

Parkinson's Patients Support Groups, Inc.

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Aug./Sep. 2011

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Researchers identify why **dopamine replacement therapy** has a paradoxical effect on cognition

EurekAlert - Dopamine replacement therapy, which is used to manage motor symptoms associated with Parkinson's disease, can, at times, adversely affect cognition.

Dr. Oury Monchi, Ph. D. in neuronal modeling and Head of Neurophysiological and Neuroimaging Research at Centre de recherche de l'Institut universitaire de gériatrie de Montréal (IUGM), which is affiliated with the Université de Montréal, and Dr. Penny A. MacDonald, Neurologist and postdoctoral fellow in Dr. Monchi's laboratory, have identified the reasons why within the framework of a clinical study recently published in *Brain: A Journal of Neurology*. This marks the second time in three months that *Brain* has published the results of IUGM researchers.

"The aim of our study was to understand the effects of dopamine replacement therapy on various aspects of cognition in patients with Parkinson's disease. When it comes to this particular disease, the part of the brain most affected by dopamine depletion is the striatum which is divided into several structures.

In Parkinson's disease, the dorsal striatum is more severely affected than the ventral striatum, which remains relatively unaffected, at least during the first phases of the disease. We observed that while dopamine replacement therapy enhances the functions of the dorsal striatum, it is at the expense of the ventral striatum which suffers a dopamine overdose, impairing its function", states Dr. Monchi.

Until now, the effect of dopamine replacement therapy on cognition in individuals with Parkinson's disease was controversial. The purpose of this study however, was to further investigate. This led to a series of laboratory tests and neuroimaging studies that allowed researchers to clearly define the distinct cognitive functions performed by the dorsal and ventral striatum, thereby shedding some light on the issue.

"The best treatment option for managing the motor symptoms of Parkinson's disease remains dopamine replacement therapy. In some patients however, it can have a negative effect on specific aspects of cognition.

Our discovery will therefore enable us to explore different medication and non-medication based avenues that could help improve the overall health of those affected. Our findings may contribute to helping develop personalized medicine - an avenue that is currently commanding a great deal of attention," exclaims Dr. MacDonald.

This article was forwarded by Steven Russell.

Disclaimer

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Potential Cause of Severe Sleep Disorder Discovered, Implications for Parkinson's Disease

Science Daily - Researchers at the University of Toronto are the first to identify a potential cause for a severe sleep disorder that has been closely linked to Parkinson's disease and other neurodegenerative diseases.

"Our research is the first to establish a potential genetic link to human REM sleep behavior disorder (RBD). That's important because between 60 and 80 per cent of people diagnosed with human RBD develop Parkinson's disease or other neurodegenerative disorders later in life," says Dr. John Peever, lead author of the study that recently appeared in The Journal of Neuroscience.

Rapid-eye-movement sleep behavior disorder (RBD) is most often characterized by violent movements that occur during dreaming sleep, also called rapid-eye-movement sleep. People who suffer from RBD do not experience normal muscle paralysis that prevents them from enacting their dreams and they often hurt themselves or their bed partners with their rapid, forceful movements. In some cases, patients need to be tied to their bed to prevent serious injury to themselves or their bed partners.

Peever's team focused on investigating a genetic cause of RBD because the underlying cause of this disorder is unknown. There is evidence indicating that reduced brain inhibition could cause RBD, so Peever's team genetically reduced brain inhibition in mice and then recorded their sleep and muscle activity.

"We found that mice with reduced brain inhibition acted just like human RBD patients and they moved violently during REM sleep," says Peever. "This link strongly suggests that patients with RBD may also have impaired brain inhibition."

They also found that RBD symptoms in mice could be alleviated by giving them clonazepam -- a drug used to treat human RBD.

Peever's research underscores the importance of identifying a cause of RBD, as 60 -- 80 per cent of RBD sufferers subsequently develop Parkinson's.

"Treating RBD could have direct implications for understanding and perhaps treating Parkinson's disease," says Peever.

This article was forwarded by Steven Russell.

Attending PPSG Board Meetings

You are welcome to drop by our board meetings and share ideas with us! We meet on the **3rd Monday** of the month between **1:00 and 3:00 PM** at the Parkinson's Institute, at 675 Almanor Avenue, Sunnyvale, CA 94085. To confirm meeting dates and time, please call us at **408.542.5610**. If you are planning to attend, please call Charmaine Eng at 408.723.8116 (dial *82 before the number).



For current lists on exercise classes, and support group information/activity calendars, please log on to www.ppsg.org. These lists are maintained by **Steven Russell**.



