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# The Beat

A publication of the North American Thrombosis Forum



## Patient Perspective: Mark's Story

*Mark's life changed dramatically when he was diagnosed with a pulmonary embolism (PE), a blood clot in the lungs. In his own words, here is Mark's story about how follow-up care saved his life:*

**M**y story starts like many others, but does not end in the way you may think, thanks to the follow-up care provided by Massachusetts General Hospital (Mass General) and Dr. Rachel Rosovsky.

I woke up on a morning in August of 2016, feeling fine. But, I soon realized I was having trouble breathing. As the minutes went by, it got more difficult to breathe. I told my wife we needed to take a ride to the hospital. I thought I was having a heart attack.

I got to the local hospital and the emergency staff was wonderful. They told me, "You are not having a heart attack. You have a pulmonary embolism (PE)."

"This was a good thing," I thought to myself. "I'm not having a heart attack."

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## Is Atrial Fibrillation Connected to Dementia?

By Umberto Campia, MD

**A**trial fibrillation (AF) is an abnormal heart rhythm (arrhythmia) that causes an irregular and, at times, very fast heartbeat. Atrial fibrillation is the most common type of arrhythmia and several million people carry a diagnosis of AF in the United States. The risk of developing AF increases with age,

and with each decade of life after the age of 40 years this risk doubles. Atrial fibrillation may cause the occurrence of palpitations (an abnormal feeling of the heartbeat in the chest), but often patients are not aware of it. While palpitations may be bothersome, the main health consequences of AF are due to other issues: first, the risk of a persistently elevated heart rate, which can weaken the heart and cause heart failure; and second, the formation of blood clots in the left upper chamber of the heart. These clots can dislodge and travel the circulatory system, where they can cause strokes, heart attacks, or block the blood flow to the limbs and abdominal organs, such as the spleen, kidneys, and gut.

Interestingly, recent studies have shown that patients with AF have an increased risk of dementia, a term that refers to various debilitating conditions, such as Alzheimer's disease, characterized by a progressive deterioration of cognitive functions and capabilities necessary for independent living. Similar to AF,



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the risk of developing Alzheimer's disease and other forms of dementia increases with age and in the presence of hypertension, diabetes mellitus, and smoking. It is well known that atrial fibrillation can cause strokes and that, in about 20% of all patients with dementia, strokes are the main culprit. However, there is growing evidence that the presence of AF increases the risk of dementia above and beyond what would be expected by the presence of the other conditions and strokes. Therefore, there is currently great interest in a possible causal role of AF in dementia, and several lines of research are actively being pursued.

### POTENTIAL MECHANISMS LINKING ATRIAL FIBRILLATION WITH DEMENTIA

Dementia in its various forms is the consequence of progressive damage to the brain from abnormal loss of neurons and other brain cells. Several mechanisms have been postulated to explain the loss of neurons, which will be summarized in *Continued on page 3*

## Upcoming Events

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

April 24, May 22, June 26, 2018

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

### Online Blood Clot Support Group

April 17 with Dr. Alec Schmaier – Treatment Options for PE/DVT: Demystifying the Drugs

May 9 with Dr. Marie Gerhard-Herman – Simple Steps to Developing a Healing Response to Stress

June 5 with Lynn Oertel, NP – Keeping Up with The Clots: The Importance of Medication Adherence

July 10 with Dr. Gregory Piazza – Back to the Basics: What are blood clots and how do they form?

NATF's Online Blood Clot Support Group offers patients the opportunity to 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 <https://natfonline.org/patients/support-groups/>. To register for this online support group, please email [info@natfonline.org](mailto:info@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!



### PATIENT PERSPECTIVE

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But I was still having trouble getting a breath.

The doctor in charge told me that they were unable to do anymore at their hospital and asked me which hospital I would like to be transferred to.

From the background, my 81-year-old mother Maureen, a retired nurse, yelled, "Mass General!"

That small statement changed the trajectory of my life.

Off I went in an ambulance to Mass General. When I got admitted, the doctor assured me that I wouldn't be waiting long and that their PE response team (PERT) was discussing my case. Within 20 minutes, a doctor walked into my room and told me that they would be removing the blood clot from my lung and that I would be prepped for surgery.

