



The Beat

AUGUST 2017

A publication of the North American Thrombosis Forum

Patient Perspective – Lynn Jennings

Lynn Jennings is an Olympic medalist and a nine-time champion of the USA Cross Country Championships. One of the greatest female American runners, she is a passionate athlete who now enjoys recreational running and rowing. In January 2014, her life changed when she suffered a pulmonary embolism. Today, she shares her experience with PE and how running saved her life.

When did you first experience symptoms of a PE, and what were they?

My first symptoms showed when I went for a hilly trail run, four days before the incident. I was uncharacteristically out of breath within minutes of starting the run, which flummoxed me. I figured I was perhaps anemic and persevered through the run, stopping to walk now and then (a definite first). I told myself I'd go for blood work on Monday, which I did. Over the weekend, I felt bad. I had to hang onto the wall going upstairs in my house because my breathing was so labored. Pre-dawn Tuesday morning is when I had to sit down on a sidewalk, unable to walk further.

Lynn was unable to finish her run and struggled to make her way home. Once there, a neighbor drove her to the hospital.

When you were in the hospital, what type of treatments did you go through?

I landed in the emergency room where many labs were taken to try and figure out what was wrong. I had a body scan, a lung scan, and a heart scan. I was hooked up to oxygen and stabilized and I was given an anticoagulant treat-

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PERT: A New Model of Care for PE

When Mark went to the hospital, he had never heard of a pulmonary embolism (PE). But at 49 years old, the business-owner and family man found himself diagnosed with a submassive PE.

It all began one Saturday morning when Mark couldn't catch his breath. When he and his wife left for the hospital, he initially thought he was having a heart attack. Upon arriving at his local hospital, he was diagnosed with a PE and sent to Massachusetts General

Hospital (Mass General) in Boston.

"I got to Mass General and they told me there was a team of doctors holding a call to discuss my case," Mark explained. "I believe there were eleven people on the call, all of them providing input into what needed to happen."

This team of doctors was a Pulmonary Embolism Response Team (PERT), and they are changing how PE is treated.

THE NEED

One in three patients with PE experience a delayed diagnosis. It can be a difficult disease to diagnose. Patients are often told that they have

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THROMBOSIS SUMMIT 2017
SEPTEMBER 16, 2017
Registration is now open!

pneumonia, the flu, or another disease with similar symptoms.

"PE can happen to everybody, including healthy people, athletes, and sick people in the hospital. It happens in every different area of the hospital. It's not just the emergency department that sees PE," explained Dr. Kenneth Rosenfield, the section head of Vascular Medicine and Intervention at Mass General Hospital and founder of the PERT consortium.

"The problem is that no one really knows who to call, no one really owns this disease. It's because the presenta-

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Letter from the Executive Director

Summer 2017 has been a busy one for NATF! We held 3 online and 3 in-person support groups, put on 2 VTE teaching programs in Boston, hosted 2 summer interns from Atlanta, Georgia, travelled to Chicago, Philadelphia, Berlin, Germany and Charleston (and are on our way to Barcelona, Spain at the end of this month!), and continued planning our annual Thrombosis Summit on September 16th and annual Celebration of Gratitude on October 18th.

We also decided that given the overwhelmingly positive response we have had to *The Beat*, and the amount of information we have to share with you, that *The Beat* is going to change from a quarterly publication to a bi-monthly publication. We are also going to offer an electronic version, which will be emailed out to all of our friends of NATF. Your support of *The Beat* has been incredible and I am excited that we are able to offer it more frequently!

On behalf of the NATF Board of Directors and Staff, I would like to thank our individual donors and corporate sponsors for their generosity: The BMS/Pfizer Alliance, Boehringer Ingelheim, BTG EKOS, Daiichi Sankyo, Janssen Pharmaceuticals, and Portola Pharmaceuticals. Without your support, the important work that NATF does would not be possible. We are truly grateful.

Best wishes for a relaxing, fun, and healthy end of Summer 2017.



Kathryn Mikkelsen
Executive Director

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ment. The head physician in the emergency room came and told me that she was very sure the cause was a pulmonary embolism.

Did you know anything about PE before you experienced it? If you had known more about PE, would it have changed how you reacted to it?

