grand Rounds at their institution.

Similar to the satellite conferences, the Grand Round series is seen as a precursor to the Web-Based Conferences.

## Web-Based Conferences

*Goals: advocacy, diagnosis and therapy, membership, participation, prevention & education, research*

*Responsibilities: Board of Directors, Advocacy Committee, Staff*

The Internet will be used to reach a greater population. 60-90 minute web-based conferences will be arranged to allow for CME accreditation for physicians, nurses, and pharmacists.

For the most part, conferences will be geared to professionals rather than the patient/advocate community. The conference agenda will be created with the goal of expanding the thrombosis dialog to a wide range of medical disciplines. Feedback/input acquired through the NATF website will also be used to determine future subjects to be covered.

Scheduling will take into consideration the wide geographic area that NATF serves. Over the course of three years, the frequency of web-based conferences will increase from quarterly to monthly.



The web-based conferences are viewed as an opportunity for collaboration with other agencies working in the area of thrombosis; this is especially true for seminars geared to patients and advocates. In addition, relationships with medical societies that represent the various disciplines in the medical community will be an asset for marketing the program.

Print and online advertisements in strategic medical/research journals will be used to encourage participation. Other thrombosis-related organizations will be asked to include information about the web-based conferences on their website. Email will also be used to advertise the web-based conferences. There will be no charge for participation, but NATF membership will be required.

### **Thrombosis Journal**

*Goals: advocacy, diagnosis and therapy, fundraising, membership, prevention and education, research*

*Responsibilities: Snell Medical*

Snell Medical is exploring external funding to support a printed NATF journal entitled "Thrombosis Rounds". Snell Medical will be fully responsible for this effort; NATF staff time or financial support will not be required.

Snell Medical proposes to publish 5-10 issues of Thrombosis Rounds annually. They anticipate a distribution of more than 90,000 clinicians, including cardiologists, hematologists, orthopedic surgeons, vascular specialists (medical and surgical), and emergency medicine specialists. Thrombosis Rounds will provide a venue for expanding the thromboembolism conversation to a range of medical disciplines. It will also serve as a source of income for NATF.

### **Marketing/Awareness**

*Goals: advocacy, diagnosis and therapy, membership, prevention and education, public policy*

*Responsibilities: Advocacy Committee, Staff*

The goal of the NATF marketing campaign is to increase awareness of thrombosis and thromboembolism to a level equivalent to its prevalence and equivalent to awareness of other devastating diseases such as cancer and AIDS. Eventually, the level of awareness about thrombosis will be directly proportional to the high incidence and prevalence of thrombosis illnesses. The ability to affect public policy, including federal research priorities and medical treatment guidelines, is also related to increasing awareness. In addition, the success in raising funds is directly linked to the level of awareness and concern about thrombotic diseases.

Organizations representing other medical diseases have increased awareness through large-scale marketing campaigns. Gearing a campaign to both medical professionals and the general public will create special challenges but will increase the leverage necessary to identify and acknowledge vascular thrombosis disease as a public health pandemic. In May 2008, NATF met with Dr. Kasisomayajula (Vish) Viswanath, Associate Professor at the Harvard School of Public Health. The meeting explored non-traditional marketing mechanisms used to raise awareness about other disease states.

### ▶ TRADITIONAL MARKETING

A Call to Action about DVT is expected from the Surgeon General's office. This announcement provides an ideal opportunity to initiate a large-scale marketing effort. An effective traditional marketing campaign is very costly, making it unrealistic for NATF, or any of the other thrombosis-related non-profit organizations, to fund. However, a collaborative effort will benefit everyone. This approach will be explored particular with the Venous Disease Coalition, which is taking the lead in a marketing effort.

Should a collaborative arrangement not be reached, NATF will focus its marketing efforts on the medical/research community by placing printed advertisements in the appropriate journals including Blood, Circulation, NEJM, and JAMA. Printed advertisements geared to the general public will be explored in the larger newspapers e.g., USA Today, Wall Street Journal, NY Times, LA Times, Chicago Tribune, Boston Globe).

