Contact: Bridget Kelly
Email: bek2003us@yahoo.com

Disclaimer: This is a personal account of Motor Cortex Stimulation at Cleveland Clinic for intractable facial pain, in October 2003. The advice does not take the place of trained professionals. I take no responsibility for personal, patient, and physician opinions and decisions based on this document.

Dedication:
The Cleveland Clinic Staff
Dr. Jaimie M. Henderson
Shelley Ogrin, NP
Dr. Kenneth Casey-Allegheny General Hospital
Dr. Thomas G. Stauss-Advanced Pain Management
All those in pain and the future of medical reform

"The tulips are too excitable, it is winter here.
Look how everything is, how quiet, how snowed-in.
I am learning peacefulness, lying by myself quietly
As the light lies on these white walls, this bed, these hands.
I am nobody; I have nothing to do with explosions.
I have given my name and my day-clothes up to the nurses
And my history to the anaesthetist and my body to surgeons."

From *Tulips*, by Sylvia Plath- *Ariel*

Abstract

In October 2003, I had Motor Cortex Stimulation (MCS) for intractable Trigeminal Neuropathy at *Cleveland Clinic* in Cleveland, Ohio. Dr. Jaimie M. Henderson was the neurosurgeon in charge of my care. Dr. Henderson is now at Stanford Medical Center in California. I will explain Motor Cortex Stimulation (MCS) in a simple way and why I believe MCS is important for atypical facial pain. When in severe pain, communication is difficult. This report will help patients consider and prepare for surgery. This personal account of MCS is not the norm. Many patients have few complications. The report is intended for anyone requesting more information on the surgical experience. It is important for patients to research for themselves, contemplate personal ethics and utilize all resources throughout the process. Please refer to Appendices A and B and the reference section when reading this document.

Trials and Tribulations

When I was very young I had frequent stiff necks and sore throats. It seemed like every other week; my parents would place me in a giant, red, antique chair. I called it the king's chair. I never understood why my parents thought that would help.

In 1995, when I was 25, I had a memorable onset of a fierce stabbing pain in the right side of my face. The pain was so bad that I had to pull over to the side of the road. Over about one year the pain changed to a constant burning pain. It was not until 2000, that I contacted the *Trigeminal Neuralgia Association* to inquire about face pain specialists near Wisconsin. I traveled to Minnesota to see Dr. Kenneth Casey. Dr. Casey is now at *Allegheny General Hospital* in Pittsburgh. Currently, *Allegheny General Hospital* does not perform Motor Cortex Stimulation (MCS) for Trigeminal Neuralgia (TN). Dr. Casey spent three hours with me in consult and several more hours in e-mail communication. Dr. Casey confirmed my diagnosis of Trigeminal Neuropathy (TN).

During eight painful years, I had cranial sacral therapy, acupuncture, chiropractic care, vocational rehabilitation, over twenty-five medications, four sinus surgeries for polyps, multitudes of tests for separate diagnostics, unnecessary dental care, hypnotism, faith healing, massage, regressive therapy and counseling, all on a pain plan which resulted in my demise. I did not wish to pursue other surgical methods. Over the years the pain got much worse.

TN as it relates to my case is a result of a B12 deficiency. It is questionable whether I was born with a congenital disorder or if I developed the deficiency later in life. A B12 deficiency requires that I take shots of B12 every month for the rest of my life. This is because my body cannot absorb the vitamin. B12 is crucial for neurological systems within the body. If the deficiency is discovered in time, injections of the vitamin can create a complete reversal of damage to the nerves. If the deficiency is not discovered in time, the nerves may continue to deteriorate even with the replaced vitamin. The body stores a reserve of this vitamin for five years.

When people ask me what TN means for me, I can only relate it to Multiple Sclerosis (MS). The cranial nerves are slowly depleting myelin, causing lesions that I do feel, but that may not be apparent on x-rays.

When I began researching possible procedures to help alleviate symptoms, neurosurgeons in Wisconsin offered only the *Gamma Knife*. Dr. Casey explained to me that this procedure was not possible for me because the radiation from the knife can deplete myelin.

In 2001, Dr. Thomas Stauss with *Advanced Pain Management,* in Wisconsin suggested that I look into brain stimulation for intractable pain. It is important for patients interested in MCS to understand differences in diagnosis for facial pain. Nerve pain or neuropathic pain results from many different problems.

The Pain! The Pain!

After years of excruciating facial pain, the solution appeared to be brain stimulation. Why? My work as a physician program assistant in infectious diseases and intensive care prompted the need to question more. Yet for me, anything that resulted in pain relief outweighed scientific explanations. I decided that medications deteriorate the body. Leads that supply an energy source seem much safer. I now often forget that I still have a demyelinating disorder because my pain diminished considerably.

The first website I encountered on my search for brain stimulation was an American initiative describing the effects of government mind control through technological devices. Although this is not possible, I am always concerned with ethics, especially within an overflow of millions of networks. Careful research from reliable sources is important.

What Is Motor Cortex Stimulation?

Motor Cortex Stimulation (MCS) involves electrode placement on areas of the motor cortex of the brain, which regulates many of the senses. Functional Magnetic Resonance Imaging (fMRI) is used to discern the region of the motor cortex corresponding to painful areas within the body.

