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Restoring Hope

Deep brain stimulation a viable option for treatment-resistant neurological and psychiatric conditions

It may be the only reason Michigan resident Cindy Warren is enjoying life the way she is today – protected from the deep depression that caused her to attempt to end her life. It also may be the only reason Burak Pekin is finally able to leave his home in Ankara, Turkey, and enjoy an evening with friends at a coffee shop. He's been relieved of many of the motor and vocal tics caused by his debilitating Tourette's syndrome. And, although Mike Hooffstetter, of New Mexico, gave up his information technology career, he has found a new vocation – providing comfort to the dying – grateful that Parkinson's disease is no longer controlling his life.

Though worlds apart geographically, what links Cindy, Burak and Mike together is that all three elected to undergo a surgical procedure known as deep brain stimulation (DBS) after all other treatment options for their conditions were exhausted. And all three chose Cleveland Clinic and its Center for Neurological Restoration (CNR) for their treatment. The CNR team is one of the most experienced in the world, having performed more than 1,000 DBS procedures.

Through DBS, the electrical activity in the brain is altered, allowing relief from symptoms interfering with normal daily functioning. (See *"What is deep brain stimulation?"* on Page 3 for more information.) Today, DBS is routinely used to relieve the symptoms associated with Parkinson's disease and other movement disorders, such as dystonia and non-Parkinson's tremor. DBS is also being studied for its effectiveness in treating severe, disabling and medication-intractable depression, obsessive-compulsive disorder and Tourette's syndrome. The Cleveland Clinic Psychiatric Neuromodulation Center (PNC) is one of only a few sites worldwide involved in the careful investigation of this technology for psychiatric disorders, according to psychiatrist Donald A. Malone, M.D., director of the PNC. The PNC is a collaboration between the Cleveland Clinic Psychiatry and Psychology Department and the CNR. The CNR's director, Ali Rezai, M.D., serves as surgical director of the PNC. (For more information about both centers, see Page 4.)

On the cover: An electrode measuring 1.27mm in diameter is implanted in the brain during deep brain stimulation surgery.



**NO LONGER RECLUSIVE,
BURAK PEKIN RECLAIMED HIS LIFE**

Now 30 years old, Burak Pekin, of Ankara, Turkey, has been battling the vocal and motor tics caused by Tourette's syndrome (a neurological disorder characterized by repeated involuntary movements and uncontrollable vocal tics) since he was a boy. His tics consisted of stomping "most of the time," sticking out his tongue and involuntary neck and arm movements. These movements became progressively worse and more difficult to control as he got older. By his third year in college, he was no longer able to suppress his motor or vocal tics, which included abrupt cursing and yelling, either in public or at home.

When Burak was 20 years old, a psychiatrist in Istanbul diagnosed him with Tourette's syndrome and prescribed haloperidol. Describing the medication's side effects as "intolerable," Burak quit taking it and continued with psychotherapy during his two-year post-college service in the Turkish Army. By the time he finished his mandatory service, he had slipped into a deep depression – Tourette's was getting the best of him, even causing him to injure himself.

"I was very miserable," Burak says of that time in his life. "I was not able to work. I was not able to do anything."

Burak moved back in with his parents and rarely left the house for the next seven years. He said he had a hard time going out in public because "most people don't understand (Tourette's syndrome)." His mother, Nevin, was saddened but said she never lost hope that medical advancements would become available to help her son.

“I was very miserable,” Burak says of that time in his life. “I was not able to work. I was not able to do anything.”

Then it happened. One day while flipping through the newspaper, Burak came across an article on a U.S. hospital’s investigational use of deep brain stimulation (DBS) for the treatment of Tourette’s syndrome. He called a friend of the family who was a doctor. The doctor referred him to Cleveland Clinic.

Burak was put in touch with Dr. Rezai and, in December 2004, Burak came to Cleveland for a month-long series of evaluations, consultations and testing. He flew back to Turkey and waited for approval for the surgery. In April 2005, Burak came back to Cleveland for the DBS.

Six months after his surgery, Burak was 90-percent tic-free and improving and the depression was gone. The surgery was not an immediate fix, however. The improvements happened slowly over time while Burak’s stimulation devices and medication were tweaked and adjusted. But, he said, he knew not to expect a miracle from the surgery.

“Dr. Rezai never promised 100-percent treatment,” he says. “He was very honest and straightforward about what I could expect.”

With his Tourette’s under control, Burak has reclaimed his life and is now able to enjoy such things as concerts and movies with friends. “Life is good now – better,” he says.

(Note: The use of DBS for Tourette’s syndrome is still investigational at this point. The Cleveland Clinic CNR is enrolling patients in its investigational study on using DBS for patients with severe and medication-intractable Tourette’s syndrome. Patients must be referred by a physician.)

What is deep brain stimulation?

Deep brain stimulation (DBS) is a surgical option for patients with Parkinson’s disease and other movement disorders. Investigation is currently under way regarding the use of DBS to treat severe depression, obsessive-compulsive disorder (OCD), Tourette’s syndrome and severe intractable chronic pain. Though some people may view psychiatric disorders as emotional in nature, there is an abnormality related to the physiology and the circuitry of the brain with these types of conditions.

DBS involves the implantation of a tiny lead containing four electrode contacts into a specific target area in the brain. The lead extends through a small opening in the skull and is connected to an extension wire. The extension wire is connected to a programmable impulse generator, or “pacemaker,” which is implanted under the skin over the chest.

The neurosurgeon is aided by computerized brain targeting and physiological-mapping technology, which precisely locates in the brain the region of abnormal functioning resulting in the symptoms of the disease. The patient is awake during surgery to allow the surgical team to assess the patient’s brain functions. While the electrode is being advanced through the brain, the patient does not feel any pain because of the unique nature of the brain and its inability to generate pain signals. Before the neurosurgeon makes the small opening in the skull, a local anesthetic is administered.

