

**Periodic Paralysis and Your Doctors?**  
**“THE LOOK AND THE SHRUG”**  
By Susan Q. Knittle-Hunter

**Part 1**  
**The Good Doctors: Thank You**

I would like to begin this article by thanking the three fantastic doctors who were instrumental in diagnosing my Periodic Paralysis and Andersen-Tawil Syndrome Type 2; Dr. M. my neurologist, Dr. P. my electrocardiologist and Dr. S. my nephrologist specialist. They are three professional, intelligent doctors, with integrity, who care about their patients and who went the extra mile to study everything they could about Periodic Paralysis: Andersen-Tawil Syndrome (ATS) in order to correctly diagnose me. I will forever be grateful to them for helping me. The story of how I found them and how they diagnosed me follows.

About 2 years ago I began to have periods of total paralysis, followed by years of partial paralysis that had been misdiagnosed as MS. The episodes got worse and began to happen more often. One morning, on my computer, I typed in the words “periods of paralysis”. Suddenly on the screen appeared the words, **”Do You Have Periodic Paralysis (PP)?”** As I began to read, I started crying realizing I had found the answer I had been looking for over the years. I found there were communication boards where people with this disease discussed it with each other. I joined the boards and read everything I could about PP.

One day, I discussed my symptoms with someone on one of the boards and she told me to check Andersen-Tawil Syndrome (ATS). It is the rarest form of periodic paralysis and she thought my symptoms fit ATS the best. I was shocked when I saw the symptoms and characteristics of the syndrome. I realized that the other members of my family, who had similar problems, and I must have Andersen Tawil-Syndrome.

I copied as much information as I could about Periodic Paralysis and Andersen-Tawil Syndrome and gave it to my nurse practitioner (I did not have a medical doctor at the time, I could not find one who would take me.) It was obvious that as much as she wanted to help me, she was very skeptical about this diagnosis. I recognized the “blank look” with glazed eyes, the “shoulder shrug”, and the “I don’t know about this.” comment. I had seen it many times before by doctors.

She had been very helpful previously, during the year that I had been with her. She did refer me to several doctors and to OHSU in Portland, Oregon. However, all tests and exams had lead to no diagnosis. I had now hit a brick wall.

One evening I was in despair over my failure to find a doctor who knew about Periodic Paralysis. Then on the evening news, I saw the weekly feature of offering direct calls to doctors with any medical question. I quickly picked up the phone. After a wait of only a few minutes, I was speaking with one of the physicians. I asked her if she had heard of

PP or knew of any doctors who might know about it. As luck would have it, she herself had a patient with it. She gave me the name of the neurologist the patient sees.

I went to my PCP with this information and talked her into giving me yet another referral. Dr. M., the neurologist eventually diagnosed me with “probable” Periodic Paralysis by the second visit after ruling everything else out. He wrote a letter telling my PCP that I needed to see an electrocardiologist right away. It was several months before I got the referral, but I finally got an appointment.

I did not know which cardiologist to see, so left that up to my PCP. I got very lucky. By the time I saw Dr. P., I was armed with as much information as possible about Andersen-Tawil Syndrome. I knew he was the doctor who would understand what my rare long QT interval heartbeat, combined with my probable Periodic Paralysis diagnosis meant. I may have Andersen-Tawil Syndrome. I presented him with all of the information I had. He was very excited about the possibility of diagnosing me and wanted to learn everything he could about it in order to help me.

He described my heart condition, by that point, as serious with no treatment, but insisted I needed to have a heart monitor implanted. He also set up a renal specialist to help diagnose, what he believed by that point to be, Andersen-Tawil Syndrome, based on all the information being presented to him by me, my PCP and the neurologist and his own research on the internet. This information about PP and ATS was passed on to the kidney specialist.

I did get the diagnosis of Periodic Paralysis: Andersen-Tawil Syndrome while in the hospital for the implant after going into paralysis and being observed by the doctors. Dr S. 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, 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.

