In Parkinson’s disease, neurons die off in two tiny areas deep in the brain’s center. Normally, those neurons produce dopamine, a chemical critical in transmitting signals between nerves in the brain. As dopamine output declines, Parkinson’s patients lose muscle control, usually seen as tremors, stiffness and difficulty walking. It’s a devastating disease that affects each individual differently — there is no straightforward timeline of how the disease will progress in each patient.

While age is the biggest factor related to Parkinson’s disease, the cause is not known. It is believed to be a combination of both genetic and environmental factors. Research is being done to identify biomarkers for Parkinson’s disease that can lead to earlier diagnosis and more personalized treatments to slow down the disease.

According to the Parkinson’s Foundation, there are more than 10 million people worldwide living with Parkinson’s disease: 10 million people who will face this devastating disease knowing there currently is no cure.

Reality

Parkinson’s disease gained national attention when actor Michael J. Fox announced he had been diagnosed with young-onset Parkinson’s disease. While much has been done since then to help fight this disease, there is much left to do.

At the University of Kentucky Brain Restoration Center, a team of physician-scientists and researchers is providing hope for patients with Parkinson’s through innovative approaches to the treatment of the disease. These approaches allow for patients to “turn back the clock” and experience symptoms of the disease to a lesser degree, leading to less interruption in their everyday lives and allowing for a better quality of life.
Always looking for ways to improve the patient experience, Craig van Horne, MD, PhD, co-director of the Brain Restoration Center, took a major step in improving patient care at UK HealthCare by helping to establish the Brain Restoration Center (BRC) at the Kentucky Neuroscience Institute (KNI). The BRC’s multidisciplinary team of researchers, surgeons and clinicians aims to not only help patients find relief from movement disorder symptoms but also to pursue innovative treatments and procedures that could possibly slow or reverse the disease’s progression.

Each of the past five years has shown a steady increase in deep brain stimulation (DBS) patients who are seen at UK’s BRC annually. From 2012 to 2018, there was a 338 percent increase in DBS patient volume.

The BRC cares not only for patients suffering from Parkinson’s disease, but also those with dystonia, Huntington’s disease, essential tremor, epilepsy and stroke.

UK HealthCare strives to provide the highest level of sub-specialty care so that no Kentuckian, no matter how sick they are, has to leave the state to receive the healthcare they need. The BRC is doing just that, while also being a destination for out-of-state and even international patients who seek the care that only UK BRC physicians and researchers can provide.

From performing a modified version of DBS that emphasizes patient comfort, to conducting a first-of-its-kind clinical trial focused on slowing the progression of Parkinson’s disease, experts at the BRC hope their collaborative efforts can make UK HealthCare a destination uniquely equipped to treat neurological disorders.
What do Parkinson’s disease and the horse industry have in common? Ann Hanley.

Since 2016, with help from her friends in the horse industry, Ann has raised over $1.4 million to help fund the essential research needed to find better treatments option, and eventually a cure for this devastating and incurable disease.

Hanley was diagnosed with Parkinson’s disease at age 49.

“I pretty much lived the gamut of everything that you could possibly expect when you hear a diagnosis like this one. And it wasn’t easy,” Hanley said.

But instead of letting fear get her down, she’s focusing her energy on lifting other patients with Parkinson’s up.

“Each time the patient comes into the clinic, I sit with them, I talk with them, I educate them,” Hanley said. “I do whatever it takes to keep them going, one foot after the other, one day after the other, to make sure they never quit, they never give up.”

That includes following them into the operating room and sitting with them through Deep Brain Stimulation (DBS) surgery – a technique that can relieve Parkinson’s symptoms for some patients.

Hanley shadows Dr. Craig van Horne, a neurosurgeon with the Kentucky Neuroscience Institute, as he sees his patients.

Even as Ann made a difference in the lives of literally hundreds of Parkinson’s patients, she felt she could do more.

“There’s no Big Pharma paying for this, and when you don’t have Big Pharma behind you, it takes funding. I’m anxious for a cure and my skin is in the game. I kind of stepped back and asked, ‘How can I help these brilliant people achieve their dreams?’”

So as the wife of WinStar Farm’s General Manager David Hanley, she reached out to the thoroughbred community to raise money in support of Dr. van Horne’s research.