In the first surgery, electrodes with a protective covering are attached to the dura matter of the brain using the established imaging. The dura matter is the first thin membrane on the surface of the brain. It connects many veins and blood vessels in the brain and spinal cord. The electrodes are guided through the neck and attached to the pulse generator or pacemaker usually placed just below the collarbone on the same side as the incision in the brain. The left brain controls the right side of the body, while the right brain controls the left. If patients have TN on the right, the surgery is performed on the left side of the brain and vice versa. Surgery on the surface of the brain is technically less invasive over

Deep Brain Stimulation (DBS), which requires entering deeper within the brain. When surgery is completed, the head is tightly wrapped with gauze. The electrodes are visible outside the gauze because testing must be performed before the electrodes are permanently placed.

After placement, the device is tested and programmed with a large computer device. If program testing is successful enough to reduce pain considerably, the electrodes will be permanently placed in a second surgery.

Medtronic is the supplier of the device implants used for surgery. Before patients investigate possible treatment facilities, refer to the *Medtronic* website www.medtronic.com. *Medtronic* is an excellent resource offering a manual guide on all aspects of brain stimulation and potential hazards. At present, *Medtronic* cannot legally give out information on MCS for intractable facial pain because it is not yet FDA approved only for this surgery. After surgery, I was given a manual on caring for the pacemaker and a remote control programmer designed to control the internal device. This booklet offers additional information on complications and care of the device. This information can also be obtained at the *Medtronic* website. See Appendix A.

If patients are considering MCS for pain be advised that trials of several modalities are required. Unfortunately, insurance companies and doctors use past treatments to determine whether patients are offered this chance.

Outside interferences can cause unpleasant sensations or damage to the device. One important, potential hazard is Electromagnetic Fields (EMF). These fields surround the earth and all living things whether from natural sources or from man-made devices. Please refer to the *Medtronic* website or pulse-generator manual for all possible interferences.

The only true interference I feel is with personal computers. Usually an individual only has problems with personal computers and other devices when working directly with inside components of the equipment. Interference produces a feeling of nausea, fatigue and sometimes excitability. Perhaps an LCD monitor or placing the hard-drive at a distance is the best choice.

I believe that the electromagnetic fields resulting from implantation are very safe. Please consult with a trained expert for scientific explanation.

HINT Electromagnetic interference from ANYTHING electrical or containing a magnet is potentially dangerous to anyone. From Earth Science studies on plate tectonics and electromagnetic fields I learned to eliminate all electrical devices that I do not truly need to use.

HINT It appears that many things can interfere with this device. Not being able to use certain medical equipment is also a potential problem for other health concerns. For me, going off medications is better for my long-term health care. Electricity is then a double edged sword.

HINT Read books about electromagnetic fields if you are interested or concerned.

The Beginning Cold Calls

My search for help involved sending letters by e-mail to five hospitals that perform this surgery for intractable facial pain. Currently very few hospitals offer MCS for intractable TN because it is not FDA approved. I researched the internet under the code words "Stereotactic and Functional Neurosurgery." I am unaware of how many centers actually perform this surgery. *Cleveland Clinic* Neurosurgery Coordinators contacted me the day after I requested a consult online. See Appendices A and B.

HINT Insurance companies may require that patients find a hospital closest to home to perform the surgery. In my case, Medicaid approved *Cleveland Clinic*.

HINT Letters must be one page and should clearly define the timeline of diagnosis and symptoms.

HINT Persevere in obtaining useful clinical contacts.

Trust and Insurance

I decided not to involve State Medicaid in the initial consult. I needed to understand first whether I was a candidate for surgery. It is a long process to get Medicaid to cover an initial consult. A consult was approximately $250 out-of-pocket.

At *Cleveland Clinic*, patients are required to work with the outpatient and/or inpatient Neurosurgery Financial Coordinator. My surgery cost $100,000 or more. This does NOT include follow-up appointments which must be obtained after surgery.

Wisconsin Medicaid paid for all my expenses including airfare, hotel, ground transportation and all meals. Wisconsin Medicaid will also pay for one guest.

State Divisions of Vocational Rehabilitation (DVR) offices recognize the need to help people with disabilities. It is important to research polices of the agencies that you work with. Vocational Rehabilitation centers help reform disability to a point of working self-sufficiency. Rehabilitation centers and Medicaid offices most likely will not discuss what they will actually pay for unless asked. The best way to discover what agencies will pay

for is to request copies of policies from agency supervisors. It is important to follow-up with agencies.

When I began researching payment, I wanted the DVR to pay for the surgery and $30,000 in needed dental work. According to policies, the DVR will consider any option for clients that result in reducing the impediment to employment. The DVR requires a rejection of services from Medicaid or Medicare in order to consider payment. State Medicaid approved MCS surgery.

When Wisconsin Medicaid approved MCS surgery, I submitted a claim to the DVR and Medicaid for dental services. Medicaid denied payment for dental work. I received a grant from the Wisconsin Vocational Rehabilitation for $30,000 to rehabilitate my teeth and jaw. This process entailed getting consults from three dentists, an oral surgeon, a pain physician and a chiropractor. The reason that consults are needed for approval is because Medicaid will not pay for cosmetic dental work under any condition. A rejection from Medicaid is required before the DVR will pay for services. Medicaid may pay for oral surgery. For TN cases, especially demyelinating disorders, it is unsafe to perform many dental procedures currently covered by Medicaid.