A Note to Our Readers:

This newsletter is for informational purposes only. Readers are advised to consult a trained medical professional before acting on any of the information in this newsletter. The fact that a particular treatment, nutrient, herb, or supplement is discussed in this newsletter in connection with any illness or condition does not necessarily mean that it is safe and appropriate for everyone or that the editor or PPSG recommends its use for that illness or any condition.



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Parkinson's Disease Patients Find Rare Physical Freedom in Berkeley-Based Dance Classes

By Lou Fancher
Correspondent

Posted: 06/22/2011 01:36:54 PM PDT
Updated: 06/24/2011 03:48:19 PM PDT

In a dance studio deep in Berkeley's Julia Morgan Center for the Arts, Carol Bryan and Claudia Johnson perform a bittersweet duet. The women sway and reach, as if to embrace, then fling one arm high and twist their torsos to end side by side, gazing into each other's eyes and smiling gently. They are dancers, and like ballerinas their work in the studio is filled with danger, pain, passion, grace and beauty.

Bryan, of Walnut Creek, and Johnson, a resident of Orinda, have Parkinson's disease, a degenerative disorder affecting the central nervous system that causes motor skill and speech disturbances.

Both make the arduous journey through the Caldecott Tunnel three times a month to attend Dance for Parkinson's, a free movement program directed by Susan Weber, a former member of the Lar Lubovitch Company.

Weber's connection through the dance world's intricate weave allows her to bring Mark Morris Dance Group's innovative program to the Berkeley Ballet Theatre, where she is the associate artistic director.

Dance for PD, fully funded by PD Active, an advocacy group founded to support ongoing community DFPD classes, pairs professional dancers with Parkinson's patients. The emphasis is on dancing, rather than therapy; accompanied at all times by live music, the classes unlock the mysterious neurological mixup that leaves PD sufferers with impaired balance, rigidity, slow muscle responses and, often, depression.

On this day in early June, Kate Mitchell co-leads the class with Weber. Mitchell, gloriously long-limbed and elegant, danced professionally with New York's CoDanceCo and received her DFPD training two years ago.

Gathered in a circle of chairs, 12 students curl and spiral their torsos as they follow Mitchell's movements. Changing levels and breathing as a group, their bodies

transition from disparate, individual anomalies to a silent, peaceful ensemble.

The Name Game, during which each dancer calls out his or her name, accompanied by a gesture, adds a lighthearted moment. Or perhaps it's the jazz riff, played with rollicking spirit by pianist Chris Houston, that causes Johnson to lift an arm and leg in perfect symmetry and sing "Claudia!" in sparkling tones.

Shaking is next, with a thrumming rhythm from the piano. These men and women, who moments before walked with complete concentration and deliberate steps into the room, are miraculously stamping, kicking and shaking their limbs with fierce abandon.

Mitchell and Weber, although delicate in their choice of words, are demanding. There's clarification and correction as Weber says, "We're making our feet intelligent and expressive," and Mitchell instructs the class to rise from their chairs and incline forward, like Olympic ski jumpers.

At the ballet barre, the music swells as heels lift higher and arms carve enormous arcs through the air. Johnson loosens her grip on the support; Bryan, her balance challenged, lifts her chin and soldiers on, despite the fear.

Weber describes a dance, Cloven Kingdom, created by renowned choreographer Paul Taylor, before introducing the dance's crablike skitters and caveman rock pounding. The class ends with a mirroring exercise, where students follow each other's improvised movements. It's a magical moment from which burst smiles, hearty laughter and exquisite, tender partnerships.

After class, Bryan and Johnson sit for an interview.

"I felt like I was dragging my feet through wet cement," Johnson describes, about the first symptoms she noticed two years ago. "It made me nervous to drive; the tunnel seemed smaller and the car bigger."

She finds it difficult to define the disease to others, especially because diminishing energy and restricted movement are a part of both aging and Parkinson's.

Bryan learned she had the disease 13 years ago, when she was 50. A former occupational therapist who loved to travel, she admits to having mixed feelings.

"I'm angry, although I've actually never said it until now. And it's hard on my husband," she begins.

Although she had treated Parkinson's patients, Bryan had an unexpected discovery when she became one herself.

"Depression is one of the symptoms. Not depression because you have Parkinson's, not as a result, but as a symptom," she emphasizes.

In addition to a drop in mood, Bryan noticed other difficulties. "The problems affected my conversations: people had to wait for me to express myself. I'd have an idea and by the time I got to speak it, I'd have forgotten," she says.