Most patients are in the hospital for about three days. The impulse generators are implanted either at the time of electrode implantation or later. The patient is placed under general anesthesia for this part of the procedure. The impulse generators are turned on for the first time within a few weeks after implantation and will need to be adjusted to ensure they work at a level proper for the individual. Programming of the stimulation is easy and painless.

DBS technology is a major improvement from the previous practice of thalamotomy and pallidotomy – surgical procedures that destroyed small parts of the brain. Unlike these earlier procedures, DBS does not destroy brain tissue and the procedure is fully reversible and adjustable over time to maximize the benefits for patients as their disease progresses. In patients with Parkinson’s disease, DBS significantly improves the symptoms of the disease while reducing the intake of medications.

DBS is not appropriate for everyone. And, as with any surgery, it is not completely without risk. But in properly selected patients, brain pacemakers are remarkably safe and effective, with benefits lasting many years.

Cleveland Clinic

Center for Neurological Restoration (CNR)

The Center for Neurological Restoration (CNR) provides innovative treatments for movement disorders, including Parkinson's disease, essential tremor and dystonia. The CNR also offers therapies for patients with intractable Tourette's syndrome, chronic pain and other disabling neurological disorders. The CNR staff has innovated deep brain stimulation surgery for the treatment of various neurological disorders and is among the most experienced in the world, implanting more than 1,000 brain pacemakers.

The CNR utilizes a multidisciplinary team approach and collaborates closely with neurology, neurophysiology, pain management, psychiatry, radiology and biomedical engineering.

Cleveland Clinic

Department of Psychiatry and Psychology

The Department of Psychiatry and Psychology offers a full range of mental health, behavioral, chemical dependency and chronic pain rehabilitation services for children, adolescents and adults of all ages. Our multidisciplinary treatment team can provide comprehensive assessment and treatment approaches tailored to meet the needs of each patient and their families.

The Cleveland Clinic Department of Psychiatry and Psychology is accredited by the Joint Commission for the Accreditation of Health Care Organization (JCAHO) and the Commission for Accreditation of Rehabilitation Facilities (CARF).

Cleveland Clinic

Psychiatric Neuromodulation Center

The Psychiatric Neuromodulation Center (PNC) is a collaboration between the Department of Psychiatry and Psychology and the Center for Neurological Restoration (CNR), offering both traditional and novel treatments to patients with treatment-resistant psychiatric disorders.

Treatment-refractory depression and obsessive-compulsive disorder (OCD) patients, in particular, can benefit from evaluation and consultation with PNC physicians who are expert in the evaluation and treatment of these conditions.

For more information on deep brain stimulation or to make an appointment with the Center for Neurological Restoration or the Department of Psychiatry and Psychology, call toll-free 800.884.9551 or 001.631.439.1578.



**WITH PARKINSON'S UNDER CONTROL,
MIKE HOOFFSTETTER FOCUSES ON HELPING OTHERS**

Mike Hooffstetter was "devastated" when, at 46 years old, he was diagnosed with Parkinson's disease. The neurologist in Austin, Texas, kept talking but "I didn't hear anything else," Mike says.

That was in 2001. By 2002, Mike, now living in Albuquerque, New Mexico, had quit his job as an information technology project manager because the disease was progressing rapidly. He was having trouble concentrating at work and the stress of his job was making it worse. A tremor in his little finger had led to a tremor in his jaw, then his left hand "going wild all the time," accompanied by a shaky left leg. His neurologists tried hard to find the right combination of medications but nothing relieved his worsening symptoms.

Previously, his neurologist had told him about DBS. "I thought she was nuts," he said, "I didn't want anything stuck in my brain." But he began to research DBS because, he said, "I just got to the point where I was so miserable."

Mike began considering Cleveland Clinic because it popped up often in his research. When a friend who was a neurologist in Washington, D.C., recommended Cleveland Clinic, he made his decision.

Mike and his wife, Judith, came to Cleveland Clinic in January. Mike underwent testing and they both met with Dr. Rezai, who told him he probably could alleviate 80 percent of his tremors. Mike had the surgery in March.

When asked about his feelings before having the procedure, Mike said he was nervous, but ready. "You get to the point where you have to do a risk-benefit analysis," he says. "The potential benefits far outweighed the risks."

Today, Mike says his tremors have lessened quite a bit. “(The Parkinson’s) is tons better and will probably get better down the line,” he said. He also has been able to cut down on his medication.

Although he has not gone back to his previous career, Mike stays very busy as the New Mexico state coordinator for the Parkinson’s Action Network. He also works as a volunteer for Hospice, going to the homes of terminally ill patients to relieve their caregivers. “If I didn’t have Parkinson’s, I wouldn’t be doing that,” Mike says. “I probably would have been too busy with my career.”

“You get to the point where you have to do a risk-benefit analysis. The potential benefits far outweighed the risks.”

– Mike Hooffstetter



Ali Rezaei, M.D., Director of the Center for Neurological Restoration, performs deep brain stimulation surgery on a patient with Parkinson's disease.



Donald A. Malone, Jr., M.D.

Director of the Psychiatric Neuromodulation Center (PNC), on studying deep brain stimulation (DBS) as a treatment for psychiatric disorders.

“DBS has only recently been used in the treatment of psychiatric disorders. Over the last 50 years there have been various attempts to stimulate brain regions to achieve changes in emotion. However, only recently has DBS technology developed to the point of being able to target very specific brain areas. At the same time, more is being learned about the neurocircuitry involved in various psychiatric disorders.

