

Finding a Doctor Who Cares
“NOT AN EASY TASK BUT POSSIBLE”
By Susan Q. Knittle-Hunter

So many people with all forms of Periodic Paralysis struggle with finding doctors who can and will help them with both a diagnosis and proper treatment. They go from doctor to doctor and disappointment after disappointment, misdiagnosis after misdiagnosis and mistreatment after mistreatment. This can go on for years with the misinformation following them from physician to specialist. Often, this will lead to a diagnosis of hypochondria or malingering and a referral to a psychiatrist. Many of the patients become depressed and begin to doubt themselves after being prescribed medications for mental disorders that invariably make the symptoms worse or different, thus creating the need for yet another referral to yet another specialist.

This vicious cycle can continue for years as the symptoms worsen and the patient becomes more disabled and debilitated. Family and friends tire of dealing with the situation and many friends are lost, marriages end in divorce and family members withdraw their support. The patient is left in more pain and despair and the humiliation can be unbearable. Many are never diagnosed and never receive the treatment they need and deserve.

I myself saw 30 different physicians in 6 years before I was diagnosed at the age of 62 after a lifetime of illness, disability and loss of friends, family and a marriage. For the most part they were rude and did not understand what was happening to me. Most of them were frustrated and believed it to be all in my head.

At one time, I was trying to find a new doctor because my previous doctor moved out of town suddenly. The new doctor I chose told me on my first and only visit, "You are too sick, I will not take you as a new patient". I started crying and cried all the way to the insurance office. I reported him and was told that he did not have the right to do that. They called it "cherry picking", but they did refer me to another doctor.

After my diagnosis I have seen eight more doctors, all of who do not know how to help me, including one who is a specialist in Andersen-Tawil Syndrome. I have been in contact with a physiologist who studies ion channelopathies who would like to help me and my family but is not sure how. I have spoken with one of the neurologists who misdiagnosed me, who has now apologizes for missing some important findings in my labs and the opportunity to diagnose me two years earlier.

I also was able to finally locate a few doctors who have been willing to work with me (two more left town after seeing them for a short while) and have read the information I provided for them about Periodic Paralysis and done some research on their own. They do not deal directly with my PP symptoms, however, but with the things they know about, such as, diabetes, oxygen therapy and referrals to specialists as I need them.

After all of my experiences with finding doctors who will work with me, I have devised a common sense plan that can assist anyone to locate a doctor (Primary Care Physician: PCP) who will be willing to work with them before they ever step into the physician's office. There will be no more insults from a person who should be showing compassion and no more leaving the office in tears and despair.

1. The most obvious place to begin your search, if you have a good doctor who has decided to move on in his or her career, is to ask your present doctor for the name of a physician who knows about periodic paralysis or who would be willing to work with you. If he or she gives you a referral, be sure to have them confer with the new doctor about your disease and provide him with as much information as possible before your first visit. You may also want to provide information of your own ahead of time.
2. If you are not that lucky, the next thing you can do if you have insurance, is to call your insurance company and request a "patient advocate" or "case manager". Most insurance companies have employees whose job is to help their clients who have "more than the average" or "out of the ordinary" medical needs.

"A patient advocate is someone who works on behalf of patients and their families during stays in the hospital or other medical situations. Many different organizations employ on-site advocates to deal with the daily needs of patients... The patient advocate's primary function is to serve the patient's needs, along with the needs of their family." http://www.ehow.com/about_5394156_patient-advocate.html#ixzz20S5HIMPe

Once an advocate is assigned to you, you will need to explain your situation and Periodic Paralysis and explain your need to find a doctor who knows about the disease or who will be willing to work with you. It would be wise to seek out neurologists, internal medicine doctors and endocrinologists. You may need to see more than one doctor before you find the "right" one for you.

3. If your insurance company does not have patient advocates and has a restrictive list of particular doctors and specialists covered in their program, again, you will need to explain your situation and Periodic Paralysis and explain your need to find a doctor who knows about the disease or who will be willing to work with you. They will sometimes do the work for you.

If not, you can go through the lists of neurologists, internal medicine doctors and endocrinologists and call each office and ask for the office manager. You will need to explain your situation and Periodic Paralysis and explain your need to find a doctor who knows about the disease or who will be willing to work with you. In most cases, the office managers will speak to the doctor or doctors about your case and get back with you if the doctor is willing to see you.

4. If your insurance is not restrictive, you will have to check your local phone book or the web for neurologists, internal medicine doctors and endocrinologists in your area and proceed with the phone calling until you find one who will work with you.

