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Personal Story: The Beginning

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This is the first of many short articles I plan to write about Susan and my experience surrounding Periodic Paralysis. My background in the fields of Mental Health and Special Education has given me the skills needed to research, record and postulate about Periodic Paralysis. My skills in Computer Technology have given me the ability to design Web sites such as ours. Much of what we have learned is through trial and error. Susan and I have often joked about how she feels like a lab rat, due to all the testing and probing. We have lost count of the number of saliva, urine, and serum samples she has given over the past year. We have acquired many medical devices to collect samples and take measurements. We have kept a written daily record of samplings. Along the way, we have made many discoveries. Sometimes these discoveries came in a flash of insight and other times we had to work for the tiniest bit of headway. Throughout the process I have made many self-discoveries. My diet has changed radically and I am free from all of the medications I was taking for pain management. Several times throughout the past 2 years, I bordered on emotional/mental breakdowns. The stress was unbearable at times. My life was crushed many times as I watched Susan spiral into a paralytic episode without knowing at the time what was happening to her. She appeared to be

unconscious. It was during one of these paralytic episodes that we made one of the most important discoveries. We discovered that Susan was fully conscious and aware of her surroundings while appearing to be totally unconscious. Of course her doctors at that time ignored this finding and continued along the path of misdiagnosing her condition as psychological in origin rather than due to a chemical and electrical malfunction. The discovery that she was aware during the paralytic episodes marked the beginning of the journey of discovery, understanding and now management of her disease. Many nights I spent researching new findings and had moments of ecstatic discovery. Each door that opened led us to another door that was closed. We searched together until we found the key that opened the next door. We searched until we found competent medical professionals who took us and their positions as healers seriously. And now we want to share what we have learned.

I am by no means a medical professional and by no means have conducted traditional empirical research. I would hope that somewhere on the planet deep within the walls of some chemistry lab there is a young doctoral student who is looking for a worthy subject for a dissertation. This is new age medicine and holds the keys to modern medical diagnosis and treatment of a wide range of ailments plaguing humankind including Periodic Paralysis. I suspect there are millions of people who suffer from the affects of chemical and electrical imbalances mainly brought about by poor nutrition, improper medical diagnoses, and improper treatment of medical conditions with pharmaceutical drugs that only make things worse.

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The Discussion about the Disease

There are many opinions about how to treat Periodic Paralysis; including hyperkalemia "elevated" and hypokalemia "reduced". Periodic Paralysis can be discussed on a variety of levels. Chemists talk in terms of chemical and electrical interactions and imbalances. Health care professionals talk about Periodic Paralysis in terms of affected organs and muscle groups. Dieticians discuss it in terms of calories and carbohydrates. Each specialty has a particular viewpoint and each specialty has valid points to add to the conversation. Mental health professionals have views that are helpful if framed in the appropriate context; which is addressing depression as a secondary effect of Periodic Paralysis and not in the context of depression being the cause of Periodic Paralysis.

Things get real confusing for people with Periodic Paralysis when the disease is improperly diagnoses as somatic in origins rather than being correctly identified in medical physiological terms. Nothing can replace the value of having "positive thoughts". But having "positive thoughts" does absolutely nothing to help manage chemical imbalances in your body.

Use your mental energies to improve your diet and improve your overall health and management of this disease. Chemical imbalances are responsible for many of the symptoms and making adjustments to chemical and electrical balances in your body will do more than anything else to help you manage your disease and have a better quality of daily life.

My understanding of Periodic Paralysis comes from being the caregiver for a

person with Periodic Paralysis. My wife, Susan, has Periodic Paralysis. Her symptoms have been there for several decades and have caused many secondary conditions that were misdiagnosed by medical professionals. She has been improperly diagnosed with Multiple Sclerosis, Neuropathy, Conversion Disorder, Diabetes, and quite possibly Fibromyalgia. However, Fibromyalgia is one of the few conditions that are probably very real because of the restless leg manifestations and the effectiveness of Mirapex medication, which supplements dopamine levels in her body. Keep in mind though that involuntary jerking motions can occur as a result of high acidity.