I was lucky to find doctors who went the extra measures to help me as they did. They are actually unusual. They were willing to accept the information I presented to them. They were willing to study it and research it. They remained open minded and willing to learn. Their egos did not get in the way of helping their patient. They are to be commended. They are to be admired and other doctors seeing patients with PP or possible PP should be willing to follow in their footsteps.

## Part Two

### How to Find and Deal With Doctors

In this section, I want to discuss ways to find and deal with doctors and medical professionals when attempting to get a diagnosis and/or treatment.

**Avoid at all cost any doctor who seems at all skeptical about Periodic Paralysis. Once you see the “blank look” with glazed eyes, the “shoulder shrug”, and the “I don’t know about this.” comment. Run, do not walk, as fast as possible, from this medical professional. Chances are the comments he puts in your records will follow you for a very long time and may taint other doctors’ view of you. Once there is any kind of resistance, it is time to move on.**

#### Finding a doctor:

1. Attempt to find doctors who know about PP or are willing to learn.
  - a. Ask your present doctors if they are willing to work with you
  - b. Ask your present doctors for referrals to other doctors who may know about PP
  - c. Check on the internet
  - d. Ask on the PP message boards
  - e. Check PP websites for lists of PP doctors
  - f. Call your insurance company
    - i. Tell them your story
    - ii. Ask for a case manager to assist you
  - g. Call internal medicine doctors’ offices, ask if they know about PP
    - i. Neurologists
    - ii. Endocrinologists
    - iii. Nephrologists
      1. Ask to speak to the office managers
      2. Explain your story to them
        - a. They can speak to the doctor for you
  - h. Search the internet for the university hospitals near you.
    - i. Search for doctors who are specialists in channelopathies
  - i. Contact your nearest MDA office to get a referral
    - i. BUT: Be very careful
      1. Many MDA clinics and doctors know nothing about PP
      2. If they do, they don’t know enough to help
        - a. They lack the latest information for diagnosing
      3. The MDA team leader (Neurologist) will look at your records and decide if he feels that you have PP or not. This could be a real problem if they do not understand PP or ATS. He can overturn your diagnosis.
      4. If they are not up-to-date on diagnosing procedures they can destroy your chances for a diagnosis by other doctors.

## Getting proper treatment:

2. Once you find a doctor who is willing to work with you:
  - a. Follow plan on this website for getting a diagnosis, if needed
  - b. Make sure she has all of your medical records
  - c. Provide her with everything you can find written on PP
    - i. Keep up on the latest on treatments
      1. Share with doctor
    - ii. Follow the plan for “Walking the Tightrope” on this website as it applies to you
      1. Give a copy to your doctor
  - d. Ask for referrals in order to develop a “Team”
    - i. Neurologist
    - ii. Electrocardiologist
    - iii. Nephrologist
    - iv. Endocrinologist
    - v. Physical therapist
    - vi. Counselor or therapist
      1. Have them write a letter stating you do not have a conversion disorder or are not faking it
    - vii. Others as needed for symptoms
    - viii. MDA doctors if possible
  - e. Ask for a letters to carry for your nearest emergency room and for the EMTs who work in your nearest ambulance company.
  - f. Go to your nearest emergency room and your nearest ambulance company
    - i. Provide them with as much information as possible about your type of PP
    - ii. Provide them with information on how to treat you
    - iii. Provide them with information on what meds you cannot have
    - iv. Provide them with your pertinent medical records
    - v. Provide them with letters from your doctor and therapist
  - g. Carry copies of all the information in “f” with you at all times
  - h. Ask for a referral to your nearest MDA office
    - i. Contact your nearest MDA office to get a referral
      1. BUT: Be very careful
        - a. Many MDA clinics and doctors know nothing about PP
        - b. If they do, they don’t know enough to help
        - c. They lack the latest information for diagnosing
        - d. The MDA team leader (Neurologist) will look at your records and decide if he feels that you have PP or not. This could be a real problem if they do not understand PP or ATS. He can overturn your diagnosis.