In an effort to obtain press coverage of thrombosis-related events/news, NATF will endeavor to create relationships with the medical editors of key newspapers and magazines (Boston Globe, USA Today, Wall Street Journal, NY Times, LA Times, Chicago Tribune, Time, Newsweek, US News, and World Report). Creating connections with members of the Associated Press and WebMD.com will also be pursued. These contacts will also be useful for printing of Op-Ed's written by members of NATF's Board of Directors and Scientific Advisory Committee.

Advertisements for NATF's programmatic efforts, such as the North American Thrombosis Summit and NATF's Traveling Fellowship, will also enhance awareness of thromboembolism.

### ▶ MEETING ATTENDANCE

Attendance at meetings of other thrombosis-related agencies is essential for building mutually beneficial relationships. The Executive Director will make a concerted effort to be a presence at these meetings. Where appropriate, a table or booth with NATF information will be displayed. Outreach to complementary organizations, such as medical societies of a variety of medical disciplines, also involves meeting attendance and the presence of an NATF exhibit in the meeting's vendor section. A NATF presence at these meetings is consistent with NATF's multi-disciplinary approach to thrombotic disease. It will also encourage NATF membership registration and participation at NATF-sponsored events by health care professionals practicing in other areas of medicine.

Attendance at medical society meetings will, in part, be determined by the size of the vendor exhibits. NATF is a small organization and cannot invest the financial resources available to large companies.

### ▶ OTHER APPROACHES

DVT is often called "economy-class syndrome" or "coach-class syndrome" because immobility during a long flight is a risk factor. European airlines include information about DVT prevention in their flight safety video; North American airlines lag behind. Some airlines include a small blurb within their in-flight magazine, but many do not. The Advocacy Committee will explore ways to work with the airlines collaboratively to increase DVT awareness among their customers.

Wearing vascular compression stockings during long flights is a non-invasive and relatively inexpensive prophylaxis strategy against DVT. NATF will work with compression stocking manufacturers/retailers to create a marketing campaign. In addition to increasing thrombosis awareness, such a campaign will be beneficial to the manufacturers/retailers, as it will increase sales.

Many large companies hold Health Fairs for their employees. Health Fairs can provide a forum for increasing awareness of thrombosis. It is unrealistic to think that NATF can be a physical presence at these fairs; however, information for distribution can be provided. The Advocacy Committee will take a lead on this marketing approach.

## Public Policy and Advocacy

*Goals: advocacy, diagnosis and therapy, prevention and education, research, public policy*

*Responsibilities: Board of Directors, Scientific Advisory Committee, Advocacy Group, Staff*

### ▶ DISCHARGE EDUCATION

The anticipated Call to Action by the Surgeon General will be an important milestone for vascular thrombosis research and treatment. However, it is considered to be the first in a chain of events.

In October 2008, the Centers for Medicare and Medicaid Services (CMS) will start a new policy for hospital reimbursement for medical treatment. Under the new guidelines hospitals will not receive additional financial coverage if any of five specified conditions occur:

- ▶ Serious Preventable Events (object left in during surgery, air embolism, blood incompatibility, etc.)
- ▶ Catheter-Associated Urinary Tract Infection
- ▶ Pressure Ulcers
- ▶ Vascular Catheter-Associated Infection
- ▶ Surgical Infection – Mediastinitis after Coronary Artery Bypass Graft Surgery (a specific surgical site infection)
- ▶ Fall and Trauma – Fractures, Dislocation, Intracranial Injuries, Crushing Injuries, and Burns

In 2009, DVT/PE, along with Ventilator-Associated Pneumonia and *Staphylococcus aureus* Septicemia may be added to the list of non-reimbursable conditions. This potential new policy will generate a great deal of discussion and debate. Its advocates expect that such a policy will eventually reduce the rate of DVT/PE occurrence during hospitalization.

