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## The Unknown Auto-Immune Disease

### Chronic Inflammatory Demyelination Polyneuropathy

“This is thy hour O Soul, thy free flight into the wordless,  
Away from books, away from art, the day erased, the lesson done,  
Thee fully forth emerging, silent, gazing, pondering the themes thou  
lovest best.  
Night, sleep, death and the stars.”

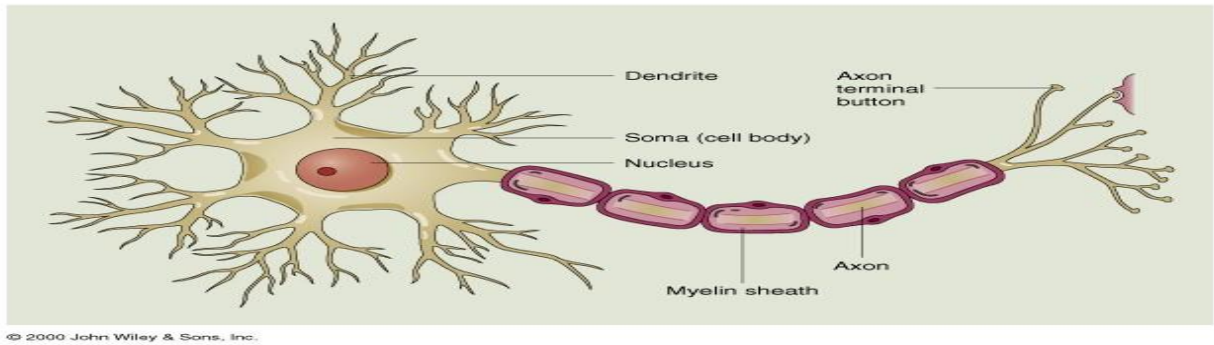
(Whitman, Walt)

I choose this Walt Whitman’s poem “A Clear Midnight” to begin because it embodies my feelings of Chronic Inflammatory Demyelination Polyneuropathy and how it affects me at the end of my day. The first line of the poem I translated into when I am lying in bed at night it is quite the days achievements are over and I have the time to ponder it is another day that I have gotten through without letting the disease run my life. Upon reading several other people’s stories it seems to me this poem reflects how each of them in their own way have chosen not to allow the disease to take over their lives or allow their lives to become the disease but rather embrace the disease and the will it has given them to fight and not become known as the sick person, but the person who has the strength to overcome.

### **What is CIDP?**

It is unclear how many people are affected by Chronic Inflammatory Demyelination Polyneuropathy (CIDP). CIDP is an auto-immune disease of the peripheral nervous system. It is the counterpart to Guillain-Barre Syndrome. Guillain-Barre Syndrome is an acute rare disorder in which your body’s immune system attacks the nervous system. It is usually triggered by an infection and causes immune mediated nerve dysfunction. About 2 in every 10,000 people are affected annually. In most cases the symptoms of muscle weakness and tingling are heightened in the first three weeks, by the fourth week, recovery usually begins. About 80% of patients diagnosed with Guillain-Barre Syndrome have a complete recovery within a few months to a year. When a patient has more than one relapse of Guillain-Barre Syndrome they are re-diagnosed with CIDP, which happens in about 5-10% of patients.

CIDP is thought to be due to immune cells that normally protect the body from infection begins to attack the nerves in the body. The myelin sheath is what surrounds the core of the nerve fiber. CIDP is said to deteriorate the myelin sheath causing the nerves to deteriorate. The nerves do not regenerate which causes tingling in extremities and weakness in muscles.



(Dubnicoff, T 5 September, 2013 Engineered Stem Cells become Myelin Super Producers  
<http://blog.cirm.ca.gov/2013/09/05/engineered-stem-cells-become-myelin-super-producers/>)

### **Diagnosis of CIDP:**

The diagnosis of CIDP is made through a clinical neurological examination. The test conducted by the Neurologist to diagnosis CIDP is to first check the reflexes in the feet, legs and arms. An absence of any of these reflexes is an indicator that a nerve issue is present. Other tests a neurologist will run are an EMG- electromyography and a NCS- nerve conduction study. These diagnostic tests will show if CIDP is the diagnosis. If a patient has a reduction in nerve conduction velocities as well as the presence of conduction block or abnormal temporal dispersion in at least one motor nerve, than the diagnosis is CIDP. A prolonged distal latency in at least two nerves and an absence of F waves or prolonged minimum F wave latencies of at least two motor nerves, leads to the diagnosis of CIDP. In some cases the EMG and NCS can be normal. There is no blood test as there is for Hepatitis C or HIV to diagnosis CIDP, although you can check for anti-ganglioside antibodies which are present in the branch of CIDP disease. They are comprised of anti-GM1, anti-GD1a and anti-GQ1b. Your doctor will also run blood work to rule out any other auto-immune disease. A spinal tap can also be done to confirm the diagnosis. If there is an elevation of CSF (Cerebral Spinal Fluid) protein found in the spinal fluid it is another indicator of the disease. The final test your doctor may want to run to confirm the diagnosis is sural nerve biopsy. If the CSF protein is greater than 1 gram the odd ratio is 51.7 it is a very strong indicator of CIDP. The biopsy is done when it is unclear in a patient's diagnosis.

### **What are the Symptoms of CIDP?**

The symptoms of CIDP are usually a combination of muscle weakness, numbness and pain in the extremities. Some people may also experience impaired balance and difficulty walking. The disease usually begins in the legs, but can begin in the arms and/or hands. Most people first sign of the disease is pins and needles sensation in the feet or hands magnified by about 10. They also will experience an extreme sensation of heat in their legs, feet or hands, to the point that it feels like bad sunburn. A person may also experience episodes of falling due to the weakness in their legs.

### **Lack of awareness of CIDP:**

CIDP is under recognized and under treated, due to its limited clinical serologic and electrophysiological diagnostic criteria. The other lack of awareness of CIDP is due to limitations of clinical trials. This is partly due to its different presentations in symptoms causing a majority of patients being misdiagnosed and left untreated. Due to so many being misdiagnosed and untreated it causes a

progression of the disease. As the disease progresses it causes further nerve damage including the axonal damage to become irreversible.

As it is similar in Multiple Sclerosis, which is another demyelination condition, it is not possible to predict the long term effects CIDP will have on an individual. The pattern of relapse and remission varies greatly in each patient. This is why correctly diagnosing the disease is very important, so the appropriate treatment can be administered. It is also important to have a good relationship with your doctors; both the primary care physician and your specialist and they are both in contact with one and other. Due to the rarity of the illness many doctors and specialist are unfamiliar with associating the disease with the symptoms. It is also important to have your physicians work together in your treatment. Most of the treatments for CIDP are experimental with different regimens depending upon the progression of the disease.

(Brian Carter Quote)

“I’ve heard claims that we can wish our way to perfect, perfect

permanent wellness, but I haven’t seen any proof of that.

Sickness and death are part of life. But you can optimize your life,

You can make progress as you strive towards perfection.”

### **Treatment of CIDP:**

Since the disease is rare, treatment is experimental, in most cases a patient will have to go through a period of experimentation with different regimens of treatment to discover the appropriate treatment. The treatment although will not correct the damage that has already been done the hope is to put the disease into a form of remission. The types of treatment a patient diagnosed with CIDP may undergo varies from patient to patient.

The first line of treatment is usually a corticosteroid, like Prednisone. Prednisone prevents the release of substances in the body that cause inflammation and suppress the immune system. The side effects of Prednisone vary from patient to patient. It can cause blurred vision, swelling, rapid weight gain and low potassium. The most common side effects are sleep problems, acne, slow wound healing, headache, dizziness, nausea, and stomach pain. If Prednisone does not work the next treatment drug used is Intravenous Immunoglobulin or IVIG.

IVIG is immunoglobins from plasma pulled from approximately a thousand or more blood donors. The most uncommon side effects of IVIG and potentially irreversible is acute renal failure, in rare cases and thrombosis. The most common side effects are eczema, headaches, chills, flushing, myalgia, wheezing, tachycardia, nausea and hypertension. If any of these symptoms occur while the patient is undergoing the infusion, the infusion should be stopped immediately and the patient monitored by the medical staff. In some patients who have had a delayed diagnosis or have not had success with the treatment of IVIG alone may require the use of both Prednisone and IVIG together. The course of a person undergoing IVIG as a therapy treatment option will require the initial treatment to be four days in a row and the infusion can be 6-8 hours long, depending on the dosage prescribed by the physician. The following treatments with IVIG after the initial treatment will be a frequency of every two to three weeks times two days. In most cases the treatment is prescribed for 3-6 months to see if there is any improvement in the patient.