Another good option, if your insurance is not restrictive and requires no referrals, is to check out the clinics in your area. The one I attend has 85 doctors and are connected to a local hospital. There should be at least one doctor willing to work with you.

You can proceed as explained previously; call and speak with one of their representatives. Explain your situation. The representative will go through the list of their physicians and chose a few that may work for you. The doctors will be consulted and one or two may agree to see you. It may be wise to spend time with each to decide the “best fit” for you.

5. Without insurance, seeking out help from your local health department can be productive. Also your local services for disabled will have some possible options for finding a local doctor. You may be able to secure a social worker. He or she may do the work for or with you.

6. Thinking “outside of the box” can bring some surprises. I was so frustrated and about to give up on ever finding a local doctor who could diagnose and treat me, when I had a wild idea.

One of our local television stations offers a wonderful service every Tuesday evening during their two-hour news coverage. A local physician, and a guest specialist of her choosing, take calls from viewers and answer medical questions.

I called and asked if she knew about Periodic Paralysis. I was shocked when she told me she had a patient who had it and that the patient saw a local neurologist who treated her. She gave me the name of the neurologist. I made an appointment and after two visits was diagnosed! (I must explain that I had all of my medical records in hand with years of medical testing ruling everything else out and a referral from my nurse practitioner.)

7. The next option I offer must be used with caution. You may search the web for specialists. Seeking out these specialists in the field of Periodic Paralysis or Andersen-Tawil Syndrome, may lead you to some severe disappointment. There are several across the United States and a few around the world. Many do not see patients and are involved in research only.

The specialists will only diagnose based on genetics or a very “pure” form of the disease. (This may be based on the fact that most of them are researchers and their funding is based on working with only those who are genetically diagnosed. This leaves out a high percentage of us.) Their view can be extremely narrow and I have been surprised that their knowledge of the disease can be severely lacking in some areas. Their only option for treatment is limited to medications that do not work for many of us. If you have other conditions co-existing with your Periodic Paralysis or do not have a known genetic code, you will be sent packing in tears and humiliation. It is not worth the time or money you may spend to travel to another state or country.

8. The Muscular Dystrophy Association (MDA) is an organization that treats patients

with muscle diseases, including all forms of periodic paralysis. In order to see their doctors you must already have a diagnosis or be referred for a diagnosis by a doctor. However, most of the doctors we have information about at the MDA Clinics, do not know about Periodic Paralysis or Andersen-Tawil Syndrome. Most offices around the country do not know about Periodic Paralysis. If you call for a referral or information, you will probably be told that they do not know what you are talking about. I have had to call many MDA offices around the country for patients to tell them that they do indeed treat Periodic Paralysis and Andersen-Tawil Syndrome patients. I refer them to this information at their own website: <http://www.mda.org/disease>

Also, although you may already have a diagnosis, you must see their doctors and be re-diagnosed before you will receive any treatment or benefits offered. If the MDA doctor does not agree with your previous doctors due to their lack of knowledge of the disease or their narrow view based on old facts and research, you may lose your diagnosis. It is not worth the chance. That being said, there are some very good MDA doctors and some of our friends with Periodic Paralysis are having some success with the ones they are seeing.

Conclusion:

Many of the people with genetic codes that have been located do have good doctors and receive good treatment and proper medication for their particular forms of Periodic Paralysis. They are very lucky. The medications help them and they can lead nearly normal lives as well.

I understand, however, it is difficult to find a doctor who will work with those of us who suffer from the effects of Periodic Paralysis, if we have not yet been diagnosed or those of us with variants for which no genetic code has been discovered yet, even if we have been diagnosed clinically (based on symptoms) or for those of us who have other diseases which co-exist with our form of PP. The truth is, very few of us will get any real help from a doctor even if we find one who knows about the disease and is kind, sympathetic and empathetic. This is due to the fact that most of us are unable to tolerate the known medications and the doctors do not know how to help us.

So, although I have a Primary Care Physician and several good specialists, Calvin and I are still left to deal with my episodes of paralysis and my other symptoms with no real help from the medical field. They do not know how to help me, but treat me well and look after the things they can; like my heart problems, power wheelchair, oxygen, diabetes strips, labs, etc. I appreciate and understand their lack of knowledge of such a rare and baffling disease.

They trust us with the plan we have created after much research and trial and error. We have created this website to pass along this information and hope to help others in a way the doctors are unable to at this time. I “walk the tightrope” daily to avoid episodes and the serious symptoms they create. This is outlined at the URL below and other places on our website and is discussed on our private discussion board.

<http://www.periodicparalysisnetwork.com/pdf/How%20I%20manage%20my%20Periodic%20Paralysis%20Symptoms3.pdf>