



*Fighting blood clots
through education*

PROPOSAL AT A GLANCE

PROBLEM/STATEMENT OF NEED

Venous thromboembolism (VTE), which comprises deep vein thrombosis (DVT) and pulmonary embolism (PE), is the third leading cause of vascular death globally and accounts for a significant disease burden worldwide.¹ It is a condition that requires immediate medical attention and thus, patients with VTE often present to acute care settings for initial medical evaluation. Communication around VTE is rife with challenges, given the urgency with which clinicians must relay considerable diagnostic and treatment information to often anxious patients and family members/caregivers. Moreover, patients presenting to the emergency room do not typically have a relationship with the clinician caring for them, a factor that further threatens the establishment of patient-provider communication, trust, and shared decision-making.²

Evidence consistently shows that effective patient-provider communication is associated with improved health outcomes, increased treatment adherence, and greater patient satisfaction.³ On the contrary, poor or inadequate patient-provider communication—specifically at the point of VTE diagnosis—can significantly impact how patients view and experience their illness and can lead to adverse psychological outcomes such as anxiety, depression, or post-traumatic stress disorder.

Following a VTE diagnosis, patients report shock, a fear of recurrence, and a feeling that VTE is “always lurking.” Over the longer term, these feelings are compounded by the risks of—or actual sustained—physical impairment, ongoing psychological trauma, and a perceived need for symptom hypervigilance. Patients also report unmet information needs, and mistrust of healthcare providers and the healthcare system at large.¹

In a recent study, Hernandez-Nino et al. described several key factors that negatively influenced the patient experience at the point of VTE diagnosis in the acute care setting^{2,4}:

¹ Genge L, et al. *J Thromb Haemost.* 2022;20:2323-2341.

² Hernandez-Nino J, et al. *Res Pract Thromb Haemost.* 2022;6:e12647.

³ Gessesse AG, et al. *Patient Prefer Adherence.* 2022;16:2509-2519.

⁴ de Wit K. *Res Pract Thromb Haemost.* 2022;6:e12651.

	<ul style="list-style-type: none"> ● Clinician word choice: The use of medical jargon, metaphors, and “alarmist language” (e.g., “you’re a ticking time bomb”) created an environment of fear and contributed to anxiety and distress. ● Nonverbal cues: Providers’ facial expressions often heightened patients’ concerns and anxiety, along with the number of clinicians that entered and exited the room without directly addressing the patient or caregiver(s). ● Incomplete information delivered to patient: Clinicians failed to thoroughly explain the diagnosis at every level, from the basic definition of VTE to the expected prognosis and implications for the patient’s lifestyle and day-to-day activities. The ambiguity of the diagnosis threatened patient perceptions of safety, leading to severe psychological distress, and in some cases, fear of death. <p>From the clinician perspective, delivering bad news or difficult diagnoses has been reported as “one of the most daunting tasks faced by physicians.”⁵ In the emergency room in particular, time constraints, a lack of rapport with patients and families, and the complexity of the diagnosis can leave clinicians feeling unprepared, inexperienced, or lacking confidence when communicating a VTE diagnosis to a patient.</p> <p>Given these findings, it is vital to address these communication pitfalls and arm clinicians with the tools that they need to optimize communication, enhance two-way engagement with patients, and improve both short- and long-term outcomes for patients diagnosed with VTE.</p>
<p>PROJECT LEADERSHIP (See Appendix A for more information.)</p>	<p><i>Scientific Chairs</i> Erik Klok, MD, PhD Professor of Medicine Leiden University Medical Center Leiden, Netherlands</p> <p>Grégoire Le Gal, MD Professor of Medicine, Division of Hematology University of Ottawa Ottawa, ON, Canada</p> <p><i>Editorial Chair</i> Aviva Schwartz, MA Director of Education North American Thrombosis Forum</p>

⁵ Monden KR. Proc (Bayl Univ Med Cent). 2016;29:101-102.

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PROPOSED DELIVERABLE	NATF has formed an international, multidisciplinary steering committee of clinicians and patients to:

- Develop and publish a formal position statement for healthcare providers comprising best practices for communicating a VTE diagnosis to patients in an acute care setting.
- Produce a toolkit that includes patient-facing resources about communication and shared decision-making.

In tandem with our position statement and patient resources, patient representatives from our task force will come together to write and publish an editorial on communication needs after a VTE diagnosis.

Topics to address in this work include:

- What is the most pertinent information for VTE patients (must-have and nice-to-have), both at the point of diagnosis and in the first three months post-diagnosis?
- Are there relevant patient subgroups to consider?
- What are the most effective, evidence-based methods of communicating to VTE patients? (Not only to provide information but to ensure that patients are listened to, with a specific focus on different settings where communication takes place, e.g., emergency room vs. outpatient clinic.)
- What is the optimal timeline to communicate necessary information to VTE patients?
- How can patients and caregivers advocate for themselves?

Active participation from patients with VTE will be critical to the success of this program to help address issues such as:

- Mistrust of the healthcare system and diagnostic process
- The psychological and emotional sequelae of a VTE diagnosis in the acute care setting
- Complex issues surrounding the delivery of health information in underserved populations and communities

This project is the first of its kind to bring together an international task force of clinicians and patients who will address the critical issue of clinician-patient communication at the point of VTE diagnosis. The International Society on Thrombosis and Haemostasis Scientific Standardization Committee (ISTH SSC) on Predictive and Diagnostic Variables in Thrombotic Disease has accepted this project for formal endorsement at the June 2023 Congress in Montreal, Canada.

