

News in MOTION

NEWS FROM THE DUKE MOVEMENT DISORDERS CENTER • SPRING 2011

Interacting with Your Community:

Driver Safety and Accessibility

by Fay Jobe Tripp, MS, OTR/L, CDRS
DUMC, Occupational Therapist, Senior II

The Primary Goal

Accessing our community with safety and in a timely manner equates to maintaining the desired independence to perform normal tasks of living. Attending to community based activities such as employment, shopping, social events, and medical appointments regularly outline our time structured day. For many individuals who experience movement disorders, this instrumental activity of daily living of driving and accessing the community presents a threatening challenge to independence. However, if we recognize that the primary goal is to perform the task at the destination (i.e. the process of getting groceries), instead of focusing on how we choose to get to the store (being the driver versus being the passenger), the perception of independence to complete our responsibilities can more easily be maintained. Commonly, drivers who have health challenges or normal aging changes will self-regulate their driving patterns. For example, they may drive only in daylight hours, lower speed zones, low traffic patterns and stay in familiar areas. These choices show good judgment to maintain safety. However, warning signs may be noticed in the driver that cause concern for the driver and family members. When driving becomes challenging or stressful due to difficulty in physical functioning, cognitive skills or visual skills, independence in accessing the community can still be maintained by delegating the task of driving through a variety of options. Following is a review of the primary functions required for driving safety.

Physical Skills

With movement disorders, such as Parkinson's Disease, physical performance is key for driving safety. Arm and leg strength, motion and coordination are necessary for managing the steering wheel, vehicle controls, and pedals. Dyskinesias and tremors may also present safety limitations. Neck and back



stiffness may limit the ability when checking blind spots or backing. Fatigue will limit functional endurance and cognitive attentiveness, especially on long trips or outings. It is important to be aware of the impact

medications have on function, and maintain your medication regimen. Slow movements known as bradykinesia, or freezing may occur and affect reactions. Reaction time, which is a combined process of physical, cognitive and visual skills, may be delayed, especially in the medicine regimen down-time. Once the destination is reached, having safe mobility skills will reduce the risk of falls. Endurance limitations should be considered.

Cognitive Skills

Driving a car requires complex cognitive processing ability that may be negatively affected by poor sleep patterns, fatigue, or medication side effects. Dementia may be present, or the person may demonstrate difficulty with slower information processing speed, or bradyphrenia. Visual spatial skills, attention and executive processing skills may be limited. Multi-tasking and divided attention abilities allow the driver to maintain awareness of the environment. Understanding what is being seen, processing information quickly and responding all contribute to reaction time. With impaired multi-tasking or processing speed, the driver is at increased risk of collision, especially when in higher speed zones. Appropriate memory skills are needed for route finding, especially with unexpected detours. With driver license renewal, a driver is required to understand road signs in a timely manner. A behind the wheel driving test may also be required.

Visual Skills

Although not commonly considered a primary limiting factor in the driver who is challenged by physical dysfunction, visual

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Important Links

Duke University is an NPF
Center of Excellence.

For more information, go to
<http://www.parkinson.org>
<http://neurology.duke.edu>



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“It’s a little frustrating that the best drug we’ve got for Parkinson’s disease is one that’s been around for 40 years. PD Patients are still faced with tough choices...as we wait for a treatment proven to modify the course of the disease.” Michael J. Fox

DOING WHATEVER IT TAKES TO ACCELERATE BETTER TREATMENTS FOR PARKINSON’S DISEASE

The Duke Movement Disorders Program, together with the Michael J Fox Foundation, has worked to raise the level of awareness for Parkinson’s Disease research. *News in Motion* is pleased to have the opportunity to share the Michael J. Fox case statement with our readers.

An Introduction to The Michael J. Fox Foundation for Parkinson’s Research

The Michael J. Fox Foundation has set one clear and simple measure of success: to accelerate the delivery of life-changing treatments—and, ultimately a cure—to people with Parkinson’s disease.

Conventional research funding wisdom holds that chances for an exceptional discovery are best encouraged by amply funding open-ended scientific investigation. This approach is important to scientific progress in the long run. But more can and must be done to translate years of investments in discovery research into new treatments.