The IVIG medication for a dosage of 50ml can cost about \$10,000. Due to the expense of the medication most insurance companies require a pre-authorization to approve the drug. This will require documentation from the physician making the diagnosis to support the necessary treatment. The insurance companies may also require any diagnostic testing and biopsy results. If a patient is responding slowly and requires another 3 or 6 months of treatment most insurance companies will require another pre-authorization to approve the medication.

If IVIG therapy does not work the next option a person with CIDP has is the use of an immunosuppressant with IVIG therapy. Some of the immunosuppressant medication being used is Cellcept. Cellcept was originally used for patients who are undergoing a kidney or liver transplant as an anti-rejection medication. It helps to suppress your immune system. The suppression of the immune system makes Cellcept an ideal drug used to help treat autoimmune diseases, such as CIDP. One of the more serious side effects of the medication a patient may experience is lymphoma. The medication will increase your risk of lymphoma and other cancers including skin cancer, cytomegalovirus, BK virus (a member of the polyomavirus family) which can damage a person kidneys and progressive multifocal leukoencephalopathy which is a brain infection and can be fatal. A patient who is on cellcept will require blood work done monthly. The blood tests that will be monitored for a patient on cellcept are white blood cell count, red blood cell count and platelets if there are any abnormalities your doctor will both decrease the dosage of cellcept and then repeat the blood test after a week to see if the blood levels return to normal. If the levels do not return to normal the doctor may choose to stop the cellcept all together and look for an alternative immunosuppressant. Some of the most common side effects of the cellcept a patient may experience are upset stomach, vomiting, swelling of the lower legs, ankle and feet and high blood pressure.

Another drug which can be used is Methotrexate if a person is not able to tolerate cellcept. Methotrexate is used in cancer chemotherapy, autoimmune disease and ectopic pregnancies. It acts by inhibiting a person's metabolism of folic acid. When methotrexate is given in high doses it is used to treat cancer as it is a chemotherapy agent. When it is used in lower doses it is generally safe and well tolerated in the use for treatment of certain autoimmune disease. Some of the side effects associated with the use of methotrexate even given in a low dose are hair loss, nausea, headaches and skin pigmentation. About 16% of patients will discontinue the use of methotrexate due to the adverse side effects they experience.

The final course of treatment for a person with CIDP is plasmapheresis. Plasmapheresis is the removal of pathogenic antibodies or circulation immune factors that are associated with demyelination. The initial treatment is 6 rounds over a two week period followed by 1 round every 6 to 8 weeks. IVIG is the preference over plasmapheresis because it is much safer and less invasive. Some of the side effects associated with plasmapheresis are anaphylaxis which is a severe allergic reaction that can include itching, wheezing or a rash. Infection, bleeding, seizures, drop in blood pressure or bruising.

Other options a patient with CIDP may consider in conjunction with the above treatment options are nutrition and exercise. It is important for a patient who is undergoing treatment for CIDP to maintain a good nutritional diet with lots of vegetables to increase their vitamin intake as well as staying away from foods with high fat content, since some of the treatments used can cause high blood pressure. It is also important to exercise especially the effected extremities to maintain strength or as it has been phrased "quality of life." Physical Therapy has been effective in teaching patients with CIDP the appropriate exercises they should be doing to maintain and possibly increase their strength in the affected extremities as well as the extremities that have yet to be affected. I have not been able to find any homeopathic remedies or alternative treatments for this disease.

## **Life with CIDP:**

Although I have the disease I have decided to put off discussing my experiences until the end of this paper and for now focus on others who have been diagnosed with the disease, how their diagnosis came to be, treatments they have under gone and are undergoing, and how it has affected their lives and the lives of their loved ones. Do others allow the disease to define who they are or is the disease just another facet of themselves? This is an important claim to be determined how a person who is ill or has a disease will react when told and how they will incorporate it in their lives or do their lives become the disease and does that choice impact how they will react to treatment?

(Langston Hughes)

Still Here

I been scared and battered.

My hopes the wind done scattered.

Snow has friz me.

Sun has baked me.

Looks like between 'em they done

Tried to make me

Stop laughin', stop lovin', stop livin'—

But I don't care!

I'm still here!

I choose the Langston Hughes poem “Still Here,” because based upon some of the stories I have heard in groups as well as found on chat lines best describes the determination of some of those whom I have found with the disease and their struggles and their fight to overcome the obstacles they faced and lead a normal life.

Jane Smith. began to experience symptoms in the summer before she turned 14. She had taken several falls, scraping and bruising her knees and elbows. Her symptoms began to progress to dropping things and having difficulties opening bottles. One day she was out riding her bicycle and she fell, the scariest moment happened when she was unable to stand up from the fall off her bicycle. Jane's mother contacted their pediatrician who referred them to a pediatric neurologist. Her condition became worse to the point that she could no longer lift her arms above her head, dress herself and she had taken another fall, down the stairs. The neurologist Dr. Jones diagnosed Jane with Guillain-Barre Syndrome. Jane's parents took her to the emergency room at Children's Hospital. Jane became weaker and weaker and her stress level escalated. She spent six hours in the emergency room and saw another neurologist, student, resident, fellow, and a nurse. Finally she had a spinal tap, which confirmed her diagnosis and a few days later she had an EMG and nerve conduction test, spending five days in the hospital and receiving three

rounds of IVIG. Kristen showed immediate improvement from the three courses of IVIG treatment but knew her life would never be the same.

Every eight weeks Jane would have relapses; this changed her diagnosis from Guillain-Barre Syndrome to CIDP. Over the course of time Jane would learn to notice the signs she was relapsing after the course of IVIG treatment. The signs she would experience are difficulty gripping a pen, tingling in her fingertips and the prevailing foot drop. Jane realized that she had to come to terms with her disease and decided to meet people who could relate to her condition. She attended her first symposium and after hearing stories from others just like her she was determined to live a healthy life and become more in touch with the connection between her body and mind. Jane began to practice Iyengar Yoga and took a healthy diet as well as the support of her husband and family she has not had a relapse in close to five years. Jane currently works as a Special Education Teacher and is the Chair for the Pittsburgh Walk and Roll. She awakes everyday with her condition and chosen to live the fullest life possible and not let her condition rule her life.

I felt the Langston Hughes poem “Still Here,” best represented Jane’s story because the first line “I been scared and battered,” shows her fear described in the beginning of the story of falling several times the bumps, scrapes and bruises. The next several lines “My hopes and wind done scattered. Snow has friz me. Sun has baked me.” These lines represent her falling off her bike and the fear she experienced falling off her bike and unable to stand, the terror she felt, the unknown of what was happening to her. The next several lines, “Stop laughin’, stop lovin’, ‘stop livin’—But I don’t care! I’m still here!” These lines describe how Jane choose not to let the disease run her life, but rather she decided to meet people like her that shared the same disease and make changes in her life through Yoga and diet. Jane chose to make a decision to not allow the disease to run her life but rather to fight. Could it be her willingness to fight and not let the disease rule her life that caused her disease to be in remission for the past five years or was it the yoga and change in her diet that caused her remission. I decided to reach out to Jane and ask her what she thought was the turning point for her that caused her disease to go into remission, I needed to understand and possibly learn from her what she thought it was.

I contacted the Pittsburgh Walk and Roll, Jane was very kind in speaking with me when I explained my situation as a person diagnosed with CIDP. I explained my story to her, the treatments I have under gone and currently undergoing and what she felt was what put her disease into remission. Jane was very frank and honest that she could not let the disease take over her life and she needed to learn to live with the disease and find a way to incorporate the disease into her everyday life. Jane told me she felt there were two key points into what she attributed to her remission; the first was the knowledge that she was not alone in this. The love and support of her family and the people from the group gave her the desire to fight, not allow the disease to control her but for her to control the disease. The second point was her attitude to change her life, she wanted to find an alternative to the IVIG treatment that she could use every day to enhance her life, give her physical strength and feels that she has found that through diet and yoga. Jane became an active member in her community and educating those around her about the disease. I found her to be a true inspiration and giving me hope that there is something else out there for me to look to as a source that I can consider as an option. I do feel the need to learn further about what others are doing to combat the disease.

