SIGN UP FOR THE SYNAPSE Study

The PDAMC’s Nabila Dahodwala, MD, and her team are conducting a study to find out if SYN120, an experimental drug, can be given to patients with Parkinson’s disease dementia (PDD) who are already being treated with a stable dose of a cholinesterase inhibitor (e.g., Aricept® [donepezil], Exelon® [rivastigmine], Razadyne® [galantamine HBr], etc.).

PDD is impairment in thinking and reasoning that affects many people. The aim of the study is to see if SYN120 helps improve cognition (the ability to think, understand, learn, and recall) and episodic memory (remembering past personal events) in PDD. SYN120 is “a dual 5-HT6/5-HT2A antagonist,” and it acts on specific nerve cell “receptors” that are involved in learning and memory.

Study volunteers will be randomized to take either SYN120 or a placebo (a pill that contains no active drug or medicine). Participants will be in the study about 6 months; they will take two pills once a day throughout the 4 months’ treatment period as well as make several visits to the PDAMC to complete a range of tests that will examine cognition, episodic memory, and tolerability of the study drug. Eight people will take part in this trial at Penn Medicine and about 80 patients total will be enrolled at 12 centers in the United States.

If you are interested in learning more about the SYNAPSE study please call Eugenia Mamikyan at 215.615.3085 for more information.

The Brain and Parkinson’s Cognitive Changes

Jacqui Rick, PhD

In 1817, James Parkinson wrote a landmark essay that described in vivid detail the symptoms of tremor, slowed mobility, shuffling gait and stooped posture that we use today to make a clinical diagnosis of Parkinson’s disease (PD). He specifically observed that the affliction named after him “spared the intellect.” For over a century after his essay was published, PD was thought to be strictly a “motor” disorder, as he called it, with no effect on thinking or memory. However, clinical observation and research conducted over the last 50 years has proven James Parkinson wrong. PD can have a profound effect on the “ intellect,” and may also cause other non-motor symptoms such as disturbed sleep, depression, anxiety, loss of smell, and constipation. The discovery of these additional symptoms became possible for two reasons: 1) the development of effective drugs for motor symptoms has enabled people with Parkinson’s (PWP) to live longer and function better and thereby manifest and report cognitive changes to their doctors, and 2) research investigations have discovered a variety of new manifestations or complications of PD that were not previously appreciated.

(continued on page 4)
Welcome to the PD&MDC

Thomas F. Tropea, DO, is a graduate of Tufts University and the University of New England College of Osteopathic Medicine. He completed a neurology residency at New York Presbyterian/Weill Cornell Medical College in New York City and served as chief resident. Dr. Tropea recently joined the movement disorders group at the PD&MDC as a clinical fellow and plans to pursue his research interest in biomarkers in PD.

Marcela Pironi graduated from Saint Joseph’s University with a bachelor of science (BS) in psychology this past May. She is very excited to join the neurology team here at Penn Medicine and will be working as coordinator for the National Parkinson Foundation’s Parkinson’s Outcomes Project, which aims to research and better understand PD and subsequently help improve survival and care for those affected.

Devin Keating came to Penn Neurology as a recent Temple University graduate. At Temple, Devin earned a double degree in neuroscience (BS) and psychology (BA). She has always had a great interest in the sciences, specifically neuroscience. Devin plans on working towards her masters, and eventually PhD, in neuroscience. Outside of research, Devin loves spending time outdoors, competing in Spartan races with her siblings and hiking with her husky puppy, Koda.

Neuropsychology and Testing for PWP

Kathy Lawler, D. Phil., ABPP

Neuropsychology is a field of study that combines understanding of neurology with psychological assessment. Thanks to the innovative testing done in this area, researchers and physicians can provide comprehensive neuropsychological evaluations that may assist in the diagnosis and management of patients with a wide variety of neurological disorders, including Parkinson’s disease.

Clinical neuropsychology is a sub-specialty within the field of psychology that examines the ways that the brain and its functions affect behavior. In a disease like PD, it is apparent that neurological changes over time affect the way patients act and think.

The clinical neuropsychologist uses standardized tests matched against data to evaluate a patient’s neurocognitive, behavioral, and emotional strengths and weaknesses. This information can then be layered over understanding of normal and abnormal central nervous system functioning. For example, if a patient were beginning to experience memory problems, we might be able to look at causes and possible solutions based on what we have found about changes in that person’s brain.

Is it Loss of Memory or Executive Function?

Some patients with PD experience problems with memory or executive functioning, but very often they are not sure what the actual concern is. Executive functions include a wide range of cognitive abilities, such as organizational skills, planning, sequencing, and problem solving. Information from the neuropsychological evaluation is helpful because it allows us to clarify whether cognitive problems are due to the disease process itself, side effects of medications, or emotional problems such as depression and anxiety, or a combination of all these factors. Neuropsychological testing provides a “blueprint” of cognitive strengths and weaknesses. Identifying and diagnosing these problems can be useful for planning and implementing intervention strategies.