For Johnson, Dance for PD is the ironic fulfillment of a childhood dream.

"I was raised on movies where everyone danced," she recalls, grateful that the class has made her able to bend and move her torso with more ease.

"No more slogging through concrete," she jokes. "I call this my hour of joy. I find my attitude and the stresses of life [are] diminished by the movement."

Bryan refers to the trip from Walnut Creek to Berkeley as "a trick," but gets a thrill out of watching her fellow dancers. She's not without happiness, she insists, but has learned to look for it in small doses: while eating ice cream, or gathering with friends.

"There's things I can't do -- so I go to something that isn't perfect, but I get something out of it," Bryan says, chin thrust forward in a gesture that could be her signature movement.

Mitchell, reflecting on the awareness she has gained from her students, says, "I've learned it's a struggle every day. And that one of the most important things about having a disability is retaining your dignity. Someone who has instability in his or her body has dancing inside. Dance for PD is not about precision or correctness, it's about finding joy."

DANCE FOR PD

WHERE: Julia Morgan Center for the Arts, 2640 College Ave., Berkeley

WHEN: First, third and fifth Wednesdays, 11:15 a.m.-12:30 p.m.

INFORMATION: E-mail dance@pdactive.org or call 510-479-6119.

This newsletter was assembled by the Morgan Center. Thank you!

My Journey Up to Parkinson's Clinical Research Advocacy

By Ronnie Wanetick

In June 2006 a tremor in my right hand led my husband, a surgeon, to suggest I see a neurologist about a possible Parkinson's diagnosis. My internist, on examination, felt I did not have Parkinson's, but referred me to a neurologist based on my husband's concern. Upon neurological evaluation, it was immediately evident; I did have Parkinson's. I had just retired from a twenty-year elementary school teaching career to enjoy a new, easier, fun life. This was not the way my story was supposed to be. I was devastated. I went into therapy.

To ease my depression and isolation, I joined the local Parkinson Network of Mt. Diablo, Walnut Creek Chapter. I immediately found friends and the support I needed. I became both Membership and Public Relations Chairman. I worked with member volunteers to create an Internet presence (PMND.NET), I created a member-to-member phone partnership program. I helped add new positions and more excellent people to our Board. I also helped create a YOPD (Young On-Set Parkinson's Disease) program that brings energy to us all. Team participation continues to enhance our Chapter experience. Support Group meetings are now extremely well attended and rewarding. The growth of our Chapter and services has been an amazing opportunity to share with others.

In 2010 I was honored to be chosen by PDF to be one of forty USA Parkinsonians to undergo a three-day training that enabled me to become a knowledgeable Parkinson's Clinical Research Liaison. I interacted with a "can do" group of dedicated men and women contributing to raising the quality of life for their fellow Parkinsonians. We attended fascinating classes led by national experts who covered topics such as the basics of clinical research and development. I learned to understand the phases and standards of differing clinical trials. We 2010 graduates were entrusted to reach out to educate and inform our communities about studies they might want to participate in. We continuously update our knowledge base with monthly or bimonthly phone and Internet conferences through PDF. We also have our own personal communication and informational section within the PDF site.

I currently interface with various coordinators to find out which research studies are enrolling or especially

need participants. Among those I currently concentrate on in the San Francisco Bay Area are UCSF, UC Davis and the Parkinson's Institute. They provide me with descriptive trial information to assist possible volunteers. If interested, the volunteers can personally contact the coordinators on site using the phone numbers or emails provided, I am expanding my informational base and am now sending information to many new PD Support Group Leaders who now are able to include their Chapter members in these research opportunities.

Adequate volunteer numbers of Parkinsonians and non-Parkinsonians can significantly shorten the length of time to complete a study, bring a successful research and new improved treatments before the FDA. How helpful to our whole community! Today, I lead a busy, active life, volunteer in the community, see friends, enjoy my husband and family, travel the world and much more. Parkinson's is a part of my life that has led me to new pathways of appreciation for all I am able to do.

This article was forwarded by Charmaine Eng.

Coping with Grief

Key points

Grief is a normal and healthy reaction that occurs when you lose someone or something important. Although it is possible to delay or postpone grieving, it is not possible to avoid grieving altogether.

Grief will subside over time. However, the grieving process does not happen in a step-by-step or orderly fashion. Give yourself all the time you need to identify, accept, and express your emotions.

Your feelings are unique. Each person handles emotions and feelings differently. Find the way to deal with your emotions that fits you.