(Robert Frost) 1874-1963

Nothing Gold Can Stay

Nature’s fist green is gold

Her hardest hue to hold.

Her early leaf's a flower;

But only so an hour.

Then leaf subsides to leaf.

So Eden sank to grief,

So dawn goes down to day.

Nothing gold can stay.

There are many interpretations people can associate with Robert Frost's poem Nothing Gold Can Stay the association I have is when we are young everything is new, its green. And shiny like gold, but as we get older our lives change things around us change. This is how I interpret the second line "Her hardest hue to hold." The next line "Her early leaf's a flower;" reverts back to line one when we are children everything being new and in the next line "Then leaf subsides to leaf.," means as we get older, days change to days, months to months and years to years. The next line "So Eden sank to grief," means our happiness can change to grief. "So dawn goes down to day.," means as the new beginning of our lives change. "Nothing gold can stay.," means everything in life changes, nothing stays the same. We will have our good times and face challenges. I found this poem to be very relevant when I read Jane's story.

Diana's journey began in October 1967, this is when she was born to two college students whom wanted nothing but the best for her, so she was given up for adoption and was adopted within thirty days. I felt it is important for the reader to know that Julie is adopted. Having a clear medical history is important to any physician, a clear medical history of not just the patient but also immediate family members, such as mother, father, and any siblings. This will help the physician assess the patient and if there is any genetic link to specific ailment they may have. In Julie's case she did not have that information to provide to doctors, so making a diagnosis may take longer. Her struggle with CIDP began when she was 28. She flew home for Thanksgiving and as she was walking in the airport towards her father who was a pediatric radiologist. Her father noticed that her gait was off. Diana told her father that she attributed it to post pregnancy but her hips were sore. Her father suggested that she go and see her doctor and have her doctor refer her to an orthopedic. Diana's doctor did some test, including asking her to stand on her toes, this is when she realized she could not, which was odd she used to dance through college age and she had not realized she had lost function in her toes. Her doctor decided not to refer her to an orthopedic but referred Diana to a neurologist.

The following day Diana went to the neurologist office and learned that her blood test for muscle inflammation came back elevated. The neurologist wanted to conduct test of his own and Julie had an EMG, a spinal tap and a muscle biopsy done. Diana referred to these test as the "push me, pull me test." (Julie, GBS/CIDP Foundation International Patient Stories [www.gbs-cidp.org/patient-stories/julies-story](http://www.gbs-cidp.org/patient-stories/julies-story)). EMG, spinal taps and muscle biopsy can be very painful, depending upon the amount of nerve damage there is. Diana's reference to it being a push me pull me test is accurate in statement to most people who have had it done, and EMG sends electric shock through specific nerve locations on a person's body, if the nerve is active it is slightly painful and jolting. The spinal tap is discomforting since you are awake for it a lying on your stomach so you cannot see what is going on and a large needle is inserted into your

spine to remove fluid. Although you cannot feel the needle go in, you do feel a sensation of pulling. A biopsy is a feeling of extreme discomfort and feels like you are being pushed, again you can't truly see what is going on but you feel fingers and hands tugging and pulling to get what they need. Most people dread when you hear the doctor say they need to anyone of these tests. Based upon the test the neurologist completed on Diana he narrowed down his search to her disorder to Multiple Sclerosis, Muscular Atrophy, Multiple Myeloma or Chronic Guillain-Barre Syndrome. The doctor told Diana to look on the bright side Chronic Guillain-Barre Syndrome is treatable. Diana thought it was easy for him to say, he was not dealing with the news, she was just told and the impact it would have upon her life. Most people just like Diana when diagnosed with any disease do not want to hear look on the bright side; at that point there is no bright side, just many questions.

Diana became very depressed after she was diagnosed as well as angry, scared and mad. Diana asked the question "why me?" All stages and the question most people go through when diagnosed with a disease that is going to change their lives and alter how they will live. Diana was not just scared for herself but also for her family, as a mother of young children what was she going to do? Diana cried, screamed and finally she and her husband decided to take matters into their own hands and began to do their research. At this time Diana also began treatment every 28 days of plasmapheresis. Diana remembers the feeling of being cold as her plasma was being removed. She also began massive amounts of steroid treatment. Diana's doctors recommended that she eliminate all the stress from her life. So she chose to stop working full time as a special education teacher.

Diana knew that she needed to learn to listen to her body and began to work on being in touch with how she was feeling. This was the tool Diana would use for measuring the effectiveness of the treatment. Many people after treatment feel very sick, the relation is like being on chemotherapy, you get nausea, and very bad headaches. The duration into how long the treatment last, varies from person to person. So people do not feel any symptoms return and others feel the symptoms return within a week or two of doing treatment. From reading Diana's story it seems her symptoms came back sooner than how long she lasted without them. During her research Diana found the GBS Foundation and Dr. Richard J. Smith in Dallas. She made a trip to Dallas and he confirmed she had Chronic GBS. Diana felt more comfortable with the confirmation from Dr. Smith since he was familiar with the disease and assisted Diana with coming to terms with the situation. Diana spent the next several years battling the disease. The flare ups would cause her to take steps backwards. Each time Diana recovered from a flare up she felt she never made it back to where she once was before that flare up. Diana soon realized that each time she had a flare up the disease would strike back the next time with more of a vengeance than the previous flare up. Diana resigned herself that this was her life and learned to live with the knowledge that she was slowly losing functioning in her arms and legs. Diana kept in touch with the foundation; she looked forward to the newest updates in treatments and progress. She would make copies of the newsletter and bring them to her doctor's office. Diana became an expert in her disease and began to educate others around her.

After nine years of her original diagnosis of Chronic Guillain-Barre Syndrome the disease was renamed Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). Diana and her family were faced with a bigger battle. In October 2004, Diana's husband was diagnosed with Pancreatic Cancer. Diana and her husband would sit together in the Hematology Oncology office both undergoing treatment for their disease. Diana was now receiving IVIG treatment and her husband was receiving chemotherapy



treatment. Diana sat receiving treatment for her disease knowing that the disease would not kill her and looked around at people like her husband undergoing chemotherapy and how unlucky they were. Diana became the care giver and provider to her husband. Ten months after Diana's husband's diagnosis he lost his battle with cancer.

Dealing with the stress Diana pushed on but she began to get worse and developed drop foot in both feet. Dropped foot is difficulty lifting the front part of your foot, people who have dropped foot may drag the front part of their foot on the ground when they walk. Dropped foot is a sign of a neurological, muscular or anatomical problem. Sometimes dropped foot can be temporary and other times it can be permanent. A person who experiences dropped foot will need to wear a brace on their ankle and foot to hold it in the correct position. Diana knew her condition was getting worse; the function in her hands began to deteriorate. She embraced that she looked different and chose to make the best of the situation, she brought crazy knee socks switched neurologist. Diana met another individual during her infusions with the Chronic Inflammatory Demyelinating Polyneuropathy. They became drip buddies. The two women made it a point to have a girl's day on the day they received their infusions, they would order lunch, bring movies and make popcorn and instead of having a depressing day they would make it a day of fun.

People would ask Diana what is wrong with her and instead of telling them she was sickened with the rare debilitating disease she would tell people "I have been blessed with a Chronic Inflammatory Disease that affects 1.5 in a million." (Julie, GBS/CIDP Foundation International Patient Stories [www.gbs-cidp.org/patient-stories/julies-story](http://www.gbs-cidp.org/patient-stories/julies-story)) Diana soon realized that this was the best phrase and people would either be speechless, say nothing or they would ask for more information and she would educate them.

In 2012 Diana had a major setback she fell in her house and broke her left ankle and required surgery. Diana had an L shaped plate and 9 screws placed in her left ankle. She experienced life in a wheelchair and did not like the experience, which drove her to become as mobile as she possibly could. The GBS/CIDP Foundation helped Diana feel as though she was not alone in her journey. She read about a Symposium in Fort Worth, Texas. The symposium was a life changing experience for Diana. When she attended the symposium she felt like she was with family, people there understood her. At the symposium Diana realized that many people were not aware of the daily living aids available. This became her new mission, to help other people with the disease discover tools available to them to help with their daily life functions. Diana left the symposium and knew that she needed to become a liaison to help others.