It was explained to me by the oral surgeon that oral surgery would cause further damage to the soft tissues. The DVR concluded that I would not be able to return to work without this dental coverage. The consults are submitted to a rehabilitation committee. In my case, the dental work was approved the first time. Vocational offices always have a policy where patients can appeal any decision. Appeals are always offered when trying to obtain Social Security Disability (SSDI), as well.

HINT If patients are on SSDI they are automatically entitled to vocational services. Patients must apply for them at State offices. If patients are not on disability, they can still apply for vocational services.

It is obvious that dentists, insurance companies and government agencies need to reform payment for dental care, especially in patients where the dental problem is a possible part of the physical condition, as is typical of TN. The dental work in conjunction with MCS surgery will provide a better recovery from illness.

Dentists like to use stimulation treatments similar to a Transcutaneous Electrical Nerve Stimulation (Tens Unit*)* to adjust the jaw and find the proper alignment. I had MCS before I had the dental work done. I would advise that any dental work be completed first because patients cannot use a Tens Unit after the MCS stimulator is placed.

I looked into High-Risk Insurance. High Risk Insurance is called HIPPA. Access to this insurance information is provided in Appendix A and the reference section. Pre-existing conditions are the main reason that patients cannot get affordable health care. Premiums are high and take months for approval.

If patients already have insurance I suggest trying Blue Cross/Blue Shield or another agency that will allow travel out of state. Many employers have several plans that patients can switch to once a year at open enrollment even with pre-existing conditions.

Insurance is an important issue. Medicaid and Medicare typically will only pay 30% of the actual cost of surgery and treatments. Hospitals will "write-off" the remainder in taxes. I looked into high-risk insurance and Blue Cross/ Blue Shield because I respect the cost of surgery. It is important to understand that payment usually goes full circle, resulting in satisfaction to the patient and the hospital, regardless of who pays for it. In some circumstances, federal assistance often pays MORE than private insurance companies. In my case, it was much easier to work with Medicaid because I did not have to deal with underwriting and paperwork to get approved.

Insurance Hints

HINT If patients already have insurance, most hospitals will require payment from the first source and use Medicaid or Medicare only as a secondary.

HINT As of October 2004, Federal MEDICARE WILL NOT approve this surgery until after it is done. An exception to this rule is California. Please consult with local Medicare offices. Talk to a supervisor.

HINT MEDICARE is available to SSDI recipients after two years on the program.

HINT Wisconsin State MEDICAID will only approve services with an impeccable recommendation from the neurosurgeon wishing to perform surgery.

HINT Wisconsin State Medicaid or Medical Assistance Purchase Plan (MAPP) is usually available only to participants that make below federal poverty level. Check with local offices.

HINT In Wisconsin, Medicaid is set-up through the county in which you live. See Appendix A.

HINT Payment should be researched in depth with all concerned as soon as you feel that you may wish to try it. It is a monopoly.

The Game: Preparing for Surgery

You won the lottery! Now it is time to plan a course of action. The first rule of this game is to trust intuition.

The Initial Consults

Before a patient's first appointment with an assigned doctor, obtain all medical records. Paper records and test reports from MRI's should be sent directly to the doctor or nurse practitioner.

At the first appointment diagnostic symptoms and history are discussed. Have all questions in writing to take to this meeting. I recommend that patients get a home physician to obtain a thin-cut MRI because the neurosurgeon may request it. It is better to have this x-ray and all other information for one appointment. Remember to physically check out MRI films and x-rays from doctors and dentists from the film library at your doctor offices. Do not put these films through airport security fields! Airport security will check x-ray folders manually. Remember to return these films to the film library in your home town.

Based on my circumstances, *Cleveland Clinic* informed me that I was a good candidate for MCS during the first visit.

HINT Please realize that individual TN cases are taken into consideration. Not every patient is a candidate for surgery and not everyone will find relief.

The appointment will not be wasted even if patients are not a candidate for surgery. *Cleveland Clinic* offers several ideas to help patients before other more aggressive measures are taken.

If a patient is a candidate for surgery, the second consult at *Cleveland Clinic* is with a psychiatrist. I felt very comfortable with a counselor that understood pain. Helpful suggestions were offered that prepared me for surgery with additional methods of treatment to try. *Cleveland Clinic* offers the most up to date medications. Appendix A offers information on *Cleveland Clinics* inpatient or outpatient pain management programs. Be honest with the psychiatrist. The surgery is now a serious consideration.

Accommodations and Entertainment

I decided before I left for Cleveland that I would try different accommodations to see which places offered the most comfort and cleanliness. I preferred to stay downtown, five minutes from the hospital. Some hotels offered transportation to *Cleveland Clinic* and negotiated rates for *Cleveland Clinic* patients. I stayed at the *Intercontinental Hotel* attached to the hospital from physician orders. Accommodations are important because patients will have several follow-up visits. Cleveland has numerous valuable experiences. A great transportation service is Red Sparrow. Contact: e-mail:rdspro@ameritech.net (216) 695-7550. See Appendix A.

