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# The Beat

A publication of the North American Thrombosis Forum

## Keys to Staying Healthy in the Hospital



**D**id you know that medically ill patients are at risk for developing a blood clot when they are in the hospital?

According to the Surgeon General, one of the most common and preventable causes of blood clots in the lungs (pulmonary embolism or PE) is hospitalization. Patients who are medically ill, meaning they are in the hospital for diseases such as pneumonia, congestive heart failure,

stroke, or rheumatic diseases, face the highest risk.

Healthcare providers work hard to protect patients by using appropriate tools to prevent blood clots, such as giving them appropriate anticoagulant medications and managing their exercise routines. However, patients need to be aware of their risk.

Here are five steps that you can take to protect yourself from blood clots if you are sick in the hospital:

### 1. GET UP AND MOVE



Immobility is a major risk factor for developing a blood clot. You should be sure to get out of bed and move as much as you are able to. "Patients can help mitigate their risk by doing things like being as active as possible, getting up and moving around, participating in physical therapy, and really engaging with their healthcare providers to be as mobile as possible," explained Dr. Geoffrey Barnes, a cardiologist and vascular medicine specialist at the University of Michigan Health System. "They can be a real partner in their care."

### 2. TAKE YOUR MEDICATIONS

Doctors prescribe anticoagulant medications for some patients that are in the hospital. Some of these drugs, such as Lovenox, involve injections. While patients don't enjoy injections, it's important that

you take the medications that your doctor prescribes.

"We need patients to be persistent in taking their medications as prescribed," explained John Fanikos, RPh, MBA, who serves as the Executive Director of Pharmacy Services at Brigham and Women's Hospital. "Hopefully patients can build their medications into their daily activities, such as their morning meal, morning shower, an afternoon TV show, or evening newscast. Patients need to take their medications as prescribed in order for them to work."

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## Uniting to Find a Cure: A Look at a Data Science Company Tackling Disease



Omar Sinno, MD, MBA

**W**hat if genetic information could help in the battle against blood clots? One company, Unite Genomics, is trying to use genetic information and big data to help speed up the research being done on different disease states.

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## Upcoming Events

### Online Blood Clot Support Group

February 4 – Dr. Suresh Vedantham will discuss post-thrombotic syndrome

February 19 - Drs. Welker and Auger host CTEPH Online Support Group

March 25 – Dr. Elaine Hylek will discuss stopping an anticoagulant

April 8 – Dr. Christian Ruff will present “Genetics and Blood Clots: What’s in the Genes?”

May 20 – Dr. John Groarke will discuss the connection between blood clots and cancer

June 18 – Dr. Margaret Fang will discuss anticoagulant reversal agents

*Please check [natfonline.org](http://natfonline.org) for more information.*

NATF's Online Blood Clot Support Group offers patients the opportunity to share common concerns, offer support to one-another, and learn up-to-date and accurate information, including new research on blood clot prevention and treatments. Dates and speakers for our upcoming meetings can be found at [www.natfonline.org](http://www.natfonline.org).

[org/patients/supportgroups](http://natfonline.org/patients/supportgroups). To register for these online support groups, please email [info@natfonline.org](mailto:info@natfonline.org).

### In-Person Blood Clot Support Group at BWH

February 26

March 26

May 21

Brigham and Women's Hospital, Boston, MA

*Please check [natfonline.org](http://natfonline.org) for more information.*

All support groups start at 7:00 p.m. and are held at Brigham and Women's Hospital. To register, email [info@natfonline.org](mailto:info@natfonline.org) or call 617-730-4120.

### NATF Spring Patient Program

May 16, 2019

The Westin Waltham Boston, Waltham, MA

Join NATF for their annual Spring Patient Program. This year, patients will learn more about important topics such as the connections between cardiovascular health and diabetes, the key role of lifestyle and diet, and more. To register for this exciting event, visit [natfonline.org/events](http://natfonline.org/events) or email [events@natfonline.org](mailto:events@natfonline.org).

For more information on any of these events, please email [events@natfonline.org](mailto:events@natfonline.org). We look forward to hearing from you!



## KEYS TO STAYING HEALTHY IN THE HOSPITAL

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### 3. KNOW THE SYMPTOMS OF BLOOD CLOTS

By knowing the signs and symptoms of a blood clot, patients can be more in-tune with their own health. Patients should be on the lookout for:

Signs and symptoms of DVT:

- Discomfort, heaviness, pain, aching, throbbing, itching, or warmth in the legs
- Skin changes in the leg, such as discoloration, thickening, or ulceration
- Swelling of the legs, ankles, or feet

Symptoms and signs of PE:

- Sudden shortness of breath

- Chest pain
- Coughing up blood
- Rapid or irregular heart rate

### 4. BE YOUR OWN ADVOCATE

Speak up for yourself when you're in the hospital.