I knew what “pulmonary” meant, but I had no idea what an embolism was. The doctor in the ER showed me my lung pictures to explain. I was shocked into silence. I had had extreme trouble breathing but no symptoms in my legs, indeed my ankles and calves were as bony and slim as ever and nothing hurt. So even if I had known more about what a PE was, I’m not sure I’d have added it all up. When I was unable to breathe on the sidewalk and when I was struggling home, I was soaking wet with sweat and my hands and feet were icy. I never added up why all that was happening or what could have been causing it. I was desperate to get home and not thinking of anything else except getting there.

If you could go back to before your experience with PE, is there anything you would want to tell yourself?

I never pieced together what was happening to me as it was happening. I lived alone, so there was nobody right there to look at me and say, “You need help.” I didn’t figure

anything was really wrong (other than maybe I was anemic) because when things really started going south, there wasn’t anybody right there to give me the perspective of, “Hey, this isn’t right.” With the PE symptoms (until I had to sit down on the sidewalk) it never occurred to me that what was happening was hospital worthy.



Can you tell me about how running, and the strength you have physically and mentally from it, affected your experience?

Being a life-long runner with so many years of elite training and performing meant I had, and have, an intimate understanding and perception of how my body feels and acts when under performance stress in times of training and racing. I had no other language for what was happening to me prior to landing in the hospital, so I grabbed the lowest-hanging fruit I could think of: anemia. Somehow in my (potentially) hypoxic state, I forgot that anemia makes you tired not gasping for breath.

Being a tough, robust, confident, and accomplished athlete means I have honed an iron-will discipline, as well as powerful, confident and optimistic thinking that has served me well in both life and running. It never occurred to me that something was “really wrong.”

I’ve always had utmost confidence in my strong body and brain and that confidence has served me well. The pulmonary embolism shook my bodily confidence hugely. I was

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PERT: A NEW MODEL OF CARE FOR PE

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tion of PE can be very subtle. I call it the great masquerader. It can masquerade as a heart attack, as a viral syndrome, or as the flu. It can masquerade as pneumonia, COPD, or just general malaise. It can be silent and subtle. Or, it can be dramatic. People often miss it or they misinterpret it."

"There's a lot of confusion about PE around who should manage it, how to manage it, and where best to manage it," he continued.

THAT'S WHERE PERT COMES IN.

"What we've done is try to stream-line it, centralize it, and eliminate the unnecessary variation in the treatment of patients with PE," said Dr. Rosenfield.

PERT

PERT stands for pulmonary embolism response team and it's a new way that doctors are dealing with PE. Developed first through the efforts of physicians at Mass General, it involves a team of physicians combining different specialties to come up with individualized treatment plans for PE patients.

PERT allows doctors to respond to PE patients in a rapid way. According to Dr. Rosenfield, it was modeled after a rapid response concept. Treatment decisions are made by a group of multi-disciplinary clinicians.

"The requirements of a PERT team are the ability to rapidly respond and to make decisions in a multi-disciplinary way. It's got to involve several disciplines, at least two and preferably more participating in the decision making," Dr. Rosenfield explained. "Part of the reason for that is that there's really no good evidence-based guidelines about how to manage any individual patient with PE. In the absence of real hard evidence, we find that the enlightened-input of multiple clinicians from different disciplines provides the best care for the patients."

THE DEVELOPMENT OF PERT

The first PERT initiative started at Mass General, but it has spread across the country. Each PERT model can differ from hospital to hospital.

"We started with probably six or seven disciplines involved. We set up posters all around the institution that said 'If you have a patient with PE...call 1-800-for-PERT.' Those posters were very effective. People were calling left and right," said Dr. Rosenfield, describing Mass General's model. "The call activates a single beeper that helps streamline the care of PE. We deploy a 'PERT fellow' to the patient's bedside and that person does a rapid evaluation of the patient in the emergency department."

From there, the PERT team holds a "go-to-meeting" call, which can be initiated within 5 minutes for patients with severe cases of PE. Over 50 doctors receive a page for the meeting and anyone available calls in. Doctors can call in from anywhere in the country. The meeting usually involves

5-15 multidisciplinary doctors, who discuss the patient's case and what treatments would be best for them.