Diana learned to become her own advocate, in March 2013 a new device for dropped foot became available, and the device was a neuroelectric stimulation system. A neuromuscular electrical stimulation (NMES) is the application of electrical stimuli to a group of muscles. It is used to stimulate the nerves in muscles with electrical impulses. The electrodes are placed over the targeted muscle area and electrical impulses are then passed through the muscle to the nerves. These impulses stimulated can help muscles that have lost their function to regain some of their function. Most people who undergo neuromuscular electrical stimulation require physical therapy to help strengthen the muscle. Diana was screened for the electronic system to see if it would work and help improve her dropped foot condition and she passed the screening process. Diana soon found out after she passed the screening process that it was not covered by

her insurance company. Most insurance companies consider treatment like these to be experimental and will not cover the expensive cost. The cost for the system per leg was \$8,000 and Diana did not have \$16,000 she would need for the system. Diana began to look for alternative funding as she knew this was the only way that she would be able to keep her legs active. Diana found DARS the Department of Assistive Rehabilitation Services. Diana met with a caseworker and 10 months later she received full funding for bi-lateral Bioness.

Today Diana has returned to work full time as a special education teacher, completing 19 years of teaching. She has maintained her health she still receives IVIG infusions every 2 weeks and continues to help others on their journey. “If you look at where I have been and then the things I have endured, my life is truly a blessing!” (Julie, GBS/CIDP Foundation International Patient [Stories www.gbs-cidp.org/patient-stories/julies-story](http://www.gbs-cidp.org/patient-stories/julies-story))

Diana’s story gives hope to others, she has been through a great deal in her 48 years of life. In comparison to Jane’s story Diana has had to endure many more struggles with CIDP through the dropped feet, which makes it much more difficult to walk and maintain balance, to her personal ordeals which she faced in her husband’s diagnosis of cancer and losing him after 10 months of the diagnosis and chemotherapy treatments. Diana has never lost the desire to fight and although she has not taking alternative fitness like Jane through yoga as it is likely do to her dropped feet she would not have been able to tolerated the movements and positions, Diana has become a beacon, teacher for others to advocate for themselves as she has done.

(Maya Angelou)

“A Plagued Journey

There is no warning a rattle at the door

nor heavy feet to stomp the foyer boards

Safe in the dark prison, I know that

light slides over

the fingered work of a toothless

woman in Pakistan

Happy prints of

An invisible time are illumined.

My mouth agape

Rejects the solid air and

Lungs hold. The invader takes direction and

seeps through the plaster walls.

It is at my chamber, entering  
the keyhole, pushing  
through the padding of the door.

I cannot scream. A bone  
Of fear clogs my throat.

It is upon me. It is  
Sunrise, with Hope

Its arrogant rider.

My mind, formerly quiescent  
in its snug encasement, is strained  
to look upon their rapturous visages,  
to let them enter even into me

I am forced  
outside myself to  
mount the light and ride joined with Hope.

Through all the bright hours

I cling in expectation, until  
darkness comes to reclaim me

as its own. Hope fades, day is gone

into its irredeemable place

and I am thrown back into the familiar  
bonds of disconsolation.

Gloom crawls around

Lapping lasciviously

Between my toes, at my ankles, and it sucks the strands of my  
hair. It forgives my heady

fling with Hope. I am

joined again into its

greedy arms.

John was a dedicated member of the UAE cycling fraternity, regularly riding 450KM a week as part of a healthy regime. Wednesday November 2, 2011 after he completed a regulation ride at the Dubai Autodrome, John began to experience a tingling sensation in his feet and within 72 hours he was in the intensive care at the American Hospital in Dubai, admitted due to ascending paralysis. Neurologists initial diagnosed John with Guillain-Barre Syndrome, after the paralysis began to spread up John's body Neurologist changed his diagnosis to CIDP. John spent five months lying on his back, hospital staff would come in and turn him every five hours and staff would have to hoist him out of bed. It has taken almost two years but John is ready to return to work, but this did not come without a lot of work. While in the hospital John lost 14kg, which translates into 30 pounds. His hamstrings shrank so much because of muscle atrophy it took him weeks to contemplate standing and before he could straighten his legs. Atrophy is the gradual decline in effectiveness or vigor due to the underuse or neglect muscles. It was a painful recover for John who at the time was 55 years old, had to relearn to walk, a painful one step at a time. He said it is interesting because your brain forgets how to balance, he would take three steps to the left and he would fall over. He said he would feel like he is all over the place looking up, looking down, out into the distance, looking left and looking right, it was as though his brain had a fog over it. It is somewhat scary to feel this way, not knowing if things are going to get better or is this as good as it is going to get.

John took the stand that he was not going to let this disease beat him. John would undergo regular plasma exchanges, undergoing seven catheter punctures in the groin and three in the chest. John would suffer deep vein thrombosis three times. Deep vein thrombosis or DVT is the forming of blood clots in one or more of the deep veins in your body, usually in the legs. Deep vein thrombosis can cause leg pain or swelling. Deep vein thrombosis is a serious condition, the blood clots in the veins can break loose and travel through the bloodstream and lodge in the lungs blocking blood flow causing a pulmonary embolism. John also underwent three spinal taps and endured numerous nerve conduction studies. John was determined not to wallow in self-pity so he embraced his physical therapy sessions while in the hospital desperate to get back to normal.

Early in 2013 John experienced a relapse while out riding his bike. It caught him off guard. Doug was thankful that the relapse happened while he was in the company of his friends from the Cycle Safe Dubai group. John was also thankful due to a change in his treatment, common sense and a new found structured approach to his recovery, John was soon back on track. John has incorporated physical therapy, a gym regimen, change in his diet and rest to his success. John has started a blog called "The fitness Hacker" [thefitnesshacker.com/linkedIn](http://thefitnesshacker.com/linkedIn) John uses the blog to investigate the intersection between technology, health and fitness. He reviews a variety of apps and gadgets, including the latest high-tech "heads-up display" system, which runners and cyclists can monitor heart rate on their sunglasses. John also explains the consequences of his being ill and how this got him interested in finding out how fit he is. John began investigating tools to measure fitness so he could get a better understanding about how much progress he made and shares this information with people on his blog, so that he may help others who have been diagnosed with this disease and how it has affected his life.

I choose the Maya Angelou poem *A Plagued Journey* to describe John's story because I felt it best described his journey when he became ill, got better and then when he came out of remission. As an avid cyclist to out of nowhere be struck with this fear when he began to feel the tingling in his feet and then to become paralyzed. Spending months in the ICU to then have to learn to walk and stand straight again. He did not know if he would ever get back to where he once was. These are all expressed in the lines in Mrs. Angelou's poem "sweeps through the plaster walls; it is at my chamber entering through the key hole pushing through the padding of the door." This was the disease grabbing hold of John, the plaster walls representing his limbs. "Cannot scream. A bone of fear clogs my throat;" this refers to John not understanding what is going on with him and the fear that grabs a hold of him. "I cling with expectation until darkness comes to reclaim me," I feel describes how John felt when he was in a state of remission and then he had a relapse.

Unfortunately no one knows regarding why patients with CIDP go into remission and what cause them to relapse. Does it have to do with a person's nutrition or exercise regimen? Or does it have to do with stress in the person's life? In John's case he was out riding his bike, so could he have been over exerting himself, it is not clear. Unlike Diana, John never discussed knowing when he felt he was relapsing. The question that needs to be asked is are those who are missed diagnosed and go untreated likely to have more relapse than those who are diagnosed and treated earlier?

When I compare all three stories it seems to me that Jane was diagnosed early therefore her myelin sheath may not have deteriorated as much as Diana's which is why she has been in a state of remission for five years. Julie seems to have suffered more nerve damage and muscle damage due to her dropped feet which is likely why she has been relapsing more frequently. Could the relapsing be due to age, since John was 55 and Diana is 48 could this be a factor associated with a person and the frequencies at which they relapse? It is very unclear why people relapse and those that do relapse like in Diana's case bring on other symptoms. As you recall, each time Diana relapse, she felt the disease come on with a much more powerful vengeance than previous and in John's case having to relearn to walk was very painful, Jane did not seem to experience such aggressive symptoms. Does physical fitness play a part of keeping the disease at bay? I don't believe so after reading Jane's story and John's because they both are active yet John's story of paralysis even though he was an avid bicyclist, gives no bearing that exercise helps in remission, especially since at the time he relapsed he was out riding his bike.

