

Periodic Paralysis and Your Community “EDUCATE, EDUCATE, EDUCATE”

By Susan Q. Knittle-Hunter

In the past six years, after moving to Grants Pass, Oregon, I have seen no less than 30 medical professionals (three in Portland and one in Ashland). The following are the statistics regarding the care I received. Seven left me; they moved away or quit practicing. One refused to see me after the first visit. He said I was “too sick”. Thirteen doctors insulted me and treated me poorly, misdiagnosed me and mistreated me or otherwise disregarded me as hysterical, conversion disorder or faking it, said I had pseudo-seizures, was “too old” to diagnose and difficult to deal with, shrugged their shoulders and gave me blank stares and sent me on my way with medications that made me sicker, gave me new symptoms and/or almost killed me. I fired four of them. (These doctors do not include the ones I saw during four emergency room visits with symptoms and misdiagnosis and mistreatment and three hospitalizations with symptoms and misdiagnosis and mistreatment.)

The remainder of the doctors did try to help me in the medical areas for which I saw them. I had to see a podiatrist, an endocrinologist, a gynecologist, a surgeon, two urologists, a physical therapist, a neurosurgeon, an EMG specialist, a pulmonologist, three cardiologists, a rheumatologist, a dermatologist, and a counselor. Some were to rule out other conditions and some treated my many other medical issues. I saw a counselor to help me deal with my failing health and I needed physical therapy to help me with my balance and weak muscles. Some doctors monitored my normal yearly tests, like pap smears. One took care of my foot problems that included, a neuroma, an extra bone in my foot and a stress fracture. Another was treating the severe osteoporosis in my spine and hips. A surgeon discovered my hiatal hernia and treated my acid reflux. Two urologists tested for interstitial cystitis and treated it. A sleep study and breathing tests were done.

After finally being diagnosed recently by three wonderful physicians, who practice in Medford, I felt it was important to let the doctors I had seen in Grants Pass know about my diagnosis. They needed to be educated. The hospital needed to be educated. The emergency room staff needed to be educated. The ambulance company needed to be educated. The people in my town needed to be educated. My local community needed to be educated about Period Paralysis: Andersen-Tawil Syndrome. I was going to do it!!! The following is the story of how I began to educate the people of Grants Pass, Oregon.

One of my previous doctors (before she moved away) diagnosed me as very fragile and very ill. She believed in treating the whole person; so she wanted to treat “all” of me. She felt I needed to see a therapist to deal with my failing health, and with the fact that my mother was dying. So during the past two and a half years I have been seeing a therapist. She has been wonderful for me and to me. She has never doubted me and been totally supportive of everything I have done. She has seen and heard everything I have been through and has been shocked by the treatment I have received by the medical professionals in this town and state. At one time, she wrote a letter for me to keep with

me at all times in case I ended up in the ER again. In it she explained that I was not mentally ill, nor suffering from any anxiety disorders, nor from a conversion disorder. She explained that she herself had seen me in the paralysis and that it was real and I needed to be treated for my symptoms.

Once I got my diagnosis, I discussed my options with her. She understood my anger and agreed with me that the doctors I had seen and had treated me so bad needed to be told of their mistakes. We discussed many ways of doing that. She told me it did not matter how I did it, but the most important thing to remember was I needed to “educate” the doctors and I needed to thank the people who helped me.

I finally decided the best way to begin was to have an article written about my disease and diagnosis in the local newspaper. I hoped that each doctor, nurse practitioner or medical professional would see and recognize me and realize the mistakes they had made with me and to me. In this way, I hoped they would be “educated” and hopefully learn to recognize the disease in the future. I hoped they would never treat another patient the way they treated me.

I set out to write a letter to the Daily Courier. It is as follows:

Hello Ms. Decker,

My name is Susan Q. Hunter. I am a 62 years old, retired special education teacher and have just been diagnosed with Periodic Paralysis/Andersen-Tawil Syndrome (PP/ATS) Only 100 other people world-wide have been diagnosed with this syndrome.

It is a hereditary condition which has been misdiagnosed my entire life and which at least 7 other members of my family have, but they too have been misdiagnosed.

It is an ion channelopathy in which potassium shifts into the muscles and paralyzes me, periodically. I become unable to open my eyes, speak and am unable to move, although I am aware of and hear everything going on around me.

Over the years of misdiagnosis, I have become permanently disabled with weak muscles, including my heart. It is recognized under MDA as a form of muscular dystrophy. There are three types, Hypokalemic Periodic Paralysis, Hyperkalemic Period Paralysis and Andersen-Tawil Syndrome. About 30 genetic markers have been found so far with others being studied in Germany.

