

MARK ROBERTS

Mark's story is one of a person who had AA long before we had the three-component medical protocol. Hopefully Mark's story and journey won't be repeated.

Forest Tennant

Dr. Tennant & Team,

I have wanted to write this email for years, but it wasn't until recently when I decided I need to do something with my life. I have been on long term disability due to Arachnoiditis since 2017 so the road to this point has been bumpy.

I first emailed Dr. Tennant in 2018 and received probably the best health advice I've ever received when I was suffering with CSF leaks despite multiple CT myelograms starting in Feb 2014. The advice he gave me to take two basic hormones (DHEA and Pregnenolone) has significantly helped reduce my CSF leak symptoms. This first CT myelogram is why I'm writing you.

I'll try to make this as short as possible. In Nov 2013 I had my 4th of 8 surgeries in Texas (I'm from Utah) in 4.5 years. During this surgery, I ended up having another full blow revision because my body wouldn't fuse. During this surgery I also had extensive bleeding in which my care nurse in my hospital room demanded my surgeon to approve a transfusion. Most importantly during this surgery, my doctor told me I got a dural sac tear during this surgery and thus started my CSF leaks. The surgeon thought the tear would heal by the time I left the hospital several days later, but it didn't. After 3 months of headaches and the unpleasant part of nausea, I got a CT myelogram.

Prior to the Myelogram, I met with the myelogram team about my test. My doctor had specifics requests of how much spinal fluid to take out, how much dye to inject back into my spinal canal and that he wanted me to sit and walk around for 45 minutes before the CT test so the dye would have a chance to move around and hopefully isolate the tear/leak. The medical team told me they couldn't do it exactly that way but after failing to get my doctor on a call I agreed to their protocol...which really wasn't that much different. The most important part of this story is that this team told me they would have me sit and move around for 30 minutes prior to going into the CT room.

During the myelogram, the technician suddenly stated they had to go talk to the lead medical person overseeing the test. The next thing I know is a nurse comes to tell me they are taking me to the CT now. I disputed this for a several minutes and stated this wasn't what we discussed just minutes ago, primarily that I'm supposed to sit and move around for 30 minutes before getting a CT.

My biggest regret is that I didn't jump off the bed and demand that I speak with the medical

team who I had just reviewed the test protocols only minutes ago. The nurse just kept telling me that I would have to speak to my doctor about the test. At this time, I was only concerned about finding the CSF leak so I finally stated my assumption that they already found the leak but the nurse wouldn't confirm. Despite my complaints I was taken directly to the CT room....directly!!!

A few days later I found I they did not find a leak. I was so disappointed that I called the hospital where the CT myelogram was performed and told them the test wasn't done as my doctor requested. A week or so later I get a letter in the mail from the legal dept at the hospital stating the test was done according to my doctor orders which I knew was completely false.

So I continued to suffer by but finally started to get some CSF leak relief until about 2 months later when I went to bed one night and had the first signs of Arachnoiditis...the severe pain, insects crawling, etc. it hit me so hard and I was so concerned that I got into a different doctor the next day express as I invite my problems and asking for an MRI. This doctor wouldn't order an MRI, so I spent the next 3 months trying to find another local doctor. I finally went back to my original doctor who finally ordered an MRI. In July 2014, I received my radiology report that basically stated I had signs of Arachnoiditis. This doctor wouldn't see me again (I wasn't a surgery candidate to him) so I had my physical therapist finally call him to ask if I had Arachnoiditis and what I should do. His response was a pain clinic will have to treat me.

I went to several doctors for the next two years, with all of them stating I did not have Arachnoiditis. I had 4 more surgeries including my 6th surgery in May 2015 for a tethered spinal cord. This surgeon didn't notice Arachnoiditis, but I suspect he didn't know what to look for. The surgery obviously didn't help.

In June 2016, I went to Phoenix for a 360-revision surgery. During my 8th and final surgery my doctor decided to do a tethered spinal cord surgery after he completely another major fusion revision. He noted Arachnoiditis once he opened me up. I did not find out until a year or two later when I got my hands on my surgical notes where the surgeon noted that my CSF flow was completely obstructed and thus no spinal fluid flow. My spinal nerve roots were completely scarred together. I now know this was very important but this surgeon failed to report it to me but this is not why I'm writing.

I'm sorry for the lengthy write-up but I feel it is important to lay out the facts. I'm well pas malpractice deadlines even though I did know enough in 2018 that something went very wrong in the middle of my battle...mainly 2014. I called 5 local law firms and got nowhere. My 6th call was promising but I received a letter a few weeks later from the law firm stating they had a conflict of interest. That was the end of malpractice claim for me because the deadline expired and I realized how hard it would be to prove after having 4 more surgeries by 3 doctors since my 2014 CT Myelogram.

Here is why I'm writing. I have spent so many sleepless nights for years suffering in pain going over what, how, why, etc. I finally had to forget and forgive. However, it wasn't until another

one of my doctors transferred to this hospital last year when I finally realized I had to do something. I'm not going to get rich or experience less pain or suffering but I need to try to help the next person, help the next medical team, and so forth. Most importantly, the Tennant and Arachnoiditis foundations has inspired me.

I am writing to see if one of your experts could read my 2014 CT myelogram to see if we can learn anything from that test. Did the dye get into the Arachnoid layer and was something known at the time that could've possibly helped me, but it just wasn't communicated. I don't expect to learn anything but what I'm hoping is that somehow, someway I can educate this hospital. I don't expect the people involved with my procedure know anything about what happened to me. I don't want to make anyone feel bad or guilty, but they do need to know in case it happens again. And maybe my CT myelogram had nothing or little to do with my Arachnoiditis, but I need to try. I feel strongly that it at least contributed to it just like my surgeon's decision not to take the time to fix the tear.

I need to make a difference in my life since the last 7-8 years haven't been pleasant for me, my wife, or my kids so I'm hoping I can get some help.

I know this was a long time ago and technology changes, but I wanted to at least ask before I try to forget and move-on. Thanks for everything you do, and I can't thank you enough for everything you are doing.

Mark Roberts