

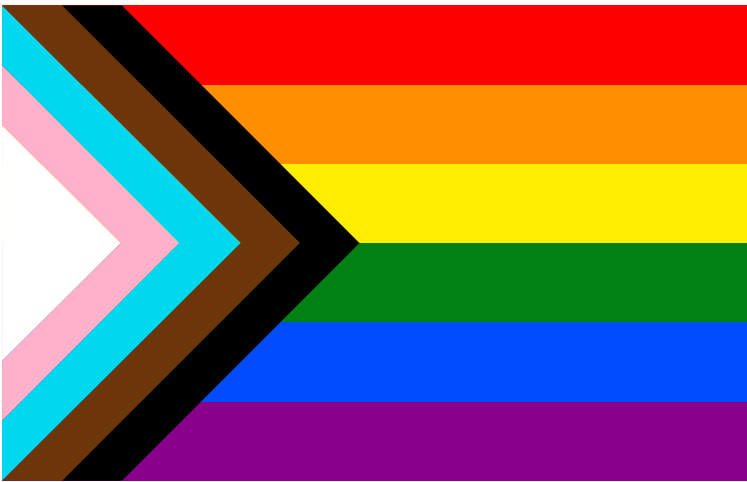


Fighting blood clots  
through education

# The Beat

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## NATF Pride: Presenting Our Latest Action Initiative

This Pride Month, NATF is excited to present an initiative that we've been working on for the last year titled *Assessing and Addressing the Risk of Venous Thromboembolism (VTE) Across the Spectrum of Gender-Affirming Care*.



Troy Keyser, MA (He/Him)  
Patient Advisor

*"The way in which NATF has brought together transgender patients and leading experts to devise recommendations for managing blood clots through a trans-positive lens is a model to keep using for all aspects of trans-inclusive care."*

Troy is a transgender man and Vice President of Partnerships at Secure AI Labs, a federated learning and analytics platform for health and life science research.

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## Newsworthy Notes: What We've Been Up To in 2022

It's hard to believe that the first half of the year is almost over! The NATF Board of Directors, Medical Advisory Board (MAB), and staff are pleased to share some exciting developments that have taken place since January.

***We've filled all open seats on our Board of Directors***

Meet Jelena Spyropoulos, NATF's Chair of Corporate Partnerships!

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Jelena will help NATF identify new opportunities and build relationships with industry sponsors, foundations, and other potential funders.

Jelena obtained her PhD in Molecular Genetics at the Albert Einstein College of Medicine in New York City and has more than 15 years of experience in the medical education industry. Jelena began her career as a medical writer, focusing on scientific publications in the areas of cancer, anticoagulation, and heart disease. She has since overseen scientific communications for several areas of medicine while maintaining a focus in anticoagulation management. Jelena currently works at Medscape Education Global and leads the team responsible for new business development.

LEFT: Jelena Spyropoulos, PhD

### We hired a summer intern

NATF is thrilled to welcome Trinie Tang to our team for the summer. Trinie is a 5th-year pharmacy student at the Massachusetts College of Pharmacy and Health Sciences and is also an Inpatient Pharmacy Intern at Brigham and Women's Hospital. During her time at NATF, she'll be helping us revamp several of our key patient resources on anticoagulation. We're excited to have her on board!

RIGHT: Trinie Tang



### We had our first in-person meeting in more than two years

In April, the NATF staff, Board of Directors, and MAB came together in person for the first time since the pandemic began. We spent two productive days together discussing strategic plans and educational priorities for the next 3-10 years. It was wonderful to collaborate and brainstorm face to face! ■

LEFT: NATF rocking our compression socks! From left to right: Allen Taylor, MD; Alex Spyropoulos, MD; Jennifer Ballard-Hernandez, DNP; Tara Lech, PharmD; Margaret Fang, MD, MPH; Jelena Spyropoulos, PhD; Aviva Schwartz, MA; Megan Piper, MBA; Kathryn Mikkelsen, MBA; Umberto Campia, MD, MS; John Fanikos, RPh, MBA; Aaron Aday, MD, MS; Joelle Hochman, RRT; Brenda Shisslak; and Maggie Newberg.



More than 1 million adults in the U.S. identify as transgender, meaning that they have a gender identity that’s different from their sex assigned at birth. Some transgender individuals pursue medical treatment to align their **gender identity** with their bodily characteristics; these treatments may include **gender-affirming hormone therapy (GAHT)** or **gender-affirming surgery (GAS)**. You may also hear the term gender-affirming care, which is an umbrella term that includes GAHT and GAS.

GAHT involves the use of hormones to develop identity-aligning characteristics like facial hair or a change in vocal tone. GAS refers to surgical procedures to also align a person’s internal self and their body; for example, chest or “top” surgery may involve the addition or removal of a person’s chest tissue.