- e. If they are not up-to-date on diagnosing procedures they can destroy your chances for treatment by other doctors or the MDA doctors.

### **Part Three**

#### **My History and Experiences With Doctors An Unfortunate But Typical Story for Many People With Periodic Paralysis**

#### **This has to stop!!!!**

In the past six years, after moving to Grants Pass, Oregon, I have seen 34 medical professionals. 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. Most of those medical professionals did a fine job of taking care of the other issues I had to deal with.

However, the most difficult part of this, for me, is knowing that I may not have become as seriously ill as I am, if the doctors I saw for my Period Paralysis issues in the last six years in Oregon and the many years before, would have taken me seriously. Everyone I saw, pretended to be reading my records and then gave us the blank stare with glazed over eyes as they shrugged their shoulders. They would tell us what it wasn't but they could not tell us what it was. Then we were dismissed and told we did not need to return.

I am most angry with the doctors from the Muscular Dystrophy Association MDA. They, of all the doctors I saw, were supposed to be able to recognize Periodic Paralysis and

Andersen-Tawil Syndrome. The following is part of the letter that I wrote to the MDA about my dealings and dealings of others I know with the MDA doctors.

Dear M.....

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One of the doctors I am most angry with is Dr A, the neurologist for the MDA in Southern Oregon. (It was suggested to me that I contact an MDA doctor by other Periodic Paralysis (PP) patients who have been successfully diagnosed and treated by them in other parts of the country.) His attitude of my being “too old” and his lack of understanding about diagnosing Periodic Paralysis correctly, set me back nearly six months, during which time I could have gotten the medical help I needed. When I saw him October 18, 2010, I was not as bad physically as I am now.

He started by telling me, “It is not usual for women of your age to be walking into a neurologists office and asking if you have Periodic Paralysis”. He told me he would not diagnose me with PP unless my potassium levels were below 3.5 during an episode. When I had the blood test done during an episode (on the way home from his appointment...50 miles away), the soonest my husband could get me to the lab was about ½ hour after the episode started. The lab technician actually came to the car to take my blood since I was unable to walk, talk, etc. The results 2 hours later showed a problem with high creatinine levels and potassium was 3.8. He did not bother to call for 8 days, though he knew the results within 2 hours. Someone in his office called and said the results were “unremarkable”, although there was a problem with the creatinine levels being too high. He never even bothered to let my PCP know of the problem. Luckily, I got a copy of it from the lab myself.

While in his office, my husband and I had tried to explain that potassium did not have to shift below normal to prove PP. His info was old. The following information will explain about potassium levels in Periodic Paralysis:

### **Laboratory Studies**

During an attack, there is usually, **but not always**, a measurable fall in levels of serum potassium, but in some patients the K<sup>+</sup> level may never fall below normal. Johnsen's series of provocative studies recorded an episode of weakness of 11 hours duration provoked by a 0.3 mmol/l fall in the serum K<sup>+</sup>, and an episode of total paralysis of 19 hours duration provoked by a one point drop. During the attack there is urinary retention of sodium, potassium, chloride and water. Base your decisions on your patient's strength and cardiac signs, not on serum potassium levels alone

[http://www.hkpp.org/physicians/hypokpp\\_er.html](http://www.hkpp.org/physicians/hypokpp_er.html)

### **How low is low?**

The question of *how low* serum potassium must be to qualify as diagnostic of Hypokalemic PP is one that is constantly raised by physicians, and is the first question we will consider.

"Physiologic basis of flaccid weakness is inexcitability of muscle membrane (sarcolemma). Alteration of serum potassium is not the principal defect in primary PP; altered potassium metabolism is a result of PP. In genetic and thyrotoxic PP, flaccid paralysis occurs with relatively small changes in serum potassium, whereas in secondary PP serum potassium levels are markedly abnormal."