Support is important during the grieving process. Support comes in many forms, such as from friends and family, by participating in activities you enjoy, or through exercises to help you express your feelings, such as writing letters or keeping a journal.

Source: WebMD

Study Helps Explain 'Sundowning,' an Anxiety Syndrome in Elderly Dementia Patients

ScienceDaily (June 27, 2011) — New research provides the best evidence to date that the late-day anxiety and agitation sometimes seen in older institutionalized adults, especially those with dementia, has a biological basis in the brain.

The findings could help explain "sundowning," a syndrome in which older adults show high levels of anxiety, agitation, general activity and delirium in late afternoon and evening, before they would normally go to bed.

"It's a big problem for caregivers. Patients can get aggressive and very disruptive," said Tracy Bedrosian, lead author of the study and a doctoral student in neuroscience at Ohio State University.

"There have been a few clinical studies documenting sundowning, but until now there hasn't been research in animals to see what's going on in the brain to explain this."

The new study found that aged mice showed significantly more activity and more anxiety-like behaviors in the hours before they would normally sleep when compared to middle-aged mice -- just like sundowning in humans.

In these aged mice, the researchers found changes in parts of their brain associated with attention, emotions, and arousal, all of which could be associated with the behavior seen in sundowning.

In addition, mice that were genetically engineered to have an Alzheimer's-like disease also showed more anxiety before sleep than did other mice.

"Some people have argued that sundowning could be explained just by a buildup of frustration of older people who couldn't communicate their needs over the course of the day, or by other factors," said Randy Nelson, co-author of the study and professor of neuroscience and psychology at Ohio State.

"But our findings suggest there is a real phenomenon going on here that has a biological basis."

The study appeared in the online Early Edition of the *Proceedings of the National Academy of Sciences*.

In the first experiment, researchers compared middle-aged adult mice (7 months old) with aged mice (29 months old) that would resemble humans in their 80s.

Results showed that the aged mice were significantly more active than middle-aged mice in the two to three hours before they would normally go to sleep.

"The middle-aged mice had a distinct pattern of activity, with three peaks of activity during their waking hours," Bedrosian said.

"But the aged mice had a flattened rhythm in which they showed the same level of activity throughout their active period."

That means that in the evening, when the middle aged mice would slow down compare to their peak activity levels, the aged mice kept going.

The mice were also tested for anxiety-like behaviors at two different times during their waking hours. The mice were placed in a maze where they were allowed to explore open areas -- which are more anxiety-producing -- or hide in enclosed areas.

The middle-aged mice showed consistent levels of anxiety at both times of the day. However, the aged mice showed more anxiety when tested soon before they would have gone to sleep, which is consistent with sundowning, Bedrosian said.

There were also differences in the brains of the aged mice when compared to the middle aged mice. The researchers looked specifically at the cholinergic system, because loss of function in that system is associated with dementia and many of the circadian changes associated with aging.

Findings in aged mice showed greater expression of a certain enzyme -- **acetylcholinesterase** -- before sleep than earlier in the day. High levels of this enzyme are associated with anxiety and agitation.

However, in the middle-aged mice, there were no time-of-day differences in the expression of this enzyme.

Nelson noted that drugs used to control levels of acetylcholinesterase are sometimes used on dementia patients, although there has been no research evidence that it actually had an effect on sundowning.

"These drugs were prescribed for other purposes, but it also seemed to calm patients down. Now we have some evidence on why it works," Nelson said.

The researchers also found differences in expression of two other proteins in the brains of the aged mice that are also associated with behavioral disturbances.

"All of these results converge to suggest there are changes in the cholinergic systems of aged mice that may be contributing to the anxiety and agitation symptoms that we documented," Bedrosian said.

In another experiment, the researchers used mice that were genetically engineered to develop Alzheimer's-like disease in their brain. They were compared, at nine months of age, to similar wild-type mice of the same age.

The Alzheimer's-like mice showed more anxiety-type behaviors when tested before they would normally sleep than they did when tested earlier in their waking period. That is consistent with sundowning in humans, the researchers said.

However, the wild-type mice showed no differences in anxiety levels based on the time of day they were tested.

Nelson said one of the theories about sundowning is that it is tied to disruptions that often occur in the biological clocks of older people, where their sleep-wake cycles are fragmented.

To test this theory, the researchers also treated the aged mice with melatonin for four weeks in order to help consolidate their circadian rhythms. However, this treatment did not work to reduce anxiety issues in the mice.