The Michael J. Fox Foundation is working urgently to bring about real-world improvements in how research gets funded. While we seek out and fund truly innovative ideas in PD discovery, we also employ new approaches for actively shepherding existing ideas to the clinic. We have fashioned ourselves as a “strategic intermediary,” a proactive and informed funder acting on behalf of patients and their families.

Our activities—from funding grants to regularly convening the world’s top PD experts—are not ends in themselves. They position the Foundation as a strategic leader for the entire Parkinson’s field, initiating and directing efforts to tackle pressing problems and forge solutions. Ultimately, they form the backbone of ability to allocate privately raised capital for the greatest possible impact and potential return on capital.

The need for new treatments for Parkinson’s disease has never been more urgent. Today, nearly five million people worldwide live with the degenerative neurological disorder.

Scientific findings continually accrue from public and private research spending worldwide. Yet newly diagnosed Parkinson’s patients are often surprised to learn that the “gold standard” PD treatment, levodopa, was invented 40 years ago. While levodopa effectively masks PD symptoms for some time, the drug is powerless to slow or stop the disease from worsening. With years of use, it becomes less effective even at subduing symptoms, and for many patients, debilitating side effects arise.

Parkinson’s is a complex disease that presents distinct challenges in the quest for a cure: By the time PD is diagnosed, underlying cell death has reached an advanced stage. Symptoms, rate of progression and severity all vary widely among individual patients.

Researchers have yet to pinpoint a cause or a way to make a definitive diagnosis of PD. No biomarker of PD has yet been discovered to aid in screening or diagnosis, and no existing animal model mimics the progression of the disease in humans to enable the testing of potentially disease-modifying candidate drugs. The blood brain barrier (which shields the brain from bacteria and other harmful agents) prevents the entry of many potentially therapeutic agents, creating a major hurdle for drug delivery.

Clinical trials, particularly for disease modifying treatments are hampered by a shortage of patient participants and a lack of objective endpoint measures—issues that lead to lengthy trials, high costs and inconclusive results.

Disease-modifying drugs that do advance to clinical trials face a higher hurdle in the approval process than drugs that merely treat symptoms.

The Michael J. Fox Foundation stands outside the traditional biomedical research system, yet sits at the hub of global Parkinson’s research. MJFF’s in-house research program team, extensively trained in neuroscience and project management, is built to prioritize the most critical projects in a wide field of seemingly equal opportunities. We review more PD specific grant proposals than any other funder; talk formally and informally with hundreds of the world’s top PD experts; and convene dozens of conferences, meetings and workshops. We set demanding standards and milestones and ask tough questions.

MJFF doesn’t passively fund proposals, but actively engages with scientists, challenging academic and industry researchers to address critical gaps in the science. Every year MJFF bring together hundreds of top researchers from academic and industry labs all over the world for formal and informal face to face meetings and workshops to set strategy and future direction, and to explore and expand research toward transformative treatments for Parkinson’s.

MJFF will continue to do whatever it takes to change the process and hasten the arrival of truly transformative treatments. However, they recognize that the task of achieving significant progress in improving the lives of Parkinson’s patients is a difficult and complex one that will require the coordinated involvement of many players. The Foundation’s success in accelerating life-changing treatments for Parkinson’s depends on the generosity of individual donors. They pledge that no organization will be more innovative, vigilant, assertive or reflective. They are single-mindedly focused on leveraging the resources entrusted to them to drive fundamental change in the system and advancements in the science to benefit PD patients now and in the future.

The Michael J. Fox Foundation for Parkinson’s Research
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PO Box 780 New York, NY 10008-0780
1.800.708.7644
www.michaeljfox.org



Another DUKE Connection in the Fight

Katie Hood, a Duke Alumnus, served as the Chief Executive Officer of The Michael J. Fox Foundation for Parkinson’s Research (MJFF). In this role, she has been critical in shaping MJFF’s strategy of intervening aggressively to close crucial gaps that slow potential treatments on their path from the laboratory to Parkinson’s patients, as well as in building a team of in-house research experts needed to implement that strategy.

A year after the attacks of September 11, Ms. Hood found fulfillment at The Michael J. Fox Foundation for Parkinson’s Research. “I’m part of this vibrant organization that is doing whatever it can to find a cure for Parkinson’s,” she said. “I love pushing the limits of how we can do this faster.”

“We want a cure,” Katie Hood said. “We take risks others don’t take.”

