



ADVOCACY THROUGH OUTREACH

Personal Stories from www.NATFonline.org

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Contents:

1. Kelly Clark: Deep Vein Thrombosis and Pulmonary Embolism.....pages 2-4
2. Nicole Giardina: My Experience With Cerebral Venous Thrombosis.....pages 5-7

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Making a Difference: Kelly's Story

Kelly Clark is a 40-year-old professional and mother of two young children, who resides in Aliso Viejo, California. In early 2007, Kelly was diagnosed with a pulmonary embolism following arthroscopic knee surgery. Thrombosis awareness, education, and prevention have now become her passion. We are pleased to welcome Kelly as a NATF Patient Advocate.

Deep Vein Thrombosis and Pulmonary Embolism

By Kelly Clark, Aliso Viejo, CA

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.



Making a Difference: Nicole's Story

21 year-old Nicole Giardina is proof that patients are their own best advocates for thrombosis treatment and prevention. Having recently suffered a left dural cerebral thrombosis after the birth of her first child, she felt compelled to share her experience in an effort to help raise awareness of the warning signs and symptoms of this condition.

My Experience with Cerebral Venous Thrombosis

By Nicole Giardina, Glendora, CA

On March 24, 2007 I gave birth to a health baby girl, Natalie Gomer. It was a difficult delivery, but I recovered just fine. Three days later we were released from the hospital and I was able to take Natalie home for the first time.

One week after coming home, I began to feel pain above my left eye. I thought the headaches were due to post-partum hormones, or possibly an epidural. I called my OB/GYN and he gave me a prescription for Imitrex (used to treat migraines), which did nothing for the headache.

Another week went by and the headaches increased. The pain was unbearable, I was experiencing nausea, vomiting, vertigo, extreme lethargy, and blurred vision. I couldn't sleep or leave my bed for several days because the pain was so severe. In just 2 weeks, I lost all 40 pounds of my pregnancy weight.

I called my primary care doctor for an appointment. They were booked, so I called my health insurance's 24-hour nurse line, where I was advised to go to an Emergency Room. My mom drove me to an Emergency Department near my home. The physician on call was curt and did not take my headache seriously. The physician ordered a CT Scan which came back normal. I was diagnosed as having a sinus infection and prescribed Vicodin for the pain and Amoxicillin for the infection. My mom and I asked if it could be an epidural headache and we were told it was not possible 2 weeks after delivery. We went home, filled the prescriptions, and I began taking them that night.

On April 14, the day after my visit to the ER, I lost all hearing in my left ear and continued to have an excruciating, unbearable headache. I returned to the ER with my father where a different physician diagnosed the headache as a post-partum anxiety headache. I was prescribed Lorazepam for anxiety and advised to discontinue the sinus infection prescriptions that the previous ER doctor had diagnosed.

Two days later, I was still suffering from the intolerable headache, unable to get out of bed or eat. My symptoms were increasing in severity and I had reached my breaking point. In desperation, my mother called a friend of the family who is a doctor. He advised us to call my primary care Doctor and demand an immediate appointment and request he order an MRI.

That afternoon I saw my primary care doctor who hesitantly ordered an MRI. Two days later, I had the MRI. We were contacted by the MRI technician and told that there was an abnormality and that I needed to go to my hospital's Emergency Department, where my primary care doctor would meet us to explain.

When I arrived at the Emergency Department, my mother and I were ushered into an office where my doctor and the Head of the Emergency Department explained that the MRI revealed a life-threatening blood clot in my brain. The exact diagnosis being a Left Dural (Cerebral) Venous Thrombosis. I was advised that I had to be admitted immediately to the hospital for an uncertain duration of time—the length of my stay would depend on how I responded to treatment.

I spent the next 4 days in the hospital and was placed on DOU. I was given intravenous heparin (blood thinning) treatment. Because the MRI had also shown Sinusitis with Mastoiditis, I was given Unasyn 3 grams every 6 hours. My PT/INR (blood thinning test) was monitored every 5-6 hours. Physically I was wasted. Emotionally, I was devastated and severely depressed. It broke my heart to be away from my newborn daughter. Not knowing how long I would be in the hospital made my sorrow that much worse. Because my daughter Natalie was so young, she could not be brought into the hospital for me to visit with her. With the help of some wonderful nurses who wheeled me out in front of the hospital—IV's and all—I was able to hold her. The visits were bitter-sweet, I knew our visits were temporary, that she would return home soon with my parents and I would go back to my hospital bed without her.

On April 21, my fourth day in hospital, my headache had subsided to a tolerable level, manageable with Tylenol pain reliever. The hearing in my left ear was returning, as was my vision, and I was tolerating food well. My INR was within therapeutic range, so the decision was made that I could be discharged from the hospital. I was placed on Keppra 750 mg twice daily to prevent seizures, Coumadin 6 mg once daily, and Augmentin 500 mg.

After discharge, I began having my PT/INR monitored every Monday at the hospital's out-patient lab and followed-up every Thursday with my primary care doctor to discuss dosing and the results of my weekly lab work.

In June, I had my first appointment with a specialist, a Neurologist from the University of Southern California (USC). She informed me that the clot was permanent and that I would have to continue to be monitored for the rest of my life. She informed me that I would stay on Coumadin for another 6 months depending on my improvement, followed by aspirin therapy indefinitely, and that I should remain on the Keppra to prevent seizures for another 3-4 months. She said having any more children would be extremely risky and that if later on in a few years, once on aspirin therapy, if I chose to try for more children I would have to be monitored very closely and would be an extremely high risk pregnancy. She explained that I absolutely had to avoid any type of injury that could cause heavy bleeding or a head injury as it would be deadly due to the

Coumadin treatment, and stressed that I keep in good physical health to avoid complications.

This August, I have a follow-up appointment with my Neurologist to get the results of the blood work she ran checking for Factor V Leiden (genetic predisposition for blood clots), Lupus, and any other diseases that may have caused my high tendency to clot.

I still suffer from headaches, some days worse than others, but they are now usually manageable with Tylenol. The Keppra medication to prevent seizures reduces my appetite and causes me to be drowsy, so I still have some days that it's hard to get the energy to get out of bed. Due to the Coumadin treatment, I have to avoid alcohol and Vitamin K in my diet since it would affect the medication. I am also very careful to avoid cuts and bruises.

I am grateful to have such a strong network of support. In anticipation of the birth of my daughter, my mom had taken time off work to help me adjust to taking care of my child. It ended up being an extra blessing because she was able to care for my daughter while I was in the hospital, and was still home to help me recover when I was released after the thrombosis. My parents Dennis and Janice Giardina, my boyfriend Eric Gomer, and his parents Gary and Karen Gomer, also help in caring for my daughter while I go to my weekly appointments.

Emotionally, I have run the gauntlet. Through the amazing support of my family and loved ones and the life-saving treatment from my doctor's, I am proud to say I am a survivor and that every day I live to see my daughter grow up is a miracle! I work hard to stick to my treatment regimen and at maintaining my emotional and physical health. I did nothing on my own, I have support every step of the way, and for me it was those people, and my daughter especially, that made all the difference.

"You gain strength, courage, and confidence by every experience by which you really stop to look fear in the face. You are able to say to yourself, 'I lived through this horror. I can take the next thing that comes along'."—*Eleanor Roosevelt*