The industry enthusiastically embraced her efforts. Fasig-Tipton, Coolmore Farm and WinStar Farm teamed up to host “Night for A Cure,” raising around $300,000 for Ann’s fund with a dinner, entertainment and an auction that featured some unusual equine-themed items, such as a framed American Pharaoh halter and a breeding season to Mshawish (Medaglia d’Oro), a recently retired Grade I winner on dirt and turf.

“I can’t begin to thank the many wonderful people who have loved and supported me with this cause,” Hanley said. “It has brought attention to our cause and allowed us to raise funds that will ultimately speed us on our way to better treatments and a possible cure for this devastating and incurable disease.”

Dr. van Horne has been exploring a novel approach to Parkinson’s treatment by transplanting peripheral nerve tissue into the brain during a regularly scheduled DBS procedure. Called “DBS+,” the technique has shown remarkable results, with a majority of patients seeing a significant reduction in disease progression.

“This kind of research science can take years and lifetimes. Patients, myself included, don’t have time, the clock constantly ticks and we are very aware of it,” said Hanley.

“As a front seat spectator in this research I feel an overwhelming sense of gratitude to these doctors. With this new funding we can move ahead with the next phase of our research, which will help confirm the promising results we’ve seen thus far.”

Ann’s tireless efforts to raise awareness of Parkinson’s disease and the research of Drs. Van Horne and Gerhardt have extended well beyond the horse industry and have penetrated the nation.

TOP LEFT AND RIGHT: The Brain Restoration team traveled to Capitol Hill in February 2017 to meet with Kentucky members of Congress.

CENTER: Fasig-Tipton, Coolmore, and WinStar teamed up to host Night for A Cure, a benefit for the Ann Hanley Parkinson’s Research Fund.

BOTTOM LEFT: Michael J. Fox Foundation CEO Todd Sherer, PhD, visited UK HealthCare and met with the Brain Restoration team in April 2017.

BOTTOM RIGHT: BRC Team and Lexington Mayor Gray with the Lexington Proclamation of Parkinson’s Awareness Month.
Medications are used to address the debilitating motor symptoms associated with Parkinson’s – tremors, rigidity and slow movement – but over time those medications lose their effectiveness. When that happens, the next step is often a neurosurgical procedure called Deep Brain Stimulation (DBS).

DBS has become a standard of care for patients with advanced Parkinson’s disease. During a two-step procedure, electrodes are placed deep in the patient’s brain. When stimulated with a mild electrical current, the electrodes interrupt the nerve signals that cause tremors and other motor symptoms. The result is a better quality of life for patients, although the procedure itself does not cure or slow the progression of the disease.

Since the 1990s, DBS has been used to treat the symptoms of movement disorders, including Parkinson’s, dystonia and essential tremor.

Typically, the surgery is performed in two stages, a few days apart. During the first stage, patients go under general anesthesia so the pulse generator (often referred to as the battery) can be implanted in their chest wall below their collarbone. Also, during the first stage an incision is made behind the ear and the leads (small insulated cables) are routed down the neck to the pulse generator.

During the second stage, patients can either be awake with a local anesthetic or asleep with general anesthesia. In this stage after specialized, computer-assisted targeting, the stimulating electrodes are placed into the appropriate area of the brain. The electrodes are then connected to the leads, making the DBS a fully functioning system.

UK’s DBS program is a leader nationally, and while the team excels in this life-changing procedure, they have not stopped pursuing Parkinson’s disease treatment improvements and breakthroughs. The team’s ultimate goal is to go beyond treating the symptoms and find a way to stop or reverse the progress of the disease.
In July 2016, the University of Kentucky Brain Restoration Center team capped off a series of conferences held at a number of renowned Chinese university hospitals by performing the first-ever Deep Brain Stimulation surgery for a Parkinson’s disease patient at The First Affiliated Hospital of Zhengzhou University.

Dr. Craig van Horne, assisted by his group, performed the groundbreaking DBS surgery at the renowned First Affiliated Hospital of Zhengzhou University in Henan. The third most populous province of China, Henan has held historical importance, housing four Chinese capitals throughout history and often being credited as the birthplace of Chinese civilization. Zhengzhou University’s First Affiliated Hospital is titled the world’s largest hospital, with over 7,000 beds.

The surgery, which appeared on the Henan news, introduced Western DBS practices to complement the neurosurgical field in Henan. The team was fascinated by how different regions of China translated to very diverse surgical practices within China. All agreed that the surgery was a critical learning moment; George Quintero, center investigator and clinical trial manager for the UK Brain Restoration Center, commented that it “used all of our abilities by combining different groups’ resources and talents to achieve one goal.”