Every person involved seemed to know exactly what they were doing and what was going to happen. They spoke to me throughout the whole procedure. When the doctor was done, he told me that he was a bit upset, because they were unable to get the complete clot out, but that they would break it up over the coming days with medication.

After surgery, I was moved to the ICU. The nurses explained everything and made sure I was comfortable. I met with a team of doctors each day, who continued to update me on my progress.

Finally, I was ready to be discharged. This is where my experience differs from most PE patients'.

As I was being discharged, my nurse sat down with me and explained to me what I needed to do after I left the hospital. As she was explaining what would happen, all I could hear was Charlie Brown's teacher going "Wah Wah Wah." My nurse clearly knew I was having trouble following,

### CTEPH Online Support Group

May 1 with Dr. William Auger and Dr. James Welker

To raise awareness about this devastating disease and provide support to patients with CTEPH, NATF is excited to announce that NATF will be hosting special Online Support Groups for patients diagnosed with CTEPH and those looking to learn more. We are pleased to have Dr. William Auger at UCSD, a leading expert in CTEPH, and Dr. James Welker at Anne Arundel Health System, founder of the NATF online support groups, as our facilitators.

### Stopping the VTE Epidemic: An Innovative, Cutting-Edge, and State-of-the-Art Action Plan

April 19 – Philadelphia, PA

April 27 – Detroit, MI

NATF will be hosting a series of free programs, designed for medical professionals, that will focus on protecting medically ill hospitalized patients from VTE. Doctors, nurses, pharmacists, and other healthcare providers are invited to join us for the opportunity to earn CME credits and learn about the latest in VTE treatment and prevention. These events are part of NATF's ongoing "Avoiding the Avoidable: Pathways for VTE Prevention in the Vulnerable Medically Ill" program series. New cities will be announced soon, so stay tuned!

Earn  
CME  
credits

so she highlighted everything on my post-discharge papers.

On the paperwork, highlighted in yellow, was a follow-up appointment with Dr. Rachel Rosovsky. I remember my nurse repeatedly saying that I had to go to this follow-up clinic.

In September, I showed up to my appointment. This was where I began to realize how serious my situation actually had been back in August.

You may be asking yourself, "How did this guy not realize how serious his situation was?"

I honestly never felt scared or had any questions that went unanswered when I was in the hospital. Everyone seemed extremely calm around me, so I never worried.

That changed when I met with an assistant working with Dr. Rosovsky. He introduced himself to me and I told him who I was. He replied, "You are the PE patient? I was on that call the Saturday you were admitted, and I'm surprised I'm actually speaking with you today."

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#### Rachel Rosovsky, MD, MPH

Dr. Rosovsky is an Assistant Physician in the Department of Hematology/Oncology at Massachusetts General Hospital (MGH) and an Assistant Professor in Medicine at Harvard Medical School (HMS). She serves as the Director of Thrombosis Research for the Department of Hematology. She earned her undergraduate degree from the University of Pennsylvania, her medical degree from Harvard Medical School and her Master's in Public Health from Harvard School of Public Health. She completed her residency at Brigham and Women's Hospital and her fellowship at the Dana Farber Cancer Institute/MGH combined program."



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the following paragraphs:

**Cerebral hypoperfusion** – The term cerebral hypoperfusion refers to a state of significantly reduced blood flow to the brain, which is not severe enough to cause immediate cell death but leads to insufficient delivery of oxygen and nutrients to maintain normal cell function. The chronic exposure to even very short, but frequent, episodes of hypoperfusion leads to brain cell malfunction and eventually death. It has been postulated that the irregular cardiac rhythm present in AF may cause beat-to-beat variability in blood flow to the brain, with a certain proportion of the beats associated with hypoperfusion. In addition, AF may lead to a chronic reduction of brain blood flow due to its effects on the pumping function of the heart. These mechanisms have been suggested by a number of experimental studies. However, human investigations in this area are difficult to conduct and definitive proof is still lacking.

