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Deep Brain Stimulation Surgery at Colorado Neurological Institute... Another success story

Just over four years ago, at 38, I was diagnosed with Young Onset Parkinson's Disease. It started, as it does for most, with a slight tremor in a finger of my left hand, which I initially wrote off as being a symptom of stress. My job in TV news had always been stressful, and I enjoyed that aspect of it, but eventually, the shaking became constant and extended to my entire hand. When I went to a doctor looking for a prescription that would relieve it, I was told I had PD, a degenerative brain disease for which there is no cure.

Fairly quickly, the tremors became more and more pronounced, and moved into my left leg as well; I developed an inability to walk normally, and my joints were becoming rigid. Despite the best efforts of CNI neurologist **Dr. Rajeev Kumar**, drug treatments did not help; all the drugs we tried caused serious side-effects before I could take a high enough dose to alleviate the tremors, which grew worse and began to affect my ability to work, not to mention everyday activities.

That's when Dr. Kumar asked me if I was willing to undergo Deep Brain Stimulation surgery. He explained what the procedure involves, and the risks that accompany it. DBS, he pointed out, does not cure PD or repair cognitive disabilities, but it can control tremors, and that's the primary symptom I was experiencing.

I agreed that I wanted to try DBS, and I met surgeon **Dr. John McVicker**, who would perform the operation. He went into great detail about the procedure and how it works. His calm demeanor is exactly what you might want in a neurosurgeon, and I found that very reassuring.

McVicker used the newest technology available, including the placement of the StarFix frame anchored onto my skull via tiny screws rather than the older, uncomfortable "halo" head frame that others have had to endure while having the operation done.

I was awake for most of the procedure, so I could answer questions and respond to Dr. Kumar as he observed my reactions to having the DBS probe placed within my subthalamic nucleus.

I was back home within 24 hours, and went back for programming on the stimulator within about two weeks. That went flawlessly, and it took **Kim Martin, RN** just minutes to stop the tremors entirely. A few more sessions of fine-tuning, and I had no tremors at all.

Now, over a month later, I can almost forget I have Parkinson's Disease. I have no tremors, no rigidity, and full use of my left hand and arm. No gait issues, either.

I'm not cured, but the symptoms are gone for now. I have my life back, and I owe that to Dr. Kumar and Dr. McVicker, who knew what to do, how to do it, and had the facility and staff to pull off a medical miracle.

NOTE: *A longer story about my experiences and a 30-minute documentary we shot during the surgery can be seen on Channel 2's website at kwgn.com/parkinsons.*

Scott Orr, patient of the
CNI William McK. & Marcia N. Thompson Center
for Restorative Neurosurgery



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CNI is privileged to send you this newsletter.

If you have a change in address, or would like us to remove your name from our mailing list, please contact us by phone at **303-806-7417**, e-mail mcmoss@thecni.org, or mail to:

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NeuroHealth Center

The CNI NeuroHealth Center is growing and stretching in new directions. Established in 2004 to treat uninsured and underinsured stroke patients, the clinic will celebrate its 4th birthday on August 19, 2008, with an open house. This interdisciplinary outpatient clinic provides physical, occupational and speech therapy to assist individuals to achieve their highest level of function. We emphasize a team approach, wellness education and community reintegration. A licensed social worker is also available to assist the patient, family and the team with benefit information, additional community resources and assistance with adjustment issues.

The NeuroHealth Center has just become a Medicare provider and accepts most major insurances, and also can see private pay clients in addition to continuing our grant based program. The NeuroHealth Center sees individuals with a broad-array of neurological problems. We offer special programs such as Lee Silverman Voice Training for increasing voice volume training for individuals with Parkinson's Disease, Vital Stimulation (electrical stimulation for swallowing disorders) and the LiteGait partial body weight support for gait training. The NeuroHealth Center has a variety of computer-based programs which address balance issues, driving readiness, cognitive and visual integration and language difficulties.