The proposed guidelines, however, do not address susceptibility to DVT/PE once a patient leaves the hospital. Inclusion of DVT symptoms on hospital patient discharge education for those patients being discharged in the absence of prophylaxis treatment, will increase awareness of high-risk patients that they have a propensity to develop DVT.

The NATF Advocacy Group, in conjunction with the Scientific Advisory Committee, will take the lead on trying to reduce the rate of DVT and pulmonary embolism after hospital discharge. NATF will work with the appropriate professional and hospital organizations to include DVT

symptoms and steps to be taken by the patients suffering from these symptoms on written information and instruction sheets given to patients at the time of hospital discharge. Relationships with organizations that will be explored include:

- ▶ Centers for Medicare & Medicaid Services (CMS)
- ▶ National Business Coalition of Health (NBCH)
- ▶ National Quality Forum (NQF)
- ▶ National Transition of Care Coalition (NTOCC)
- ▶ Quality Improvement Organizations (QIO)
- ▶ Society of Hospital Medicine

The general approach will be to modify existing tools related to DVT prevention and care. The process of creating national standards for discharge papers is viewed as an opportunity for collaboration with other thrombosis-related organizations such as NATF.

#### ▶ FUNDED RESEARCH

With greater awareness of thrombotic diseases comes an increased call for advances in research and treatment. The NATF Board of Directors and Scientific Advisory Committee will work with NHLBI to encourage increased levels of funding for basic, translational, and clinical thrombosis research.

## **PRIORITY #7: COLLABORATION AND OUTREACH**

### **Collaboration with Thrombosis-Related Organizations**

As outlined in Table 6, several organizations focus on vascular thrombotic disease. Each has a unique mission and niche. The job ahead, particularly in terms of education, awareness, and advocacy, is enormous in scope and can most readily be accomplished through collaboration and synergy. NATF values and seeks these collaborative efforts. Strategic and tactical alliances eliminate duplication of effort, achieve economies of scale, and maximize the assets of those involved. In addition, mutually collaborative relationships benefit the individual agencies, the field of vascular thrombosis, and, most importantly, patients susceptible to thromboembolism. The specific programmatic efforts described within this work plan will be adjusted as collaborations develop.

Both the Board of Directors and the Executive Director will play important roles in forming and maintaining collaborative relationships with thrombosis-related agencies. The Board of Directors will be responsible for reaching out to colleagues involved in these organizations. The Executive Director will be responsible for creating relationships with the administrators of these organizations. NATF will invite representatives (both organizational staff and volunteers) to NATF-sponsored programs. In addition, NATF will make a concerted effort to be a presence at events sponsored by these organizations.

**Table 6: North American Agencies Focusing on Specific Areas of Thrombosis and Cardiovascular Disease**

**American Heart Association (AHA)**

*Non-profit agency*

Mission: To build healthier lives, free of cardiovascular diseases and stroke.

Primary Focus: Cardiovascular Health Care Professional and Patient Education, Advocacy, Research

**American Stroke Association (ASA):** Focuses on reducing risk, disability and death from stroke through research, education, fundraising and advocacy.

**American Society of Hematology (ASH)**

*Non-profit agency*

Mission: To further the understanding, diagnosis, treatment, and prevention of disorders affecting the blood, bone marrow, and the immunologic, hemostatic and vascular systems, by promoting research, clinical care, education, training, and advocacy in hematology.

Primary Focus: Hematology Education and Advocacy

**American Thrombosis & Hemostasis Network (ATHN)**

*Non-profit agency*

Mission: To reduce and provide stewardship of a secure national database, adherent to all privacy guidelines, which will be used to support clinical outcomes analysis, research, advocacy, and public health, reporting in the hemostasis and thrombosis community.

Primary Focus: Hemostasis and Thrombosis Data and Analysis

**The Anticoagulation Forum (ACF)**

*Non-profit agency*

Mission: To promote coordinated management of oral anticoagulation through the model of anticoagulation clinics.