To bring or not to bring

Unfortunately, I packed like I was going to Europe for a few months. I was in Cleveland approximately two weeks. While in the hospital, patients will want to be comfortable. I recommend the following:

- Shoes for running. Just kidding.
- Medical cards, identification and doctor contact information. Patients cannot go through airport and government security after the pacemaker is placed. Make certain that you have a *Medtronic* identification card when leaving.
- After a day or two, patients are allowed to wear loose-fitting street clothes in the hospital.
- Slippers. Skid free socks are provided.
- Toiletries. The hospital does provide good personal care items, but I preferred my own.
- Books or Magazines. I must have brought 10 books. Be advised that reading in the hospital is difficult.
- Music and Movies. The Epilepsy Monitoring Unit offers music and a library of movies.
- Laptops are not recommended. Computers may interfere with the device. Don't plan to work there.
- There is a phone in every room. It costs $3 a day mandatory and is billed to your home number. No cell phones are allowed! Cleveland Clinic has an 800 number. Family or friends can call this number to reach patients directly. If you need to call them, remember to bring a calling card. Calling cards are also available in the gift shop.

Haircut!

I was a bit dazed by the hair cutting experience. Patients will need to decide whether they want the entire head shaved or just at the area of incision. The incision in my case was approximately seven inches wide on the left side of my head, above the left ear and in the shape of a sideways U. I wish I had my hair cut short the weekend before surgery to make the shaving less difficult. Consider a hair donation to charity.

If individuals have brain surgery, they can NEVER wear wigs while in recovery. Wigs can cause infections. I purchased several head scarves and some baseball caps.

HINT Wear these head coverings only when going out. Keep the head coverings clean! I had enough coverings for one week and washed them frequently.

HINT If patients dye or perm hair, try to refrain from this for six months before surgery. Dye and chemicals burned my scalp. I decided that it is unsafe to use these products as they could get into the body through a cut or through air borne inhalation. It is possible that patients can return to hair treatments one year after surgery. Please consult with your physicians.

A Day of Tests

Patients will be sent a list of tests with approximate times for the third day before surgery, usually on a Friday. Testing lasted all day and required traveling throughout the hospital maze. I was pleasantly greeted and assisted by the hospital concierge. Many trendy food vendors are on site along with fabulous hotel restaurants. Tests may vary based on individual circumstances.

- Chest x-ray
- Electrocardiogram (EKG)
- Laboratory Medicine/ Blood tests
- Neurosurgery meeting
- Computer questionnaire
- Hospital Admitting interview
- Preoperative Clearance-Anesthesia
- Functional MRI

Day of Surgery – Last Call

On the day of surgery, I arrived at MRI within the *Cleveland Clinic* radiology section, at 6:30 am. This is also where I had my head shaved. It felt a little strange at first to get my head shaved. Try to imagine world peace. After some final MRI testing I went to pre-op. At this point, my belongings were recorded and taken by security.

I only waited about an hour in pre-op. I thought of nothing really, except that Dr. Henderson told me that I would be partially awake for the procedure. This is enough to scare the living daylights out of anyone. Being awake sometimes helps physicians understand areas of the motor cortex in relation to corresponding body movements. Right before surgery, Dr. Henderson told me I would be sleeping. Relief!

Mapping the Brain

Growing up I would never believe that someone would "map" my brain. When I decided to do this, all I could think about was a story-line from some strange movie. I was completely awed by research on the many pathways within the brain. On October 6, 2003, I found out what it was like.

MCS surgery relies on fiducial markers which are taped to the scalp before the brain is imaged. In the operating room the orientation of these markers is used to register the brain images. Once the motor cortex is mapped, the computer shows the relationship between surgical instruments and the brain. With imagination this can be the most interesting part of the process. Imaging is done on the day of tests and again in surgery.

Remember there are two surgeries, one to place the device for testing and one for permanent placement if testing works. After surgery, MRI's are not used and cannot be used for future imaging because of Electromagnetic Interference (EMI).

Cleveland Clinic performs the two surgeries all in a one week hospital stay. Other hospitals may discharge patients for testing. Included in Appendix A and the reference sections are excellent articles on understanding imaging and the entire surgical procedure.

Recovery Room Radio Head

In recovery, it felt like a crowbar had been attached to my skull permanently. I believe this pain was caused by existing Temporomandibular Joint dysfunction (TMJ). TMJ pain is different than neuropathic pain and may not be affected by stimulation. I felt a great deal of pressure and pain.

HINT Ask the doctors and nurses for ice and medication if you need it. Remember that certain medications cannot be given after brain surgery.

HINT Deal with personal ethical issues before you decide to have this surgery.

It was curious to actually have an implant in my head. I felt like a contemplative radio, static and all. When I started thinking of possible failure after just coming out of having my head cut open, a whole rift of potential circumstances began to flood the inner world. I could not sleep and could not be given a sleep aid because of surgical requirements. I remembered a scientific article on MCS that informed that I should feel immediate relief right after surgery. I did not! Hospitals vary on trial methods. Some hospitals do not turn the device on right away. Instead, testing occurs on the following days.

General Hospital "Testing"

I was in the hospital for seven days. Under normal hospital standards and circumstances without complications, patients will be in the hospital approximately five days. Patients are usually discharged the day after the second surgery.

HINT Patients CANNOT fly for one week after surgery.