The PNC at Cleveland Clinic has been involved with research in this area for more than five years. Patients with severe obsessive-compulsive disorder and major depression have received investigational treatment with DBS. This work is being done in cooperation with several other national and international research sites. The preliminary findings are quite promising, and the research is ongoing. As this research progresses, it may bring hope to patients who have few other options.”



Ali Rezaei, M.D.

Jane and Lee Seidman Chair in Functional Neurosurgery and Director of the Center for Neurological Restoration (CNR), on future uses for deep brain stimulation (DBS).

“DBS surgery, also known as brain pacemaker surgery, is a safe and effective therapy for patients with advanced and medication-intractable Parkinson’s disease, tremor and dystonia. The Cleveland Clinic team is among the most experienced worldwide with DBS surgeries. The benefits of DBS for patients with movement disorders over the past decade have resulted in the investigation of the use of DBS for intractable chronic pain, epilepsy, Tourette’s syndrome, major depression and obsessive-compulsive disorder. Brain pacemaker technology and evolution is similar to where heart pacemakers were 20 to 30 years ago. DBS will be increasingly utilized over the next decade for treatment of various neurological and psychiatric disorders.”



DBS GAVE CINDY WARREN FROM MICHIGAN A LIFE-SAVING OPTION

Cindy Warren, of Brighton, Mich., said it was “desperation” that led her to Cleveland Clinic for DBS. The 53-year-old has been struggling with severe depression for years.

“It was just horrible,” Cindy says. “I had these feelings of wanting to self-abuse, of hating myself. I was having a hard time getting through the day.” Her wake-up call came in March 1999 when she tried to commit suicide. “I don’t think anyone really realized how depressed I was.”

Cindy, a special education teacher, had been in therapy for about six years prior to her suicide attempt. She had been diagnosed with depression, although she says she’s really not sure what triggered it. Years of psychiatric therapy and antidepressant medications did not seem to help her. She was hospitalized after her suicide attempt in 1999, and the ensuing years were filled with

trials of “10 or 12 different antidepressant medications, being hospitalized four times, at least, and over 100 ECT (electroconvulsive therapy) treatments.”

The ECT treatments (a procedure in which an electrical charge is delivered to the brain via electrodes applied to the scalp) helped for a few weeks at a time, but they took a toll on her short-term and long-term memory.

“Although ECT was helping to save my life in many ways,” Cindy says. “I was unable to remember things about people, which made me feel stupid, and the depression spiraled.”

Cindy’s psychiatrist talked to her about DBS and the study being done at Cleveland Clinic. She said applying for the treatment at Cleveland Clinic “was not a tough decision.” Meetings with Drs. Malone and Rezai led to her acceptance to undergo DBS in November 2005.

The surgery, she says, “feels pretty much like a miracle.” She is much less anxious in social situations and is enjoying traveling with her husband. Others in her life have noticed a dramatic change. “I don’t feel like a depressed person,” Cindy says. Her medications are being slowly reduced, and she is starting to enjoy being around people again.

Cindy had to retire from her previous job because of her depression, but she is pursuing volunteer work and calling friends she hasn’t seen in a long time. She’s even joined an Optimist Club.

“If I can give people some hope, I’d like to be able to do that,” Cindy says of talking about her experience. “I’ve been there and I know what it’s like when you feel like you have no hope left.” ■

Write a Letter to Tomorrow

If you are scheduled to undergo a medical procedure in the near future, your story could serve as an inspiration to others – and writing it down may help you in your own healing as well. Consider writing a “Letter to Tomorrow” about your experience and to the one thing you’re looking forward to after your recovery.

Cleveland Clinic is compiling “Letters to Tomorrow” to use on a special Web site. Our hope is that the letters will foster support and create a feeling of community among people who are facing medical treatment. All letter writers remain anonymous.

Your Letter to Tomorrow could make a real difference in both your life and the lives of those you might inspire. If you have a story, consider sharing it.

For more information and to view letters, visit www.letterstotomorrow.com.



Q & A

Diagnosing Heart Disease Earlier



Most fatal heart attacks are caused by the accumulation of fat and calcium deposits in the coronary arteries, which are often not detected until they are large enough to be visible during a coronary catheterization. Cardiologists now have a new imaging tool, coronary computed tomography angiography (CTA), which can detect heart disease in its earliest stages. Richard Grimm, D.O., answers questions about this new technology.

Richard Grimm, D.O., answers questions about this new technology.

What is coronary CTA?

Coronary CTA is a noninvasive technique that offers detailed images of the coronary arteries. It uses computed tomography (CT) – a type of X-ray in which the beam moves in a circle around the body – to image the heart and arteries, thus creating many different views and providing much greater detail. The X-ray data is sent to a computer that displays it in two-dimensional form on a screen.

What are the advantages to coronary CTA?

While different types of cardiac imaging are used in diagnosing heart disease, most of them show only hardened or calcified plaque. By the time the plaque is calcified, coronary artery disease is well advanced. Coronary CTA reveals early-stage, non-calcified plaque, allowing diagnosis of the beginning of coronary artery disease.

Who is a candidate for the procedure?

Coronary CTA is not appropriate for everyone. Because it is new, its use and application are evolving. Currently, the Cleveland Clinic Heart and Vascular Institute recommends coronary CTA for people with chest pain or other symptoms that may be related to heart disease, or for people who have had a stress test that is inconclusive.

What are the benefits to the patient?

Coronary CTA is a noninvasive procedure. It requires only about 30 minutes, from patient preparation to completion of the scan. For many patients, it can rule out the need for cardiac catheterization.

Patients must be referred by their physician for a coronary CTA. For an appointment with a Cleveland Clinic Heart and Vascular Institute physician, please call toll-free 800.884.9551 or 001.631.439.1578. ■

e-Cleveland Clinic

MyConsult Guided this Family to Appropriate Treatment

MyConsult® is an online second opinion service available for patients with life-threatening or life-altering diagnoses.