*“Our hope is that we can help clinicians across the country provide better care to folks in the trans community. We’re also hopeful that our work will result in guidance for trans people all across the country to help them understand what their blood clot risk may be and how they might be able to navigate a conversation with their own clinician about gender-affirming care.”*



Robert Goldstein, MD, PhD (He/Him)  
Project Leader

## GLOSSARY

<b>Cisgender</b>	A person whose gender identity aligns with their sex assigned at birth
<b>Gender-affirming hormone therapy (GAHT)</b>	Hormonal therapy that aims to align one’s gender identity with their physical characteristics and attributes
<b>Gender-affirming surgery (GAS)</b>	Surgical procedures that change sex characteristics to affirm a person’s gender identity
<b>Gender identity</b>	A person’s internal sense of their gender
<b>Sex</b>	Sex (male or female) is assigned at birth and typically determined by the appearance of external genitalia
<b>Intersex</b>	A term used to refer to situations in which a person is born with reproductive or sexual anatomy that doesn’t align with the typical definitions of female or male sex
<b>Transgender man</b>	A man who was assigned female at birth
<b>Transgender woman</b>	A woman who was assigned male at birth

Adapted from [Swe NC, et al. Metabol Open. 2022](#) and the [It Gets Better Project LGBTQ+ Glossary](#)

Research shows that gender-affirming care improves mental health and quality of life in transgender people. The inverse is also true: withholding gender-affirming care may cause significantly negative impacts on transgender individuals. But as with all medical therapies and surgeries, gender-affirming

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care is not without some risk – and the risk for blood clots is important to consider in a patient’s care plan.

Both hormone therapy and surgery are established risk factors for deep vein thrombosis (DVT) and pulmonary embolism (PE). Estrogen is known to raise the risk of blood clots, and several studies have shown an increased risk for blood clots in transgender women using oral estrogen for GAHT. Surgery itself—and the days to weeks following an operation—are considered high-risk periods for the development of blood clots in all patients.

However, most of the evidence we have about blood clot risk is based on studies of **cisgender** people; that is, people whose gender identity corresponds with their sex assigned at birth. To date, there haven’t been any clinical trials done to explore the risk for DVT or PE in the transgender population.

“All too often the medical treatment of transgender patients, specifically relating to blood clots, is based on limited data. Without a set of best practices to draw from, the transgender community can’t get optimal care,” explains Diva Martinez, a Patient Advisor for the initiative.

“These limited data and lack of consensus on best practices can also lead to clinicians withholding gender-affirming care or requiring transgender patients to stop their hormone therapy for surgeries unnecessarily – a very traumatizing experience for a population already at a higher suicide risk,” says Troy Keyser, another Patient Advisor for the initiative.

Dr. Robbie Goldstein, an expert in LGBTQ health and former Medical Director of the Transgender Health Program at Massachusetts General Hospital, agrees. “When patients come in looking to start GAHT, we have a conversation about the risks and the benefits of hormone therapy. When we talk specifically about estrogen therapy, I mention that there’s a theoretical risk of blood clots. We don’t know the exact risk associated with each type of estrogen that we prescribe to our patients, and we don’t know if there’s a risk for testosterone hormone therapy. That is to say that we don’t have a lot of ‘gold-standard’ evidence to understand exactly what is happening in the trans population as far as blood clot risk – but we do have a tremendous amount of clinical experience.”

*“Research on blood clot risk must continue to enhance and improve the standards of care used to treat the transgender community. It is only through this vital research and the discoveries made from it that clinicians will be able deliver optimal care to our community.”*

Diva is a transgender woman and is currently the Director of Clinical Operations and Development at Alnylam Pharmaceuticals.



*Diva Martinez (She/Her)  
Patient Advisor*

Under Dr. Goldstein’s guidance, NATF has brought together clinicians, researchers, and transgender patients from across the country to develop recommendations on managing blood clot risk in transgender individuals. The initiative is currently being peer reviewed. ■



## Upcoming Patient Events



### **CTEPH and You: A Webinar Series**

Chronic Thromboembolic Pulmonary Hypertension (CTEPH) is a rare condition that can occur in patients who've had a pulmonary embolism (PE). While CTEPH can be life-threatening, it is curable. Our June webinar will focus on CTEPH treatment. To learn more, visit [thrombosis.org/cteph-and-you](http://thrombosis.org/cteph-and-you)

**June 14, 2022**



### **Support Groups for Newly Diagnosed Patients**

*Hosted by Joelle Hochman, RRT, Chair of Patient Engagement and Education*

We're pleased to offer a virtual support group specifically for patients who've recently had a blood clot.\*

**June 16, 2022**

*We will not be hosting support groups in July and August. They will resume in September!*

\*This group is primarily geared towards patients who've had a blood clot in the past 12 months, but participants at any stage of diagnosis are welcome! If you're a longtime reader of *The Beat*, please help us spread the word about this support group! More information can be found on our [website](#).

## **Save the Date!**

### **Optimizing Health after a Cardiovascular Event: An Evening with the Experts**

Have you or a loved one recently had a heart attack, stroke, blood clot, or other heart-related event? Join us as we welcome a panel of experts to discuss what you can do to prevent a second event and to answer your questions about topics such as cholesterol, nutrition, and exercise.

**October 6, 2022**

**5:30-9:00 PM**

**Fairmont Copley Plaza Hotel, Boston, MA**

To register for these virtual meetings, please visit [Patient Events](#) on our website.

## NATF Board and Staff

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