**Vascular inflammation** – Population studies indicate that the presence of elevated blood levels of certain inflammatory proteins, such as C-reactive protein (CRP) and interleukin-6 (IL-6), are associated with a 3-fold increase of developing dementia. This evidence suggests that inflammation may participate in the mechanisms of brain cell damage and loss that leads to dementia. Interestingly, the same inflammatory markers have been associated with an increased risk of developing AF. As the presence of AF may lead to increased levels of CRP and IL-6, AF can lead to a self-perpetuating inflammatory state, which, in turn, increases the risk of dementia. However, further study is necessary to clarify the role of AF in the inflammatory theory of dementia.

**Cerebral small vessel disease** – While the occurrence of symptomatic stroke is a widely recognized risk of AF, the occurrence of “silent” brain damage, which is reported in up to 80% of patients with AF, is less well appreciated. The mechanisms underlying this form of brain pathology are not completely understood, but small strokes in the deep areas of the brain and damage to small brain vessels with small areas of hemorrhage (microbleeds) are likely significant contributors. Importantly, this type of brain damage may explain why AF may lead to dementia, even in the absence of strokes.

**Brain atrophy** – Intriguing evidence from a population study in which participants underwent brain MRI suggests that AF may lead to a loss of brain volume. In particular,

the presence of AF was associated with lower volumes of total brain and gray and white matter (the two main types of brain tissues). Furthermore, participants with persistent AF had lower volumes than those with intermittent episodes of AF. Consistent with a duration of exposure-effect relationship, the longer the time a person had been in AF, the more brain tissue they had lost. As the association between AF and loss of brain volume could not be fully explained by the presence of other conditions or previous strokes, additional mechanisms are likely at play. These observations are compatible with the hypothesis that patients with long standing AF have less cerebral perfusion than those with only intermittent AF. However, confirmatory evidence is still lacking.

## DOES TREATMENT OF ATRIAL FIBRILLATION REDUCE THE RISK OF DEMENTIA?

If the hypothesis that AF contributes to the onset of dementia is true, effective treatment of AF should reduce its occurrence. To date, no studies have been specifically designed to test this hypothesis. However, an observational study has shown that AF patients who underwent radiofrequency ablation therapy, which currently is the most effective way to restore the normal rhythm in AF, had significantly lower risk for dementia than patients who did not have an ablation. Future study is warranted to understand the impact of rhythm restoration by catheter ablation or pharmacological approach on the risk of dementia in AF patients.

## CONCLUSIONS

Atrial fibrillation and dementia are common diseases associated with aging. They share common risk factors, and recent evidence indicates that AF itself may increase the risk of dementia. Research studies conducted to date have shed some light on the links between AF and dementia. However, definitive proof of this link is still missing, and the putative mechanisms remain elusive. Given the impact of dementia on quality of life and the societal costs associated with this condition, there is an unmet need for further study in this field.



**Umberto Campia, MD**  
Vascular Medicine Specialist  
Brigham and Women's Hospital

## Introducing CTEPH Online Support Group

Join NATF on May 1 for a special CTEPH online support group.

CTEPH stands for Chronic Thromboembolic Pulmonary Hypertension, which is high blood pressure in the vessels of the lungs caused by a clot that blocks blood flow. Patients who have suffered from a pulmonary embolism (PE) are at a higher risk of developing CTEPH. Approximately 2-4% of patients who suffer from a PE develop CTEPH.

Common symptoms of CTEPH include fatigue, shortness of breath, and exercise intolerance. Symptoms may progress to include chest discomfort, coughing up blood (hemoptysis), fainting (syncope), light-headedness, and leg swelling (edema). Just like a pulmonary embolism, CTEPH can be difficult to diagnose and treat.

To register, visit: <https://natfonline.org/events/cteph-online-support-support-group/>



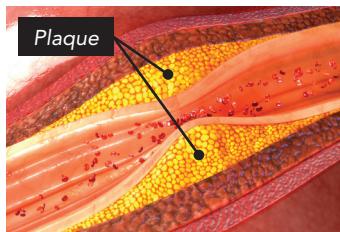
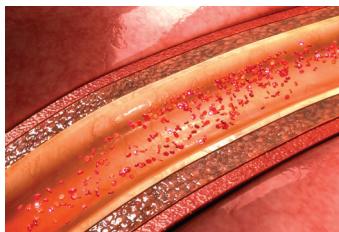


## Discovering PAD: Learn the Signs and Save a Life

Peripheral artery disease (PAD) is a silent killer that many patients don't know they have until they experience its consequences. Over 8.5 million Americans are living with this disease, which puts them at risk for stroke, heart attack, and more.