MyConsult User: Erik Kroon, 33, aerospace engineer

Patient: Lars Kroon (Erik's son), 19 months

Hometown: Rotterdam, The Netherlands

Diagnosis: Lars was born with hydrocephalus (an abnormal accumulation of water-like fluid in the head) due to a brain tumor originally diagnosed as choroid plexus carcinoma (a rare cancer that affects the production of spinal fluid, with a 40-50 percent chance of survival).

Initial treatment: Beginning just days after birth, Lars underwent two surgeries to remove the tumor and install a shunt to drain the spinal fluid, followed by an aggressive chemotherapy campaign. After six months, however, the tumor relapsed and Lars began refusing food.

First experience with MyConsult: "There was a fair amount of controversy regarding the diagnosis," says Lars' father, Erik. "I chose the second opinion service because Cleveland Clinic has specialized knowledge and experience in this area."

Second opinion, provided by Joanne Hilden, M.D., and Tanya Tekautz, M.D., pediatric hematologists/oncologists at Cleveland Clinic's Children's Hospital:

Diagnosis: atypical teratoid rhabdoid tumor, a rare and aggressive cancer with less than 20 percent survival. Recommendation: Surgery, followed by local radiation and high-dose chemotherapy with stem cell rescue or, if surgery is skipped, start radiation without delay prior to chemotherapy. "Because total removal of the tumor was considered unlikely and the risk of damaging Lars' vision was significant, we made a very tough decision to skip surgery," Erik says. "Lars is currently finishing his treatment and is surprisingly cheerful, considering all he's been through."

Erik's feelings about Cleveland Clinic: "I'm very pleased with the service; it was provided very quickly, and I am reassured that my son is receiving the best treatment."

Get Connected!

In addition to second opinions, MyConsult allows you to evaluate your eligibility for a particular procedure or treatment or obtain a personal nutrition consultation.

Connect to MyConsult through e-Cleveland Clinic:
eclevelandclinic.org.

Minimally Invasive Surgery Gives Cayman Islands Man Freedom from Pain

Self-described as a “typical male,” 56-year-old Rick Alpert would seem anything but typical. The former Bostonian moved to the Cayman Islands 10 years ago, just one year after undergoing a kidney transplant. He survived a heart attack and triple-bypass surgery in 2002.

Rick was enjoying life with his wife and 6-year-old son on a beautiful Caribbean island when he began experiencing pain shooting down his legs for no apparent reason. He initially sought help from a chiropractor, but did not find relief.

“As the weeks and months progressed, I learned to work through and walk through the pain,” says Mr. Alpert. “Then one morning I awoke and could not get out of bed.”

A trip to the doctor’s office and a few tests later, Rick learned that he had spinal stenosis, a common condition among men and women over 50, caused by a narrowing of spaces in the spine (backbone), which puts pressure on the spinal cord and/or nerves.

On a referral from his local physician, Rick traveled 500 miles to Cleveland Clinic Florida in Weston in hopes of finding an end to his pain. That’s where he met Robert Biscup, D.O., Chairman and Director of Cleveland Clinic Florida’s Spine Institute.



Rick Alpert and his wife Julia.

A spinal surgery pioneer, Dr. Biscup is internationally recognized for his expertise in minimally invasive spine surgery. He leads a multidisciplinary team of medical experts that together treat a full spectrum of back and neck problems, including spinal stenosis.

With the help of International Patient Services at Cleveland Clinic Florida, Rick was able to schedule all his physician appointments and diagnostic tests, including an MRI, within a two-day visit. That included a consult with a cardiologist and kidney specialist, in addition to the spine team, because of his medical history. The diagnosis of spinal stenosis was confirmed, as was the need for surgery.

According to Rick, “When Dr. Biscup recommended surgery, I was ready. He and John Booher, his physician assistant, really put me at ease by explaining my condition and the course of treatment in great detail.”

Earlier this year, Dr. Biscup performed a minimally invasive micro-decompression procedure, removing a cyst and pieces of bone that were putting pressure on nerves along Rick’s lower spine. Unlike traditional open surgery, this newer approach required a single small incision, less than two inches long. It was performed under spinal anesthesia, which allowed Rick to remain awake during the entire procedure.

Thanks to the minimally invasive nature of micro-decompression, Rick was on his feet the same day of surgery and able to leave the hospital one day later.

“I was amazed at how much better I felt; the shooting pain was gone immediately,” Rick says. “During my week of recovery in Ft. Lauderdale, I was enjoying lunch at the beach with friends. Today I’m still feeling great and very thankful to Dr. Biscup and the entire staff at Cleveland Clinic Florida.”

For more information about the Cleveland Clinic Florida Spine Institute, call toll-free 800.884.9551 or 001.631.439.1578. ■

Cleveland Clinic Florida has a New CEO

Bernardo Fernandez, M.D., Chairman of the Division of Medicine and head of the Section of Vascular Medicine at Cleveland Clinic Florida, became Chief Executive Officer of the hospital this summer after Robert Kay, M.D., retired as CEO June 1.

Dr. Kay, who served Cleveland Clinic for nearly three decades, continued working with Cleveland Clinic Florida's operations on a consulting basis throughout the summer.

Dr. Fernandez, an internist who specializes in vascular medicine, joined Cleveland Clinic Florida in May 1991. Born in Havana, Cuba, Dr. Fernandez is a graduate of the Ponce School of Medicine in Ponce, Puerto Rico. He completed his residency at Cleveland Clinic's main campus in Cleveland, Ohio.

Dr. Fernandez has published numerous articles on vascular disease and treatment and was a leading investigator for several vascular therapy trials. He is a frequent presenter and lecturer at medical symposia throughout Florida and the Caribbean and serves as a member of the editorial board for the journal *Periphery* and a manuscript reviewer for the *Journal of Vascular Medicine and Biology*.

