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## **Patient Experience: Pulmonary Embolism Survivor**

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Hi, my name is Leslie Lake and I'm a pulmonary embolism survivor. This happened to me in June of 2018. I live in New York City, and New York City in 2018 are actually important things to know, because one would think that having a pulmonary embolism in New York and in 2018, that I as a patient would have received a lot of information from healthcare professionals when I had my PE. I received nothing. I left the hospital really scared, and really sick.

What happened to me? In June of 2018, I was walking back to my apartment, all of a sudden had a really hard time breathing going up a slight incline and thought I was having a heart attack. I managed to make my way back to my apartment holding on to the side of buildings and called my doctor's office who had just retired. I was told that I couldn't come into their office because I would be considered to be a new patient. Long story short, I ended up in the emergency room. I really didn't want to go to the emergency room. The first thing that I will tell a patient is if you feel any kind of symptom whatsoever, just go, that is the most important thing. Trust your body because you usually know that something is wrong. In my case, I knew something was really wrong. I ended up in the emergency room. It took about nine hours before anybody did a scan of my lungs to see why I was having a hard time breathing. I had actually had my period when I went to the emergency room, and they decided at the hospital that they would do three gynecological exams on me. I think that's probably because I'm female, and the healthcare professionals don't really know what the signs and symptoms of a blood clot are.

Anyway, I ended up being diagnosed having a pulmonary embolism, which is a blood clot in your lungs. I ended up going into the ICU. I had never been in a hospital before. Not ever. The only person I knew who was in the ICU was my father and that's where he died. I was terrified of going into the ICU. I spent basically two days there trying to figure out what was going on. They had me hooked up to an IV, which turned out to be heparin, which is a blood thinner. I was woken in the middle of the night by a doctor who asked me if I knew what was going on. I said I had a blood clot in my lungs and she said, "Oh, no, you have many blood clots in your lungs," and turned around and walked out and left me there.

So began my journey. Before I was released, they wanted to make sure that I could actually walk about 50 yards down the hospital hallway, which I could do. A pulmonologist came to see me and asked if I had taken any long flights recently and I said, "No." He spent about five minutes with me, and then they gave me a prescription for a blood thinner and sent me home. I had nothing, absolutely nothing. This led me to

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try to get as much information as possible as a patient. I started like many people who have access to the internet, online, trying to do my own research. That led me to a place called the National Blood Clot Alliance. The National Blood Clot Alliance is the only patient-advocacy group in the United States focused purely on blood clots, so DVTs and PEs, and it's an online facility for patients to get information. The information was so good that I ended up actually joining the board and I'm now chairman of the board of the National Blood Clot Alliance. There's a reason for that as well.

As I began to do my own research on what had happened to me, I learned very quickly that most patients actually do leave without information, so I was not unique in that I was not given any information. However, as a female and having been put on a very heavy dose blood thinner and having my period, obviously, I had very heavy bleeding, and I couldn't actually reach the doctor to see if that was normal or not. It wasn't normal, so a lot of abnormal things were happening to my body. Anyway, as the research continued, I started to learn that women and African Americans in particular, were at much higher risk of blood clots as high as 30% to 60% higher for African Americans than Caucasians. Is it because they're not treated the same? Is it because they have a higher incidence level? There are a lot of unknowns. The same thing with women, women tend to get treated differently. I was treated differently. I was having a hard time breathing. I couldn't breathe, but yet, they insisted upon doing three gynecological exams on me. If you're an African American woman, and you're pregnant, it is one of the leading causes of maternal death for women, a pulmonary embolism. So much of this can actually be controlled in a hospital setting. We know that there's a tremendous level of disparities between who gets treated, how they get treated, and their outcomes over a certain amount of time. Learning all of that, I came to the National Blood Clot Alliance. I started out knowing absolutely nothing. After a period of 30 days, learned a lot about signs and symptoms. I was terrified of having an actual pulmonary embolism again.

I want to just talk about the patient perspective and what happened to me that led me to become an advocate. It really stems from the fact that I had this event. I received no information. I live in a major metropolitan area where you would think the information would be at the hands of both my fingertips and the health care providers, and it wasn't. If I can have access to people and doctors in New York City, imagine people who don't have access to it, what they're going through. The National Blood Clot Alliance was really a safety net for me. I want to provide that same safety net to other patients, no matter where they may be in the country. Especially for people who we know have much higher incidence of recurrence or just blood clots in general.