Naganand Sripathi, MD, Director of Neuromuscular Clinic, Assistant Professor, Department of Neurology, Henry Ford Hospital

"It becomes evident to those who read the entire body of literature that while some patients with HypoKPP exhibit serum potassium readings of 2.0 and below during episodes, others may experience paralysis and arrhythmias with K<sup>+</sup> readings which are still within normal limits. The determining factor is not the level of the serum potassium written on the lab slip but the condition and response of the patient."

[http://hkpp.org/physicians/dxing\\_hypokpp.html](http://hkpp.org/physicians/dxing_hypokpp.html)

In primary HypoPP the K level is low during attacks. In HyperPP, K levels may be elevated; however, the K level remains within the normal range in up to 50% of cases (Plassart et al., 1994; Chinnery et al., 2002).

<http://brain.oxfordjournals.org/content/129/1/8.full.pdf>

When I saw Dr. A, I hand carried all of my medical records with me and he had received 50 pages from my PCP. He did not seem at all interested in reading through any of it. It is interesting that he NOW wants to know my history and information.

What is disturbing to me is that he wants to know, "How you got diagnosed since the last time he saw you. He didn't believe you had it." (Words of C from the Eugene MDA office). He called my PCP and wanted to know. She did not have all of my information because she is new to me and did not request it, though I thought she had the report from the hospital. (My PCP called me and asked me to sign a release of information for Dr A so he could see the records from OHSU.)

When I spoke with C in a second conversation, asking her about the above statement, she said he just wanted to be "educated", as did the other MDA doctors on the team; but I can't help believe that he wants to try to disprove my diagnosis due to her first remark. I will not allow him to try to discredit and embarrass three professional, intelligent doctors, with integrity, who care about their patients and who went the extra mile to study everything they could about Periodic Paralysis: Andersen-Tawil Syndrome (ATS).

I can understand the "team" needing to see my records and I could agree to that, if Dr A was not part of the "team".

Another problem is that C had told me at least 3 times that I need to think about going to Portland for my MDA services rather than Medford. Her reasoning is that they know more in Portland. Well, I know different:

First, my daughter tried to get an MDA packet from the Portland office. The person she spoke with denied that they treated people with Periodic Paralysis. I, of course took care of that problem with an email.

Second, I have been seen by Dr. C and Dr. L at OHSU in Portland. They ignored the fact I was having a paralytic episode during the muscle biopsy being preformed by Dr. C (due to the lidocaine). He was too busy talking with Dr. L and one or two other people in the room. They were discussing Dr. C's upcoming trip to Japan to do some lecturing. He was taking his son on the trip. I was choking and my heart was in tachycardia and my chest was tight and in pain....I was not hooked up to any devices for monitoring, but when they heard me, they asked what was wrong.....I could not answer...then Dr. L hollered..."Are you asleep?" I was finally able to barely answer..that I was having one of those episodes (paralysis) and that my chest hurt and my heart was pounding. No one did anything to help!!!! Just went back to their conversation. My husband had to help me afterwards due to my weakness.

When I returned a month later (had to drive 250 miles again) to get the results of the previous exam and muscle biopsy; Dr. L gave me the results. He said that nothing showed up on the biopsy and their conclusion was that I had nothing neuromuscular nor mitochondrial. (It is interesting that the test results indicated I had myopathy....changes in size and shape of fibers...indicative of Periodic Paralysis ) My husband and I asked about the periods of paralysis that I was having. I told him I had one while I was having the muscle biopsy and asked him if he remembered hollering at me and me telling him about it? He denied even being in the room!! Then he dismissed me and said, "Go have a good time while you are here in Portland". I told him that, "If I could have a good time, I wouldn't be sitting in this consult room with you". (I had episodes all the way there in the car and had them all the way home.) We asked him what to do and he said he was referring me back to my PCP and dismissed us.