Since the disease is rare, many doctors do not even know about the disease, which makes it difficult to diagnosis and treat. Many people need to go through regimens of different treatments before they find out that works. Would this disease be better known if a celebrity was diagnosed with it? Would there be more research of the disease being done and how to combat the disease. When you hear Parkinson's disease many people think of Michael J. Fox. He was very outspoken when he was diagnosed with the disease and the research he is doing to combat the disease. He setup a foundation called the Michael J. Fox Foundation for Parkinson's Research, so does this help when there is a celebrity with the disease to give it more attention to the public and to researchers. I think it does as I have not been able to find any celebrity who has been open to having the disease. Research is the key in helping to treat any disease and the lack of research being done by neurologists on this disease is scary. Some neurologist I have experienced are not even versed in the disease. Yes they learn about it in their medical training but it seems to be rare that they do not focus on it and the treatment of it. A number of doctors not just neurologist I have seen when they review my medical history ask what is CIDP, I think it is funny

because I did not go to medical school, yet here I am explaining what the disease is to someone who has. I find it ironic and frustrating at the same time. Frustrating because I feel healthcare professionals should know about the disease. A healthcare professional take an oath to do no harm, isn't it harmful to the patient when the provider is not informed or knowledgeable of the disease and proactive in treating and find a cure for the disease.

“The Road Not Taken”

(Robert Frost) 1874-1963

Two roads diverged in a yellow wood,  
And sorry I could not travel both  
And be one traveler, long I stood  
And looked down one as far as I could  
To where it bent in the undergrowth;

Then took the other, as just as fair,  
And having perhaps the better claim  
Because it was grassy and wanted wear,  
Though as for that the passing there  
Had worn them really about the same,

And both that morning equally lay  
In leaves no step had trodden black.  
Oh, I kept the first for another day!  
Yet knowing how way leads on to way  
I doubted if I should ever come back.

I shall be telling this with a sigh  
Somewhere ages and ages hence:  
Two roads diverged in a wood, and I,  
I took the one less traveled by,  
And that has made all the difference.

I choose the “The Road Not Traveled,” by Robert Frost to begin to describe my own journey and will use pieces throughout to discuss my experiences and how this poem relates to my life and how I handle the illness. When we are born life is not mapped out for us, we are given many choices, and we can choose what school we apply to for college, what we are going to study in school, where we are going to live and who we will date and marry and even if we are going to have children. What we cannot choose is if we are going to get hurt or become sick. As in the poem we are faced with two roads, choices to make and we have to make the decision that is best suit for us. The road that is going to give us what we most desire in life, but in choosing that road are we compromising the aspects in life such as our health that we cannot control. When you are diagnosed with a disease you begin to question if I did this in life would I be sick, would this have happened to me? A person always questions if a decision they have made is the right one, based upon the impact it has had on us currently, it is called uncertainty. Just as in the poem when Frost refers to “two roads diverged in a wood, and I, I took the one less traveled by, and that has made all the difference.” Choosing one road, or path did this somehow impact my life as a whole and alter what would have happened if I choose the other direction. In the two lines, “Yet knowing how way leads on to way I doubted if I should ever come back.”, refers to we cannot go back and change

the past, what's done is done. Even if I thought for a moment that if I made other decisions than the ones I made I cannot go back and change them. I have to learn to accept the choices I have made and the outcomes associated with that choice. A person cannot live their life with regret, as life is too short, we have to accept the choices we have made and the outcomes of those choices including if it leads to illness or disease.

My journey began in 2009. I began feeling burning in my feet and calves and tingling in my fingers. I experienced episodes of dizziness and even periods of brief black outs. As someone who works in health care for over fifteen years, I do not make the best patient. After having several falls including hitting my head my husband made me agree to go to the doctor. I made an appointment with a neurologist who did a bunch of blood test and sent me for several MRI's of brain, neck, and spine. At that point I was not very sure what he was looking for but he started me on a dose of prednisone. When I went back to review the results he told me that I am B12 deficient, I have a herniated disc in my back and I have a tarvol cyst in my brain. Tarvol cysts are also known as perineural cysts or sacral root cyst. These cysts are dilation of the nerve root sheaths and are abnormal sacs filled with spinal fluid and can cause progressive nerve pain and muscle weakness. I thought okay this is it so what is the treatment for it, the doctor said I want you to have a spinal tap, before I confirm my diagnosis and we begin treatment, The next day I went in for the spinal tap, I have to say I have had an epidural when I was delivering both my children but this was painful. Once you are numb you lay down on a bed face down the only thing you see is the floor, it is a very unsettling experience. The tap took about a half hour, I recall the anesthesiologist telling me that I am a very slow drain and they need to obtain several vials of spinal fluid. When the test is over you are taken back to recovery and lay there for about an hour. You are given discharge instructions where you are told for the next 24 hours you need to lie on your back completely flat because it is possible that spinal fluid can leak out and cause you to loose feelings in your legs and arms. Several days later I return to the neurologist office and he reviewed my test result which showed that I had elevated CFS protein levels and this could indicate a number of things but had no relation to the tarvol cyst. In fact he felt the cyst was small enough that it had no impact on the symptoms that I was experiencing. He felt it was better that I see another neurologist who had more experience with multiple sclerosis and referred me to NYU's multiple sclerosis department. All I am thinking is he thinks I have multiple sclerosis.

The following week I went the NYU's department of neurology with my husband and mother, who were both there for moral support. The first doctor that came in was a fellow. A fellow is a doctor who has completed medical school but is going through specialized training in a specific area of medicine. He did no exam, just asked a lot of questions for about a half hour. The questions ranged from my personal health to my immediate families and to my sex life. I gave him copies of my test results and he left the room. About fifteen minutes later he returned with one of the physicians. The first thing she said to me is it is not multiple sclerosis, she did not examine me, but rather said I want you to have some blood work done and I am going to give you a prescription for the numbness and dizziness. All I am thinking is okay is anyone going to tell me what is wrong with me and how can you give me medication when you have not even examined me. I was not comfortable with the situation but I thought okay she is the doctor; she went to medical school she must know what she is talking about. When we left we told my mother what happened and my husband who is a doctor himself could not believe what he just witnessed, but we said okay do the blood work and try the medication, because in the end I just want to feel better.

The medication made me feel worse, so I of course stopped taking it and my blood test results which included sexually transmitted diseases such as syphilis came back negative. Syphilis is a sexually transmitted disease that can be transferred with direct contact with syphilis sore. In latent stages of syphilis a person can experience muscle weakness, difficulty with coordination, numbness and dementia, thankful I did not have syphilis. The doctor could not explain to me what was wrong and said if you are still experiencing these symptoms in several months I should come back and see her. Of course I decided at that moment that I would not continue to see her since I did not feel that she really did anything to determine what was wrong with me. I decided it was best to find another doctor and see if they could

help me. I did my research to see who in my area was best suit for me to see was and scheduled my appointment.

## Mirror

(Sylvia Plath)

I am silver and exact. I have no preconceptions.  
Whatever I see I swallow immediately  
Just as it is, unmisted by love or dislike.  
I am not cruel, only truthful,  
The eye of a little god, four-cornered.  
Most of the time I meditate on the opposite wall.  
It is pink, with speckles. I have looked at it so long  
I think it is part of my heart. But it flickers.  
Faces and darkness separate us over and over.

Now I am a lake. A woman bends over me,  
Searching my reaches for what she really is.  
Then she turns to those liars, the candles or the moon.  
I see her back, and reflect it faithfully.  
She rewards me with tears and an agitation of hands.  
I am important to her. She comes and goes.  
Each morning it is her face that replaces the darkness.  
In me she has drowned a young girl, and in me an old woman  
Rises toward her day after day, like a terrible fish.

I choose the poem by Sylvia Plath "Mirror" because it best describes who I have evolved into over the years since I was diagnosed. A mirror does not represent the reflection of who we are perceived to be but rather a true reflection of ourselves from the inside. In the line "I am not cruel, only truthful," means I view life differently, I no longer sugar coat things. I am straight forward in my responses. Life is too precious and you do not have time to sugar coat things, some people would refer to it as not having a filter but I refer to it as being blunt, stating what is on my mind. In the lines that follow regarding the placement of the mirror on the wall and it is part of my heart but the flickers of faces and darkness separate us over and over, refer to life has become so routine. It has become difficult to be spontaneous let alone plan things, the constant testing you endure, surgery, and treatments. Changes in medication regimens make it difficult to plan something even three weeks out. Since it is not clear how I would respond to treatment and the side effects that I may potential endure make it difficult, so I end up sticking with my daily routines. In the following paragraph refers to your reflection being excepting of your true self, not just a physical appearance but of the cognitive and emotional appearance. I have accepted I have this disease and it is part of my life but it does not define who I am. There are days I may not feel as well as others but it is important that I continue with my life every day and not succumb to the disease.