“Patients can do a lot to empower themselves and protect themselves from the risk of developing a blood clot,” stressed Dr. Christian Ruff, a cardiovascular specialist at Brigham and Women's Hospital. “In the hospital, they can make sure that they are receiving appropriate prophylaxis for blood clots. Patients are their own best advocates, so they should be sure to talk to their doctors about receiving the appropriate prophylaxis for the prevention of blood clots.”

### 5. STAY INFORMED

In order to be an advocate for yourself, you shouldn't be afraid to ask questions when you're in the hospital. This comes into play after patients leave the hospital too. Asking the right questions can help you find the right care after you are discharged.

*“It's important for patients to know that when they leave the hospital, they are in the best position to help make sure that they are doing all of the things they need to do to help lower their risk of a complication after discharge,” explained Dr. Ruff. “I would recommend to all patients that they talk to the physicians caring for them in the hospital, most importantly, but also their outpatient or primary care doctor, and ask if there are things they could be doing or medications they could be prescribed that would really help protect them during the post-discharge follow up.”*





## UNITING TO FIND A CURE

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For this edition of *The Beat*, NATF sat down with the Chief Medical Officer of Unite Genomics, Omar Sinno, MD, MBA, to give patients a look into the world of genomics, data science, and the important role patients play.

Unite Genomics is a data science company from the University of California Berkeley's Big Data Genomics Group. The company focuses on enabling the analysis of large amounts of electronic health record data and patient genomes to accelerate the development of new treatments and cures for a wide range of diseases.

**Q:** If you were to describe Unite Genomics to a patient that had no background in science, how would you describe what Unite Genomics does?

Our genomes hold the answers to many of our most challenging medical conditions. Unite Genomics collects health record data and saliva samples from thousands of patients with similar medical histories, performs genome sequencing on select samples, analyzes this data, and turns it into information that gives scientists and doctors an unprecedented view into how our bodies work. The information Unite produces shows scientists where in the genome to look for the next generation of therapies and cures, and it shows doctors how very small differences in our genomes will affect our response to the treatments they prescribe. Together, these impacts mean huge, underserved patient populations receiving new and improved therapies, and millions of individuals receiving the right treatment first, with no guesswork or trial and error.

*Data plays a large role in Unite Genomics' process. In order for Unite Genomics' efforts to work, they rely on patients who have different diseases to donate their genetic information.*



**Q:** Why is it important for patients to donate their genetic information to a company like yours?

By contributing your information to a company like Unite, you are joining millions of individuals in a movement to make healthcare more tailor-fit to the individual and their unique genetic background. We want to move away from the need to try 3 different drugs before finding the one that will best work for you. We also want to limit the chance that you will be prescribed a drug that will cause a negative reaction. By donating your health data to

companies like Unite, you are paving the way for a profound improvement in the future healthcare that our children and grandchildren will receive, and here is how: since the first human genome was sequenced in 2001, millions of patients have had their genomes sequenced and from those sequences, we have discovered over 20 million differences between those genomes. However, nearly two decades later, we still only understand the consequences of less than 1% of those differences. We can see the differences in individuals' genomes very clearly but we don't know how they impact our health. To learn how to use a patient's individual genetic background to tailor care for that patient, we need to understand how these differences impact our bodies. And to do that, we need to look at thousands of patients who have similar genetics, and see how their health

events compare to those of patients with different genetics. This all depends on the contribution of information to the data pool by thousands of thoughtful, determined patients who want to create a better future for themselves, their children, and their grandchildren.

**Q:** Why should patients donate their genetic information to Unite Genomics? What information do patients receive from Unite Genomics?

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## Bring Support to your Community!

NATF is looking for patients or healthcare providers that would like to start a blood clot support group in their area.

With short appointment times, it can be difficult for patients to get the answers and support they need to understand and process their blood clot diagnosis. Starting a blood clot support group with the North American Thrombosis Forum can help!

Don't take our word for it! One Boston support group member described their experience as, "Very encouraging. It became very clear that life after a blood clot is certainly a possibility and a real positive possibility."

*If you, or someone you know, may benefit from starting a blood clot support group, email [kmeredith@natfonline.org](mailto:kmeredith@natfonline.org) to learn more.*





## **The Anticoagulation Action Initiative: A simple, direct, and patient-centered plan for VTE prevention in hospitalized medically ill patients**

North American Thrombosis Forum is thrilled to announce a new, exciting consensus document, “The Anticoagulation Action Initiative: A simple, direct, and patient-centered plan for VTE prevention in hospitalized medically ill patients.”

This new initiative is a consensus document that is designed to provide concise, up-to-date and patient-driven recommendations to healthcare providers on how they can prevent deep vein thrombosis (DVT) and pulmonary embolism (PE) in medically ill patients while they are in the hospital and after discharge.

The Surgeon General estimates that up to 180,000 PE deaths occur annually in the United States. The report also cited hospital-acquired venous thromboembolism (VTE) as a common and preventable adverse outcome. While many of these patients are properly protected with prophylaxis, several new developments in the field have emerged and NATF is dedicated to ensuring that medical professionals across North America are kept up-to-date on the latest in VTE prevention strategies during hospitalization and post discharge.