Dr. Kay, a nationally recognized pediatric urologic surgeon, joined Cleveland Clinic in 1980 as head of its Section of Pediatric Urology. He had joint appointments in pediatric surgery, the Glickman Urological Institute and Taussig Cancer Center. He was appointed Chief of Staff in July 1999, making him responsible for all of the hospital's physicians and researchers.

Cleveland Clinic and Mubadala Development to Create Cleveland Clinic Abu Dhabi

Cleveland Clinic and Mubadala Development in Abu Dhabi, of the United Arab Emirates, signed an agreement in September to establish a preeminent world-class hospital in Abu Dhabi to be known as Cleveland Clinic Abu Dhabi. This initiative is set to create a new benchmark for the development and promotion of healthcare services in the Middle East.

Under the terms of the 15-year agreement, Cleveland Clinic will establish, develop and operate a world-class specialty hospital and clinic in Abu Dhabi using the Cleveland Clinic systems, procedures, guidelines and standards. The hospital will incorporate Cleveland Clinic's medical group model, providing a spectrum of specialty services that will be planned and developed based on the results of a comprehensive health economic impact study. The result of the agreement will therefore be an extension of Cleveland Clinic's model of medicine and clinical capabilities in Abu Dhabi.

Cleveland Clinic Canada – Offering World-Class Care to Our Neighbors

Cleveland Clinic is taking its pioneering approach to health and wellness to Canada. The Toronto Health and Wellness Centre, which opened in October, will become the hospital's Canadian campus.

Preventative lifestyle management programs will be available in conjunction with our partner, Canyon Ranch – one of the world's most renowned wellness lifestyle providers. Cleveland Clinic Canada, in cooperation with Canyon Ranch, will go beyond everyday executive health programs by providing a personalized, solution-based evaluation, treatment and prevention plan. World-renowned physicians will provide professionals with comprehensive clinical evaluations, nutrition guidance, customized exercise plans, stress-

reduction training and integrative healing techniques to nourish the mind and body.

Through the new campus, Canadians will have access to leading-edge medical diagnostic expertise, individual treatment and the most advanced technology provided by leading professionals in cancer prevention, cardiology, gastroenterology, endocrinology, orthopaedics, sports medicine and more.

Cleveland Clinic Canada can provide a seamless referral service for care at Cleveland Clinic in Ohio.

For more information on Cleveland Clinic Canada, call **888.507.6885** or visit ClevelandClinicCanada.com. ■

Genetics Research

Translates to Specialized Patient Care

Cleveland Clinic's new Center for Personalized Genetic Healthcare at the Lerner Research Institute's Genomic Medicine Institute (GMI) combines research and medical care for patients who have been diagnosed with or suspect they may be at risk of developing genetic-based diseases.

"Typically, laboratory-based human genetics research and clinical care are scattered in two or more separate locations," said Charis Eng, M.D., Ph.D., GMI Chair. "In the GMI, researchers and clinicians in the center work side by side to deliver care specific to an individual and his or her family."

The center has two main goals. First, to use translational human genetics research to optimize patient management and to deliver evidence-based genetic counseling to improve care for patients with a wide range of conditions – from rare genetic diseases to more common health problems such as heart disease and cancer.

Second, the center aims to coordinate and provide the infrastructure to perform clinical and translational investigation in genomic medicine. For example, patients' samples are collected and stored in a biorepository – essentially a "frozen library" of genetic samples that is a critical part of the foundation for GMI's and its collaborators' translational research activities.

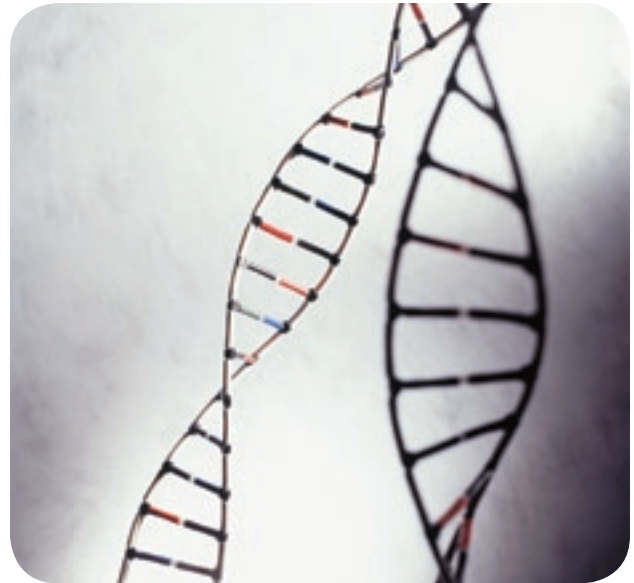
"As we see more patients, we'll have more samples to investigate. Larger sampling provides more comprehensive and productive genetics research," Dr. Eng said.

The center also plays a key role in the cycle of patient care: Cleveland Clinic clinicians can refer patients to the center for genetic risk assessment and counseling; likewise, the center can direct patients, who are self-referred or referred by physicians outside Cleveland Clinic, back to the system's clinicians for more specialized care.

The center's genomic medicine practitioners and genetic counselors, who all see patients, work closely with GMI's laboratory-based researchers to individualize management of medical conditions based on a patient's unique situation.

"The center will move patient care from the former 'one-size-fits-all' approach to management of genetic disorders that is specific to a person," Dr. Eng said.

Dr. Eng said there are three primary components to personalized genetic healthcare.



Personalized medical care. Patients are seen by a team of specialists that work together to address genetics issues with patients who have inherited conditions or have a positive family history. It uses the expertise of the many departments within Cleveland Clinic.

