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No More Hospitals, No More Surgeries

Ed. Note: *The opinions expressed below are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Anyone with a medical problem is strongly encouraged to seek professional medical care.*

My name is Lorraine Aranda, I was born in Hollywood, California. I am 48 years old and I live near the ocean just as I always wanted to. As a young girl and while I was growing up I seemed to catch any and every disease a child could, and some different ailments that no one else had. When I turned into a young woman my menses was particularly painful, the cramps started about a week before and got worse until the event finally arrived. I was hunched over in pain and eating aspirin by the handful. When I told my mom of the pain she told me that all women experience pain during this time of the month and I had to get used to it. Maybe I didn't communicate as best as I could but I got the message; suck it up. Being sick in our family meant the sickee was put into bed, the door shut and ignored until mealtime. It didn't pay to be sick in our household.

Fifteen years of' sucking it up. Fifteen years of being misdiagnosed and several doctors later I was told I had Endometriosis, a particularly painful disease for women. I was operated on when I was 27. When I woke up the surgeon told me they had to take the left ovary and Fallopian tube and the endometrial matter was attaching itself to various parts inside me; organs, connective tissues, muscle, etc. and I would probably have problems all my life. Chance of getting pregnant = 20%.

For the next 9 years, no matter what was happening in my life, my illness ruled my life. I had to plan ahead, watching my Period Book as I called it, to make sure there was a better chance of my being well enough to attend the theater, dinner date, parties, etc. I had to cancel at the last moment so many times my friends finally got used to it. I endured six surgeries in those 10 years, removing huge cysts each time to relieve the pain. One surgery led to another and another... Not one doctor would listen to me when I told them to yank it all out because of my age. They wanted to give me a chance to have children. I was raising five stepchildren so the thought of infertility was not a great concern to me as it is for many who suffer the disease.

I finally got the surgery that ended that illness and after recovering I promised myself that I would never, ever go back to the hospital. I've learned since to never say never as it seems to be a red flag for God to test you with. All through the pain I had with that disease I also had extreme neck and shoulder problems, and pinched nerves along the back. All part of endometriosis I was told. As the pain got worse through menses I believed them.

After I recovered I still had sharp, striking pain in the neck and shoulders with tingling sensations in the arms & hands...stress I was told. One lady told me I wasn't breathing right and for $65 an hour she would teach me. After a major car accident I had, hit from behind, my symptoms got worse. After an MRI in 2001 I was finally diagnosed with Syringomyelia, at least I finally had an answer to all the pain. My disease is a liquid filled cyst inside the spinal cord from the base of my brain stem to past the middle of my back. As it elongates and contracts it disturbs and destroys all the nerve endings causing extreme pain, exhaustion, disorientation, balance, organ problems, headaches, limb weakness...lets just say the list continues.

The first neurosurgeon I met told me there is no cure and only an operation to aspirate the cyst could be attempted. He warned me though to hold off on the operation as long as I still have use of my legs because any operation in the spinal cord is risky and I could become a para or quadriplegic from the operation alone. I take large doses of pain pills, muscle relaxants, sleeping pills and more just to keep going. I tried to keep working but the pain became too much so I became disabled and quietly retired to my apartment.

I studied my disease, got to know it. I joined the ASAP (American Syringomyelia Alliance Project) and chatted on line with others with this disease. Again and again I was told that one surgery led to another what with infections, scar tissue growth, shunt moving out of place or clogged, the list went on. Endometriosis had been the same; one surgery following the other. I spent so much of my youth in hospitals being misdiagnosed and going through surgery after surgery that I decided to do as the 1st surgeon suggested; to hold off on operating until I absolutely have to. I'm tired of hospitals, the smells, the cries of pain, the tests, the blood letting...I just don't want to go back until I have to.

I've had to slow down and to accept my limitations, it is a hard lesson and I'm still learning. I know that I might face an operation in the next 5 years or so but for now I am content to let the future be the future and deal with each new symptom as it occurs.

--Lorraine Aranda

Would you like to share your perspective? Submit to: director@conquerchiari.org Type "Perspectives" in the subject line.