The diverse specialties among the doctors allow PE to be approached in a unique way.

"We all learn from each other," explained Dr. Rachel Rosovsky, a hematologist that is part of the PERT team at Mass General. "We all have different strengths, knowledge, and experience. I think bringing that together to come up with the best decision for the patient is what is making this so successful."

"The full range of treatments are considered for every patient," Dr. Rosenfield said. "It's worked incredibly well. Over the past 5 years, we've taken over 800 calls. It's a lot of work and a lot of contribution, but I think the patients have greatly benefited from this multidisciplinary approach."

Out of the success of the PERT initiative rose the PERT Consortium. The Consortium aims to guide and influence PE care nationally. With the help of the PERT Consortium, hospitals across the country are creating PERT teams individualized to fit the needs of each institution. All of these teams are working to combine their data and experiences to develop the best protocols for PE care.

FOLLOW UP CARE

A key part of Mass General's PERT initiative is follow up. Dr. Rosovsky started and runs a follow up clinic that mimics what the PERT team does in the hospital.

"About two years ago we realized that all of these patients were getting an incredible multi-disciplined, rich experience in the hospital, where all of these people were thinking about them and coming up with a plan," she said. "Then, they were being discharged,

usually to the attending doctor or maybe their primary care doctor. We realized we weren't doing a really good job of following these people once they got out of hospital. They were losing out on the experience they'd had there. We thought, 'why not continue that?'"

The clinic is held twice monthly. The PERT doctors meet to develop short and long-term plans for their patients.

MARK'S STORY

It was the follow up care that changed Mark's life.

Dr. Rosovsky contacted Mark a week after he was released from the hospital and invited him to come meet with her. He went to the clinic and had blood drawn, hoping to find out why he had experienced a blood clot.

Mark's doctors discovered that his clot was caused by multiple myeloma, a form of cancer.

While Mark had a new battle to face, he was glad to understand why he developed his PE. By discovering his cancer, he could seek treatment and avoid another PE.

"I feel extremely fortunate for the strides they've taken at Mass General," he said, describing his experience with the PERT team as seamless. "I was a ticking time bomb

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NATF hosted a booth at the 3rd annual PERT Consortium meeting with the help of summer intern Avanti Upad.

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terrified by what happened to me. I remember being in the hospital that week and being afraid of leaving the safety of my room and the incredible care of the doctors, nurses and specialists. I was afraid I'd drop dead on the sidewalk. That was the first time I'd ever experienced that feeling of complete bodily vulnerability.

What was your recovery process like for you? Does your experience with PE still affect you?

My recovery was probably textbook, but it didn't feel that way to me. My body felt completely weak, exhausted, and assaulted when I was finally released to go home. I was determined to get back outside to walk my dog, Towhee, and to run again, but all of that took much longer than I would have ever anticipated. It was a triumph to retrace Towhee's and my steps a week after I got out of the hospital. I was given specific instructions about not running for a while but tried anyway and realized, once again, the experts knew what they were talking about. So, I worked to build

my strength by walking with Towhee as much as I could. It was slow going, but I did it. I didn't go into the forest for quite a while, because I was still haunted by the idea that I might drop dead and didn't want to be alone on a trail far from help. My confidence came back as my strength rebuilt.

Can you tell me more about your recovery? What type of treatment did you receive?

I was on Lovenox for a while and then on warfarin. Dealing with the dosing of the warfarin was a real trial with daily visits to the lab. That was a real adjustment! I successfully got off the warfarin exactly one year after going on it. I did not start running regularly again until August, almost seven months later. In the interim, I biked, hiked and walked and did a little bit of sculling. Mostly I allowed myself to heal fully. Even that summer, I was getting out of breath just walking up slight inclines.

I began running again and started with one mile. I built back up and was running free, healthy and with true vigor 1.5 years after the PE. I didn't really feel like my full

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The IDEA Summit

In May, NATF attended the 2017 IDEA Summit in Washington D.C., entitled "Advocacy's Engagement of Employers and Payers in the New Healthcare Landscape." It was an exciting trip that highlighted the importance of healthcare advocacy and offered enlightening insight into the relationship between advocates, employees, employers, and health insurance providers.