I have two reasons for wanting to tell my story. The first is for education. Periodic Paralysis is something that needs to be recognized and understood, especially by the doctors in this town. I have been to no less

that 30 doctors and been to the emergency room 3 times in the past 5 years and have been treated so badly, that I fear going the ER now . I have had lies and horrible things written in my medical records and been diagnosed with conversion disorder and psuedo seizures. All of this while being paralyzed, unable to open my eyes, speak or move, the entire time hearing everything and scared to death not understanding what was happening to me.

About a year ago, I began to believe I may have PP. As I researched, I became sure of it. The story from there to my diagnosis last week, is unbelievable.

Here is the story I sent to my family and friends last week:

Hello Family and Friends.....I made it through one of the toughest days of my life.....I had a heart loop recorder inserted in chest with only lidocaine to numb it, because I cannot tolerate any meds. I told them the lidocaine would send me into paralysis, so they used a type without epinephrine and felt assured it would not cause paralysis. As luck would have it (and I knew it) 1/2 way through the procedure, I went into paralysis. By that time the device was already implanted. The doctor and rest of the team were watching my heart doing it's thing (tachycardia, arrythmias) saying things like, "Look at the huge T-waves" and reading off numbers that I didn't understand and ohing and awing. He proceeded to explain my disease to them. Then when I was able to answer questions, they all began to ask me questions about it...remember... what I have, Andersen-Tawil Syndrome..... only 100 other people, world-wide, have been diagnosed with.

As they were ready to take me to recovery, I noticed an IV drip in my arm. I got horribly upset and asked what it was. They told me "saline". I swore and told them I was not supposed to have that. They then removed it. What I did not know was that it had been on me the entire procedure. I thought they had just hooked it up and then took it off after I told them that.

I went back to recovery and was doing fairly well, except for slipping in and out of small paralysis episodes.

My heart doctor had put together a "team" for the rest of the procedures they were going to do for a confirmation of how my potassium shifts and how to treat it. The plan was to put me in ICU and have a kidney specialist direct the testing and an Intensivist to monitor all signs and symptoms and be there to treat my symptoms which could include my heart stopping.

I called Shari to tell her how well I was doing and tell her the plan to pass on to everyone.

Just as the kidney specialst showed up to tell me the plan and ask me a few questions, I began to have trouble answering his first question. I slipped into the worst episode of paralysis to date. My heart began to beat at a sustained heart rate of 130 to 140 bpm for over the next hour. My blood pressure was at 168/80. I felt like an elephant was on my chest. I could feel and hear my heart racing and

the horrible pain from it. I could not have any pain meds or any meds to slow my heart because it would have made it worse. Everyone was in astonishment watching the heart monitor and not knowing what to do. Calvin was so afraid and I thought I was dying. I could hear everything but was unable to open my eyes, or speak. I could not move, just hear everything and feel all the pain and pressure. The doctors kept saying they had never seen anything like it and the nurses kept touching my hands, arms and face, telling me they were sorry they couldn't help me.

(The saline drip caused this...if you have PP/ATS never let them put a saline or glucose IV in you)

My heart finally began to slow down over the next hour. I was finally able to open my eyes and could speak a little. Finally, I was doing very well. The doctors decided to proceed as planned and told us the plan to put me in ICU and load me with carbs to start the paralysis again and then test my potassium levels through the paralysis process, etc.

They got me upstairs and had me ready to begin the next phase. Calvin left to go home and get some much needed rest. The kidney specialist came in at that point and said, "We have decided not to proceed with the testing and are sending you home now." I asked why? His reply floored me....."We don't need to do anymore testing...there is no doubt you have Andersen-Tawil Syndrome (ATS). Everything we have read tells us that you could die if we do the testing we were going to do, if you have ATS. We are going to give you Diamox to treat your paralysis symptoms, but because you have ATS it may not work for you....but we want to try". I thanked him and told him I already knew that but was taking the chance for the little hope I had that the meds might help me...otherwise there is not much else I can do for a better quality of life.

I already had the diagnosis of Periodic Paralysis (PP) from my neurologist, but now I had the diagnosis of the type of PP.