The impact on family. If a person has a medical condition, it affects the lives of other members of the family. Counselors discuss issues of how a disease may be inherited and which members of the family are at risk for the disorder. In some cases, genetic testing is available. Genetic counselors can assist with arrangements for testing family members.

Personalized support and education. The language and concepts of genetics are challenging for many people to understand. And living with an inherited disease or coping with the risk of developing or passing on a disease is difficult. The center provides counseling, support and education to patients to help with these issues.

For more information, visit: clevelandclinic.org/medgen. ■

Around Cleveland Clinic

Keeping you up-to-date on our latest news

Prostate Cancer Studies

The Glickman Urological Institute continues to define the state of the art in prostate cancer research. Recently, it published results of a study on patients with recurrent cancer after prostate removal. It showed that half of these patients would benefit from radiation treatment. This information is of critical importance to doctors who treat this disease. They've also developed a statistical model that can predict the probability of recurrence of prostate cancer. It's a graph that can be used to help urologists and prostate cancer patients decide whether to surgically treat localized prostate cancer.

Hair-Loss Study

Following a review of scientific literature, a multidisciplinary Cleveland Clinic team found that the treatment of iron deficiency, through diet or supplements, may help regrow hair. The team's findings appear in the May issue of the *Journal of the American Academy of Dermatology*. Cleveland Clinic physicians routinely screen patients with hair loss for iron deficiency.

Both C-Reactive Protein and Cholesterol Need to be Lowered to Control Coronary Artery Disease

A Cleveland Clinic-led study showed that intensive use of the cholesterol-lowering drugs known as statins reduces the progression of plaque buildup in the coronary arteries by reducing C-reactive protein (CRP), a measure of inflammation in the arteries. Until now, there was no evidence that targeting CRP could reduce the disease burden, according to study leader Steven Nissen, M.D., Chairman of Cardiovascular Medicine. Results suggest that statin therapy should target CRP as well as cholesterol.

First FDA-Approved Implantation of an Artificial Heart as a Bridge to Transplant

Cleveland Clinic was the first center in America to implant the CardioWest Temporary Total Artificial Heart after U.S. FDA approval of the device. Nicholas Smedira, M.D., Thoracic and

Cardiovascular Surgery, implanted the pneumatic biventricular pump to keep the patient alive until a transplantable heart becomes available.

First Use of a Surgical Robot for Spinal Surgery

Isador Lieberman, M.D., and Edward Benzel, M.D., Cleveland Clinic Spine Institute, performed the world's first robotic spine surgery using the SpineAssist robot, made possible by Cleveland Clinic's collaborative relationship with Technion University in Israel, which developed the robot.

First Use of New Device to Treat Atrial Septal Defect

Pediatric cardiologists Lourdes Prieto, M.D., and Larry Latson, M.D., were the first physicians in the United States to use the Transcatheter Patch to close an atrial septal defect (a hole in the wall between the heart's right and left atrium). The patch is unique because it is metal-free, thus offering a lower risk of complications. A 7-year-old girl from Buffalo was the first to receive the catheter-delivered treatment as part of an initial limited trial.

Major Heart Transplant Center

Few medical centers have ever performed more than 1,000 heart transplants. But surgeons at Cleveland Clinic Heart and Vascular Institute have performed more than 1,200 since 1984. Significantly, the survival rate of Cleveland Clinic heart transplant patients exceeds national expectations for this procedure. In 2005, according to the Scientific Registry of Transplant Recipients, 93 percent of Cleveland Clinic adult heart transplant patients were alive one year after surgery. This is fully 5 percent better than the nationwide survival rate with similar case complexity.

For more information on any of these news briefs, call toll-free 800.884.9551 or 001.631.439.1578.

Outcomes Data Available

The latest editions of outcomes data from Cleveland Clinic are available. Our outcomes booklets offer summary reviews of medical and surgical trends and approaches. Charts, graphs and data illustrate the scope and volume of procedures performed at Cleveland Clinic each year. To view outcomes booklets on Cleveland Clinic medical and surgical disciplines, visit clevelandclinic.org/quality.

Young Girl from Denmark Seizure-Free After Surgery

Shortly after Nanna Andersen was born, she unknowingly gave her parents the biggest scare of their lives: She stopped breathing. Several times.

Ultrasound tests showed that the apnea was caused by subependymal hemorrhage (bleeding) on the left side of her brain. The bleeding had caused a stroke, leaving Nanna with brain damage.

As Nanna grew, she learned to walk with a slight limp and use her left arm exclusively, as she had very little control of her right arm. Thankfully, her vision and speech were unimpaired. But her cognitive development was delayed; now 11 years old, she has a developmental age of about seven.

Despite her limitations, Nanna lives a “sweet, happy life,” says her father, Kjeld Andersen, 42, an automobile painter from Alslew, Denmark. She goes to school every day and enjoys swimming and riding horses. She adores her 13-year-old brother, Kewin.

When she was 8 years old, Nanna’s happy life was suddenly threatened again. She had developed severe epilepsy as a result of the brain damage.

Her first seizure was “very big, very scary,” her father recalls, “and her epilepsy grew worse quickly. She went from no seizures to having seizures every day.”

Nanna’s doctors tried a half-dozen medications, but the drugs became less and less effective over time. Because they didn’t have the necessary expertise to operate on Nanna in Denmark, her doctors suggested that the family travel to Cleveland Clinic, where she would be treated by some of the best pediatric neurologists and neurosurgeons in the world.

“Nanna is lucky because she was very young when the damage happened,” says pediatric epileptologist Elaine Wyllie, M.D., Head of Pediatric Neurology at Cleveland Clinic. “As her brain grew, many functions, such as speech, which normally would be located on the left side, actually developed in the right side of her brain.”