Primary Focus: Patient Care Advocacy, Health Care Professional Education

**The Coalition to Prevent Deep-Vein Thrombosis**

*For-profit agency*

Mission: To reduce the immediate and long-term dangers of deep-vein thrombosis and pulmonary embolism (PE), which together comprise one of the nation's leading causes of death. The Coalition will educate the public, healthcare professionals and policy-makers about risk factors, symptoms and signs associated with DVT, as well as identify evidence-based measures to prevent morbidity and mortality from DVT and PE.

Primary Focus: DVT Public Awareness, and Policy

**ClotCare**

*For-profit agency*

Mission: To help others improve lives by providing both patients and healthcare providers with the most up-to-date information and expert insight on optimal use of antithrombotic and anticoagulant therapy. In achieving this end, ClotCare seeks to be the premier source to which patients and clinicians turn to get information on these therapies used to prevent and/or treat unwanted blood clots that cause heart attacks, strokes, and other potentially catastrophic events.

Primary Focus: DVT Patient and Health Care Professional Information and Resources

**Table 6: North American Agencies Focusing on Specific Areas of Thrombosis and Cardiovascular Disease (continued)**

**The Hemophilia & Thrombosis Research Society (HTRS)**

*Non-profit agency*

Mission: To promote the care of persons with hemophilia and other bleeding or clotting disorders through collaborative research and postgraduate education. The Society was incorporated in 1994, and has grown to include a membership of clinicians, scientists, health care providers, and industry representatives whose focus is hemostasis and thrombosis. HTRS is dedicated to promoting implementation of clinical research that will improve the care of persons affected with disorders of hemostasis and thrombosis, in particular those persons with hemophilia. The HTRS is especially interested in supporting the development of the next generation of clinicians dedicated to this field.

Primary Focus: Hemophilia and Thrombosis Physician Education

**National Alliance for Thrombosis and Thrombophilia (NATT)**

*Non-profit agency*

Mission: To prevent, diagnose and treat thrombosis and thrombophilia through research, education, support and advocacy.

Primary Focus: DVT Patient Support and Education

**Quebec Society of Vascular Sciences (QSVS)**

*Non-profit agency*

Mission: To create a multidisciplinary forum in order to optimize vascular disease management.

Primary Focus: Physicians, Researchers, Professionals, and Groups Whose Profession, Occupation, or Mission is Related to Vascular Sciences.

**The Thrombosis Interest Group of Canada**

Mission: To further education and research in the prevention and treatment of thrombosis.

Primary Focus: Thrombosis Health Care Professional Education

**Thrombophilia Awareness Project**

*Non-profit agency*

Mission: To help persons affected by thrombophilia by serving as a portal to a wide array of diverse and up-to-date information, education, treatment, research, peer support and more.

Primary Focus: Thrombophilia Patient Education

**Vascular Disease Foundation (VDF)**

*Non-profit agency*

Mission: To reduce death and disability from vascular diseases and improve vascular health.

Primary Focus: Vascular Disease Public Awareness, Health Care Professional Education, Patient Education and Support

**Venous Disease Coalition (VDC):** The Coalition provides opportunities for members of the public, health care professionals, clinician investigators and basic researchers, professional health societies, government and health policy agencies, and other public and private organizations to work collaboratively to improve public health by providing educational programs regarding venous disease.