From recovery I was transferred to a step-down unit similar to an intermediate care unit. In the step-down unit my vitals were checked approximately every fifteen minutes. I arrived in this unit at about 7:00 PM on the day of surgery. The surgery took approximately four hours.

The next morning, I was transferred to a private room in the Epilepsy Monitoring Unit (EMU) at *Cleveland Clinic*. On this unit, I was video monitored for potential seizures. Pacemaker testing began in the afternoon, the day after surgery.

I remember a family of a patient in the next room entertaining with a toy. *ELMO* sang *Hokey Pokey* over and over. The song kept repeating. More and more I learned the simplicity within my new brain device.

When I woke up, I realized that the actual pacemaker was not in normal placement below the collarbone. It was near my stomach on the left side.

HINT Consult with surgeons on where to place the pacemaker. I think that it is more comfortable to have the device in near the stomach. The pacemaker is approximately 3 x 3 inches in size, so it is somewhat large. I did not have enough flesh to place the stimulator comfortably below the collarbone.

HINT If patients are women of child-bearing years and want children, reconsider this surgery. Patients cannot get ultrasounds once the generator is placed. M*edtronic* does not have any conclusive reports on the effects of stimulation and pregnancy.

The programmer used by physicians reminded me of a video game controller. It is a larger version of a black-box, hand-held remote control, with a receiver and antenna that medical professionals use to program the internal power source. A small patch connected to this computer programmer was placed over my pulse generator to turn it on and begin program testing.

I will never forget that first test. An electric shock pierced through my head. The first thing I thought of was that I had developed TN on the left side of my head. I tried to remain calm. I was not supposed to feel anything on the left, where the incision was placed. The doctors theorized that the sensation would diminish. Unfortunately, I felt something terrible and it was not good news.

The electrical sensation on the left resulted in a discussion on whether or not to remove the device. I would not let this happen until the doctors discussed what may be occurring. The problem was with the dura matter. The dura in my brain appeared to be more sensitive than other people may experience. It is potentially more invasive to cut the dura out because of its protection to the brain. In the second surgery to place the electrodes permanently, the dura was safely cut out. I was on my way to pain free days.

The Days After

After surgery, I was given a small remote control device of my own. The controller is designed to allow patients to adjust the stimulation. It some cases, patients only use this device to turn it off and on. The 9 volt battery in the remote control must be changed every 3-6 months. At this point, I was also given the *Medtronic* manual on the device.

Brain surgery was a complete life altering event. I was discharged a couple days after the second surgery. I spent the week at the *Intercontinental Hotel* attached to the hospital. At this time, I faced my fears. I worked extensively with Shelley Ogrin; Nurse Practitioner, in clinic for four days. Ms. Ogrin really helped me understand the big picture. She was able to program the pacemaker to a comfortable level. I was advised that complications can arise. Below is a list of my complications.

Technical Difficulties

Medications: Make certain that patients bring all current medications to the hospital. It is important that patients follow physician instructions on decreasing or stopping certain medications or supplements. Prescriptions given at the hospital usually must be paid for out of pocket unless in the state of residence. Discuss ALL surgical medications with doctors.

Computer: Blues! It is possible that the device will not work at first or will eventually fail. I had no discernment of this because the result of it not working meant unending and frequent medical care, medications and pain. Some patients will be able to control the stimulation with the personal remote control. I will not be allowed to do this because of seizures. In my experience, personal computers interfere with this device.

Fear: Before surgery, I thought of what it was going to be like to become a robot. I do not feel robotic now but contemplated personal ethics involved. At 33, I had to consider longevity and pain relief. I had no fear until I woke from surgery. The fear eventually subsided.

Infection: I developed an infection at the surgical incision cite after the sutures were removed. Sutures are usually removed at home because they must be left in approximately ten days after surgery. Infections can cause serious complications and can result in removal of the device. I imagined the *Pollyanna Phenomenon* from my previous work in infectious diseases. Discuss the surgery and follow-up with home physicians.

Stiffness: My neck was stiff for a long time. This resulted from previous TMJ, neuropathy and the "newness" of the leads running through my neck. Patients must be careful initially with movement or manipulation.

Seizures: In one of my follow-up visits, I had a seizure while being programmed in the office. I lost consciousness and had to be admitted overnight. My physicians explained that I have a low-seizure threshold. All of my future programming must be done on an inpatient basis. Patients must consider the effects of seizures before this surgery.

Love: I chose not to involve family and friends on this journey. I am certain that significant people in my life would have interfered with the process. I needed to be alone as much as possible.

Energy: Fatigue is a problem after surgery. Recovery can be slow. The sensations from the device may feel a bit strange at times.

Does Stimulation Fail?

There are approximately 10,000 ways to program the pacemaker. This is why trials are needed. The doctors will tell patients there is a possibility that the efficacy of this device may eventually fail.

I believe failure does not exist with this energy source. Instead the thousands of programs provide for readjustment even at low seizure thresholds. After careful thought, I believe as an intelligent layperson, the potential of this device far exceeds what we now realize. Thinking about the networks within the body in relationship to patterns of electricity and energy, the solutions exist for just about every disorder. Simplify. I am certain scientists make the “whys” more complicated.

As I tapered off morphine, conclusions on why this stimulation works manifested but I am not a scientist. Different trials are being performed to understand. The more I think about this, the more I believe stimulation has the potential to combat many disorders. The technology has been around for centuries.

