

An Arachnoid Cyst Story

I will never forget the words my first neurologist said to me after reading the radiologist report of an Arachnoid Cyst in the Posterior Fossa. ***“These cysts are congenital and never cause any of the symptoms you are experiencing.”*** I was sitting in his office twitching away, unable to control my leg muscles when I pleaded, “Can you please just take a look at my MRI films, after all it cost me 1400 dollars to get this thing done?!”

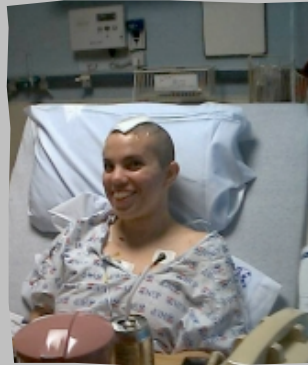
The neurologist reluctantly took a look at my MRI and then turned pale. He immediately apologized saying, “If that is a cyst, it is flattening your cerebellum and occipital lobes, you need to get to a neurosurgeon straight away.” He then proceeded to give me all of his sample Neurontin packets because he was sure I would start seizing. He didn’t even charge me for that appointment because he felt so guilty that he almost turned me away!

I went on to have over twenty-five surgeries, eleven of which were in my brain, in the next twelve months, all because of my Arachnoid Cyst!

When I moved to the UK, I was back to square one, no neurologist here has ever been able to accept that my Arachnoid Cyst is causing any of my symptoms. I have been told that I am “imagining everything” and that “it is all in my head”. After twenty something surgeries, that is what I have been told. Sometimes I am baffled by the ignorance, but I am still here to tell you that I will spend the rest of my life raising awareness for Arachnoid Cysts, Never give up, none of us are alone in this nightmare, and with persistence and this pamphlet, you can get a doctor to take your Arachnoid Cyst seriously.

All the very best,

Dia



ACA and ACF Present:

Arachnoid Cyst Pamphlet for Doctors



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Dear Doctor,

Symptoms Arachnoid Cyst Patients May Experience

Will you please take the time to consider the symptoms which your patient, _____, is experiencing? This pamphlet was printed from the website of Arachnoid Cyst Awareness Organization, a non-profit organization based in the USA, UK and Australia that helps support arachnoid cyst patients from around the world. Arachnoid Cyst Friends Group and Arachnoid Cyst Awareness have come together to produce this pamphlet. These two websites combined have thousands of members who seek answers to questions that aren't being addressed. We all have one thing in common, an arachnoid cyst.

Many of us suffer from the same symptoms. Given that we are in the thousands our question to you is how can we all be wrong? We realize the majority of medical communities across the globe have the opinion our disease is congenital and, therefore, cannot be a basis for our symptoms. We hope, however, that you will take the time to look over our websites, statistics and polls to formulate your own opinion.

We also invite you to view over 1400 signatures on the Arachnoid Cyst Petition: <http://arachnoidcystpetition.com> . Many of the comments left by patients from around the world, are similar. Will you please take a moment to read through them to see how arachnoid cysts are affecting lives?

Thank you for your time and consideration!

Graciously,

Dia DiCristino, Chairman of Arachnoid Cyst Awareness Organization

www.arachnoidcystawareness.com

www.arachnoidcystnetwork.com/acanetwork

and Royalyn Hayes, USA Liaison Officer of ACA and Co-Founder of Arachnoid Cyst Friends

www.groups.yahoo.com/group/arachnoidcystfriends/

Headache
Severe head pain
Back pain
Balance issues
Numbness and tingling
Tinnitus
Unexplainable ear pain not due to infection
Difficulty swallowing (Dysphagia)
Loss of vision or other visual disturbances (e.g. Palinopsia)
Low blood pressure
Low body temperature
Nausea and/or Vomiting
Seizures and/or tremors
Memory problems
Aphasia (Language Difficulties)
Processing difficulties
Trouble urinating (Incontinence)
Spasticity
Dystonia
Rigidity
Muscle Weakness
Fatigue
Irritability