For example, a patient might complain of memory problems, but testing may show that the primary difficulty has to do with executive functions like organization. If the patient can’t effectively organize information that they want to remember, they will be less likely to retain it. The neurological process of moving involves gathering new information and moving it from our temporary memory to permanent storage. We can do this by grouping things into categories, such as food, animals, or locations and chunking these items together.

We might also ask the patient to design mnemonic devices like imagery, which will help link the new information to previous memories. So to remember the name “Mary Brown,” at a party, you might picture Mary with her little lamb, wearing a Daniel Boone hat.

If we can help the patient put together strategies for more effective encoding of new information, he or she will be more likely to succeed. And with these new techniques and enough home practice, it may be possible to improve executive function skills to assist with memory.

UPCOMING EVENT

A Walk to Stamp Out Parkinson’s

October 10, 2015

8 am to noon

Martin Luther King, Jr./West River Drive

With an expected attendance of over 1,500, this is the biggest awareness-raising, family-friendly gathering of people with PD, their families, care-partners and colleagues in the region. Over the last 13 years, the walk has raised over $1.9 million that is reinvested back into the community and partnerships like Penn’s PD&MDC and Good Shephard/Penn Partners Dan Aaron Rehab Center.

Honorary Walk Chair David Murphy of 6ABC and co-chairs Kenneth Kolaski (“Team Kolaski”) and Gina Giachero (“Jenn’s Movers and Shakers”) will kick off the festivities. Join in on a live demonstration of a Dance for PD and yoga class. Register, donate or create a team now at stampoutparkinsons.org or call Wendy, Rebecca or Sally at 810.688.4292 for help to get started.

Support Group News

PD SUPPORT GROUP LEADERS WORKSHOP

Thursday, November 12, 2015

10 am-2 pm

Hilton Philadelphia City Avenue, 4200 City Line Avenue, Philadelphia

This is a great opportunity to network with other leaders. Call Sue at 215.829.7273 for more information. Formal invitation and agenda will be sent out soon.

2 The Transmitter – Penn Medicine

Penn Medicine – The Transmitter 3
The Brain and Parkinson’s Cognitive Changes

When do Cognitive Symptoms Appear?
As many as 20 percent of newly diagnosed PD patients can show subtle signs of cognitive impairment as compared with their non-PD peers. Physicians increasingly assess both motor and non-motor symptoms of PD and recognize the importance of diagnosing dementia or mild cognitive impairment (MCI) when appropriate.

What is Dementia?
Dementia refers to a decline in a person’s memory, reasoning and thinking abilities sufficient enough to interfere with social and occupational functioning. A person with dementia lacks the ability to independently organize daily activities and responsibilities and usually requires assistance for routine tasks such as managing finances, keeping track of medications, and organizing daily schedules. It is difficult for doctors to assess these deficiencies in the brief time frame of an office visit. However, careful questioning of the patient and care partner by a social worker or psychological counselor can provide a realistic profile of the patient’s functional status. In addition, a global screening instrument such as the Montreal Cognitive Assessment (MoCA), or a more detailed battery of neuropsychological tests, can add to a comprehensive snapshot of the patient’s capacities for independent living.

What is MCI?
When cognitive changes have occurred but functional status is not impaired, a physician might diagnose a patient with MCI. Many view MCI as pre-dementia, but research at the Parkinson’s Disease and Movement Disorders Center (PDMD) has shown that patients can revert back to normal cognition after having MCI. Even patients with dementia can bounce between moments of relatively sharp memory, short-term memory lapses and alertness to periods of being very foggy or inattentive—a unique feature of cognitive impairment in PD.

Differences between Parkinson’s and Alzheimer’s Cognitive Problems
Cognitive decline in PD can follow a different clinical course than cognitive decline in Alzheimer’s disease (AD). For example, the chief complaint among patients with early AD is typically short-term memory loss, while PD is more likely to experience problems with attention, organizational ability, or decision-making as their first symptom. This difference is consistent with what we know about areas of the brain and neurotransmitters that are most affected by the two different diseases. In the early stages of AD, the brain has the typical pathology of that disease (plaques and tangles) in the hippocampus of the temporal lobes—the most important area of the brain for forming new memories. Older memories are more widely distributed in the brain. The primary cause of cognitive decline in PD is, however, is a microscopic abnormality inside the brain cell called the Lewy body. Over time, these Lewy bodies become widespread or disrupt the neural circuitry of the brain.

Research and Testing at the Penn Udall Center
The Morris K. Udall Center at the PennMD is a leader in PD research—one of only ten such National Institutes of Health (NIH) funded centers in the country.