He told me how humbled he felt to be diagnosing me. He said he was just an ordinary MD..nephrologist...not like the big and powerful doctors who wrote all the info on PP and ATS back East. But after seeing what happened and going over all the facts and by the process of elimination and studying all of the latest research I had presented to them and the family flowchart I had put together with all of the family medical history and all of your input....including Kristen's toes!!!.....he felt he had no other choice. He told me I had done all the work and had done an excellent job of presenting it all to them. Without that, I might never have got the ATS diagnosis also. He had never heard of ATS before, none of them had, but they had been researching and studying it.

Thank you Family, for answering the little questionnaire's I sent out and all of your input and patience with me over the years.

He has dictated a report which each of you will get. You can then give it to your doctors. My children have a 50/50 chance of having it and of passing it on. All of you must get checked. The Long QT interval heartbeat is nothing to ignore.

Thank you all for your best wishes and kind words and thoughts.

My second reason is to thank the few people/professionals in this town who believed me and helped me and encouraged me to keep fighting for a diagnosis,

so I could help my family and hopefully try some of the medications that could help to reduce the episodes in number and severity.

If you are interested in this story, please contact me at:

XXXXXXXX XXXXXXXXX or email me back at this email address.

R W gave me your name. Thank you, Sincerely, Susan Q. Hunter

Within a few days, I heard from the editor. She told me that she was giving my letter to one of the reporters. About a week later a reporter called me. He took my story over the phone. I was caught off guard without my information in front of me. I was somewhat frustrated before it appeared and did worry about how he was going to present it without all the info. He sent out a photographer after he wrote it. The photographer only took the pictures and had nothing to do with the story, although I tried to tell him more. I did give him some more information to give to the reporter.

As it turned out, it is somewhat over simplified and some things are definitely not correct or he gave a different twist to the truth, but it does give attention to Periodic Paralysis. My pictures are not good because I was nervous when the reporter was taking the picture, it was also during the first few hours of the Japan earthquake and everyone was very solemn and worried. At least after reading it, others may research it and get help if they feel they have it.

The reporter made it sound like I am doing fine now...but we all know that isn't right. I don't have episodes during the day right now, but have them all night long. I have awoken no fewer than 4 times the last several times in paralysis while have heart problems.

He also left out any "thank you" I had asked for.

All in all, however, he did a good job and I am sure that the doctors and medical professionals and my community were "educated" if they read the article.

Here is the article:

<http://www.periodicparalysisnetwork.com/pdf/pressrelease03-19-2011DailyHeraldSusanHunter.pdf>

Despite the few discrepancies, I was very thankful to the reporter for a job well done and wrote a letter to the editorial page thanking him and the others that did not get mentioned.

Thank you Jim Moore for the great article you wrote about me and Periodic Paralysis. It is a much misunderstood and underdiagnosed disease. Many people around the world are trying to get a diagnosis and treatment. My husband Calvin and I are developing a website to aid in understanding the disease, getting a proper diagnosis, managing the symptoms, and assisting caregivers and family

members and to assist doctors on how to recognize, diagnose and properly treat their patients in a timely manner.

This website can be found at www.periodicparalysisnetwork.com

I would also like to thank the few people who supported my husband and I during the past few years and helped me to keep going and stay alive while seeking a diagnosis: Rosie Watne who never doubted me, Tim and Carol at Lincare, Laurel at Interpath, Ron at Action Rehabilitation, Dwain and Suzanne, Ken and Gigi, Bill and Dorothy Heinline, and Alexia, Karen and Kathy for their support while trying to get their own diagnoses. I want to especially thank my Neurologist, Cardiologist and Renal Specialist for believing me and going the extra mile to research for me and the Cardiology Recovery Team at Rogue Valley Medical Center for their excellent work and care during my short but eventful stay with them. Lastly I want to thank my husband Calvin for his love and constant vigil monitoring my vitals and researching to keep me alive. My diagnosis was really a combined effort and would not have been possible without you all.

This was printed but the names were left out, so I want to honor my friends and the others who helped me by printing the original version here.

Now that I have “educated” some of the people in my community through a newspaper article, I will look at other ways to further educate locally. The following is a list of ideas I created to help me get started. You may want to try some of these in your community:

- *Start a support group*
- *Speak at schools, colleges*
- *Talk to ambulance companies.*
 - *Talk to the hospitals*
 - *Host hospital seminars*
 - *Contact local TV news*
- *Tell your neighbors and friends*
- *Have family spread the word*
- *Have your doctor speak for you*
 - *Talk to health dept*
 - *Speak at church*
 - *Talk at work*
- *Talk to the insurance companies*
- *Speak at clubs like Lion’s Club and Rotary*

If you are not able to appear in person for interviews or meetings, Skype is a useful tool for communication.

Let’s start “educating”!!!