Just like Diana and Jane, I have seen more than one doctor. The next doctor I saw reviewed the test that were already done and decided to schedule me for an EMG. I had never had one before so of course did not know what to expect. The best physical description I can provide to someone who has never had it before is think about your cell phone vibrating and EMG is about four times stronger than the vibration of a cell phone. The procedure was done on my legs and arms. The doctor stated at the end of the test that you have carpal tunnel syndrome in both of your hands and if I do not have Multiple Sclerosis than it is peripheral neuropathy. He puts me on prednisone and sends me for additional studies.



I had different evoked potential tests done. Evoked potential tests measure electrical activity in certain parts of the brain based upon responses to sensory input. Demyelination causes nerve impulses to be slowed or non-existent. A VEP or Visual Evoked Potential is when the patient is placed in front of a screen and an alternating checkerboard pattern is displayed. A VEP causes visual stimulus. A Brainstem Auditory Evoked Potential or BAEP is when a patient hears a series of clicks in each ear. A BAEP is used to determine if the auditory nerves are functioning properly. Somatosensory evoked potential tests indicate if the spinal cord or nerves are pinched. They are short electrical impulses to the arms or legs. A Motor evoked potential can detect lesions along the motor pathway of a person's central nervous system. They are recorded from muscles following the direct stimulation of exposed motor cortex.

In 2010 I had a VEP, BAEP and MEP done, I recall the process being very long and sometimes uncomfortable. The test results went directly to the doctor who interpreted the information. He informed me that I did not have MS and he was not clear what he was dealing with. I recall frustration setting in as this is not what I wanted to hear. I was hoping that he would tell me you don't have MS but it is this..... and it can be treated. Bottom line I was tired of doing tests and just wanted to feel better. Frustrated I choose not to continue with the doctor in fact I made a decision not to continue with any doctor or seek treatment. I was feeling as though the medical system was failing me, I also wondered could it all be a psychosis.

For two years I did not see anyone regarding my condition but I knew in the summer of 2012 I was getting worse. I had fallen several times over the course of a week. I began to forget things, my legs felt as though they were constantly on fire and I began to lose all sensation in my feet and toes. In August I had an accident and broke my heel in several places, including directly in half. My husband and his partner upon reviewing the MRI could not understand how I was walking and not screaming in pain. I explained to them that I did not feel anything in my foot and lower part of my legs, it was a scary thought. I agreed to see another neurologist and try and seek treatment. That September when my foot finally healed I saw Dr. P. Magda.

I recall I did not like him initially; I brought him copies of all the diagnostic tests, blood work and spinal tap results. He took a detailed history and physical, checked my reflexes in my elbows, legs and feet, he noted my left foot reflex was absent. Dr. Magda decided he was going to have me repeat some of the tests as well as he wanted me to have SSEP test and another EMG. The SSEP test was to be done at Cornell in NYC. I can compare it to an EMG except it was 5 times stronger. I remember the technician who was administering the test asking me multiple times throughout the process if I was diabetic. At first I could not understand why and when I asked my husband he said it was because I likely had neuropathy and most times neuropathy is associated with diabetes. A week later I returned to Dr. Mar's office for an EMG and a NCV- nerve conduction velocity study. A NCV determines the adequacy of conduction of nerve impulses as it courses down a nerve, detecting nerve injury. Needles are used with electrodes attached and it's extremely painful. Upon completion of the test and review of the SSEP he said I have peripheral neuropathy damage that is consistent with CIDP. He said there are two ways to confirm the diagnosis for sure through a blood test checking me for certain auto-immune diseases including Anti-GM1, Anti-GD1a and Anti-GQ1B or I can have a nerve biopsy. I choose the blood work since they are the less invasive of the two. The results came showing I had Anti-GD1a. Dr. Mars decided that the best course of treatment for me was IVIG with a medication called Gamuguard. He set it up so my treatments would be done at the Dyson Center in Poughkeepsie; the Dyson Center is an infusion center. My first appointment would be for four days at 50 ml each day and then twice every three weeks.

The infusion center was a scary place, not because of the needles but because of the patient's. It was emotionally hard seeing so many people there getting chemo therapy treatment, plasma transfusions, courses of antibiotics and other patients receiving IVIG. The nursing staff was nice, making me feel comfortable, explaining everything they were doing. The first day was from 8 am till 2 pm and the nurse did a heplock. A heplock is leaving the needle in the vein and taping it in place so they will be able to re-

access the vein the next day without being stuck again. The next day I returned to the infusion center, the nurse accessed the vein through the original needle and about the last half hour of treatment my vein blew and the medication went in my arm under my skin causing it to become enlarged so the nurse did not helplock the IV needle again, instead she removed it and suggested I put warm compresses on my arm that evening to reduce the swelling. The next morning I awoke and could not even stand up. I had the worst headache anyone has ever experienced. My entire head from my forehead all the way around and back on my forehead hurt. I called the infusion center explained what I was feeling and could not make it today, but I will come the following two days. I laid back down and tried to sleep the day away but it did not work the headache was too painful. Finally in the evening it began to subside and the following two days I completed the next two rounds of treatment. About four days after my last treatment the skin on my hands began to peel, and became red similar to a bad sunburn. I went to my doctor he did blood work and gave me a steroid cream, the blood test results came back several days later and I tested positive for Rocky Mountain Spotted Fever.

#### Eleanor Roosevelt 1884-1962 Quote

“You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, ‘I have lived through this horror. I can take the next thing that comes along.’ ... You must do the thing you think you cannot do.”

I choose the quote by Eleanor Roosevelt because it represents the struggle I had, the horror and fear I felt when I was diagnosed. The fear of the unknown about the disease, how will it affect not just me but my family, will my children be in danger of being struck with the disease? So many questions rose in my mind, but now that I have an understanding of the disease and it is not genetic, so there was no fear that I could have passed the gene on to my children. My task is simple learn to live with the disease and not let the disease become my life but a part of who I am, this what I feel Eleanor Roosevelt meant when she said “I have lived through this horror. I can take the next thing that comes along... You must do the thing you think you cannot do”, for me that is live my life as I have always done as a wife, mom, best friend, employee and a person living with CIDP.

Rocky Mountain Spotted Fever (RMSF) is a tick-borne disease caused by the bacterium *Rickettsia*. It is potentially fatal to humans in both North and South America. The disease is transmitted to humans by the bite of an infected tick species. In the United States the tick species affected are the American dog tick, Rocky Mountain Wood tick and Brown dog tick. The symptoms associated with RMSF are fever, headache, abdominal pain vomiting and muscle pain and a rash will develop. If RMSF is not treated in the first few days it can be deadly. The first line of treatment is Doxycycline and is most effective if started before the fifth day of symptoms. The initial diagnosis is made based upon the symptoms and medical history and confirmed by blood test.

I freaked out when I was told by my primary care doctor that I had tested positive for RMSF. I cried and told my husband this was why I was so apprehensive about going on the IVIG. IVIG is composed of thousands of people's immunoglobins and putting them in your body. How do I know someone did not have the RMSF and donated there immunoglobins and I have now put that in my body and now I have RMSF. It was a very scary thought and my husband tried to calm me down, telling me that IVIG retrieved from donors are tested for major infectious diseases, unfortunately, RMSF is not one of them. Of course I was skeptical because I am in health care and have worked over ten years in third party reproductive medicine. In third party reproductive medicine since we are governed under the Food and Drug Administration testing for potential egg donors is rigorous. We test donors for all different types of infectious and sexually transmitted diseases. Donors are tested twice through the process including seven days before the egg retrieval and creation of the embryo to make sure they are negative; I realized donors are not tested for RMSF.

My doctor started me on doxycycline and sent me to an infectious disease specialist who said RMSF is rare and there are no known cases in the area, but he will retest me, even though, he is sure that it is a false positive. He recommended that I should continue on the doxycycline until we have the new results. The blood was sent out stat and several days later the results showed a negative result to RMSF so to my relief it was a false positive as the infectious disease doctor indicated. Although the results were a false positive it still raised many questions in my mind with proceeding with the IVIG treatment. Am I at risk for possibly contracting a disease from the treatment, is the risk worth it. I struggled with this for a month; I spoke with my neurologist and told him after I received the negative result my concerns and what guarantees could I be given that this would not happen. Unfortunately my doctor could not give me any guarantees, although he was not aware of any case that a person was infected through IVIG, it was a risk I had to decide if I would take. After a month of no treatment I began to feel myself relapsing, I experienced several falls and weakness in my legs and dropping things, my husband took notice of this as well. We talked about the pros and cons on continuing with the IVIG and decided that I had to overcome my fear and continue with the IVIG. I called my neurologist and was told that I was ready to go ahead with the treatment and two weeks later I returned to the treatment.

