Cerebral Venous and Dural Sinus Thrombosis (CVT)

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Cerebral venous and dural sinus thrombosis (CVT) is less common than cerebral arterial thrombosis, and has an unpredictable clinical course. The true incidence of this disorder is unknown because it is probably underdiagnosed. Some studies estimate that it affects 3-8% of the population, predominantly women. Classically, with thrombosis of the deep cerebral venous system, patients present with severe headaches, seizures, impaired brain stem reflexes and long tract signs and rapidly progress to coma. However, partial syndromes with a diverse spectrum of neurological symptoms also exist. These less severe clinical presentations of CVT, which may lead to initial misdiagnosis, depend on the extent and location of thrombosis and venous collateral vessels, the degree of venous congestion and the rate of thrombus progression.

Although the evidence is not conclusive, anticoagulation appears to be safe and may be associated with improved outcomes, even in the presence of cerebral hemorrhage. Alternative treatment options, which are just emerging, include endovascular procedures such as intrasinus thrombolysis. Given that the identification of venous obstruction has important therapeutic implications, this diagnosis should be strongly suspected in patients with severe headaches with or without other associated neurological signs, who have risk factors for CVT. Magnetic resonance imaging (MRI) with magnetic resonance venography (MRV) are the diagnostic modalities of choice. Many risk factors have been identified for CVT but the most common ones include, female gender, hypercoagulable disorders, oral contraceptives, pregnancy, and peurperium. Differential diagnosis includes mass lesions (intraparenchymal hemorrhage, epidural or subdural hematoma tumors, brain abscess), stroke, trauma, toxins, or headache syndrome including complicated migraines.

In summary, new onset headaches in a headache free individual or changes in pattern of stable headaches with or without neurological changes should prompt immediate neurological evaluation. Neurological changes which may accompany headaches associated with CVT include: language or speech difficulties, visual loss or double vision, weakness in arm or leg, seizures, loss of consciousness, clumsiness or tremor. The neurological evaluation in these cases should include a detailed examination as well as imaging studies, preferably MRI.

My Experience with Cerebral Venous Thrombosis (CVT)

On March 24, 2007 I gave birth to a healthy 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 postpartum hormones, or possibly the 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. I was told they were booked, so I called my health insurance’s 24-hour nurse line, where I was advised to go to the 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, but 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 postpartum anxiety headache. I was prescribed Lorazepam for anxiety and advised to discontinue the sinus infection prescriptions that the previous ER doctor had diagnosed.

Making a Difference: Nicole’s Story

21-year-old Nicole Giardina is proof that patients are often 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.

To learn more about how you can make a difference, visit www.NATFonline.org/policy_advocacy.html.

If you are interested in becoming a NATF Patient Advocate, please email info@NATFonline.org.
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 Giar-
Our Mission

The North American Thrombosis Forum (NATF) is a nonprofit organization that focuses on unmet needs and issues related to thrombosis and cardiovascular diseases such as deep vein thrombosis, pulmonary embolism, myocardial infarction, peripheral arterial occlusive disease, and stroke. The five areas of major focus are: 1) basic translational research, 2) clinical research, especially diagnosis and therapy, 3) prevention and education, 4) public policy, and 5) advocacy. NATF’s legacy will be to improve patient care, outcomes, and public health by supporting thrombosis-related programs, such as novel research projects, innovative educational programs, public policy initiatives, regulatory issues and advocacy, and to broaden training opportunities for physicians, scientists, and other health professionals.

How You Can Help

As a Fledgling Organization, we rely upon your participation, energy, spirit of volunteering, and philanthropy that characterize the culture of North America. With your support, NATF sponsors several multidisciplinary thrombosis education programs annually: 1) “Proactive Prophylaxis,” a multidisciplinary symposium geared to healthcare professionals, patients, and caregivers, and 2) the NATF “Thrombosis Summit,” an annual event focused to meet all five NATF mission points. NATF strives to promote the educational events of our partner thrombosis organizations. Support of NATF educational programs ensures that we can continue to offer a comprehensive web-based network for both healthcare professional and patient education resources.

NATF is committed to providing support to Training Programs that will advance future leaders committed to careers in academic medicine and science. The NATF Traveling Fellowship allows Junior Faculty and Fellowship Trainees the opportunity to expand their fund of knowledge, as well as build positive and enduring relationships with others in the field of thrombotic disorders. Your contribution can help to expand this program to allow for additional scholarships in the coming years.

For more information, please visit our website: www.NATFonline.org

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