

Patient Advocacy
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Introduction

More than 900,000 people in the United States are estimated to develop venous thromboembolism or clots in the veins every year. Of these, about 380,000 people develop deep vein thrombosis, which occurs in the inner veins of the leg.

Pulmonary embolism a serious and often fatal complication of deep vein thrombosis, affects about 530,000 people in the United States annually and almost 300,000 people die each year in the U.S. due to blood clots in the veins and this number is greater than the number of people who die each year of AIDS, breast cancer, or automobile accidents combined.

My Story

I returned to work just a few short days after undergoing arthroscopic knee surgery from a tilted kneecap. Within two weeks, I started experiencing severe pain in my knee and calf. The swelling was increasing, and it felt hot to the touch. In fact, there was so much swelling that you could not see the natural crease behind my knee. I just assumed it was part of the healing process after knee surgery, since I had never heard of deep vein thrombosis (DVT) before. When I returned to my orthopedics' office for my 2-week follow-up appointment, I explained my symptoms; the swelling of my knee, excruciating pain, and inability to sleep because of that pain. None of the pain medication I had been given provided any relief. My doctor instructed me to go home, elevate my knee, and continue to ice it. I got the distinct impression that he thought I was just trying to get more pain medication, which offended me. I remember getting into my car after that appointment and calling my father crying, powerless to understand why I was in so much pain, and unable to believe there was nothing anyone could do to relieve it.

At work 6 days later, I had just returned to my desk after chatting with a co-worker over coffee, when I suddenly lost consciousness. When I came to, I experienced a shortness of breath that felt like I was suffocating. I was freezing cold, but sweating. Fortunately, I am a member of our company's medical response team and CPR/First Aid certified, so I knew immediately that something was wrong. I called out to a co-worker who was also on the response team, and asked for help. She brought the oxygen to me, while other members of the medical response team arrived. Even with the oxygen I was unable to breathe. I then asked her to call 911. After just a matter of minutes, the paramedics arrived to find me having difficulty breathing, my skin was colorless, and my lips had turned blue. They immediately rushed me into the ambulance and transported me to the hospital. While in route, I went into full cardiac arrest and they began CPR.

The Emergency Room doctor was able to revive me upon arrival at the hospital. My parents arrived shortly thereafter. Later that morning I seized, and went into another

cardiac arrest. With CPR, they were able to revive me once again. The medical team ordered a CT scan and found a massive pulmonary embolus (large blood clot in the lungs) and several smaller blood clots. At this point, the Attending Physician went to my parent's and told them I would not survive. He suggested that my family members and friends be called to come and say their goodbyes. My sister flew in from Memphis, Tennessee, and my brother drove down from Santa Barbara. Family friends also arrived. I am a single mother of two young children, who were taken out of school and brought to the hospital immediately so they could say goodbye to their mommy. Everyone has said to me "I can't believe what you went through," but to me, I can't believe what my family must have endured that day. My parents, having to witness their daughter laying unconscious with tubes down her throat, were forced to make terrifying life or death decisions about my treatment. The doctor informed them that there was a drug called tPA (tissue plasminogen activator), which could potentially dissolve the clot—at a cost. The risk of hemorrhage was severe. At that point no one thought there was much of a choice—I was going to die either way. My parents allowed the doctor to administer the tPA and also implant a permanent Vena Cava Filter to help prevent future clots from going into my lungs. Remarkably, several hours later, I began to show signs of improvement.

I spent the next 7 days in the Intensive Care Unit before I was able to go home. It took another 2 months before I was able to return to work. In order to prevent future blood clots, I will be on warfarin (blood thinning medication) for the rest of my life. Because of this, I have had to come to terms with the fact that my whole lifestyle will have to change. I will no longer be able to have children, and there are many physical activities I can no longer participate in. In spite of this, I am so grateful to be alive! I am grateful for the quick thinking of those paramedics, and my ER doctor.

Recovery has been slow. It seemed to take a long time for my lungs to return to normal. Simple things, like walking to and from the mailbox, made me completely out of breath. I continued to experience chest pressure for months. I also had damage to my vocal chords from being intubated, which today has almost healed.

8 months later, I still have a DVT in my left leg. I also have a few veins that have no blood flow due to the clots. I suffer from pain and swelling as a result of the DVT. Some days the pain forces a slight limp when I walk. Though I find some relief in the morning, as the day goes by the pain, discoloration, and swelling increases. I have become accustomed to wearing open-toed shoes because of the unpredictable swelling. I have also, on occasion, caught myself dragging my foot because my leg feels so heavy. Over the past 8 months, I have been to so many different doctors and each one tells me something different. An Interventional Radiologist at UCLA said he couldn't remove the clots because they are "too old". I even had another doctor tell me that DVT is not painful.

Looking back, I can't help but think that if the symptoms of DVT had been in my discharge papers from my knee surgery, I would have gone to the emergency room on my own and not had to rely on my doctor for the diagnosis. The only symptoms

mentioned in my discharge papers were the symptoms of possible infection at the incision area—yet, now I know that knee and hip surgery are risk factors for DVT. Maybe at my doctor's office when they originally scheduled the surgery, I could have been given a pamphlet on DVT to educate me on the risks and symptoms—another missed opportunity at prevention. Today, I truly believe that a simple pamphlet listing the warning signs and symptoms of DVT could save the lives of so many people. Not just patients having surgery, but patients who are hospitalized, woman on birth control or hormone replacement therapy, or just released from giving child birth, and other individuals who might be at risk. DVT and pulmonary embolism (PE) are like a ticking time bomb. Had I known the warning signs—had my doctor thought to order an ultrasound of my legs—my children and family would never have had to hold my hand and say goodbye to me.

Why I became a Patient Advocate.

It has now become my passion to raise public awareness, educate patients and health care providers, and improve thrombosis medical standards.

Why NATF is forming a Patient Advocate Program?

NATF has recognized how patient advocacy can help to provide some simple changes in our medical standards that could help save lives.

At the 2007 Thrombosis Summit, I was part of the NATF Working Group Session on Advocacy. The group was comprised of both patients and health care professionals.

The following three action items were suggested to help NATF raise awareness and promote patient advocacy:

1. **Discharge Papers** – Educating patients upon discharge of the warning signs and symptoms
2. **Support groups nationwide**
3. **DVT FAQ** – Fact Sheet/Website for new patients

Closing

The NATF Patient Advocacy Committee will work with congruent organizations to implement awareness strategies such as these in the next few years.