<p>PROJECT OBJECTIVES, METHODS, AND TIMELINES</p>	<p>The main objective of this project is to publish a manuscript in a peer-reviewed journal that provides clinicians with practical, patient-centered recommendations for communicating a VTE diagnosis in the emergency room setting (based on the best available data and consensus among healthcare professionals and patients).</p> <p>To achieve this objective, NATF will adhere to the following methods and timeline:</p> <ul style="list-style-type: none"> • Conduct literature searches: Months 0-2 • Hold two global taskforce meetings to discuss findings and finalize plans for discussion phase: Months 0-2 • Hold additional taskforce discussions: Months 3-7, to include 1 in-person meeting and monthly virtual meetings • Conduct Delphi: Months 7-10, to include two taskforce meetings to discuss findings and finalize plans for discussion phase and two taskforce meetings to discuss progress and findings • Write a scientific paper: Months 11-13 • Submit the manuscript to a peer-reviewed medical journal: Months 14-15 • Develop an appendix of patient resources in accordance with the recommendations of the taskforce. (The committee understands that the best resources for patients will vary widely depending on a variety of factors such as social norms, language, healthcare system structure, etc. To that end, we will develop one set of resources to serve as a template that individual healthcare professionals or health systems can modify using best practices outlined in our manuscript.) Months 14-15
<p>GOALS AND OUTCOMES</p>	<p>The primary goal of this project is to improve patient outcomes by optimizing communication between clinicians and patients at the time of VTE diagnosis.</p> <p>Secondary outcomes include:</p> <ul style="list-style-type: none"> • To improve the quality and comprehensiveness of information provided to new VTE patients and their families • To improve physician confidence and skills when engaging in active dialogue with VTE patients and their families • To maximize patient and caregivers' understanding of VTE, their particular diagnosis, and how it will be managed • To improve care outcomes for VTE patients, and in particular, the long-term psychosocial burden that can result from poor communication • To improve adherence to prescribed treatments • To improve patient trust in the health system

	<p>To measure these outcomes, we will partner with the ISTH and other societies to deploy a brief clinician survey on knowledge and attitudes around communicating a VTE diagnosis, and the implementation of the toolbox in routine practice.</p>
TARGET AUDIENCE AND MARKETING/AUDIENCE GENERATION	<p>The target audience for this program is any healthcare physician involved in the acute and long-term care of VTE patients.</p> <p>To promote these initiatives, NATF will use a combination of social media, email, conferences, and advertisements. We will also rely on members of the Steering Committee as well as relevant professional organizations to help us promote this work and improve VTE outcomes worldwide.</p> <p>NATF will maintain an active web and social media presence throughout the duration of this project. We are active on five social media platforms: Facebook, Instagram, Twitter, LinkedIn, and YouTube.</p> <p>We anticipate reaching thousands via our social media channels and the NATF website.</p>
ABOUT NATF	<p>The North American Thrombosis Forum (NATF) is a nonprofit organization dedicated to improving the lives of those affected by blood clots and related diseases. Through our comprehensive resources and innovative programming, we strive to educate patients and healthcare providers about thrombosis and its complications.</p> <p>Our commitment to strengthening patient-provider communication makes NATF unique. We create educational materials for <i>both</i> clinicians and patients, with the aim of facilitating bidirectional communication between the two groups.</p> <p>NATF has a long history of developing and executing educational programs like the ones detailed in this proposal.</p> <p>To date, we have successfully published four Action Initiatives/Consensus Statements:</p> <ul style="list-style-type: none"> ● Arrington-Sanders R, et al. Assessing and Addressing the Risk of Thromboembolism Across the Spectrum of Gender-Affirming Care: A Review. <i>Endocr Pract</i>. 2022; Online ahead of print. https://doi.org/10.1016/j.eprac.2022.12.008 ● Connors J, et al. Approach to Your Patient with Cancer-Associated Thrombosis. <i>The Oncologist</i>. 2021;26.

	<ul style="list-style-type: none"> • Barkoudah E, et al. Extended Venous Thromboembolism Prophylaxis in Medically Ill Patients: An NATF Anticoagulation Action Initiative. <i>Am J Med.</i> 2020;133:S1-S27. • Ruff CT, et al. North American Thrombosis Forum, AFib Action Initiative Consensus Document. <i>Am J Med.</i> 2016;129:S1-S29. <p>Any organization that supports an NATF educational program will benefit from their association with a nonprofit whose ultimate purpose is to save lives by providing education and support to healthcare providers and patients. NATF provides our partners with several opportunities for exposure, along with access to our large, diverse, and growing clinician and patient audiences and our leadership. Partners will be recognized on all materials developed as part of a supported program), recognition on the NATF website, and other recognition opportunities as agreed upon.</p>
NATF LEADERSHIP	NATF EXECUTIVE BOARD <p>President <i>Samuel Z. Goldhaber, MD</i> Professor of Medicine at Harvard Medical School Associate Chief and Clinical Director of the division of Cardiovascular Medicine Brigham and Women's Hospital</p> <p>President-Elect <i>Christian Ruff, MD, MPH</i> Associate Professor of Medicine, Harvard Medical School Director of General Cardiology, Cardiovascular Medicine Division Brigham and Women's Hospital</p> <p>Treasurer <i>John Fanikos, RPh, MBA</i> Assistant Professor of Clinical Pharmacy Practice at Northeastern University and at the Massachusetts College of Pharmacy Director of Pharmacy Business and Financial Services at Brigham and Women's Hospital</p> <p>Co-Chair, Research & Science <i>Jawed Fareed, PhD</i> Professor of Pathology and Pharmacology Director of the Hemostasis and Thrombosis Research Laboratories Loyola University Medical Center</p> <p>Chair of Patient Engagement & Education <i>Joelle Hochman, RRT</i></p>

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Appendix A.
VTE Global Communication Steering Committee Members and Countries Represented