That made it possible for neurosurgeon William Bingaman, M.D., Head of Epilepsy Surgery at Cleveland Clinic, to remove the most damaged parts and disconnect the entire right side of Nanna’s brain – in a procedure called hemispherectomy – without destroying her ability to function.

“We were able to ‘unplug’ the horribly dysfunctional part of Nanna’s brain where the seizures came from, with minimal new deficits,” explains Dr. Wyllie. “Her peripheral vision is affected on one side, but she retains her central vision and speech, as well as her previous levels of mobility.”

Most importantly, “We expect her to remain seizure-free,” Dr. Bingaman predicts.

Drs. Wyllie and Bingaman would like to see more children like Nanna benefit from epilepsy surgery. “Too many kids are suffering from epilepsy that could be cured,” says Dr. Wyllie. “And the earlier the better so they can grow up without seizures and learn to be independent.”

Nanna’s parents dream that one day she will be able to live happily on her own, taking care of herself. “That’s our highest hope for her,” Mr. Andersen says.

“Everyone at Cleveland Clinic has been very sweet and helpful, and the medical care is extraordinary,” he says. “We’ve had a wonderful experience.”

For more information on epilepsy surgery, call toll-free 800.884.9551 or 001.631.439.1578. ■



Dr. Wyllie and Nanna Anderson

A Life-Saving Journey to Cleveland Clinic Florida

Pediatrician Rafael Stefan, of Puerto Rico, suffered many years with a chronic disease called ulcerative colitis. The severity of ulcerative colitis, which is an inflammation of the small intestine and colon, varies from person to person. About half of patients have mild symptoms. Others, like Dr. Stefan, may suffer debilitating symptoms.

During one particular flare-up, the 65-year-old doctor was hospitalized for 10 days. On the recommendation of his physician, Dr. Stefan sought treatment at Cleveland Clinic Florida. And so began a life-saving journey.

World-class medicine

Cleveland Clinic Florida has long been a leader in the treatment of colorectal diseases. Doctors from around the world travel to the Weston campus to learn from Steven Wexner, M.D., – an innovator of surgical techniques, and Juan Nogueras, M.D., along with their colleagues in the Department of Colorectal Surgery.

Over the course of two surgeries, conducted three months apart, Dr. Nogueras restored Dr. Stefan's quality of life and relieved his symptoms of ulcerative colitis.

However, while recovering in the hospital following the second surgery, Dr. Stefan began to experience chest pains. He was quickly taken to the cath lab where a 95 percent blockage was discovered in the left main artery of his heart.

"We call this type of lesion a 'widow-maker'," explains cardiothoracic surgeon Douglas Boyd, M.D. "They often go undiagnosed until one day the person goes into sudden cardiac arrest and dies."

Dr. Stefan's heart care team responded rapidly following the diagnosis and introduced a temporary heart-assist device that alleviated his chest pains and reduced the strain on his heart. Within an hour, he was in the operating room with one of the country's best heart surgeons. Dr. Boyd performed emergency off-pump coronary artery bypass, restoring blood flow to the heart and preventing certain death.

According to Dr. Stefan, "The coordination of care between Dr. Nogueras and Dr. Boyd was excellent. During my open-heart surgery, Dr. Nogueras was there until the very end. He supported my wife throughout the whole episode."



Juan Nogueras, M.D., left, and Douglas Boyd, M.D.

World-class service

Patients travel near and far to seek out care at the hands of the talented and renowned surgeons at Cleveland Clinic Florida. For international patients like Dr. Stefan, Cleveland Clinic's reputation for providing world-class medicine is enough to merit traveling abroad, but the level of service and care provided make it a true "destination."

It is the role of International Patient Services to make sure international patients feel welcome. They provide assistance with scheduling appointments, securing lodging, arranging interpretation services, and coordinating hospital admissions and financial transactions.

"The people at Cleveland Clinic Florida were nothing short of marvelous," says Mrs. Stefan. "I want to thank everyone from the surgeons to the nurses to the service personnel."

Today Dr. Stefan is leading an active, healthy life.

"I feel great," Dr. Stefan exclaims. "I look forward to visiting Cleveland Clinic every year. I don't think there's a better place in the world for health care."

"We are proud that Dr. Stefan has made Cleveland Clinic Florida his source for specialty medicine," adds Dr. Nogueras. "Our staff works very hard to make patients feel at home."

For more information about colorectal surgery or the Cleveland Clinic Heart and Vascular Institute, call toll-free 800.884.9551 or 001.631.439.1578. ■

Global Patient Services

Thousands of patients each year travel to Cleveland Clinic from every state in the nation and more than 80 countries around the world. Global Patient Services is a full-service department dedicated to meeting the needs and requirements of both out-of-state and international patients who receive their care at Cleveland Clinic and Cleveland Clinic Florida.

The National Center and the International Center, which comprise Global Patient Services, provide facilitated access to appointments and professional services. Their highly specialized and customized concierge programs include travel arrangements (with airline discounts when available), interpreters for all clinical appointments, lodging and more.

For more information, call **216.444.6404** or visit **clevelandclinic.org/gps/services**.

Helping You Choose Quality Health Care

Cleveland Clinic offers a detailed guide on the Internet to help our international patients make informed decisions about their health care options. You'll find information on more than 20 medical and surgical specialties that explains the latest treatments and shows our results for many different specialized procedures and surgeries. You'll also find data on how Cleveland Clinic compares to other healthcare centers, our patient satisfaction ratings and points to consider in evaluating quality care at different medical centers.

We hope this information will help you make better choices and participate more fully in your own care. To access the quality and results information, visit clevelandclinic.org/quality.

No Passport – Just Password

If you have access to the Internet, you have access to Cleveland Clinic's world-class physicians. With MyConsult®, our electronic second opinion request, you can obtain a personal, confidential consultation from a Cleveland Clinic expert from anywhere in the world. All information you submit online is secure and confidential and can be read only by you and Cleveland Clinic.