The most disturbing thing about this is that when I was researching for the MDA Clinic in Portland, I discovered that **he** is the doctor for MDA who diagnoses Periodic Paralysis! How could I go back there after being treated like that???

Due to the doctors' lack of concern, my diagnosis and treatment were set back almost a year. If I could have been diagnosed a year ago...I may not have become this serious.

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I hope the above information can help you to understand just what this disease has done to my life and that of my family members and what it does to others who have it. I hope you can also understand how horrifying it would be for me to have some doctor enter the scene at this point in my life and attempt to discredit me, my doctors and my family. He

had his chance to diagnose me and help me, but he dismissed me with little regard for my feelings and that of my husband.

There is another point I need to make about the MDA doctors in Oregon, both Northern and Southern. C suggested that because of my knowledge and understanding and experience with this disease and Andersen-Tawil Syndrome, that perhaps I could “educate” the MDA doctors and others about it. I can do that. My husband and I are writing a book about it and we are developing a website:

<http://www.periodicparalysisnetwork.com/>

The following passage is our mission statements:

*The Periodic Paralysis Network was created to provide a “hands on” approach to understanding the disease, getting a proper diagnosis, managing the symptoms, and assisting caregivers and family members. We will attempt to discuss issues relating to Periodic Paralysis in practical language. Our hope also is that the medical professionals dealing with individuals with Periodic Paralysis may come to our site and learn more about how to recognize, diagnose and properly treat their patients in a timely manner.*

We are only at the beginning stages, but hope to be up and running as soon as possible. As it is, at this point, we do have quite a bit of information already posted that can be useful for understanding, diagnosing and treating Periodic Paralysis. It is straightforward and anyone can contact us for more in-depth information. We are not giving any medical advice, just simple ideas and plans that can help the processes along. These are things we have learned by trial and error along the way.

That being said, I was expecting to find doctors at the MDA who could help me and others with PP and ATS; doctors who knew about and could diagnose PP and ATS; doctors who might be well read on the latest medications and treatments for PP and ATS; doctors with knowledge of the latest medication trials and studies and doctors with open minds and a willingness to learn. I did not find that. Maybe my personal experience can change that. I would hate to have another person with PP be treated as I was treated and end up as I have ended up.

In one last statement, I would like to address the treatment my brother received when he saw the MDA doctor, Dr. P S at UCLA in Los Angeles, California. He was also told he was “too old” and diagnosed as having diabetic neuropathy. My brother’s endocrinologist disagrees since it is not even clear that my brother has diabetes. Dr. S also has a lack of understanding about how to diagnose ATS. He said he would only see my brother again if I had a genetic diagnosis. I have been diagnosed clinically.

As far as diagnosing ATS simply based on genetic testing, it would exclude 30% to 40 % of people with the Syndrome.

I have sited two articles below, which explain this.

### How Common Is It?

Andersen-Tawil syndrome is a rare genetic disorder; its incidence is unknown. About 100 people with this condition have been reported worldwide.

Type 1 accounts for about 70% of all cases of Andersen-Tawil syndrome.

Type 2 accounts for the remaining 30% of cases of Andersen-Tawil syndrome.

### Genetics & Inheritance

Andersen-Tawil syndrome type 1 is caused by mutations in the KCNJ2 gene. The cause of cases of Anderson-Tawil syndrome type 2 is unknown.

[http://www.inheritedhealth.com/condition/Andersen-Tawil\\_Syndrome/37](http://www.inheritedhealth.com/condition/Andersen-Tawil_Syndrome/37)

ATS is caused by missense mutations or small deletions ([Plaster et al., 2001](#); [Tristani-Firouzi et al., 2002](#); [Ai et al., 2002](#); [Andelfinger et al., 2002](#); [Donaldson et al., 2003](#); [Hosaka et al., 2003](#)) in *KCNJ2*, encoding the inwardly rectifying K channel, Kir 2.1 ([Plaster et al., 2001](#)), in approximately two-thirds of the affected individuals (ATS1) ([Plaster et al., 2001](#); [Tristani-Firouzi et al., 2002](#); [Donaldson et al., 2003](#)). The molecular lesion(s) have not been identified in ~ 30% of subjects including kindreds not linked to *KCNJ2*.