Throughout this process as caregiver, I have spent countless hours researching the causes of her condition. There are not many medical professionals who understand this disease and will probably do more harm than good in prescribing treatments with pharmaceutical drugs. I have found most of these drugs to aggravate Periodic Paralysis symptoms to the point of causing irregular heart waves and metabolic acidosis. Both of these conditions can be life threatening. Prescribing something as simple as oxygen never crosses their minds because they don't understand the disease and the disease process and secondary organ effects. Telling someone to exhale as much carbon dioxide from their lungs as possible in a rapid manner while in a state of hyperacidosis seems too simplistic. But in reality this is the body's way of compensating for highly acidic blood levels. The comprehension of this disease seems to be outside even the imagination of most medical professionals. They just do not have the skill-set or willingness to learn, to be relied upon to diagnose and treat the disease process. At this point in time we are on our own as caregivers and patients until the science can catch up with reality.

I have learned that I am on my own. I have learned to trust my own judgment but only when my judgments are supported by medical evidence. Throughout the process, I have learned how to use many medical devices including an

oximeter, ph meter, cardy potassium meter, digital blood pressure cup, thermometer, blood sugar meter and many other medical devices. The learning curve has been sharp and steep at times. Sometimes I felt like I only had minutes to make decisions about another person who was in life threatening distress.

There have been moments when I felt unbearable stress. By nature I am a pro-active person. I have learned to not indulge myself in self-pity or self-doubt. I constantly remind myself that this disease my wife suffers from is not about me. She is the one in distress and in need of comfort and treatment. Self-pity is very destructive. I have also learned to keep hope alive. I have always had hope that things would improve mainly because the only alternative is to fall into the trap of losing hope, which leads to despair, and inaction. As a caregiver you have to remain hopeful even when events appear to be otherwise. The person with the disease needs the care and encouragement to fight on. Awareness about the disease will help everyone keep the perspective that this disease can be managed even without the help of medical professionals who don't understand mainly because they refuse to listen. As caregiver you will need to be strong and not personalize what is said. And most recently I have learned that I need to allow Susan to experience and express all of the emotions she feels no matter how uncomfortable they make me feel. Feelings of hopelessness and despair often accompany the progression of the disease and especially when you both don't fully understand what is causing the condition.

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Acidosis

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It's all about the Acid.

Acids play a key role in potassium shifting. The following excerpt was taken from a comprehensive publication regarding Metabolic Acidosis.

“A metabolic acidosis can cause significant physiological effects, particularly affecting the respiratory and cardiovascular systems.” Metabolic acidosis can cause “Shift of K^+ out of cells causing Hyperkalemic.” (['Acid-base pHysiology' by Kerry Brandis, 1981](#)).

After having some conversations with a medical lab regarding the science behind the measurement of Anion Gap, I discovered many alarming issues that are worth sharing. The first issue relates to how a condition/state of metabolic acidosis is determined. As further research on my part has pointed out, there are 3 types of measurements and several methods used to determine a state of metabolic acidosis. These processes get real complicated and practically incomprehensible for anyone outside the range of professional chemistry. I have yet to find someone with this expertise who can talk in practical terms. This might be due to several reasons. The first reason being that the subject is so highly technical that it cannot be discussed in layman's terms. The second reason being that very few scientists can explain scientific concepts in down-to-earth language. The third very real possibility is that the science behind measuring metabolic acidosis is flawed and has serious limitations.

Since I cannot get straight answers from professionals then I will continue to believe that the science seriously flawed. Here is the first response I received

from a medical lab in this area regarding the measurement of Metabolic Acidosis and Anion Gap.

“Anion gap (AG or AGAP) is a value calculated using the results of an electrolyte panel. It is used to help distinguish between anion-gap and non-anion-gap metabolic acidosis. Acidosis refers to an excess of acid in the body; this can disturb many cell functions and should be recognized as quickly as possible, when present. AG is frequently used in the hospital and/or emergency room setting to help diagnose and monitor acutely ill patients. If anion-gap metabolic acidosis is identified, the AG may be used to help monitor the effectiveness of treatment and the underlying condition. Specifically, the anion gap evaluates the difference between measured and unmeasured electrical particles (ions or electrolytes) in the fluid portion of the blood. According to the principle of electrical neutrality, the number of positive ions (cations) and negative ions (anions) should be equal. However, not all ions are routinely measured. The calculated AG result represents the unmeasured ions and primarily consists of anions, hence the name “anion gap.”

There are two ways to calculate the anion gap; with or without the potassium. Interpath Laboratory calculates with the potassium and our reference range reflects this.