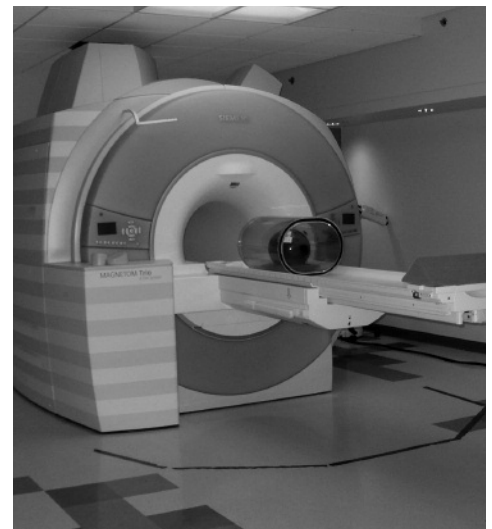
The NeuroHealth Center continues to be involved in interdisciplinary clinics with **Dr. Karen Theriot**, **Dr. Rajeev Kumar** and **Dr. Ira Chang**. They focus on Movement Disorders and Spasticity, Huntington's Disease and the MS Rehab Clinic in conjunction with the Rocky Mountain MS Center. We hope to offer a vision clinic with **Dr. Tom Politzer** and a wheelchair seating clinic with **Dr. Karen Theriot** in the near future. These clinics provide patients and their families with an excellent evaluation and recommendations in a half-day or one-day format which is concise, informative and collaborative.



Please join our celebration on August 19, 2008 from 4 PM to 7 PM in the NeuroHealth Center in the 701 East Hampden building, Suite 415. Come meet our therapists and try out some of our new equipment—test your balance skills, cognitive agility, and perceptual skills.

What's New at CNI

In 2008, Swedish acquired a **3-T MRI**. The technology of the 3-T MRI lends itself in particular to enhancing image quality for neurological diagnosis in the areas of stroke, epilepsy, brain tumor detection, epilepsy, multiple sclerosis, ALS, Parkinson's disease and Alzheimer's disease. The 3-T MRI platform will allow Swedish to increase patient satisfaction by decreasing exam time, and increase physician satisfaction by enhancing our current MRI applications and image quality. This technology will allow the CNI member physicians to provide more comprehensive care to our patients.



Dealing with Grief and Loss

Grief is a powerful process that all of us have experienced if we have lived long enough to experience some sense of loss. The most noted work on grief is Elisabeth Kubler-Ross' book, *On Death and Dying*. In this book, she noted the five stages of grieving that people experience which are denial, anger, bargaining, depression and acceptance.¹ Dr. Kubler-Ross' work was based on interaction with terminal or dying patients; however, grief is experienced by all who suffer any kind of loss. This can include, but is not limited to, loss of a career, loss of mobility, loss of ability, etc. If a person does not allow himself or herself to grieve the loss or losses, he or she will become what is labeled "stuck" in counseling terminology. This is not limited to illness. For example, a former professional football player may come to every football season feeling depressed because he is no longer in the game. This may be expected in the first season or two, but if he is still "stuck" there fifteen years from now, he has not properly grieved the loss of his career.

When it comes to brain tumor patients, they can experience several losses simultaneously. Due to the tumor plus neurosurgery, they lose a part of their brain and function. How would any of us respond to that? As I talk and interact with these patients, I can tell where they are in the grieving process by their response. Almost all, after hearing the diagnosis, go into denial, saying, "This is not happening to me. This cannot be

true." Some patients must have medication for depression because this stage of grieving can be so overwhelming, especially if the loss is great, such as someone with a Ph. D. who can no longer teach or a harpist who can no longer play the harp. In our culture, we also see this process as linear, as in "I have gone through step one, now I am on step two, etc." The grieving process is actually cyclical, where one person may go through all stages several times. Someone else may also cycle through anger, bargaining and depression a hundred times before he or she finally reaches acceptance.