<http://brain.oxfordjournals.org/content/129/1/8.full>

The following is the criteria for making a clinical diagnosis:

### Table 3 Diagnostic criteria for ATS

**(1) A clinically definite diagnosis requires two of the following three features:**

- a. PP
- b. Prolonged QTc interval or ventricular ectopy (identified on ECG or Holter)
- c. The typical ATS facies including:  
Low set ears, ocular hypertelorism, small mandible, fifth digit clinodactyly, syndactyly

**(2) Alternatively, a diagnosis may be made with one of the three features above and an affected family member meeting two of three.**

<http://brain.oxfordjournals.org/content/129/1/8.full.pdf>

Based on the above criteria, I was diagnosed by meeting a, b and c. Therefore, my brother could be diagnosed based on a, b or c and my diagnosis.

In a paper written by and just updated by Dr Rabi Tawil himself, it is stated that Type 1 and Type 2 are **indistinguishable** in how they are manifested. They can't find any difference in people with Type 1 or Type 2. The cause is the difference; in Type 1 the cause is known, in Type 2 the cause has not yet been found.

## Here is the research:

### Periodic Paralysis: Andersen-Tawil Syndrome Type 2

#### Type 1 and type 2

Two types of Andersen–Tawil syndrome are distinguished by their genetic causes.

- Type 1, which accounts for about 60 percent of all cases of the disorder, is caused by mutations in the [KCNJ2 gene](#).<sup>[1][2]</sup>
- The remaining 40 percent of cases are designated as type 2; the cause of the condition in these cases is unknown.

The protein made by the *KCNJ2* gene forms a [channel](#) that transports potassium ions into [muscle cells](#). The movement of potassium ions through these channels is critical for maintaining the normal functions of skeletal muscles which are used for movement and [cardiac muscle](#). [Mutations](#) in the *KCNJ2* gene alter the usual structure and function of potassium channels or prevent the channels from being inserted correctly into the cell membrane. Many mutations prevent a molecule called PIP2 from binding to the channels and effectively regulating their activity. These changes disrupt the flow of potassium ions in skeletal and cardiac muscle, leading to the periodic paralysis and irregular heart rhythm characteristic of Andersen–Tawil syndrome.

Researchers have not yet determined the role of the *KCNJ2* gene in bone development, and it is not known how mutations in the gene lead to the developmental abnormalities often found in Andersen–Tawil syndrome.

[http://en.wikipedia.org/wiki/Andersen-Tawil\\_syndrome#Type\\_1\\_and\\_type\\_2](http://en.wikipedia.org/wiki/Andersen-Tawil_syndrome#Type_1_and_type_2)

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#### Molecular Genetic Testing (Written by Dr Tawil himself)

##### Andersen-Tawil Syndrome

LQT7, Long QT Syndrome 7, Andersen Syndrome. Includes: Andersen Syndrome Type 1, Andersen Syndrome Type 2

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Initial Posting: November 22, 2004; Last Update: May 13, 2010.

“**Gene.** *KCNJ2*, encoding the inward rectifier potassium channel 2 protein (Kir2.1), is the only [gene](#) known to be associated with Andersen-Tawil syndrome type 1 (ATS1).

**Other loci.** To date, no other loci have been identified to account for ATS (termed Andersen-Tawil syndrome type 2, or ATS2) in the 40% of [kindreds](#) not linked to *KCNJ2*.”