## Outreach to Medical Specialties

Outreach to complementary organizations, such as medical societies of a variety of medical disciplines, is an integral piece of NATF's work plan, as the approach will facilitate increased awareness and advocacy. In particular, mutually beneficial relationships are important with organizations that assemble clinicians that will contribute to a multi-disciplinary approach to thrombosis. Such organizations include:

- ▶ American Academy of Family Physicians
- ▶ American Association for Bronchology and Interventional Pulmonology
- ▶ American College of Cardiology
- ▶ American College of Chest Physicians
- ▶ American College of Clinical Pharmacists
- ▶ American College of Emergency Physicians
- ▶ American College of Obstetricians and Gynecologists
- ▶ American College of Physicians
- ▶ American Diabetes Association
- ▶ American Heart Association
- ▶ American Neurological Association
- ▶ American Pharmaceutical Association
- ▶ American Society of Clinical Oncology
- ▶ American Society for Clinical Pharmacology and Therapeutics
- ▶ American Society of Hematology
- ▶ Association of Orthopedic Surgeons
- ▶ International Society of Thrombosis and Haemostasis
- ▶ International Union of Angiology
- ▶ National Institutes of Health/National Heart, Lung, and Blood Institute
- ▶ National Nursing Staff Development Organization
- ▶ Society of Hospital Medicine

The outreach plan will also extend to scientists engaged in basic research focused on thrombosis.

Both the Board of Directors and the Executive Director will play important roles in NATF's outreach. The Board of Directors will be responsible for reaching out to influential colleagues who can encourage relationships between NATF and their field of medicine/research. The Executive Director will have the role creating relationships with the administrative infrastructure of the organizations.



## MEASURES OF SUCCESS

NATF's vision is the improvement of patient care, outcomes, and public health of thrombosis and cardiovascular disease. Advancements in prevention, diagnosis, and treatment are the ultimate indicator of NATF's success. However, acquiring such data demonstrating this outcome is not in the realm of any one organization. Indirect measure, such as increased membership, website usage, and event attendance, will be used to demonstrate NATF's success in achieving the organization's goals.

### NATF Website Usage

The number of website visits and usage for 2007 is provided in Table 7. A measure of success will be an increase in NATF website usages:

- 1) Increase of 10% for all indicators during the 2008
- 2) Further increase of 10% in the average number of pages viewed per visit and 25% increase in the number of visits, hits, and visitors/day for each of the next three years

**Table 7: Anticipated NATF Website Usage**

<b>NATFonline.org</b>	<b>2007</b>	<b>Projected '08</b>	<b>Projected '09</b>	<b>Projected '10</b>	<b>Projected '11</b>
Site Visits	31,912	35,103	43,880	54,849	68,561
Total Hits	61,491	67,640	84,550	105,688	132,110
Average Number of Page View/Visits	1.93	2.12	2.34	2.57	2.83
Average Number per day Visitors	120	132	165	206	258

### Membership

A NATF membership drive was initiated in March 2008. Within the first three months, 200 people joined NATF with a free membership. Approximately 50% of the members are from the Atlantic and Northeastern regions of the United States, and 50% are primarily from other regions of the United States.

As NATF's efforts grow, a measure of success will be increased membership (Table 8), with a minimum of 250 new members per year. The geographic diversity should expand beyond the United States and should begin to include members throughout North America such as Mexico and Canada.

**Table 8: Anticipated NATF Membership Growth**

	June '08	December '08	December '9	December '10	December '11
Members	500	≥ 600	≥ 850	≥ 1,000	≥ 1,250

### **Educational Events**

Attendance at NATF-sponsored educational events is an important measure of success. Attendance of at least 200 participants during the September 27, 2008 Thrombosis Summit will be considered a success. Since the Proactive Thrombosis Prevention Forums are regional events, success will be considered with at least 100 attendees at each Forum. The total number of participants in NATF-sponsored programs will expand as the number of programs increases. Poor attendance will trigger a reassessment of the specific programmatic efforts.