The research endeavor that earned us the important Udall Center honor is focused on learning about cognitive decline in PD. We are exploring identifying predictors of dementia called biomarkers. In the same way that cardiologists measure and treat cholesterol as a biomarker for predicting heart disease, we hope to one day discover a chemical in the blood or spinal fluid, or a finding on a magnetic resonance imaging (MRI) scan, that we can measure in order to reduce the risk or delay the onset of dementia.

The Penn Udall Center has accomplished much in its eight years of funding, but we are still in need of PDWP who have not previously had deep brain stimulation or been diagnosed with dementia to participate. The study activities include: (1) a single lumbar puncture to collect spinal fluid; (2) a single MRI of the brain; and (3) annual interviews that include neuropsychological testing and a blood draw. The annual visits can be done at home.

There is so much that we don’t understand about PD, especially how to determine the risk of developing cognitive impairment. The only way to increase our knowledge base and take steps toward more effective treatments, or even a CURE, is through a total and ongoing commitment to research. Our research is completely dependent on VOI, a PDWP to participate in our studies. Please ask your neurologist about how you can get involved, or contact me directly to find out which research studies are right for you.

For more information about cognitive decline in PD, or about participating in a study, please contact Dr. Rack at 215.829.7778.

FOCUS: A Patient Perspective on Multi-Tasking
Susan Jeffrey

I never gave multi-tasking much thought. It came automatically with the territory of raising children, working, preparing and shopping for meals, talking on the phone, making lists of what needed to be done, and keeping up with family and friends. Now with cell phones, and driving and texting, it has become a new ball game for people who juggle many balls at once. Those who study brain function say people are not as effective if they try to do more than one or two things at the same time. Research has shown that the more you do, the less effective you become. And as you age, the brain needs to focus more on fewer activities to be most effective.

As for me, I can no longer do any multi-tasking. I can’t do the simplest things, like walking and talking at the same time. That’s one of the reasons having Parkinson’s disease is so frustrating. I have to walk, but I have a list of things to remember—like taking big steps, swinging my arms, twisting my hips (no robot walk), standing up straight, breathing—and that is just for inside my home. Outside, I have to look for cracks in the sidewalk, check to make sure there isn’t a dog or bicycle in my path, and judge the curb properly. Add wind, rain, sun or snow to the mix, and a simple walk can become a nightmare. With all these things to remember (with PD they are part of my conscious thinking) there is no room for more.

One of the therapies for PD is cognitive exercise. I do best when there are few or no distractions. Sometimes counting is helpful when I walk. But window-shopping is difficult...too bad!

Executive issues and decision-making with many options are difficult. Thinking can be slowed or impeded, finding the correct words can be hard, and memory of recent events is sometimes hazy.

Many people think of PD as a tremor, but that is just one of its many symptoms. Cognitive impairment, difficulty chewing and swallowing, depression, cramping, rigidity, balance, oddities in posture and gait are other possibilities. Fortunately, most patients don’t have all the symptoms, but it would be difficult to choose from an unpleasant list of disabilities even if you could.

There are treatments ranging from medication to brain surgery which can modify the symptoms. And there are pleasant things that are helpful including exercise, massage, dancing, and meditation. Talking, writing and drawing help, too.

So be in the moment, concentrate on one thing at a time, and be effective!

About the author: Susan has been battling PD for 15 years. She was a former chair of the Philadelphia Zoning Board and a member of the Historical Commission of Philadelphia.
Cognitive Rehabilitation
Adapting to Your One-Track Mind
Julia Wood, MSc, OT/L

All of us have memory lapses from time to time. It’s common to forget where you placed your keys or to lose words that you used to just pop into your mind. But many people with Parkinson’s may actually develop cognitive deficits over time. The good news is that the type of rehabilitation that was pioneered for stroke and brain injury has been adapted for use with PD. Although there are not a lot of good research studies showing the effects, anecdotal evidence from patients who undergo this type of therapy indicates positive results. With training, patients can remain as functional as possible so that they are able to remember when to take medication, how to follow a recipe, and what time they need to get to appointments.

Agreeing to the need for therapy

Many of our patients are highly functional and intelligent, and do not wish to acknowledge changes that may be going on. It’s scary to think that their brain isn’t working the way it used to. And yet, their intellect may be just fine! It’s the processing that’s altered.

Think about a computer. Huge amounts of data are stored inside, but there are times when you press keys over and over and simply can’t get your Word document to open! It doesn’t mean you’ve lost anything—it’s just that the process is slower and it takes longer to get the information. Once patients’ anxiety about “losing their mind” can be eased, they may be more willing to be assessed for cognitive rehab.