What happened? Fast forward. I had basically two hospitals that I was running on parallel paths, which I know is very unusual. There's a high recurrence rate of pulmonary embolism if you've had one. What was my main objective? My main objective was to stay alive. I was terrified physically. I was terrified mentally, and I think most healthcare providers don't understand the mental health component of what we patients are going through. We need that physical safety net. We need that mental

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safety net. We need both of them available to us. Lucky me, I had access to doctors in New York City, and I know I'm lucky and I know I'm privileged. Hospital number one said to me, stay on the blood thinners and in six months' time, we're going to take you off. We're going to put you on an aspirin. If you have any chest pains, call the emergency room, tell them that you're having a heart attack as opposed to a blood clot, because a lot of people don't know what a blood clot is. That wasn't an acceptable answer. I did all kinds of research myself. I ran on a parallel path with another hospital. I knew there were research projects out there, and it was pretty clear that the evidence said if you were what's called unprovoked, which means they don't know why I had the blood clot. There are many reasons why you can get them, but they don't actually know why I had it. If you don't want to have another recurrence, stay on your blood thinner. They said you're going to have to be on it probably for life. Did I want to be on a blood thinner for the rest of my life? Probably not, but do I want to stay alive? Absolutely. Because I found that there was such inadequate information in the hospitals and by the doctors and by the nurses. We all know that the health care systems are overwhelmed, to begin with. I'm not blaming them for what had happened, the lack of information, but it really drove me to want to make a difference, to be able to support other people. Knowing that I had access, knowing that I now had this relationship with the National Blood Clot Alliance, I thought to myself, I'm in a position where I can actually learn from what happened to me and help other people.

Here I am almost three years later. We refer to it as my “clotiversary”, we patients. I'll be coming up on my three-year anniversary in June of 2021. What will I say to a health care professional and to a patient? To the health care professional I say, we're scared as patients. We're understanding maybe one out of every ten words that you may be saying to us. You need to give us material. You need to be able to direct us someplace, send them to the National Blood Clot Alliance. The information is on the internet, call us up, I'll be more than happy to give information, but give us information, answer our questions, know that there are periods in people's recuperation, 0 to 30 days, really super important. We know that the recurrence rate is high. I thought I was having another PE because my body felt different than it had ever felt before. I needed somebody to say to me, “hey, this is normal and this isn't normal.” Unfortunately, I had to learn that myself. Having resources available to patients is really important. Speaking in plain language to a patient; a lot of times, I didn't actually understand what the doctors were saying to me because they speak in a different language than we do as laypeople. Really just slow it down, make it a little more simple for people and make sure they have that safety net, make sure that you're available or somebody is available or there's another patient available who's already gone through this for them to talk to. Take their call, take their emails. Again, provide them with as much information as possible.

For the patient, you are going to experience things both physically and mentally that you've never experienced before. I didn't know what it was like to be on a blood thinner. I didn't know what would happen to me. I didn't know that when I brushed my teeth, my gums would bleed. Little things like that. If you're a female and you have your period, it's



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going to impact you. What should you be doing in terms of exercise? Some people can go back to exercising sooner than others. It took me a long time to get re-engaged. It's okay to ask these questions and it's okay to be scared.

The mental side is the hardest side. It's almost three years for me. I still suffer from it. I don't think there's any patient out there who won't say this hasn't impacted me mentally. The body heals itself. Blood thinners after you have your blood clot incident, they don't heal the blood clots in your body, but they prevent new ones from happening. Your body will take care of the existing blood clots themselves. It takes time, but the mental side, that's the really hard part. It's normal to be scared. It's normal to be frustrated, it's normal to be confused, and you shouldn't feel bad about that.

To both healthcare providers and to the patients, I want to say, that's okay, work together, create those two safety nets. One is information and awareness on the physical event that's happened to you. The other is the mental side of the equation and the physical side might heal faster. The mental side might take a little longer, and it's okay. That's why we're all here today discussing this so that you have the information to control your outcomes and to help other people as well. That's why I joined NBCA. That's why I advocate for other patients because I don't want anyone to go through what I went through in 2018.