##### Genotype-Phenotype Correlations

**Individuals with clinically defined ATS are phenotypically indistinguishable, regardless of the presence of a *KCNJ2* mutation (ATS1) or absence of a *KCNJ2* mutation (ATS2) [Tristani-Firouzi et al 2002, Donaldson et al 2003].**

In a single large [kindred](#) with the *KCNJ2* Arg67Trp [mutation](#), periodic paralysis was observed only in men, cardiac symptoms only in women, and [congenital](#) anomalies in both [Andelfinger](#)

[et al 2002](#)]. However, this apparent sex-limited bias in clinical presentation has not been confirmed [[Donaldson et al 2003](#), [Davies et al 2005](#)]. “

<http://www.ncbi.nlm.nih.gov/books/NBK1264/>

I am requesting that my brother can be seen in another clinic in the Los Angeles area, not associated with Dr. S, namely at the U of Irvine. His endocrinologist has written a prescription to be seen at an MDA clinic for diagnosis of “probable Periodic Paralysis”.

At this point I would like to say that I will not be actively seeking assistance from MDA any further. However, my brother, W (Los Angeles, California) and my daughter S (Portland, Oregon) and several other family members who are very ill, will (Ohio, Texas and Salt Lake City). My hope is that they will receive the treatment and respect they deserve.

Thank you, Sincerely,

Susan Q. Knittle-Hunter

## Part Four

### The List of Doctors and My Experiences With Them the Past 6 Years An Outline

#### Doctors in Grants Pass, Medford and Portland: March 2005 to February 2011

\*=Left the area

#=I fired them

Green=Helped me

Red=Treated me with neglect or rudely

1. \***T L**: Nurse Practitioner....quit after a few months.
2. **Dr. C**...Neurologist...one visit...said nothing wrong
3. #**R M**: Nurse Practitioner...said I had MS (dared me to go to OHSU... “Zebra”...mad about meds...constant bladder infections)
4. **Dr. C**...Foot doctor...extra bone in foot
5. “**Dr. D**...Rheumatologist...Fibromyalgia, “nothing else wrong”... Mirapex...yanked on my leg
6. \***Dr. S**...Neurologist...didn’t think anything wrong...suggest OHSU but Ray didn’t tell me.
7. \***Dr S**...Cardiologist...ran tests...found small heart...and other small heart problems..left

8. **L N**...Cardio Assist
9. **Dr. Y**...Dermatologist..Rosacea
10. **Dr C**...Gynecologist...found Osteoporosis
11. **\*Dr H**...Endocrinologist...Forteo...all test normal..left
12. **Dr. L**...Surgeon...diagnosed hiatal hernia and acid reflux
13. **Therapy**...physical therapy
14. **\*Dr. D M**: Really tried to help me (left before I got the results of MRI) blood in urine
15. **Dr. R W**...Neurologist OHSU...Not MS...ordered MRI...got back with me 1 year later about MRI results
16. **Dr. G**...Urologist...Interstitial Cystitis
17. **Dr. M**...Urologist...kidney xray and other tests..wanted to do a procedure using anesthesia had to decline...
18. **R W**...Counselor to help me with my health decline and to deal with my mother's impending death.
19. **\*Dr. H**: MD... Refused to take me as a patient...said I was "too sick"
20. **#Dr. S**: MD.. Had huge seizure-like episode.Treated me horribly. Lied about me in hospital record. Accused me of being suicidal due to assistive directive, being a drug attack, faking..took my meds away...gave me other more serious meds..caused seizures. (Fired him)
21. **#Dr. T**: MD...Did not care or try to find out what was wrong. Gave me anti-psychotic meds to help me sleep. I got sicker, weaker...more seizure like episodes. (Fired her)
22. **Dr. S**...Neurologist...tainted by Dr Trandinh...said.."No MS...No Seizures"...no help or ideas...but referred me to Neurosurgeon due to problem in neck.
23. **Dr. A**...Nuerosurgeon so concerned said I needed to be seen at OHSU Could not operate on neck..it would paralyze me. Said to not see anymore neuros in southern Oregon.
24. **#L PJ**: Nurse Practitioner Seemed to care in beginning. Realized all meds were causing symptoms of ataxia, tremors, tardive dyskinesia, and seizure-like activity, etc. Tried to help, then began to stall, not help, wouldn't follow thru, etc, etc. referrals were hard to get...problems with office help...did not act upon important lab info..walked out when I needed her...did not take us seriously ...almost killed me by not recognizing serious symptoms of my heart and breathing.
25. **Dr. G**: EMG accused me of faking, although discrepancies showed up on testing.
26. **\*Dr. I**: Neurologist...OHSU...Did testing...said "don't know what it is maybe we can name it after you"...left before he could give me results of all testing