Total Recall and Imagination- The Months After

As I explained above, stimulation can reach many other symptoms of disorders. Relating my disorder to MS, muscles are weakened along with all cranial nerves.

I tried a few experiments with the stimulation myself. Not all of my theories were correct. I thought if I turn the stimulation off at night, it would make it last longer. This is partially true. Turning it off has nothing to do with efficacy, instead it preserves the battery. The internal battery is surgically changed approximately every three years.

Some TN patients do not feel pain while at rest. I decided that turning it off at night simply gives the brain a break. I also wanted to feel the stimulator go on in the morning. Not all patients feel stimulation, only the effects. For me, stimulation feels like a cooling massage along the nerve.

Turning off the device was approved by my physicians. When off, I was also able to discern what the stimulation is actually doing. I awaken frequently at night because of dental adjustments. When I wake, I attempt to write. What I personally discovered is that my cognition from myelin depletion returns to an unbeneficial level only when the stimulation is off. When the stimulation is on, I am clear in communication, I feel physically more in balance with my body, and cognition returns to a near normal state.

Most medications used for MS and TN symptoms can deteriorate the body and mind significantly. Under stimulation I do not need any medication, that is, unless scientists find a way to re-grow myelin. Again, this disorder is all about the nerves. The insulation

around the nerves depletes, in turn, the electrical stimulation compensates the nerve responses to the brain.

What stimulation does not do at present is combat the fatigue of nerve attacks. There are still exacerbations of symptoms. It is only POSSIBLE that stimulation can slow the process of demyelination.

I believe my recovery was slow because of an already depleted immune system. Two surgeries with anesthesia are physically demanding. Of course, these are my beliefs. Patients should consult with physicians and/or obtain second opinions.

HINT Before surgery prepare physically. Work on heart rate by walking or other forms of exercise.

The effects of MCS changed my life. My nerve pain was reduced by 80%.The main side effects of MCS were fatigue and intermittent weakness. I also had a bit of short-term memory loss, but I am not certain this is related to stimulation. So far, computers interfere with the device, but I still use them with caution. I believe that dental implants made of metal also may interfere. My dental work is now ONLY made of porcelain, not fused to metal.

It is important to note that returning to life after surgery is difficult but manageable. I was in pain for eight years and ill for many more. Before surgery I had great difficultly writing comprehendible sentences and speaking because of pain.

Life after surgery is a relearning process. I needed to adjust to feeling better and begin to make decisions about the future. I lost everything to this disorder.

I need to remain realistic about the future and the efficacy of this device. For now, I am happier than I have ever been. I require no prescribed medications. Follow-up care with *Cleveland Clinic* is every six months to a year unless stimulation becomes ineffective.

HINT Make certain that home physicians are clear about their role in surgical care. Patients need to look for professionals that are familiar with the device either from knowledge of other forms of stimulation or through Deep Brain Stimulation (DBS). Medicaid and Medicare will allow patients to travel for care even if another physician is available in the State of residence.

HINT The actual stimulation method is similar to Spine Stimulation which is performed at many pain clinics and hospitals for disc and spine problems. The remote control device used to adjust stimulation is identical. *Medtronic* will instruct physicians if they wish to learn about programming the device.

I am excited about the future of stimulation. Some friends and acquaintances feel that having an implant counters natural processes within the body. Questioning is good, after all, are implants for millions of people the answer? MCS is a personal decision that needs careful research. My own rationale is that as human beings we need to discover why the electrical circuits in our bodies are misfiring in the first place and how this relates to nature. Environmental awareness makes the simplicity of the pacemaker a natural solution. Stimulation improved the quality of my life and freed me from a lifetime of morphine or other medications with terrible side effects.

Conclusion

I currently have many dreams recalling past times in my life including the giant, red, antique king's chair that I would have sold to have this surgery. Motor Cortex Stimulation has so much potential. I look forward to the day when hospitals and governments recognize that many other treatments for this disorder are destructive. This recognition will allow physicians and insurance companies to approve MCS surgery before other already known failed treatments are applied. There is hope for the future.

Please contact me for further assistance. It is my intent that this report will help many people make informed choices about MCS as a potential treatment option. See Appendix A.

Appendix A:

Surgical Steps & Resources on the Cleveland Clinic Experience

Created by: Bridget Kelly, May 2004

SURGICAL STEPS		RESOURCES
THE CLEVELAND CLINIC		http://www.clevelandclinic.org/neuroscience/ http://www.clevelandclinic.org/neuroscience/treat/movement/dbs.htm http://www.clevelandclinic.org/services/eclinic.htm http://www.clevelandclinic.org/about/visit/ http://www.clevelandclinic.org/psychiatry/services/chronicpain.htm
INSURANCE		http://www.bluecares.com/healthtravel/index.html http://www.cms.hhs.gov/medicaid/mcontact.asp http://www.dhfs.state.wi.us/Medicaid2/handbooks/all-provider/pdfs/provrights/all-provrights.pdf http://www.cms.hhs.gov/ncd/searchdisplay.asp?NCD_ID=240&NCD_vrsn_num=1 http://www.jan.wvu.edu/SBSES/VOCREHAB.HTM
ACCOMODATIONS **ENTERTAINMENT** **TRANSPORTATION**		http://www.clevelandclinic.org/about/visit/lodge.htm http://www.hiltongardeninn.com/en/gi/hotels/index.jhtml;jsessionid=G33EQ4WBPIYHACSGBIXMVCQKIYFCVUUC?ctyhocn=CLEGWGI http://www.holidayinn.cleveland.ichotelsgroup.com/?_IATAno=99504440 http://www.wyndham.com/hotels/CLEPS/main.wnt http://www.cleve-visitors-guide.com/ http://www.fatfishblue.com/ http://www.littleitalycleveland.com/ http://www.clemusart.com/ http://www.rockhall.com/ http://www.playhousesquare.com/# http://www.gcrta.org/
PREPARATION **PACEMAKER**		http://www.locksoflove.org/donate_hair.php http://www.aans.org/education/journal/neurosurgical/sep01/11-3-4.pdf http://www.medtronic.com/neuro/paintherapies/pain_treatment_ladder/neurostimulation/screening/neuro_screening.html http://www.medtronic.com/neuro/paintherapies/pain_treatment_ladder/neurostimulation/screening/neuro_imp_of_scs.html

Appendix B:
Sample of Hospitals offering Motor Cortex Stimulation (MCS) for Intractable Pain
Created by: Bridget Kelly, September 2004

This Appendix shows a small list of hospitals that will consider Motor Cortex Stimulation (MCS) for pain. If a hospital near the patient performs Deep Brain Stimulation (DBS) for tremor, they may also consider Motor Cortex Stimulation (MCS) for pain. Many of the centers listed have physicians that trained at *Cleveland Clinic.* MCS is fast becoming a treatment option for intractable pain. Remember that the treatment of choice is usually the *Gamma Knife*, so be careful. Check for any insurance complications before making an appointment. If individuals would like to add to this list, contact me.

California

Jaimie M. Henderson, M.D.
Stanford University School of Medicine
Adult Neurology and Neurosurgery Clinic
300 Pasteur Drive, Boswell Building, A301
Stanford, CA 94305-2015
650-723-5574
http://www.stanford.edu/dept/neurosurgery/about/team/faculty/henderson.html

Colorado

Robert E. Breeze, M.D.
University of Colorado Health Sciences Center
4200 E. Ninth Ave.
Denver, CO 80262
303- 315-7571 Email: robert.breeze@UCHSC.edu
http://www.uchsc.edu/neurosurgery/patient-information/functional-neurosurgery.htm

Connecticut

Alain C. J. de Lotbinière, M.D.
Stereotactic and Functional Neurosurgery
Yale University
333 Cedar Street
P.O. Box 208082
New Haven, CT 06520-8082
neurosurgery@yale.edu or email to alain.delotbiniere@yale.edu
http://info.med.yale.edu/neurosur/faculty/lotbiniere.html

Florida

Department of Neurosurgery
University of Florida
Box 100265 Gainesville, FL 32610-0265
352-392-4331 or
800 633-2122 ext. 24331

Shands at University of Florida
352-392-4331
1-800-749-7424
https://shands.org/offices/office_detail.asp?ID=65
http://www.neurosurgery.ufl.edu/
http://mdc.mbi.ufl.edu/

Illinois

Joshua M. Rosenow, M.D.
Northwestern Memorial Hospital
675 N. St. Clair, Galter 20-250
Chicago, IL 60611
312-695-8143
877-926-4664
http://nmhphysicians.photobooks.com/Disclaimer.asp
http://www.nmh.org

Ohio

Ali Rezai, M.D.
Cleveland Clinic
Department of Neurological Surgery / S80
9500 Euclid Avenue
Cleveland, OH 44195
216-444-5670
http://www.clevelandclinic.org/services/eclinic.htm
http://www.clevelandclinic.org/neuroscience/

Massachusetts

Emad N. Eskandar, M.D.
Wang Ambulatory Care Center-021/Neurosurgical Service
Massachusetts General Hospital
Fruit Street
Boston, MA 02114
Appointments: 617-724-6590
Referral@Neurosurgery.MassGeneral.org
http://neurosurgery.mgh.harvard.edu/functional/

Texas

Tony Whitworth, M.D.
University of Texas Southwestern Medical Center
5323 Harry Hines Blvd.
Dallas, TX 75390-8855
214-648-8500 http://swnt240.swmed.edu/swneurosurg/whitworth.htm
http://swnt240.swmed.edu/swneurosurg/contact.htm

Wisconsin

Brian H. Kopell, M.D.
Medical College of Wisconsin
Department of Neurosurgery
9200 West Wisconsin Avenue
Milwaukee, WI 53226
414-805-5483
414-805-5400
E-mail: ns@mcw.edu
http://www.mcw.edu/display/router.asp?docid=154

References

Advanced Pain Management. (2004). Retrieved May 11, 2004: http://www.apm-wi.net/

American Society for Stereotactic and Functional Neurosurgery. (2004). Retrieved May 19, 2004: http://www.assfn.org/whatsnew/painsurg_0402.asp

American Association of Neurological Surgeons. (2004). Retrieved May 5, 2004: http://www.aans.org/library/search.aspx?SearchTerm=motor+cortex