In 2018, NATF will be focusing on PAD to help patients learn about what it is and what symptoms they should be on the lookout for.

### WHAT IS PAD?



Healthy artery vs. artery with plaque buildup

Peripheral artery disease is a manifestation of atherosclerosis in which the buildup of cholesterol-rich plaques causes narrowing of the arteries of the legs resulting in a significant reduction of blood flow to the muscles and other tissues. Atherosclerotic plaques can develop in many other arteries of the body, and the presence of a blockage in one artery is usually a sign that plaques have developed in other arterial beds. Indeed, PAD is often associated with coronary artery disease (CAD), in which plaques restrict blood flow in the vessels of the heart.

"Patients that have PAD, which is caused by blockages in the vessels that bring blood to the leg, very often have blockages in other vessels, such as the vessels of the heart," explained Dr. Umberto Campia, a vascular medicine specialist at Brigham and Women's hospital.

Because PAD affects blood flow, it can lead to lifestyle limiting symptoms, disability, and other serious health complications.

"Patients who have PAD are at risk for 3 main complications: amputation, heart attack, and stroke," said Dr. Campia, outlining the different risks that PAD patients face.

### WHO IS AT RISK FOR DEVELOPING PAD?

Certain patient populations are more at risk for developing PAD than others.

As patients age, their risk for developing this disease increases. They are more likely to develop other risks for PAD, such as high cholesterol, high blood pressure, or diabetes. Patients who smoke are also at an increased risk.

"Patients should be more aware of the fact that, if they have risk factors for blockages in the heart, they are at risk for developing blockages in their legs," Dr. Campia commented. "Smoking, together with diabetes, is the strongest risk factor for PAD. Patients who smoke or have diabetes have 3x the risk of PAD than people who do not smoke or have diabetes."

### WHAT TYPE OF SYMPTOMS SHOULD PATIENTS BE LOOKING FOR?

The main symptoms of PAD include pain, cramping, and tiredness in the legs when patients are walking. This feeling

often stops if patients stop moving and rest.

"Usually the symptoms include pain in the legs when patients walk, which stops when they stop walking. Patients should be paying attention to symptoms that may be mild, like having weird aches and pains when they walk or if their legs tire easily," said Dr. Campia, while stressing that not all patients with PAD will experience these symptoms. "Only 30 percent of patients with blockages have these typical symptoms. Many patients have very generic symptoms, such as heavy legs or pain in the legs that last even after they've stopped walking."

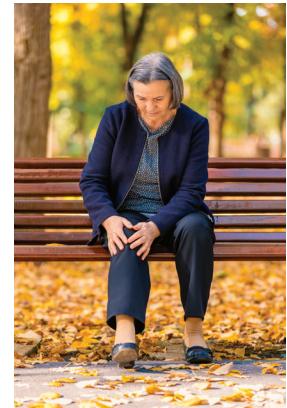
The lack of specific symptoms for PAD makes it difficult for many patients to get the diagnosis and treatment they need.

"The majority of patients who have blockages and don't have recognizable symptoms, don't get them treated. The problem is that even if you don't have symptoms, the fact that you have blockages in other parts of your circulation puts you at risk for heart attack and stroke. Also, the blockages in the legs can get worse and worse and there may not be enough blood flow to keep the tissues of the leg, specifically the feet, oxygenated. So, they may develop ulcers," explained Dr. Campia.

### HOW IS PAD TREATED?

PAD is treated with healthy lifestyle changes and different medications.

Traditionally, healthcare providers have focused on addressing the risk factors for PAD to help patients avoid it. This includes encouraging patients to quit smoking and treating related health issues, such as high blood pressure, high cholesterol, and diabetes.



Until recently, secondary prevention for patients with PAD meant treating them with aspirin or clopidogrel. However, new results from a recent trial, called the COMPASS trial, are bringing this treatment to the next level. The results of the trial suggest that a low-dose anticoagulant paired with aspirin could help better protect patients.