Nelson said melatonin alone may not work because it doesn't deal with the disruptions in the cholinergic system that was identified in this study.

"We need to study whether treating cholinergic dysfunction alone or in combination with melatonin treatment will help deal with sundowning symptoms," he said.

Other co-authors of the study were Kamillya Herring, an undergraduate student, and Zachary Weil, assistant professor, both in neuroscience at Ohio State.

“Get In” and “Get Out!”

By George Pratte

As an avid bicyclist I commuted to and from work and enjoyed the exercise and the sense of freedom. When PD and I became buddies, I realized that my occasional falls were only early symptoms of PD. After looking into three-wheel bicycle options I discovered the recumbent trike. Little did I know there were so many variations.

After meeting Dana from “Bent-Up” Cycles, I knew that I was fortunate to have met a specialist in three wheel bicycles. With the accessory of handicap extensions my new “greenspeed” recumbent trike became my joy and also became famous around our retirement community.

After a fall and a bruised tail bone I found it difficult and actually painful to get in and get out of my new trike. Seeking a solution to my situation and anticipating future movement limits, I discussed my problem with an accomplished long-distance biker. He knew exactly what angle, pull, and equipment was needed to assist me. He purchased and installed all the pulley, ropes and straps for my unique “get in” and “get out” system. This allows me to continue to enjoy my recumbent trike despite Pd limitations.

This article was forwarded by Charmaine Eng.

Mindfulness Meditation Training Changes Brain Structure in 8 Weeks

Mass. General-led study shows changes over time in areas associated with awareness, empathy, and stress

Participating in an 8-week mindfulness meditation program appears to make measurable changes in brain regions associated with memory, sense of self, empathy and stress. In a study that appeared in the January 30 issue of *Psychiatry Research: Neuroimaging*, a team led by Massachusetts General Hospital (MGH) researchers report the results of their study, the first to document meditation-produced changes over time in the brain’s grey matter. (January 21, 2011)

www.massgeneral.org/about/pressrelease.aspx?id=1329

Planning Daily Activities with Parkinson's Disease

Parkinson's disease can affect many aspects of a person's daily life. However, with careful planning and activity moderation, the effects of Parkinson's can become much less stressful and intrusive.

The following suggestions offer guidance to overcome some of the difficulties associated with the disease.

Plan periods of rest. Be sure to get plenty of rest. You may need to plan at least one rest period every day. **Conserve your energy.** Using less energy with daily tasks can help you have more energy to do more activities during the day. You may need to cut down on some of your activities or use energy-saving devices or techniques.

Energy Conserving Tips for Those with Parkinson's

Simplify your tasks and set realistic goals. Don't think you have to do things the same way you've always done them. **Plan your activities** (chores, exercise, and recreation) **ahead of time.** Space them out throughout the day. Do not schedule too many things to do in one day. Do the things that take more energy when you are feeling your best. **Do not plan activities right after a meal.** Rest 20-30 minutes after each meal. **Ask for help.** Divide the tasks among family and friends. **Get a good night's sleep and elevate your head when sleeping.** Be careful not to nap too much during the day or you might not be able to sleep at night.

Getting Dressed With Parkinson's:

Get dressed while sitting in a chair that has armrests -- this will help you keep your balance.

Roll from side to side to get pants over your hips. You can do this while sitting in a chair or lying down on your bed. Choose wrap-around clothing instead of the pullover type. Also **choose clothing that opens in the front**, not the back so you don't have to reach behind you. Wear clothing with large, flat buttons, zippers, or Velcro closures. Use a button hook to button clothing. Use a dressing stick if you have shoulder weakness to get your coat or shirt on or off. Use a zipper pull or attach a leather loop on the end of the zipper to zip pants or jackets. Wear slip-on shoes or buy elastic shoelaces that allow you to slip your shoes on and off without untying the laces. Use devices such as a sock donner and long-handled shoehorn for additional assistance.

Source: WebMD

Upcoming Events at the Parkinson's Institute

- 8/10** **Treatment Side Effects**
1:30-3:30 pm
- 9/8** **Newly Diagnosed Seminar**
1:30 pm
- 10/5** **Stem Cell Awareness Day**
1:00-3:30 pm.
- 10/12** **The Management of PD in your Everyday Life**
1:30-3:30 pm.
- 11/3** **Newly Diagnosed Seminar**
1:30 to 3:30 pm.
- 12/6** **Family Treatment of PD**
1:30-3:30 pm.

RSVP: Register at www.theipi.org, under *News and Events*; or call **408.734.2800**.

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