- 27. Dr. C:** Neurologist...OHSU...Did testing...said “don’t know what it is maybe we can name it after you”... did muscle biopsy...did not notice paralytic episode during it caused by lidocaine...too busy talking about his trip to Japan with Dr L and one or two others.
- 28. Dr. L:** Neurologist...OHSU...after driving 250 miles...told me muscle biopsy was normal and that I had no neuromuscular diseases or mitochondrial diseases although changes in shape and size of muscle fibers did show on the biopsy. When I questioned it...he said we should go have fun while we were in Portland. I told him...”if I could have fun I wouldn’t be sitting in his office” and reminded him of the periods of paralysis...he sent us on our way...with nothing further to say. Later found out he is in charge of Periodic Paralysis for MDA.
- 29. Dr. M:** Cardiologist None of my records were there..had not been sent by Linda.He said nothing wrong, but did order 24 hour urine catch...came back normal ...never asked to see my records...
- 30. #Dr. A:** Neurologist for MDA...got a referral after talking to others on message boards who said MDA can diagnose and treat PP. Started by telling me I was too old to be asking if I had PP...told me he would not diagnose unless potassium levels were below 3.5 during an episode. When I had test done it was ½ hour too late and showed a problem with creatinine levels...potassium was 3.8...he did not bother to call for 8 days, though he knew the results within 2 hours. Someone in his office called and said results were “unremarkable”. We had tried to explain that potassium did not have to shift below normal to prove PP. His info was old.  
After being treated so poorly, I decided not to return to him...too much ego to listen to the most current info on diagnosing PP...didn’t care enough to get back with me although the lab was very concerned about creatine levels. He did not care to see all of the records I brought to the appointment.
- 31. Dr. R S:** Internist..called when on Channel 5 News. Asked if she knew any doctors who knew about Periodic Paralysis. She told me about Dr. Maukonen.
- 32. Dr. M:** Neurologist...took me seriously, believed me...ran a few last tests then gave diagnosis of “Probable Periodic Paralysis” ...said I needed to see an electro cardiologist due to long QT on Holter Monitor.
- 33. Dr. P:** Electro cardiologist...believed it to be Periodic Paralysis, possible Andersen -Tawil Syndrome, due to long QT, and other symptoms...need a heart loop monitor implanted. Calls in a team (Renal Specialist and Intensivist) to help diagnose me in the hospital while there for heart procedure. (As of 05/19/11...told me he can do no more for me. Doesn’t need to see me again. He will refer me to any ATS Clinic in the country.)
- 34. Dr. St:** Renal Specialist...diagnosed “Periodic Paralysis with Long QT. Probably a type of Andersen-Tawil Syndrome”. (No other type of Periodic Paralysis has long QT except Andersen-Tawil Syndrome.)This was after seeing me in an episode for over 40 minutes with tachycardia sustained above 140 and with long QT arrhythmias and with my past history, all else ruled out and a family history of all the above and my own characteristics and that of my family.
- 35. \*Dr. T:** Present PCP (06/09/11 Dr. T is leaving the area. I know longer have a PCP.)

I am now searching for a doctor who can and will treat me. We are selling our home and going to travel around the country. There is no sense staying in a place with no medical treatment.