You will need a copy of your medical record before you begin, and you will be required to send this information to Cleveland Clinic in the United States.

Follow these steps to obtain a consultation:

- Go to elevelandclinic.org and select MyConsult® from menu
- Select Remote Second Opinion from MyConsult® menu
- Select Click Here to Register (No Social Security number needed)
- Fill Out Questionnaire and follow the instructions

You will receive your second opinion in approximately 10 business days after your medical record is received at Cleveland Clinic. We'll send you an e-mail when your opinion is ready for review online, and we will mail you a hard copy of the physician's second opinion report approximately one week after the consult is complete.

Hotel Accommodations Conveniently

Located on the Cleveland Clinic Campus in Cleveland

The Cleveland Clinic Guesthouse offers 232 large guestrooms with special furnishings and amenities designed for extended stays.

Podcasts: From the Cutting Edge of Medicine

Hear it now! See it now! Cleveland Clinic news and information is now available in convenient audio and video podcast form. Cleveland Clinic podcasts give you breaking news from the cutting edge of medicine, in-depth information on diseases and treatments, and moving real-life stories. See and hear the answers to questions like:

- Can brain implants stop depression?
- Are there alternatives to hysterectomy for fibroids?
- What is the special injury that threatens women athletes' knees?
- Will sleeping on its back distort a baby's head?
- Are you a candidate for bariatric (weight loss) surgery?

Download our podcasts onto your iPod for yourself, your family or friends. Don't use an iPod? No problem – most computer systems support podcasts, so you can play them right on your computer.

Hear and see why Cleveland Clinic is one of the world's most sought-after medical centers. For audio, go to clevelandclinic.org/podcast; for video, go to clevelandclinic.org/healthedge, and get tuned in!



The InterContinental Hotel and MBNA Conference Center features 300 luxury guestrooms, including 29 suites, two specialty restaurants, a five-diamond restaurant, two lounges and a fitness center.

The InterContinental Suites Hotel offers 163 beautifully appointed suites that include a living room, dining area, microwave and refrigerator.

For reservations at any of these facilities, call toll-free **877.707.8999** or contact the Cleveland Clinic medical concierge service at **800.223.2273, ext. 55580** for assistance.

Cleveland Clinic CD-ROM Available

Learn more about Cleveland Clinic by viewing a CD-ROM that contains informative videos, overviews, Web links and downloadable documents regarding:

- Cleveland Clinic
- HealthLink Offices
- Cleveland Clinic Florida
- Global Patient Services
- Second Opinions
- Cleveland, Ohio

To request a complimentary copy of the CD-ROM, call toll-free **800.884.9551** or **001.631.439.1578**.

Resources

General Information

For general information about Cleveland Clinic's services, physicians and news, visit clevelandclinic.org or call **800.223.2273**.

Cleveland Clinic Florida

For information about Cleveland Clinic Florida located in Weston (near Ft. Lauderdale), visit clevelandclinic.org/florida or call **877.463.2010**.

Cleveland Clinic Canada

For information about Cleveland Clinic Canada, visit clevelandcliniccanada.com or call **888.507.6885**.

Online Services

e-Cleveland Clinic is your online resource for a second opinion. To find out how to use this service, visit eclevelandclinic.org.

Health Information

To subscribe to Health Extra, our free online health newsletter, visit clevelandclinic.org/healthextra. For health information, visit clevelandclinic.org/health.

Quality Measures

For information on the criteria most often used to measure quality in health care, visit clevelandclinic.org/quality.

Cleveland Clinic is a not-for-profit multispecialty academic medical center. Founded in 1921, it is dedicated to providing quality specialized care and includes an outpatient clinic, a hospital with more than 1,000 staffed beds, an education division and a research institute.

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Cleveland Clinic Excels In Latest U.S. News Rankings

Hospital Ranks 3rd in Nation, 11 Specialties Rank Among Top 10; Heart Services Earn No. 1 Spot for 12th Consecutive Year



Cleveland Clinic has been ranked among the top three hospitals in the country, according to the latest *U.S. News & World Report's* annual survey of "America's Best Hospitals." For the 12th consecutive year, Cleveland Clinic's heart program has been ranked No. 1 in the nation. The report, which rates hospitals in 16 specialties, ranks Cleveland Clinic among the nation's best in all, and 11 Cleveland Clinic specialties are ranked among the nation's top 10.

Complete 2006 rankings for Cleveland Clinic are: cancer, 13; digestive disorders, 2; ear, nose and throat, 7; endocrinology, 7; gynecology, 8; heart and heart surgery, 1; kidney disease, 3; neurology and neurosurgery, 5; ophthalmology, 14; orthopaedics, 5; pediatrics, 20; psychiatry, 20; rehabilitation, 22; respiratory diseases, 7; rheumatology, 4; and urology, 2.

For details, visit clevelandclinic.org.

Cleveland Clinic Launches \$1.25 Billion Campaign

Cleveland Clinic recently announced Today's Innovations, Tomorrow's Healthcare, a philanthropic campaign to raise \$1.25 billion. Success will boost the not-for-profit academic medical center's already exceptional patient care, research and educational programs.

Today's Innovations, Tomorrow's Healthcare will bring together the best minds with the most sophisticated technology, in the finest facilities, to inspire the scientific discoveries and care advancements needed to defeat disease.

Campaign support will benefit patients, redefine medicine and create new opportunities that have a direct impact on healthcare practices worldwide.

To learn more, visit clevelandclinic.org/giving or call 216.444.1245.

TODAY'S INNOVATIONS → TOMORROW'S HEALTHCARE
CAMPAIGN FOR CLEVELAND CLINIC



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RANKED
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