Grant allocations more than doubled between 2007—when Ms. Hood became CEO—and 2010, reaching \$50 million. On her watch, the foundation has supported \$230 million in research and has become the world’s second-largest funder of Parkinson’s research, after the federal government.

Katie Hood was recently selected as one of NY’s best and brightest by Crain’s NY Business.... The recent Class of 2011 “40 Under Forty” was released at the end of March. <http://mycrains.crainnewyork.com/40under40/profiles/2011/katie-hood>

Katie Hood has recently stepped down as CEO of the Michael J. Fox Foundation to handle pressing needs of her young family.

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skills can present significant limitations. The function of the eye changes naturally as a person ages, and the presence of additional eye disease complicates visual skills further. Medications may contribute to visual changes or visual hallucinations. Visual acuity for near and far distance should be maximized by use of prescribed corrective lenses. Visuo-motor skills (tracking, convergence, or saccades) may be impaired. Diplopia, or double vision, may occur when the eyes do not align properly. Peripheral vision alerts the driver of traffic or pedestrians to the side, and is an important compensatory skill if neck and back motion is limited. Contrast sensitivity is the ability to see differences between an object and the background, and can become difficult in bright glare or dull lighting. Depth perception is the ability to tell how far away an object is, and may be impaired if one eye acuity is stronger than the other. Visual perception skills, or understanding what is seen, may be slower.

Maximize Driving Safety or Delegate

Maintaining good health habits, physical exercises, and involvement with cognitive challenges may help a driver to maintain his or her abilities. The responsible driver will be open to constructive and supportive feedback from a family member or physician. In some instances, a driver may be able to safely self-restrict and incorporate compensatory strategies. In other circumstances, driving should clearly be discontinued. Incorporation of family members, friends, and community transportation options should be used. It is helpful for the driver with declining skills to maintain an attitude of receptiveness to feedback, and discuss realistic alternatives with caregivers to ensure that the primary goal of community accessibility is reached.

If there are concerns regarding driving, participation in a Clinical Evaluation with an Occupational Therapist who specializes in driving assessment may provide guidance. Objective measures based on researched safety guidelines, including a behind the wheel driving assessment completed by a certified driving instructor, will provide concrete feedback regarding safety. Information for driving rehabilitation specialists, educational materials, and alternative transportation options can be found at:

The Association for Driver Rehabilitation Specialist (ADED): www.driver-ed.org

American Occupational Therapy Association (AOTA): <http://www.aota.org/older-driver>

AARP: http://www.aarp.org/home-garden/transportation/driver_safety/

Helping Hands: <http://ahelpinghandnc.org/>

Eldercare locator: <http://www.eldercare.gov/Eldercare.NET>

American Red Cross Medical Transportation: <http://chapters.redcross.org/nc/centralnc/events.html>

The Surgical Treatment of Parkinson's Disease

by Patrick Hickey, DO
Duke Movement Disorders Fellow

Parkinson's disease (PD) may affect 1 million Americans, making it the second most common neurodegenerative illness in the United States. This condition impacts a person's ability to control voluntary movements (termed "motor symptoms"). While motor symptoms are thought to result from a loss of specific dopamine-producing neurons originating deep in the brain, other symptoms of PD are not directly related to movement (termed "non-motor symptoms"). These include constipation, sleep disorders, anxiety, pain, loss of smell, and others.

Many people with PD notice only mild symptoms for months to even years, and medications often provide significant improvement early in the disease. Over time symptoms and disability typically progress and medication needs to be adjusted accordingly. In some people, medications eventually do not provide adequate relief of symptoms; they begin to experience fluctuating motor control, dyskinesia, and inconsistent response to their medication schedule. Surgery can provide an alternative therapy at this stage.

Deep Brain Stimulation

Deep brain stimulation (DBS) was approved by the FDA for the treatment of PD in 2002 and remains the preferred surgical procedure for advancing symptoms. Thin wires are passed into areas of the brain involved in the generation of abnormal movement. These are then connected to a neurostimulator that allows the manipulation of DBS settings and the control of PD symptoms. DBS can significantly improve motor fluctuations, dyskinesia, and often allows for the reduction of medications.

DBS is not recommended for every patient and studies have shown that proper surgical referral is an important first step for success. The ideal candidate continues to respond well to medications like levodopa (Sinemet®),

has movement disability despite titration of medications, and no evidence of significant cognitive impairment. Symptoms that are the most responsive to medication will typically be the most responsive to stimulation. Severe side effects are not common though must be weighed against possible benefits.