The UK team visited the Zhengzhou Hospital a day after the surgery to check on the patient. The surgery’s outcome was successful; the patient was able to walk and move more fluidly, and was released from the hospital a few days later.

This surgery set the precedent for many DBS surgeries to follow. The DBS program at The First Affiliated Hospital of Zhengzhou University has since developed and DBS surgeries are now much more common. As a whole, the process highlighted a newfound optimism and cooperative spirit in tackling a source of pain for a noteworthy portion of the elderly.

This landmark surgery was one major component of UK’s participation in Central China’s Inaugural Sino-US Neuromodulation Forum held at Zhengzhou University’s First Affiliated Hospital. The forum provided a unique opportunity for researchers, surgeons, and others in the medical field from China and the United States to share their experiences through presentations and meetings that specifically explored DBS and neuromodulation. It also facilitated a deeper understanding of Parkinson’s disease from the patient’s perspective. Ann Hanley in these conferences she not only shared her personal struggles in conquering obstacles presented by Parkinson’s disease, but also inspired doctors in this field through her creation of a research fund for Parkinson’s.

Overall, both the surgery and the forum united two very different cultures of medical and surgical practices. As described by George Quintero, it was an “opportunity to get a Chinese perspective. Because diseases have worldwide impact, seeing medicine from another country’s angle is not only eye-opening, but immensely valuable.” This trip initiated the relationship between the University of Kentucky medical branch and The First Affiliated Hospital of Zhengzhou University, which will subsequently contribute to collaboration between the two universities’ research fellows.
To find a way to stop or reverse the progress of Parkinson’s disease, the team at the Brain Restoration Center launched a first-of-its-kind clinical study aimed at stopping or reversing the degenerative effects of Parkinson’s.

The study combines the established DBS treatment with a graft of a patient’s own peripheral nerve. Peripheral nerves – nerves outside the brain and spinal cord – have regenerative qualities that nerves in the brain do not have. The team hopes to leverage those regenerative effects within the brain, potentially halting or reversing nerve damage caused by the disease.

“What we are really going after is the Parkinson’s disease progression,” van Horne explains. “We’ll look at it at two, three, four, five years out. We’re asking whether we can keep that process from getting worse, stop it altogether or maybe improve it long term.”

DBS+ takes a pencil-tip-size plug of nerve cells from the patient’s ankle and grafts it into one of two areas where neurons are dying. There, the grafted cells release chemicals believed to rejuvenate the brain’s weary dopamine-producing neurons.

The study is the first to combine DBS with peripheral nerve transplantation and gives patients the best of both treatment worlds.

With a focus on the patient experience and comfort, the nerve is transplanted at the same time as the DBS surgery, so patients do not have to undergo additional procedures. To test the effect of the nerve graft, researchers can simply turn off the pulse generator implanted during DBS and evaluate the patient’s symptoms at a baseline level.
THE HAUNTING TRUTH ABOUT PARKINSON’S DISEASE*

10 MILLION+
People worldwide are living with Parkinson’s disease

MEN ARE
1.5 TIMES
More likely to have Parkinson’s disease than women

THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) RATED COMPLICATIONS FROM PARKINSON’S DISEASE AS THE 14TH CAUSE OF DEATH IN THE UNITED STATES

ABOUT
1 MILLION
Americans live with Parkinson’s disease

APPROXIMATELY
60,000
Americans are diagnosed with Parkinson’s disease each year

THE COMBINED DIRECT AND INDIRECT COST OF PARKINSON’S, INCLUDING TREATMENT, SOCIAL SECURITY PAYMENTS AND LOST INCOME, IS ESTIMATED TO BE NEARLY $52 BILLION PER YEAR IN THE UNITED STATES ALONE

* According to the Parkinson’s Foundation.
Transformational gift that started it all

The story of the Brain Restoration Center truly begins with Dr. Byron Young, former chairman of neurosurgery at UK. Young was the first neurosurgeon in the state of Kentucky to perform a Deep Brain Stimulation surgery for Parkinson’s disease.