The first method is with the potassium:

$$\text{Anion gap} = ([\text{Na}^+] + [\text{K}^+]) - ([\text{Cl}^-] + [\text{HCO}_3^-])$$

The second method is without the potassium:

$$\text{Anion gap} = ([\text{Na}^+]) - ([\text{Cl}^-] + [\text{HCO}_3^-])$$

Both are valid calculations, but you have to use the correct reference range for the calculation that you are using, reference ranges are not interchangeable. Reference ranges are important because reference (normal) ranges are dependent on instrumentation, testing methodology and populations (age, sex, race) served. These ranges are not universal and are determined by the clinical laboratory scientists who performed your testing.”

I did some more research after receiving this response and came up with some more questions. Specifically, I asked them to look at 3 lab reports. One conducted by the local hospital. Another one was obtained from a hospital in Medford, which was only a copy of the labs already conducted, by the local hospital. The third example was from the lab that I was talking with for further clarification about the methodology. Here is the second reply.

“The method used to test the Sodium, Potassium, and Chloride assays is **ion-selective electrodes**. The Carbon Dioxide is enzymatic and detected by a colorimetric method. The anion gap reference range was determined using literature and confirmed by our actual patient population.”

The second reply actually answers my original question about the testing methods used to determine acidity. The science is credible but the interpretation of the results is not credible. What they are saying is that they use “literature” (of unknown origins) and “actual patient population” to determine the standard by which they determine what is normal and what is outside of normal range in deciding what is acceptable and what is diseased. If the "actual patient populations" they are using are 50% seriously obese and the other half are suffering with diabetes and heart disease, then their sample population from which they are making inferences is seriously flawed. Anyone who has completed an introductory college course in statistics knows that a broad range

of individuals accounting for a wide array of variables is needed to correctly identify a normal sample base and range. According to what they are saying, this lab is using its own sample population to set normal standards. I am curiously waiting for their next reply.

It is a losing battle trying to get labs to explain what they are doing and how they are doing it. And to make matters even more confusing, the standards get changed even as copies of identical lab reports are distributed through different outlets. All of the labs in question were taken at Three Rivers Hospital and the acceptable norms were changed for no explainable reason. One set of reports showed Susan's Anion Gap as within normal ranges. We obtained a copy of the same identical lab reports from a hospital in Medford and the standards had been changed reflecting that her Anion Gap was higher than normal and that she was in a state of Metabolic Acidosis during the times she was in the hospital. No one at Three Rivers Hospital ever questioned the high acid readings and the hospital has not responded to inquiries. If they had actually taken the time to look closely at Susan's lab results, (considering the unusualness of her condition) her condition would have been identified and proper treatment given. A simple infusion of Potassium Bicarbonate might have reversed the paralytic outcomes of having too high a level of acidity in her body. Her potassium levels always came back as being within normal ranges so it was important for them to look at her physical symptoms to further identify her condition. She was having heart arrhythmias and trouble breathing due to high acidity and Hyperkalemia due to high potassium levels (which were determined to fall within "normal" ranges by the hospital but actually were in "high" ranges for her).

It was somewhat understandable that they didn't question the potassium results but missing the high levels of acidity due to inaccuracy of the labs was pure negligence. They need to be held accountable but there is not a system in place to hold medical professionals, lab technicians or hospitals accountable for their mistakes other than to take them to court. Who can afford a lawyer and what doctor will testify against another doctor? The system is stacked against the

patient and this is exactly why we are ranked so low in quality of health care across the world. We spend more and get less. There is no accountability. No one is minding the store. No one is paying attention to what they are doing or even why they are doing it. There is no accountability for hospitals and especially not for medical doctors and laboratory technicians. You take your life into your own hands when you walk, crawl or get delivered by ambulance through their doors.

I wouldn't go as far as to assume there is some kind of massive conspiracy going on to keep people ill, but as we all know, stranger things have happened when we are dealing with pharmaceutical companies, the Food and Drug Association and the American Medical Association. They are in the business of treating diseases and business is booming.

Several things are certain at this point in time. Medical professionals have very little knowledge of the science behind those numbers we see on lab reports. Medical professionals have very few treatment options for serious illness outside of administering pharmaceutical drugs or performing invasive surgeries. For most people this doesn't mean a heck of a lot because they never get seriously ill. For the rest of us with physical symptoms of unknown origins, this means a lot. We are left alone to figure out what is causing symptoms that medical professionals are unable to address. We have very few people who are real healers in this country or people who understand the basics of the rudimentary causes of human disease. This opens the doors to quackery and charlatry and very sick people getting taken advantage of in their personal quest to get well. My favorite form of quackery is in the area of using mental imagery or positive thinking to control disease processes or cure metabolic based illnesses. When people are desperate for answers to mysterious health conditions, people will spend everything they own to find a cure.