The Action Initiative will touch upon several key topics, including:

- Analysis of available randomized control trials
- Information on patterns of care delivery and transitions of care
- VTE scorecards and safety dashboards
- How to write order sets for VTE prevention in hospitalized medically ill patients
- Solutions and tools to calculate VTE appropriateness and bleeding risk
- The role of clinical pharmacists to ensure education and improve compliance in patients

The Anticoagulation Action Initiative is designed to help a wide range of medical professionals that interact with this vulnerable patient population.

“This is a collaboration between hospital medicine, cardiovascular medicine, hematology, pharmacology, and nursing,” expressed Dr. Ebrahim Barkoudah, Chair of the Anticoagulation Action Initiative and Associate Director of the Hospital Medicine Unit in the Department of Medicine at Brigham and Women’s Hospital. “The Action Initiative will provide practical recommendations on transitions of care from the hospital to discharge, and beyond. The goal is to create prophylaxis recommendations that will ensure protection from VTE in vulnerable medically ill patients during stay and after discharge.”

While educating healthcare providers is the main goal of this Action Initiative, NATF is also dedicated to making resources available for patients.

“In addition to the consensus document, the North

American Thrombosis Forum will develop a website dedicated to sharing videos and online material featuring these groundbreaking recommendations for our patients and our community,” explained Dr. Barkoudah. “This will include patient-centered materials that will empower our patients to be informed about the risk of developing deadly blood clots during hospitalization and after discharge.”

***The Anticoagulation Action Initiative will be published in the American Journal of Medicine in 2019. Be on the lookout for this important Action Initiative!***



Dr. Ebrahim Barkoudah



## UNITING TO FIND A CURE

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Unite Genomics has the most sophisticated data analysis abilities of any genomics company, so contributing to Unite will produce the greatest societal impact from your data. If you are selected, Unite Genomics sequences your genome for free (it currently costs \$1000-\$3000 to have your genome sequenced) so that you have it when it becomes useful to your doctor in directing your care.

*It is important for patients to know that only those specifically selected will have their genome sequenced. This is not a service automatically provided to everyone who donates their information.*

**Q:** People are concerned about giving away their genetic information because of privacy issues. How does Unite Genomics handle keeping this information protected?

The first question any patient should ask before contributing their data is: will my information be kept private? Unite Genomics de-identifies all data before anyone outside of Unite can interact with it. This means that we make sure that there is no way that anyone can tell that any piece of information is yours, or even that you contributed at all, unless you explicitly give us permission to tell them. We might ask your permission for this on a case by case basis, if we think it will significantly speed up the scientific discovery process in that particular instance.

The second question any patient should ask is: even if the data will not have any ties to me when people outside of Unite interact with it, will the sensitive data that exists within Unite be secure and protected from a data breach? We take this very seriously at Unite. Unite was cofounded by one of the world's leading experts in cybersecurity and who has been teaching cybersecurity in the University of California, Berkeley's Electrical Engineering and Computer Science Department for over two decades. Data security is built into everything we do. We store data in encrypted form, so that it looks like random gibberish to anyone but us, we use state of the art cybersecurity defenses, and we keep the encrypted data in locked data centers with security guards on duty 24 hours a day, 7 days a week.

**Q:** What future would you like to see for Unite Genomics? What is the company's mission or goal?

We live in the Information Age, but we have yet to tap into the most powerful piece of information that ties us all together: our genomes. For every Unite employee, and every patient who contributes data to the Unite effort, Unite is a means to shift the discovery of life-changing medical discoveries into hyperspeed, helping scientists and doctors solve the presently unsolvable and create a much healthier future for all of us. If we all work together, we will see millions of patients receive therapies we helped discover, and millions more patients get the right treatment first. Just as today we look back and reflect at how different life was before we created the internet, soon we will look back and marvel at how many discoveries we made and lives we helped once we Unite.

*Thank you, Dr. Sinno, for sharing your work with us!*

*To learn more about Unite Genomics visit [www.unitegenomics.com](http://www.unitegenomics.com).*

## AC FORUM 15TH NATIONAL CONFERENCE THE DIPLOMAT BEACH RESORT FORT LAUDERDALE APRIL 11-13, 2019

This national conference brings together more than 900 physicians, pharmacists, and nurses for presentations by the leading experts in the field of anticoagulation.

The program includes special lectures focusing on recent advances and important issues in anticoagulation therapy, meet the experts lectures, poster presentations of original research, and exhibitors.

### Session Highlights

- Combined Therapy – Afib, Coronary and Peripheral Disease
- Optimizing Anticoagulation Clinics
- Controversies and Challenges in VTE
- Moving the Needle – Creating Change at the National Level
- Improving Safety and Quality in Anticoagulation Care
- What Is the Anticoagulation Provider To Do? Real-World Dilemmas

### EARLY BIRD REGISTRATION

Now open at [www.acforum2019.org](http://www.acforum2019.org)



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