How do we know someone has overcome grief? We can observe his or her life and see their attitude as well as their lifestyle. One person, who we will call "Victor" has demonstrated a positive attitude and has been working full time. Victor is now an undercover narcotics agent. The scar from his craniotomy seems to be a "star" because people on the streets may think it is from a fight or something else traumatic. Even though Victor experienced a serious diagnosis along with a loss that most people could not comprehend at his age, he has proven that life can be lived to the fullest and enjoyed. Perhaps we can all learn something from his example and do the same.

¹ Elisabeth Kubler-Ross, *On Death and Dying*. Scribner, a division of Simon and Schuster: New York, NY, 1968.

Research Update

The CNI Research Department continues to be very active in conducting studies in many of the CNI Centers. With the arrival full time of **Dr. Rajeev Kumar** in the CNI Movement Disorders Center, the number of studies opened for patients suffering from Parkinson's (PD) and Huntington's disease (HD) has rapidly increased. Currently, there are five studies open in HD with some looking at pre-symptomatic patients and others involving new treatments. There are two studies active in PD, and two that have just completed enrollment with an additional two studies are in the process of being initiated.

Drs. Don Frei, Chris Fanale and Don Smith and the CNI Stroke Center have four studies looking at treatment in the acute phase of ischemic strokes, prevention of secondary stroke and treatment of intracranial disease to prevent additional strokes. The Center has just completed participation in two major stroke studies, one of which enrolled over 20,000 participants worldwide. **Dr. Ed Arenson** and the CNI Brain and Spinal Tumor Center are involved in one study and currently

looking at two others for the treatment of brain tumors and side effects of treatment. In addition, **Dr. Arenson** is reviewing outcome data on treatment of high grade brain tumors by the program and will have a paper ready for submission and potential publication by September. **Dr Kelsall** and the CNI Center for Hearing is involved in two sponsored studies in addition to looking at many facets of the treatment and diagnosis of hearing problems with the goal of publishing and/or presenting the information at national meetings. **Dr. Don Frei** with the Interventional Neuroradiology program in conjunction with the CNI Stroke Center has completed a study and is preparing a single center publication of their results in addition to being part of the multi-center publication of the results.

Research is very active in many CNI Centers and offers patients treated through CNI a unique opportunity to have access to studies they would not otherwise be able to consider. These studies also give physician members the opportunity for publication and acknowledgement in many other places.

Support Groups

CNI CENTER FOR BRAIN & SPINAL TUMORS

Healing Services are held the 1st Wednesday of every other month at 5:30 p.m. in the Swedish Medical Center Chapel.

Patient and Family Support Group—Meets the 1st Wednesday of the month.

Please contact Lorre Gibson for more information, times and locations at 303-806-7420, or lgibson@thecni.org.

DEEP BRAIN STIMULATION (DBS)

A DBS support group has been formed. The group meets quarterly. **For more information, please contact Kim Martin at 720-974-4093.**

EPILEPSY

The CNI Epilepsy Support Group meets the 3rd Tuesday of the month. The meeting is a combination of education and support and is open to patients with epilepsy and their families. Meetings are held at Swedish Medical Center, Conference Center. **For more information please contact Peggy Hugger, RN at 303-762-6677.**

CNI CENTER FOR HEARING

Adult Cochlear Implant Recipients Group—A support group for adults with cochlear implants or adults considering implants. Meets several evenings each year at Swedish Medical Center.

Cochlear Implant Parents Group—A support group for parents of children with cochlear implants or parents who are considering implants for their children. Meets several evenings each year at Swedish Medical Center.

Contact Judith Stucky at jstucky@thecni.org or 303-806-7416 for more details or visit the web site at <http://www.thecni.org/hearing/supportgroups.htm>.

STROKE SUPPORT

For stroke survivors and caregivers. Meets in the Conference Center at Swedish Medical Center. **For more information, please contact Wade Jensen at 303-357-5441.**

BRAIN ANEURYSMS

The Brain Aneurysm Support Group meets the 3rd Monday of every month. The group meets from 6:30-8:00 pm in the 2nd floor conference center at Swedish Medical Center. **For more information, please contact Carol Gill at 303-779-1821.**

PARKINSON'S DISEASE

Parkinson's Association of the Rockies (PAR) manages over 30 PD support groups in Colorado, Wyoming and Western Nebraska. **You may contact them at 303-830-1839 or visit their web for a complete list of dates, locations and times at www.parkinsonrockies.org.**



Charles Louis, stroke survivor and CNI volunteer, gave a moving keynote speech at the recent Hiawatha Davis Health Initiative Luncheon, sponsored by the Black United Fund of Colorado.