"The treatment that we've had so far has been only moderately effective at reducing the risk of amputation, stroke, and heart attack," explained Dr. Campia. "But, now, with the results of the COMPASS trial, we have a better way to reduce the risk because we are more effective at treating the clot."

"We have evidence that a low dose of a blood thinner, called rivaroxaban, in combination with aspirin, is able to reduce heart attack, stroke, and amputation much more than aspirin alone, with only a slightly higher risk of bleeding," Dr. Campia continued. "With this new combination therapy, we can help to reduce the three risks associated with PAD."

### AWARENESS SAVES LIVES

Despite the serious nature of PAD, not many people know what it is or what symptoms they should be talking to their doctors about. In a study designed to gauge general public awareness, only 26 percent of respondents were

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## DISCOVERING PAD

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familiar with PAD. Among those familiar, only 1 in 4 of them knew that PAD increased a patient's risk of heart attack and stroke. Even fewer knew that it could lead to amputation.

By raising awareness around PAD, NATF hopes to help more patients recognize their symptoms, get diagnosed, and receive the treatment they need.



## PATIENT PERSPECTIVE

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That was the first time I realized how serious my situation was.

When Dr. Rosovsky arrived, I was greeted with a big smile.

She told me they were starting an aftercare program to ensure blood clot patients understood what had happened to them, what treatments were available to them, and to find out what had caused the blood clot in the first place.

She explained that when people don't understand what happened or why they are on a certain medication, there tends to be a high rate of folks who stop their treatment. When that happens, patients can develop recurrent blood clots that can be deadly.

Dr. Rosovsky was part of the PERT team that discussed my case and decided on my best treatment back in August. She told me we were meeting to determine what had caused my PE, how I was doing, and my treatment, so that I could avoid any recurrent blood clots in the future.

She asked me to tell her my story and she took copious notes. She was interested, because I didn't have any clotting gene or any family history of clotting. I was also mildly anemic. She decided to run some tests and took some blood.

On Monday, September 12, 2016, I get a call from Dr. Rosovsky. She told me that she wanted me to come in and meet her and her colleague Dr. Andrew Yee, ASAP. They arranged to meet me on Wednesday. I met with Dr. Rosovsky and Dr. Yee, and she explained that they had found out what had caused my blood clot.

"You have a form of cancer called Multiple Myeloma."

**Multiple Myeloma is a form of blood cancer that develops in the center of the bones, an area known as bone marrow.**

They explained what the cancer was and how it affects individuals. At this point, Dr. Rosovsky told me Dr. Yee would treat me for the cancer moving forward, but she will still be my PE doctor.

From that day forward, I have only felt better. I am forever grateful for the follow-up treatment plan that my doctors implemented.

I want other patients to know that follow-up care is so important. When you're sick, your care doesn't end when you leave the hospital. Sometimes, it's just beginning.

**Mark was able to go on to receive treatment for his cancer. He would like to give a special thank you to his mother, Maureen, who did not miss a single treatment session during the year he was actively being treated. Mark's story highlights the importance of follow-up care. Patients who have experienced a blood clot should always pay close attention to what their doctors tell them and be sure to stay on top of their medical appointments.**

**Thank you, Mark, for sharing your story!**

Are you inspired by stories like Mark's? You can help patients similar to Mark by starting a support group in your community. Join us in the fight against blood clots and email: [info@natfonline.org](mailto:info@natfonline.org).

## 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.

## Introducing NATF's Newest Staff Member

Courtney Johnson is the new Associate Director for the North American Thrombosis Forum (NATF). She is responsible for the day-to-day operations of the NATF office. Courtney graduated from Boston University's Sargent School of Health Science and Rehabilitation in 2012 with a Bachelor's degree in Health Sciences. Prior to joining NATF, Courtney was an office manager in the physical therapy field, helping patients recover from injuries and promoting a healthy lifestyle. She wants to use her knowledge of the healthcare field to further promote awareness of thrombosis and to help educate people to prevent blood clots. Outside of work, Courtney loves to play soccer and spend time with her family and friends.





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