The next round was rough I developed very bad headaches and vomiting. The neurologist decided that he would switch the type of IVIG medication from Gamugard to Gamunex and piggy back the treatments with rounds of prednisone to offset the side effects that I was having. For the next round of treatments I started 60 mg of prednisone one hour prior to each treatment and for two days after and then the dose of prednisone would go down to 40 mg for two days and then 20 mg for one day. It seemed to help offset the side effects and I was able to function like normal. The next step was for us to come up with a nutritional program. I met with a nutritionist it was recommended that I incorporated foods high in potassium and vitamins B and C into my diet. The potassium would help in the event I began to develop muscle cramps or blood clot in my legs. Vitamin B12 deficiency could lead to numbness and burning in the extremities, which are signs of neuropathy. When testing a person who has demyelination disease, vitamin B 12 level is one of the first tests many doctors will perform. The vitamin C was to keep my immune system up so I am not so susceptible to illness like the common cold. Supplemental vitamin C should be at least 75 milligrams per day for women and 90 milligrams per day for men. The nutritionist and I came up with a list of foods I should be eating and things I should stay away from such as foods high in cholesterol. Below is a daily list of foods that I eat.

#### Breakfast:

8oz of cottage cheese/whole grain cereal/egg whites (a choice of anyone)

Banana

Slice whole wheat toast (plain or with jelly)

Decaffeinated coffee or tea

This is the one area I will not agree upon I do not like decaffeinated tea or coffee so I have my coffee with caffeine.

#### Lunch:

6 oz grilled chicken or fish

1 cup of stemmed vegetables

1 cup of chopped fruit or whole fruit

Brewed unsweetened tea or water

I opted for water. I do not care for brewed tea. At minimum I drink about a liter and a half of water.

Snack:

1 cup of pretzel, popcorn or unsalted nuts

Dinner:

6 oz of Chicken, Fish or steak grilled

½ cup rice, mashed potatoes or baked potato

1 cup of fresh steamed vegetable

Desert:

1 cup frozen yogurt or frozen sherbet.

The change has been hard for me, although I do not like cake and cookies and I am not a big chocolate eater. I enjoy caffeine and soda. That has been the hardest change; I never took a liking to diet soda so it was not easy to switch to diet soda. The change has not been easy for my family as well; my husband was on board, if I had to change then we all need to change. My kids did not like the lack of good food as they called it and the abundance of vegetables and fruits they have in place of cookies and ice cream, so now and then I will make a big Italian dinner with chicken parmesan, meatballs baked ziti, all which I will not eat, it is not because I know I shouldn't but after cooking all day I get turned off and am not hungry so I will opt to have a salad. After tackling my nutrition I knew that I had to do something more to keep up my strength. I knew my muscles were weak many times my hands would become so sore that I would have difficulty typing let alone holding something or picking something up. Going up and down stairs I would need to hold on to the banister. I am not that old when I was diagnosed I was in my thirty's but I felt like I was in my late sixties. I began to look into what I could do to help support the physical strength I had left.

Unnamed Quote

(T.S. Eliot)

“Only those who will risk going too far can possibly find out how far one will go.”

I choose the T.S. Eliot quote because it is not up to anyone but me, who can decide what my physical limitations are. I know my body, what I can feel and what I cannot feel and although I can have someone help me find the type of exercises I should do they cannot decide what my toleration and determination will be. It is determination that determines how successful you will be.

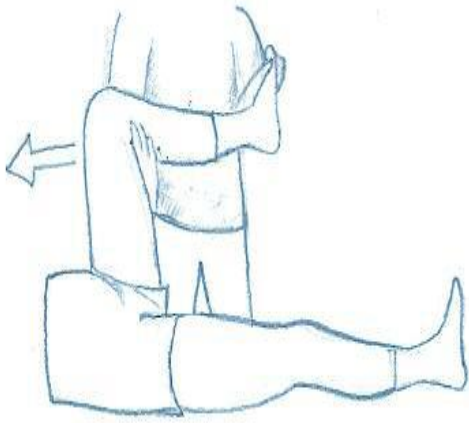
I spoke with my neurologist to ask if there were any exercises that I should do to keep up and possibly increase my strength in my muscles. Granted I was scared about any exercise regimen, when I was in my teens and twenties I would go to the gym and work out for an hour, using the treadmill and light weight training to maintain tone in my arms, sit ups for my abdomen. Work outs that many of us do at the gym but I knew this would not be the same. Since the nerve damage is so severe in both of my legs, I can no longer feel anything in either of my feet or below my knees, I was not sure what exercise I could do. Exercises that would have the least impact on my body without me knowing. My neurologist suggested that I see a physical therapist that specializes in treating patients with neuropathy and

demyelination disease. It was not easy most physical therapists specialize in sports injury or broken bones or work on people who have had procedures such as a total knee replacement.

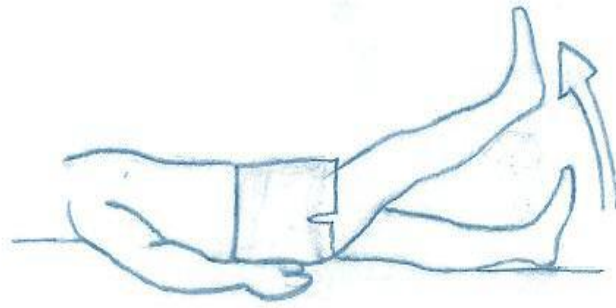
I figured the best place to seek this type of help was look at physical therapy facilities who work with wounded veterans. At these facilities the therapists tend to work with patients who have lost limbs, or suffer from nerve damage and know how to treat patients and the proper exercises. I contact my local veteran's facility and was given the name of a few therapists. Although most of the therapists were employed with the VA, some would be willing to take on private clients of course at a fee, since they could not bill my insurance company, I pay them and then submit to my insurance company for reimbursement as an out of network benefit.

I met Tim two weeks later; he came to my home to do a physical assessment, after speaking several times over the phone. Tim was assessing my range of motion, reflexes, and strength in my leg such as in a sitting position he would place his open hand above my knee and tell me to push it away. He would do the same thing with my arms. He would ask me to squeeze his hand with my hand as hard as I could again to assess the strength I had in my hand. He would also have me grasp different items such as pins; paper clips to assess my dexterity. He would have me do some of the same exercises that the neurologist would have me do such as stand on one foot, or simply just walk. He was attempting to assess my gait and balance. The assessment is typically about an hour to an hour and 15 minutes long. Afterward we sat and spoke about what exercise would work the best for me, since I had no feeling in my feet running on a treadmill is not really an option. Walking would be good; he did suggest that I should always have someone with me in case I fell. Swimming was another good exercise he suggested, since we feel weightless in a pool I could work on kicking in place the water would act as a resistant, bicycle motion is also good it will help me keep up muscle in my thighs as well as motion of my hips. We worked on some exercises for going up and down the stairs due to the inflammation and pain in my knees. We worked on a few exercises for my hands and arms working with light weights. He suggested 2 lbs. weights so that there was a minimal risk of straining myself.

The most important thing I felt that I learned during the evaluation was every person is different and the exercise regimen should be tailored to fit the patient's needs not the patient tailored to fit the exercise regimen. The physical therapy has been great, but I began to look for other therapies I could use to help me feel better. The side effects of the medication take their toll, I thought about therapies offered to cancer patients such as yoga, musical therapy and acupuncture as options.