Various Options to Support CNI's Mission

Cash

Gifts of cash provide CNI with much-needed financial assistance. Outright gifts have an immediate impact on the services and programs because they can be used to support a variety of current needs.

Appreciated Stocks

You can secure a long-term investment in today's volatile stock market by investing in the future of neurological care. A gift of long-term appreciated marketable stocks or securities will help you save taxes twice. Such a gift will provide an income-tax charitable deduction and capital gains tax savings.

Real Estate

When you give a gift of a home, investment property, time share or real property to CNI, you may claim an income-tax charitable deduction based on the full market value of the gift, avoid capital gains taxes, and eliminate certain costs associated with the transfer of real property. Gifts of real estate can also provide income to you.

Personal Property, Cars and Art

You may wish to give CNI items that we can turn into essential funding that allows us to continue supporting patient care, research and outreach. CNI will consider these gifts on a case by case basis.

Life Income Gifts

You can make a gift to CNI that allows you to hold an interest in that gift for your lifetime or for a specified term of years. After that time, the funds become available to CNI. For example, you can set up a charitable trust which allows you to receive income from that trust for a specified period, or for life. When you make your gift, you not only receive an immediate tax deduction, but you also have the satisfaction of knowing that the plans you make today will help to support CNI for the generations to follow.

Matching Gifts

Many businesses have demonstrated their support for CNI by matching, or multiplying, their employees' gifts to us, up to a set amount. Before you make a gift, you may want to ask whether your employer participates in such a program. Certain restrictions apply to matching gifts; please consult your company's personnel office for further information.

Endowment Gifts

An endowment gift is maintained in perpetuity, and only a portion of the annual investment return is used for the purposes specified by the donor. The rest of the investment yield is returned to principal. Thus, over the years, the fund can grow and ensure the program's viability.

Planned Legacy Gifts / CNI Legacy Society

Planned gifts are gift arrangements that have specific tax advantages and often include lifetime income to a beneficiary or beneficiaries named by the donor. A planned gift may be as simple as a life insurance policy or a bequest made through your will or living trust. A planned gift maximizes your giving potential and can even allow you to ensure your future financial security or that of a loved one. The CNI Legacy Society has been established to acknowledge individuals and families that help ensure the future of CNI.

IRAs, 401k, 4013b and Other Tax-Deferred Funds

These traditional tax deferred retirement accounts are powerful vehicles for accumulating tax-deferred savings. By donating these assets to CNI you can avoid paying taxes, increase your legacy for your heirs, and help individuals with neurological disorders.

As with all financial considerations, we urge your attorney, tax advisor or financial consultant to discuss potential tax advantages and other aspects of your charitable giving with you. **For information on how to support CNI and its programs through the above vehicles or any other please contact John Stephenson at (720) 974-4094 or at jstephenson@TheCNI.org.**

CNI Mission Statement

The mission of the Colorado Neurological Institute is to enhance the delivery of personalized, comprehensive and state-of-the-art care to patients with neurological conditions through coordinated patient care, education, research, and outreach activities.

Upcoming Events

Colorado Neurological Institute's
20th Anniversary Gala
Featuring the legendary band "Flash Cadillac"



SATURDAY, OCTOBER 4, 2008 / SEAWELL BALLROOM
CHAIRS: Bonnie Mandarich and Pamela Ruschmeyer-Helm

Contact Mary Catherine Moss at 303-806-7417.

CNI

For information about how to help support CNI through contributions or volunteer efforts,
or to subscribe to InTouch with CNI please call us at 303-788-4010 or write to us at:
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A return envelope has been included for your convenience.