"This summit focused on how advocacy organizations can engage with employers because there has been such a shift to the role employers are playing in healthcare," explained Matt Stella, National Policy & Advocacy Director, Cardiovascular & Diabetes, at Johnson & Johnson Healthcare Systems Inc. "It used to be that very large organizations were self-insured. Now, much smaller organizations are going down the self-insured route. They are playing a very prominent role in the benefit design, which can affect which therapies and medications are available to employees."

This was the 3rd IDEA Summit held by Johnson & Johnson Healthcare Systems Inc. IDEA stands for "Partnering to Inspire Change Through Insight, Discussion, Empowerment, and Advocacy." NATF was one of 48 advocacy organizations there. Attendees represented a wide range of health concerns including diabetes, mental health, and heart disease. This diversity created a very engaging and collaborative atmosphere. While each area of health faces different challenges, many issues, such as transitions of care, are surprisingly similar.

"This is something we've now done for three years," Matt said. "We've changed the topic, covering everything from patient engagement to the political landscape. We realized based on feedback from our partners that there was a big gap in the space of employer engagement in advocacy organizations."

The day opened with Diane McClune, Vice President

of the Pittsburgh Business Group on Health, giving the first talk, "Employers and Employee Health. Where do Professional and Patient Advocacy Organizations Fit in?"

The next speaker was Fred Goldstein, President of Accountable Health. Fred's topic was, "Employer Demands Driving Payer Changes: How Advocacy Can Support Both Employers and Payers." Fred stressed the importance of advocates working together to help patients better engage the healthcare system. The market is rapidly changing and there is a movement towards value-based care. Advocacy groups, like NATF, help patients gain a better understanding of their disease, allowing them to better engage the healthcare system.

Following Fred's talk, there was a panel discussion to expand upon Fred and Diane's topics. Panelists included representatives from the advocacy space, the employer space, and the payer space. The speakers touched upon the importance of healthy employees in the workforce. When employers empower their employees to be healthy, through providing comprehensive healthcare and through modern HR policies, they benefit. Healthy employees are more productive, do better work, and require fewer sick days. Advocates like NATF can leverage this important connection when pushing for better patient healthcare.

Johnson & Johnson plans to continue their important work and to build on this year's IDEA summit.

"It's about really driving better patient outcomes and improving access for patients. At the end of the day, that's really at the core of what we do from a patient advocacy perspective," Matt explained.

NATF staff attends conferences and summits like this one to remain on the forefront of patient advocacy. These events help us to engage with other advocacy groups and to take the pulse of patient needs across the country.

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self, especially on up-hills, until the year and a half mark. In August of 2016, I was in the Alps for a month of high altitude hiking and I trained hard for it all summer to prepare. I knew upon completion of the training, and then the trip, that I was back to full strength. I am back to all my usual exploits: nordic skating and classic skiing, running, road cycling, hiking, sculling. My heart and lungs are 100%. I've never felt more thankful and appreciative or lucky.

Are you still on any type of treatment?

I am not on any kind of treatment and I've made a full recovery. In the end, the diagnosis was an unprovoked PE. Before the PE, I did not have a primary care physician (PCP) and had not had a physical or anything of that sort in years. I figured if it took that whole huge team at the hospital to get me well again so I could be out in the world, then I should do my part for self-care. I dutifully go to a PCP and got all the backlog of physical work done so that I was doing my part to honor the work that went into making me whole again by so many caring medical professionals.

I am beyond grateful to the professionals at Legacy Good Samaritan Medical Center in northwest Portland, OR and in particular to my attending physician, Dr. Marilyn Replogle, as well as the over-the-top superb nursing staff who took incredible care of me. I was an extremely coachable athlete and I took that same approach with everyone who was caring for me. If they told me to do something, I did it. Dr. Replogle told me she was unsure why I was still here, that it was keeping her up at night and she wanted to figure out why this had happened to me. Her honesty and professional care gave me the confidence to face what had occurred and to commit to getting healthy. I am indebted to her.

Do you have any messages for others dealing with PE?

My message: rely on the experts around you, get informed about what has happened, and learn everything you can.

Most of all: listen completely to your body as you recover. There is no timetable except the one your body sets. It took me a long time to trust my body again, and I got there by listening and absorbing fully how I felt. I guess I just mimicked completely what got me to the top as a world-class runner: I listened to my body and to the experts who guided me.