Blue Cross/Blue Shield Association. *Health Care Anywhere*. (2004*).* Retrieved May 5, 2004: http://www.bluecares.com/healthtravel/index.html

Centers for Medicare and Medicaid Services. *State and Federal Medicaid Contacts.* (2003). Retrieved on May 5, 2004: http://www.cms.hhs.gov/medicaid/mcontact.asp

Cleveland Clinic. (2004). Retrieved May 11, 2004: http://www.clevelandclinic.org

Cleveland Museum of Art. (2004). Retrieved May 5, 2004: http://www.clemusart.com/

Fat Fish Blue. (2004).Retrieved May 5, 2004: http://www.fatfishblue.com/

Greater Cleveland Visitors Guide. Victory Vision. (2004). Retrieved May 5, 2004: http://www.cleve-visitors-guide.com/

Greater Cleveland Regional Transit Authority. (2001). Retrieved May 5, 2004: http://www.gcrta.org/

Hilton Hospitality, Inc. *Hilton Garden Inn Downtown Cleveland* (2004). Retrieved May 5, 2004:http://www.hiltongardeninn.com/en/gi/hotels/index.jhtml;jsessionid=G33EQ4WBPIYHACSGBIXMVCQKIYFCVUUC?ctyhocn=CLEGWGI

InterContinental Hotels Group, Inc. *Holiday Inn Cleveland Ohio*. (2004). Retrieved May 5, 2004: http://www.cleveland.ichotelsgroup.com/?_IATAno=99504440

InterContinental Hotels Group, Inc. *Intercontinental Hotel Cleveland*. (2004). Retrieved May 11, 2004: http://www.ichotelsgroup.com/h/d/ic/home?refid=1

Locks of Love, Inc. (2004). Retrieved May 5, 2004: http://www.locksoflove.org/donate_hair.php

Mayfield Murray Hill Merchants. *Little Italy*. (2004). Retrieved May 5, 2004: http://www.littleitalycleveland.com/

Medical College of Wisconsin.(2004). Retrieved September 26, 2004: http://www.mcw.edu/display/router.asp?docid=154

Medtronic Inc. (2001). Retrieved May 5, 2004:
http://www.medtronic.com

MGH Neurological Services. (2004). Retrieved May 5, 2004:
http://neurosurgery.mgh.harvard.edu/

National Library Service. Pub Med. *Pollyanna Phenomenon.* (2004). Retrieved May 5, 2004
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?CMD=search&DB=pubmed

Northwestern Memorial Hospital. *Neurological Surgery*. (2003). Retrieved May 5, 2004:
http://www.nmh.org/services/neuro_surg.html

Plath, S. (1961). *Ariel*. New York. Harper Perennial.

Playhouse Square Center. (2003). Retrieved May 5, 2004:
http://www.playhousesquare.com/#

Radiological Society of North America, Inc. (RSNA). *Functional MR Imaging (fMRI) – Brain.* (2004). Retrieved May 5, 2004:
http://www.radiologyinfo.com/content/functional_mr.htm

Red Sparrow Transportation. (2004). Retrieved May 5, 2004: http://rdspro.net

Rock and Roll Hall of Fame and Museum. (2004). Retrieved May 5, 2004:
http://www.rockhall.com/

SBSES/GLL. (2004). Retrieved May 5, 2004:
http://www.jan.wvu.edu/SBSES/VOCREHAB.HTM

Social Security Administration. (2004). Retrieved May 11, 2004: http://www.ssa.gov/

Stanford School of Medicine. Department of Neurosurgery. (2004). Retrieved September 26, 2004: http://www.stanford.edu/dept/neurosurgery/about/team/faculty/henderson.html

Trigeminal Neuralgia Association. (2004). Retrieved May 5, 2004:
http://www.tna-support.org/

University of Colorado. Department of Neurosurgery. (2004). Retrieved September 26, 2004:
http://www.uchsc.edu/neurosurgery/patient-information/functional-neurosurgery.htm

University of Florida. Movement Disorders Center. (2004). Retrieved September 26, 2004:
http://mdc.mbi.ufl.edu/

University of Florida. Department of Neurosurgery/ Shands. (2004). Retrieved September 26, 2004: http://www.neurosurgery.ufl.edu/

University of Texas Southwestern Medical Center. Department of Neurosurgery. (2004). Retrieved September 26, 2004: http://swnt240.swmed.edu/swneurosurg/whitworth.htm

West Penn Allegheny Health System. (2003). Retrieved May 11, 2004: http://www.allhealth.edu/agh/

WGBH Educational Foundation. *A Science Odyssey: Probe the Brain*. (1998). Retrieved May 5, 2004: http://www.pbs.org/wgbh/aso/tryit/brain/mapcortex.html

Wisconsin Department of Health and Family Services. *Wisconsin Medicaid and Badger Care.* (2000). Retrieved May 5, 2004: http://www.dhfs.state.wi.us/Medicaid2/handbooks/all-provider/pdfs/provrights/all-provrights.pdf

Wyndham Hotels and Resorts. Wyndham Cleveland at Playhouse Square. (2004). Retrieved September 26, 2004: http://www.wyndham.com/hotels/CLEPS/main.wnt

Yale School of Medicine. Department of Neurosurgery. (2004). Retrieved September 26, 2004: http://info.med.yale.edu/neurosur/faculty/lotbiniere.html