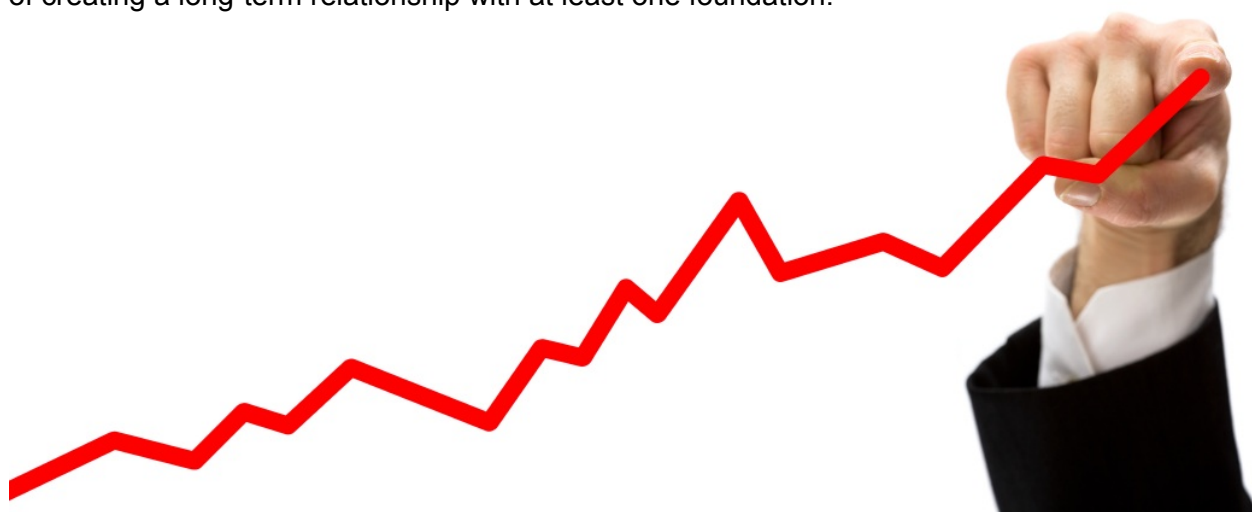
Web-Based Conferencing will be initiated in the fall of 2009. Participation should increase as the program develops. By the third conference (Spring 2010), the initiative will be considered successful with a participation of at least 50.

### **Fundraising**

Currently 99% of NATF's budget is supported by pharmaceutical educational grants. Expansion of fundraising efforts is needed to support the work described in this plan. The fundraising campaign will be considered successful if:

- 1) Sufficient funds are raised to support all programmatic efforts
- 2) The donor base is broadened to include greater contributions from:
  - ▶ Individual donors
  - ▶ Philanthropic foundations

Each year there will be at least one fundraising event targeted to individual donors. In addition, each year at least three to four grants will be written to philanthropic foundations with the hope of creating a long-term relationship with at least one foundation.



Summer 2008 - Spring 2011

NATF WORK PLAN

PROGRAM TIMELINE	2008		2009			
	Summer	Fall	Winter	Spring	Summer	Fall
<b>NATF: The Organization</b>						
Advocacy Committee	1-2 Conversations/quarter					
Scientific Advisory Committee	1-2 Conversations/quarter					
Organizational Structure					Review and ratify organization structure	Draft and ratify Business Plan
<b>Priority #1: NATF Website</b>						
Website	General Upgrade	Interactive Forums live	Normal Upkeep			
eThrombosis		Launch Phase I				Launch Phase II
<b>Priority #2: NATF Sponsored Courses and Symposia</b>						
Thrombosis Summit		Sept 27				Sept 26
Working Group Discussion		Sept 26				Sept 25
Proactive Thrombosis Prevention Forum	Arrange Forums in other locations		Boston April 4	1 Additional Forum		
<b>Priority #3: NATF Traveling Fellowship</b>						
Traveling Fellowship	08 Applicant Deadline	08 Fellow Announced	Market Fellowship at Grand Rounds/Satellite Meetings	09 Applicant Deadline	09 Fellow Announced	
<b>Priority #4: NATF Membership</b>						
Membership	Ongoing through programmatic efforts					
<b>Priority #5: NATF Fundraising</b>						
Fundraising	Develop strategy for fundraising	Begin implementing strategy	Ongoing fundraising focused on government agencies, pharmaceutical companies, philanthropic foundations, and individual donors			
<b>Priority #6: New Initiatives</b>						
Satellite Conferences			3 Satellite Conferences: ACP, Internal Medicine (April 23-25 in Philadelphia); ISTH, (July in Boston); American College of Emergency Physicians (October in Boston)			
Grand Rounds		1-2 Grand Rounds with N.E. focus	2-4 Grand Rounds with larger geographic focus: Target for March (State Thrombosis (DVT) Awareness Month)			
Web-Based Conferences						Initiate 1 per quarter
Thrombosis Journal	Negotiation	Thrombosis Journal (1 per month) by Snell				
<b>General Marketing</b>						
Traditional Marketing	Build Press Relationship	Anticipated Call-To-Action – printed advertisements; Press coverage of Thrombosis Forum; continued PR efforts				
e-Advertising	Ongoing					
Public Policy and Advocacy	Identify key players and build relationships; Develop strategy and timeline		Implement strategy			
<b>Priority #7: Collaboration and Outreach</b>						
Meeting Attendance	Ongoing attendance at approximately 6 meetings per year (e.g. NATF, SVM, ASH, etc.)					