The Duke University Movement Disorders Center offers one of the most active DBS programs in the country and works closely with the stereotactic neurosurgical team. To schedule an appointment with one of our physicians please call (919) 668-7600.

Cell Transplantation

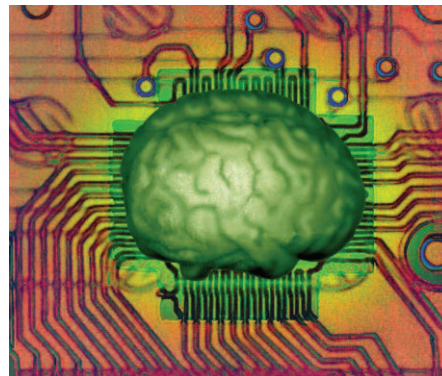
Early studies evaluating the effectiveness of stem cell transplantation in PD were encouraging and many patients showed significant motor improvement after surgery. These small open-label studies led to three larger trials designed to better assess its effectiveness. Unfortunately, transplantation showed no benefit compared to "sham surgery" (placebo) in these studies. Additionally, up to half of transplanted patients developed uncontrolled dyskinesia that continued even when medications were completely stopped. What caused these atypical movements is not known. Though the grafted tissue incorporated well into the brain, pathologic changes typical of PD have been found in the grafts. These findings have raised concern for the long-term benefit of this procedure.

Many questions remain regarding the future of stem cells and PD. Different cell sources are under investigation and debate is ongoing as to which is the most likely to be successful. It appears much work is needed before cell-based therapies become an established treatment for PD.

Gene therapy is another emerging surgical treatment that has received a great deal of attention lately as the first positive results for a double-blind trial of gene therapy in PD were recently reported. This is encouraging and exciting news for the future of this field, which has shown promise to improve the motor disability associated with this disease.

Gene therapy involves packaging genes into non-replicative viruses and using them as delivery vehicles to target deep brain structures. A number of gene therapy strategies are currently under clinical investigation. These include the replacement of genes involved in producing dopamine, those that alter the firing of neuronal structures, genes that boost the effectiveness of oral levodopa, as well as those that produce neurotrophic factors.

Neurotrophic factors have been shown to protect the degeneration of dopaminergic neurons, the same ones that are lost in Parkinson's disease. By preventing neuronal loss, PD symptoms may be improved and the progression of the disease may be slowed. Duke University is currently participating in a clinical trial evaluating the efficacy of Neurturin, a neurotrophic factor, in advanced PD. **For more information about participation in this trial please contact Lisa Gauger at (919) 668-1538.**



Upcoming Special Programs...

Parkinson's Disease 101: An Introduction

June 3, 2011 and November 4, 2011

This class is designed for the newly diagnosed individual and their loved one.

The afternoon will be filled with information about Parkinson's disease and resources.

Program held at the Millenium Hotel 2800
Campus Walk Avenue Durham, NC 27705

To register, please contact Arlene D'Alli, MSW,
LCSW at 919-684-5128

Parkinson's Disease Exercise Group

Who: Anyone referred to Duke Health and
Fitness Center following an assessment from
a physical therapist.

What: A 45 minute exercise class including
functional training using bands, weighted
bars, medicine balls and free weights.
Balance work to improve posture and stability.
Stretching to increase flexibility.

Where: Duke Health and Fitness Center, 3475
Erwin Road, Durham, NC 27705

Cost: \$124 per person for 8 week program

Contact Anna Martin at 919-660-6810 for
more information

Links for Movement Disorders News, Updates & Information

Duke Neurology Website
<http://neurology.mc.duke.edu>

The American Academy of Neurology
<http://www.aan.com>

Northwest Parkinson's Foundation
<http://www.nwpcf.org>

Parkinson Pipeline Project
<http://www.pdpipeline.org/>

Parkinson's Disease and the
Art of Moving
[http://www.parkinsonsexercise.com/
argue_workshops.html](http://www.parkinsonsexercise.com/argue_workshops.html)

We Move
<http://www.wemove.org/>

Local Support Groups
[http://www.parkinsonsassociation.
org/meetings.cfm](http://www.parkinsonsassociation.org/meetings.cfm)