Sometimes patients come to us because their neurologist requests a baseline or has noticed deficits during appointments. But often, in our department, the patients themselves acknowledge problems they are having in different areas. This would trigger us to give a MoCA (Montreal Cognitive Assessment) or minimal neurological screening.

What does the screening test for?

The MoCA identifies lack in visual-spatial judgment, naming objects, executive function, verbal fluency, abstraction, delayed recall, and orientation (where you are when you’re interviewed). In addition, we work with the patient and care partner to find out where the problems are: is it distraction, the ability to follow tasks, turning on the wrong switch, when to take medication, or remembering and showing up at appointments?

What types of training are helpful?

We find that following a recipe is a wonderful way to improve executive function, since you can’t cook without following steps in a certain order. If patients also have trouble with vision, we may suggest that they put a post-it note over the lower half of the recipe and move it as they work, to keep their attention on the specific task at hand.

Sometimes, we’ll do what we call dual-path training: We’ll ask the patient to walk or turn and at the same time, name items alphabetically as they move. Or we’ll have patients hand-write their work sheets, since many PwP have handwriting issues. This way, they can combine their improvements in motor and cognitive skills.

We encourage care partner involvement, since the patient will need help at home with cues and reminders to use various strategies. So often, the care partner may say, “I thought he was just being stubborn—no, that he didn’t remember.” By getting the couple involved together, both can be helped. Patients don’t need a special prescription for cognitive rehab, which is considered part of the work they do with an occupational therapist.

Our recommendation for treatment plans is based on how far patients have to travel to see us. We may see them once a week for 8 to 10 weeks, but it’s better to see them twice a week for 6 to 8 weeks. And of course, we’re expecting that they will do their homework!

Therapeutic activities and compensatory strategies

Every PwP is unique, of course, and some will need more therapeutic work, using puzzles like Sudoku, word searches, work sheets, and even origami (which helps with fine motor skills as well as following directions). Others need compensatory strategies for memory, such as calendars, phone medication reminders or alarms, and a dedicated anchor point in the home where they always put their keys or phone. Most patients need a combination of both.

One enormously important skill all patients (and frankly, all people) can use is mindfulness training, a single-point focus in the present moment. This ancient technique involves dedicated concentration on one breath or one task at a time and teaches ways to train the mind to put distraction aside. We have our patients simply sit and breathe for 3 to 5 minutes (which can seem like an eternity) and count the breaths. Then we’ll ask them to apply this focus to some simple chore like emptying the dishwasher. The idea is to just pay attention to the one activity they’re involved with. If they get distracted and start thinking about something else, they are to stop, take a breath, and return to what they were doing. Some cognitive deficit is exacerbated by anxiety, and once patients slow down and take one step at a time, they are able to complete the task.

What can I get out of cognitive therapy?

Above all, PwP who go through cognitive rehab gain a lot of confidence. They are able to see that if they slow down and use the various strategies at hand, they can do much of what they always did—only slower!

Those who complete a cognitive rehab course also have fewer falls. They learn to walk unsteadily and pay more attention to their movement, adding to their sense of accomplishment.

Practicing these various strategies may also allow patients to regain brain fluidity, better ability to follow steps in order, and, most importantly, to find different and more efficient ways to approach the same task. By streamlining thought processes, cognitive rehabilitation can make a big difference for those with PD.

THE PARKINSON COUNCIL NEWS:

Wendy Lewis

The Parkinson Council’s 5th Annual Spring Swing on April 22nd at the Pyramid Club was a wonderful event for a great cause. The Parkinson Council raised over $30,000 for PD research and quality of life initiatives for local families.

The evening’s emcee, Nicole Michalik (G102’s Nik the Web Chick and Mix106’s Nicole from Chio in the Morning), shared her personal story and welcomed Dr. Tsao-Wei Liang to share examples of how the Council invests in local programs for people with PD. The evening ended with the fabulous Lindy and Blues Dancers who brought the “swing” to Spring Swing!

The 15th Annual Parkinson Golf Classic was held at the Philadelphia Cricket Club on June 15th and raised over $335,000 ($100,000 more than last year!) to support local investments in education, research, comprehensive care and programs for people with PD in our region.

We are grateful to have effective leaders like Ken and Nanci Gilbert and a stellar 2015 Golf Classic Planning Committee.

The Parkinson Council held its first annual “Acting Parkinson’s” Tennis Tournament at the Philadelphia Cricket Club in Chestnut Hill on Monday, June 29th. It was a great day for partnerships and teamwork, raising over $3,800 for movement programs. Players had the rare treat to play on the historic and scenic grass courts for a great cause.

Thanks to 250 local families and friends, the 8th Annual Avalon Flip Flop Walk on July 18th raised over $16,000. $1,000 more than 2014. Led by the amazing Storbeck family, the Avalon community rallied around their efforts to raise awareness and funds for Parkinson’s research!