During his time with UK, Dr. Young had the opportunity and privilege to care for Virginia T. Barrow. Through the consultations and treatment process, a friendship developed between Dr. Young and the Barrow family. To honor her after her passing, Mrs. Barrow’s husband, John, daughter, Caroline, and son-in-law, Collin, wanted to show appreciation to Dr. Young for the compassionate care he provided, by creating and endowing the Virginia T. Barrow Chair in Brain Disease Research within the UK College of Medicine’s Division of Neurosurgery. The family’s contributions to the fund were matched by a state program and now have a $2 million impact on the important ongoing neuroscience research at UK. This endowment has grown significantly over the years and is actively used to support research activities within the UK Department of Neurosurgery and currently supports the research efforts of Drs. Craig van Horne and Greg Gerhardt, the co-directors of today’s Brain Restoration Center.

The BRC wouldn’t be what it is today without the relationship that began many years ago between Dr. Young and the Barrow family. To honor her after her passing, Mrs. Barrow’s husband, John, daughter, Caroline, and son-in-law, Collin wanted to show appreciation to Dr. Young for the compassionate care he provided, by creating and endowing the Virginia T. Barrow Chair in Brain Disease Research within the UK College of Medicine’s Division of Neurosurgery. The family’s contributions to the fund were matched by a state program and now have a $2 million impact on the important ongoing neuroscience research at UK. This endowment has grown significantly over the years and is actively used to support research activities within the UK Department of Neurosurgery and currently supports the research efforts of Drs. Craig van Horne and Greg Gerhardt, the co-directors of today’s Brain Restoration Center.

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To date, 70 patients have gone through DBS+. Preliminary results are promising and indicate that the procedure helps control symptoms and might slow the disease’s progression.

The BRC team recently published results in the *Journal of Neurosurgery* from the preliminary study of the first eight participants that showed they performed a safe and feasible procedure that for the group overall showed a clinically important improvement in movement one year after the surgery. Van Horne and his team, observed improvements in the severity of tremor and stiffness that are some of the hallmark symptoms of Parkinson’s disease.

The remarkable aspect to this study compared to other interventional approaches to modifying the progression of Parkinson’s disease is that participants do not have to choose whether to have the DBS, often the medical standard of care, or an investigational approach. In this study, participants receive both. It has the potential to change how future studies in Parkinson’s disease will be carried out.

A PROMISING FUTURE
Participating in DBS+ research procedure helps philanthropist Gayle Zoeller stay active in the face of Parkinson’s disease

“‘She’s like the Energizer bunny’“

Gayle Zoeller has lived with Parkinson’s disease for decades. Only 50 years old when she was diagnosed, the disease came as a shock to Gayle and her husband, Chet. But in the years since her initial diagnosis, Gayle has become a force in the Parkinson’s community, leading a community of support, activism and philanthropy. She’s also a living embodiment of how far Parkinson’s treatment has come.

The Road to Diagnosis
Gayle was in her 40s when she started showing symptoms. After several incorrect diagnoses—there’s no definitive test for Parkinson’s, making the diagnosis a process of elimination—she started treatment with a neurologist and a movement disorder specialist in Louisville, where she and Chet live.

“We’ve seen a lot of people handle the diagnosis and the disease differently,” said Chet. “Some people just kind of shut down, go in their house and don’t come out again, but Gayle just met it head-on. She didn’t want to just sit back and say ‘poor old me.’ She went after it.”

While there is no cure for Parkinson’s, there are a variety of treatment options available. Each patient is different, responding to medications and treatment protocols differently. Gayle was on several different medications and ended up being treated by several doctors at Cleveland Clinic and the Muhammad Ali Parkinson Center in Phoenix, as well as by a movement disorder specialist in Louisville. But her disease continued to progress.

“It ultimately got to the point where she needed to do something more than the meds,” said Chet. “I was beginning to become very dyskinetic, where I would be shaking, and it was getting to the point where my medicine wouldn’t take care of it as much as I would like,” said Gayle. “I knew it was going to be a downhill struggle if I didn’t do anything.”

Participating in DBS+ research procedure
Through a mutual friend in the Parkinson’s community, Gayle met Dr. Craig van Horne, a neurological surgeon and Parkinson’s expert working at UK HealthCare’s Kentucky Neuroscience Institute. Dr. van Horne had recently developed a new procedure to help alleviate the symptoms of Parkinson’s, called DBS+. The procedure involves transplanting nerve tissue from a patient’s ankle into the brain during deep brain stimulation surgery. Dr. van Horne thought Gayle could be a good candidate for the procedure.

Gayle ultimately underwent DBS+, becoming the 14th patient to ever receive the procedure.