*Active Hip Flexion  
(Gravity Reduced)*

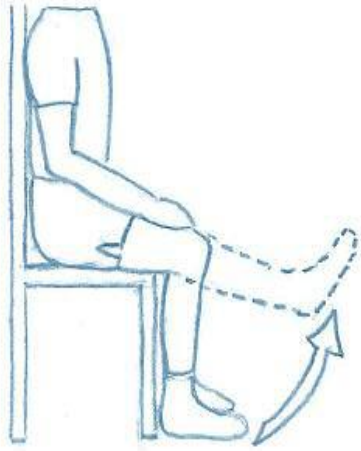


*Active Hip Flexion (Against Gravity)*

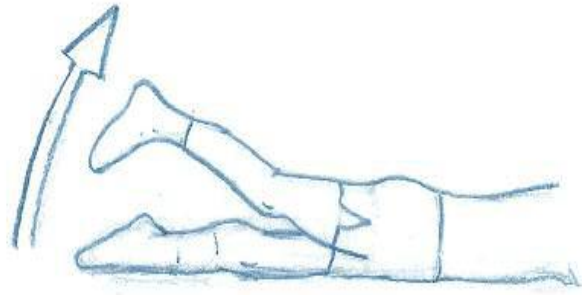
*Active Knee Extension  
(Gravity Reduced)  
(Against Gravity)*

*Active Hip Extension*

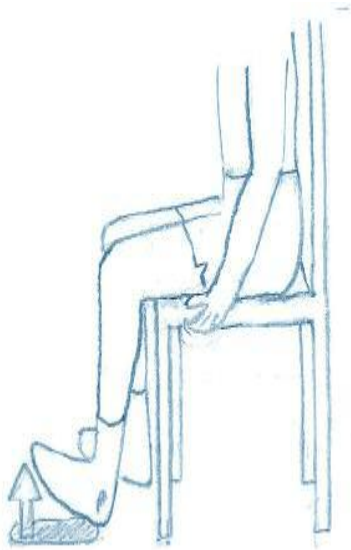




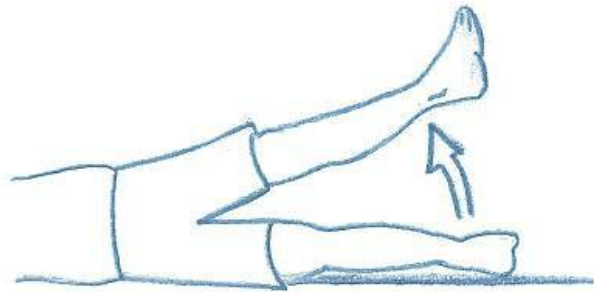
*Active Ankle Dorsiflexion (Against Gravity)*



*Active Hip Abduction (Against Gravity)*



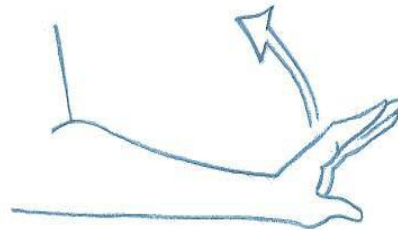
*Active Shoulder Flexion (Against Gravity)*



*Active Elbow Flexion (Resistive Exercise)*



*Active Elbow Extension (Gravity Reduced)*



*Active Wrist Extension (Against Gravity)*

*(Hansen, Matthew David DPT, MPT, BSPTS IG Living Exercises for CIDP August-September 2010 [http://www.igliving.com/magazine/articles/IGL\\_2010-08\\_AR\\_Exercise-for-CIDP.pdf](http://www.igliving.com/magazine/articles/IGL_2010-08_AR_Exercise-for-CIDP.pdf))*

I am all this, I AM ME



(Dunnlover 2008)

I know but not completely

Of how I feel or who I am

I believe but I can't be sure

I look ahead but behind for answers

I see the future but don't forget mistakes

I am questioning the unanswerable

I am confident but unsure

I am board but I am not

I am lonely but with people

I am tired but can't sleep

I am happy but I am troubled

I am here but I am lost

I am thoughtful with no answers

I am strong but I am scared

I am tolerant of most but not of me

I am waiting but not going any where

I am quite but have a lot to say

I am silent but screaming

I am willing but I am patient

I am colorful in a world of black and white

I am loving and I am loved

I am free and I am faithful

I am all this

I am me.

I choose the poem “I am all this, I AM ME” because it is a symbol of who I have become over the years. Things happen in life to everyone, it can be an illness, a death a birth but they do not define who we are, but rather become a part of who we already are. They are a part of our emotions and we choose to decide what emotions are hidden and what emotions rise to the surface. As I have mentioned before when you are diagnosed with an illness/disease a person goes through phases. Diana, John and myself all experienced different phases from fear to anger to acceptance and fight. What I had to learn to do as I know from reading Julie’s story is put my life into perspective and not be known as the person who is sick with CIDP, but I am a mom, student, employee, caregiver, wife, friend and CIDP is part of who I am.

Discovering who I am, took some time. Physical therapy, only offered me physical help I knew that I had to find emotional therapy to take out my frustrations. I looked at yoga as an option but with my balance being so erratic and not feeling anything in my feet or lower legs I was afraid. Afraid I would lose balance during a pose and break a bone. I began to look at acupuncture. Working in the fertility field many of our patients would ask about acupuncture and if we could refer them, I thought if our patients think it helps with becoming pregnant then maybe it will help me. The first time I went I was nervous, all I thought is, I am going to allow someone to stick tiny needles in me, I will truly be a human pin cushion. Some people when they do acupuncture they infuse it with electrodes, and some with heat, others just the needles. I opted to just use the needles, which are inserted into pressure points to relieve pain. “A recent review found that acupuncture can reduce nausea among patients receiving chemotherapy.” (Author Unknown 2013 <http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/complementary-alternative/therapies/acupuncture>) There is also ongoing research studies being done to decide if acupuncture helps people with peripheral neuropathy as well as growing research into acupuncture helping with depression, sleep disturbance and drug addiction. From a personal stand point I believe it relieves tension, with so many things going on in a persons daily life, dealing with an illness treatments and the side effects, it is nice to have a form of tension relief. I have not found that it relieves my symptoms from the treatment such as the headaches, nausea and pain due to the inflammation. When I have completed an acupuncture session I feel as though a weight has been lifted. I go every week to week and a half for about 40 minutes. What I can relate this to is as in yoga, you meditate, or a massage therapist relieves knots in a persons back this is my form of meditation. I lay there and all the worries disappear and I feel refreshed.

I have not been able to find anything that works to elevate the symptoms of inflammation or pain associated with CIDP. Most doctors I have seen will offer me pain medication, anti-inflammatories such as Prednisone. It is a bit frustrating that many doctors will offer a pill as a solution, I mean between my primary care physician, neurologist and rheumatologist all have offered me Prednisone at some point. I have tried Prednisone in the past and it did not work. The doctors see how inflamed and swollen my hands are but unfortunately there is not much that can be done without taking another medication or increasing the dose of a medication I have already been on. I do not want to become dependent on pills so I looked for other methods. What I have found that helps me with the pain and inflammation in my hands is a soak in warm water or even swimming. In swimming you are weightless in a pool, you do not have support your balance you just float. When you move your hands in the water it feels like a massage in-between your fingers. There is no pressure on your hands you can lay them on top of the water and make a patting motion up and down on the water provides a cooling sensation. I have tried a number of things to alleviate the pain and swelling in my hands and have not come across anything that works. I have tried massages, corto-steroids, and creams. I even put my hands in the freezer nothing has worked except the water.

Other techniques I have tried is music, especially during treatments. The music allows my mind to drift away and not think about the medication going through my system. It is not any particular music although nature and classical music seem to be popular based on research. Just the beats of music by Eric Clapton or Foreigner songs all seem to work, some songs even take me to memory lane and I think back to when I first heard the song, what grade I might have been in. The music can flood my memory and I am not thinking about the treatment or when they are accessing my port.

Unfortunately I have not been able to find any current research studies and no one at the group I attend have heard of any. I think for me the worst part is not knowing if there will be an actual treatment option that does not have a “maybe” or “hope” on the label. I believe one day this will happen and not just for my disease but for many. What we have to learn is strength, draw strength from something you are passionate about.

“Our passion is our strength” (Armstrong, B. J.  
[http://famouspoetsandpoems.com/thematic\\_quotes/strength\\_quotes.html](http://famouspoetsandpoems.com/thematic_quotes/strength_quotes.html))

My passion and strength is my family, the love and support they give me every day gives me the courage to get up and live my life. I am thankful for everyday I have. In the end there is no disease, it is just me, wife, mom, daughter, sister, best friend, student, co-worker, employee, CIDP recipient.

“Strength is a matter of made-up mind.” (Barrie, J.M. 1860-1937)  
[http://famouspoetsandpoems.com/thematic\\_quotes/strength\\_quotes.html](http://famouspoetsandpoems.com/thematic_quotes/strength_quotes.html))

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