Last: keep moving. Run, walk, bike, swim, hike, do yoga..... do. not. sit!

Interested in learning more about Lynn? She will be sharing her personal journey at the upcoming NATF Celebration of Gratitude. Tickets and details are available online at www.natfonline.org. Email Events@natfonline.org to learn more.

PERT: A NEW MODEL OF CARE FOR PE

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without anyone knowing."

Today, Mark is receiving treatment for his cancer and is on an anticoagulant, but he's feeling great.

"I feel better every day. I get stronger every day," he remarked, praising the nurses and doctors he's been working with. "The care I've gotten at Mass General is bar none."

If you would like to learn more about PERT, visit the PERT Consortium website at pertconsortium.org

Thrombosis Summit 2017 Registration is now open!

When: Saturday, September 16, 2017
7:30 AM – 12:00 PM

Where: Joseph B. Martin Conference Center
77 Avenue Louis Pasteur
Boston, MA 02115

This special half-day educational conference will focus on treatment breakthroughs and updates on venous thromboembolism, stroke prevention in diabetes, atrial fibrillation, and more. It is designed for physicians, pharmacists, nurses, nurse practitioners, physician assistants, and allied health care professionals. Patients, family members and caregivers are also encouraged to attend.

*Healthcare providers can earn up to 2.5 CME credits for attending this program, which is accredited for both ACCME and ACPE credits.

\$49.99 Registration fee includes continental breakfast, networking coffee break, all clinical sessions, the Arthur A. Sasahara Annual Lecture, parking at the venue, and an electronic syllabus.

Register online at www.NATFOnline.org.

2017 Celebration of Gratitude



CELEBRATION
OF
GRATITUDE

"Going the Distance" for the North American Thrombosis Forum

October 18, 2017

Joseph B. Martin Conference Center

NATF would like to invite you to join us for the 2017 Celebration of Gratitude, our new premier fundraising event. It will be an exciting night of inspiration, thanksgiving, and fun. First, join us for an evening cocktail hour and then hear from our guest speaker, Olympic medalist and blood clot survivor, Lynn Jennings.

For more information and registration, visit www.NATFOnline.org.



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Upcoming Events

In-Person Blood Clot Support Group at BWH

Sept. 26, Oct. 30, Nov. 28, 2017

All support groups start at 7:00 p.m. and are held at Brigham and Women's Hospital. To register, email NATF at events@NATFonline.org or call 617-730-4120.

Online Blood Clot Support Group

NATF's online Blood Clot Support Group offers patients the opportunity to share common concerns, offer support to one-another, and to learn up-to-date and accurate information on research in the field of VTE. Dates and speakers for our upcoming meetings can be found at www.natfonline.org. To register for this online support group, please contact events@natfonline.org or call 617-730-4120.

European Society of Cardiology Meeting

August 29, 2017

Barcelona, Spain

"Stopping the VTE Epidemic in Hospitalized Medically Ill Patients: An Innovative, Cutting-Edge, And State-of-The-Art Action Plan"

2017 Thrombosis Summit

September 16, 2017

Joseph B. Martin Conference Center

This special half-day conference is designed for physicians, pharmacists, nurses, nurse practitioners, physician assistants, and allied health professionals. Patients, family members, and caregivers are also encouraged to attend.

2017 Celebration of Gratitude

"Going the Distance" For the North American Thrombosis Forum

October 18, 2017

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American Heart Association Scientific Sessions

November 13, 2017

Anaheim, CA

"Preventing Pulmonary Embolism and Stroke: A New Era of Enhanced DOAC Efficacy and Safety – Focus on Case-Based Cardiovascular Patient Management"

Avoiding the Avoidable: Pathways for VTE Prevention in the Vulnerable Medically Ill.

December 2, 2017

Joseph B. Martin Conference Center

NATF will be hosting a series of educational programs across the United States that are designed for medical professionals and will center on protecting medically ill patients from VTE.

Healthcare providers will have the opportunity to earn CME credits.

For more information and to register, visit www.regonline.com/VTEBoston.

For more information on any of these events, email events@natfonline.org or call 617-730-4120.
We look forward to hearing from you!