“It was like I didn’t have Parkinson’s,” she said. “I didn’t know how dyskinetic I was. It was wonderful to not have the shaking anymore.”

Four years later, Gayle’s tremors remain well-controlled. “All indications are that it’s working for her,” said Chet. “She’s had Parkinson’s for 25 years, and just looking at her, you wouldn’t realize that she has Parkinson’s at all. She’s like the Energizer bunny.”

Giving Back and Pushing Forward
Almost as soon as she was diagnosed, Gayle became a Parkinson’s activist. One of her first major achievements was traveling to Washington, D.C. to advocate for the Morris K. Udall Parkinson’s Research Act of 1997, which would provide funding for Parkinson’s research across the country. The bill passed in only three years—a remarkably short timespan. As a direct result of the bill, hundreds of thousands of dollars were distributed to Parkinson’s research centers around the country. The bill and its associated funds led to the development of Parkinson’s Research Centers of Excellence, including one at UK HealthCare’s College of Medicine.
Due to the type of research being done by the BRC team, where the trial calls for no additional drugs to be administered before, during or after the DBS surgery, there are no large pharmaceutical companies investing in this work because they won’t financially benefit from the success of DBS+.

“This type research is unique – most research for disease takes place in a laboratory and involves chemicals or drugs and will often be sponsored by drug companies who stand to make a lot of money by marketing the drug,” Ann Hanley, patient with Parkinson’s and program director of the Brain Restoration Center. “In this case, however, we use cells taken from the patient’s own body. The benefit goes to the patient alone – there is no big profit involved.”

A major advantage of the DBS+ process is that the BRC team is able to maximize the reach of philanthropy dollars for research because DBS is the standard of care for people with Parkinson’s disease at that stage of the disease and therefore is an insurance reimbursable. This means that the DBS+ procedure is a minimal added expense because it’s done during an insurance reimbursable procedure.

Philanthropy is vital to continuing to fund this innovative treatment plan for Parkinson’s disease and to help fund future clinical trials that could change the world of treatment options for individuals with movement disorders.

Philanthropy gifts allow flexibility for the physician-scientists and researchers as they are able to evaluate results and adapt the process in real time as results become available. Typically, with a grant design, a study may be locked in for the duration. Meaning that in the middle of the trial, if the researchers discover a more efficient or effective process, they must wait until the end of that grant study, design a new study and reapply for funding instead of having the ability to adjust as developments arise.

Through philanthropy, researchers are able to take advantage of the newly described concept of an Adaptive Clinical Trial design. This new approach allows them to slowly and carefully work through the details of the study while maintaining the flexibility to adapt the design to incoming results that are so critical to optimize a process at this early stage in development. This results in the researchers being better poised to optimize a Phase II trial design to begin to assess the efficacy of this potential therapy.
At the University of Kentucky, the physician-scientists of the Brain Restoration Center and Kentucky Neuroscience Institute care for patients with the most recent therapies and advanced technologies, while our researchers work against the clock to discover new ways to help.

This important life-saving, life-changing work would not be possible without philanthropic support. These gifts are essential to help conduct basic and clinical science research, deliver world-class care to patients and train the next generation of future leaders in the neurological field.

We invite you to join in our fight against Parkinson’s disease. Each year, 60,000 lives change with a Parkinson’s diagnosis. Let’s end that! Your generous gift will allow us to:

• Enroll more qualified Parkinson’s patients in the DBS+ clinical trials so we can learn more about this promising procedure.

• Provide infrastructure for evaluating results of the trials and sharing our findings with colleagues through medical journals in hopes of furthering the study.

• Train future neurologists and neurosurgeons who can carry on this life-changing work.

To learn more about how you can make an impact on the lives of Parkinson’s patients, please contact UK HealthCare Office of Philanthropy at 859.323.5374 or lisa.greer@uky.edu.

“We have patients who come from **all over the country** who want to be a part of what we are doing. This is one of a kind. Some patients seem to show a change in the progression of the disease, which is what really excites us and shows we have to **continue with the study**. We are at a point where we can’t give up, we have to keep going. If we get to share what we are doing here, we could be **changing not just Parkinson’s in America, but the bigger picture**.” – Ann Hanley
BRAIN RESTORATION CENTER TEAM
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Nader El-Seblani
Geetanjali Gera, PhD, PT
Greg Gerhardt, PhD
Zain Guduru, MD
Ashley Guillani, DNP
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