PROGRAM TIMELINE	2010				2011			
	Winter	Spring	Summer	Fall	Winter	Spring	Summer	Fall
<b>NATF: The Organization</b>								
Advocacy Committee								
Scientific Advisory Committee								
Organizational Structure								
<b>Priority #1: NATF Website</b>								
Website	Normal Upkeep							
eThrombosis				Launch Phase III				
<b>Priority #2: NATF Sponsored Courses and Symposia</b>								
Thrombosis Summit				Summit				Summit
Working Group Discussion				WG				WG
Proactive Thrombosis Prevention Forums		Boston	2 Additional Forums		Boston	3 Additional Forums		
<b>Priority #3: NATF Traveling Fellowship</b>								
Traveling Fellowship	Market Fellowship	Deadline	Award	Market Fellowship	Deadline	Award		
<b>Priority #4: NATF Membership</b>								
Membership	Ongoing through programmatic efforts							
<b>Priority #5: NATF Fundraising</b>								
Fundraising	Ongoing fundraising focused on government agencies, pharmaceutical companies, philanthropic foundation, and individual donors							
<b>Priority #6: New Initiatives</b>								
Satellite Conferences	3 Satellite Conferences per year							
Grand Rounds	4-6 Grand Rounds with larger Geographic Focus: Target for March (State Thrombosis (DVT) Awareness Month)				6-8 Grand Rounds with larger Geographic Focus: Target for March (State Thrombosis Awareness Mo.)			
Web-Based Conferences	1 per quarter			1 per mo.	Monthly web-based conferences: 3 per quarter; Add another 1 per quarter to target patients/advocates			
Thrombosis Journal	Thrombosis Journal (1 per month) by SNELL							
<b>General Marketing</b>								
Traditional Marketing	Continued effort for coverage of thrombosis-related events							
e-Advertising	Ongoing							
Public Policy and Advocacy	Implement Strategy							
<b>Priority #7: Collaboration and Outreach</b>								
Meeting Attendance	Ongoing attendance at approx. 6 meetings per year							

MEMBERSHIP

Patients and Caregivers  
Health Professionals

*Scientific Advisory Committee*

Genetic Factors

eThrombosis

Obesity

Translational Research

Arterial

Hospital Administrators

Health Care Policy

Medical



**NORTH AMERICAN THROMBOSIS FORUM**

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Roxbury Crossing, MA 02120

Nurses

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ADVOCACY

Venous Disease

Multidisciplinary

Proactive Thrombosis Prevention

Venous Thromboembolism

Compliance

*Stroke*

Physician Assistants

ADVOCACY COMMITTEE

PREVENT

Clinical

Peripheral Arterial Disease

Advanced Age

Thrombosis

Blood Clots

Thrombosis

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Pharmacists