



PD SENTINEL

CONNECTICUT PARKINSON'S WORKING GROUP

Winter 2015

In this Issue

New Treatment...
page 1

Editorial
page 2

Panel Discussion
page 2

Progress Report
page 3

High-intensity
Resistance Training
page 4 - 5

FYi
page 5

Mama Said
page 6

Calendar
page 8



New Treatment – Aims to Save Parkinson's Patients from Their Worst Nightmare

Every time we walk, talk, type on a computer, compute a tip at a restaurant, eat, read a book and continue to breathe, we owe a “thank you” to our brain—comparable to a computer’s central processing unit. Although the adult human brain only weighs an average of three pounds, it’s responsible for controlling almost every single thing our bodies can do, whether we’re aware of it or not.

In contrast to how important the brain is, scientists still know very little about it. According to the National Institute of

Neurological Disorders and Stroke, scientists have studied the brain for centuries, but it is only in the past 10 years that they’ve been able to crack a bit of the code. They’re now able to identify how different parts of the brain control specific body parts; but they’re still mystified by the way intelligence, dreams and other mental phenomena work.

Scientists studying the brain face an even bigger challenge when it comes to

Continued on page 7

Editorial

By Kendra Hough, Editor

COCOONING

What is it about cocooning that makes it so easy to slip into? Not unique to P.D., the concept has been around since the 80's. Thinking literally, a cocoon delineates a small area, is held fast, perhaps in a tenuous position, is sheltered from weather and other disturbances, makes exchanges with others impossible, conserves warmth and energy, makes need for sustenance minimal, provides a questionably protective shell, and facilitates invisibility, and enhances the possibility of survival.

I cocoon and bet you do too. All of the above characteristics at times can be very appealing. Sometimes it seems to be concurrent with depression, but sometimes not. At times it feels like just withdrawal from overload like in job meltdown just without a job.

I think cocooning is an effort to stop the mad race. P.D. takes a great toll, and we all pay the price. I think viewing cocooning in a positive way can diminish guilt about it and let it be a healing restorer of energies necessary to maintain coping mechanisms.

So what if you don't want to go out today. So what if reading and eating ice cream is all you want to do today. You just don't want a visit, or to shop, or to talk. Appointments, doctors, pills, therapy, small bites and small sips, canes and poise pads, enough already. Worry...about falling, choking, big steps and loud ah's, buttons and zippers...can be exhausting. You as well as I deserve a respite. Go for it and welcome the metamorphosis! Gather strength for onward motion!!

Comfort's Sweet Song

By Kendra Hough,

I will allow myself to be comforted with friendships tune...

I will beckon and ask and request help with tasks mundane...

I will try and internalize the undisputable fact....

That if needs not verbalized are left unmet....

it's no fault of friends who just cannot guess...

what might be just right, what would be best.

Will try to reach out in up times and down.

Trusting others may realize from their lives unknown.

I will try to take care of myself as they would....

Comfort's sweet song, enduring and good.

Panel Discussion

By Jill R. J. Baldwin

This past October 30, Middlesex Hospital's Grand Rounds continuing education credit lecture presented a panel discussion to educate the nursing staff about the unique problems a person with Parkinson's disease (PD) has when hospitalized.

The Grand Rounds program was organized by Judy Bahr, MSN, RN-BC, Coordinator of Nurses Improving Care for Healthsystem Elders (NICHE). Judy shared her personal connection and understanding of the disease as the daughter of a person with Parkinson's. Participants on the panel in addition to Judy Bahr were: Jed Podoloff, pharmacist; Kendra Hough RN, person with Parkinson's; and, Steve DeWitte, RNG, patient advocate.

A brief overview was given describing the various PD medications and the contraindications that other pharmaceuticals have on a person with Parkinson's, especially when hospitalized for something other than PD. Kendra Hough spoke of her experience living with PD, sharing a very frank personal account of how PD has impacted her life. She emphasized the new

definition of PD and the importance of understanding the significance of non-motor signs in the progression of the disease.

Steve DeWitte provided a current overview of PD research, what's ahead in the PD research pipeline, and also how patient participation in clinical trial research is essential to the development of better treatment options and ultimately a cure.

The evening brought to light the necessity for nursing staff to be trained about the special needs of people with Parkinson's, each of whom exhibits a unique variation of symptoms, and the importance of PD medication to be administered on time. Of equal importance is the ability for medical staff to look beyond a person's PD when a patient presents with unrelated symptoms.

Thank you Kendra (Connecticut Parkinson's Working Group) and Steve (Connecticut Advocates for Parkinson's) for bringing PD awareness to the Middlesex Hospital nursing staff and advocating for all people with Parkinson's.

Progress Report

As I sit at my desk on this late December morning, it's hard to believe that we're at the start of winter and on the verge of a new year. Where does the time go?

I wanted to take a moment or two to wish you all the best for the new year. And may the powers that be, wherever in the world they are, make significant advances in curing or at least halting Parkinson's disease. I read lots of hopeful news that major breakthroughs are on the horizon, so we all carry on and hope that one day very soon one of these breakthroughs will come to fruition.

Let me address some changes and news concerning CPWG. As I told you last time we began the year with an aggressive plan to cut printing and distribution of our newsletters to those who really want it. We now seem to have a serious core readership at under 100 and still have some left over for our library and to give to new members. That worked beautifully and we're saving over half the money on printing and postage.

The Middletown Dance program I am happy to say is doing wonderful with a healthy turnout every Monday. Lucky for us the Middletown Senior Center has moved to its new home down the street. It has much more room than the one community room upstairs we were using. That was great for our needs and with more people joining us it was time for a bigger room.

Our open house for the dance program in September was standing room only. We had guest visitors and a terrific turnout. I like seeing new people join us, timid at first, but after a week or two they're right in there. I'm happy to report that the Senior Center as of the new year has yet another Parkinson's program thanks again to people honoring Lenny Zwick and making contributions to CPWG – this one slanted on exercise and we hope it will take off like the dance program has done.

So with the help of these very generous people such as Jane and Andy Kampf,



FROM THE PRESIDENT

By Jeffrey LaGrange



who are honoring the memory of Lenny Zwick by being involved in the annual Pro-Am golf tournament and who have made a donation to our dance program keeping it going strong, a few people who have left us this year and wanted donations in their memory to go to CPWG,



plus our core membership who always come through at appeal time, I am proud to report that we are looking strong in the financial area. We're holding our own and yet have two programs to help people exercise and dance.

We are lining up people to speak – it seems to me that everyone I ask to speak (and Jill Baldwin asks probably twice as many) that nearly everyone says “where do you want me and when?” I get calls all the time telling me how terrific our newsletter is, where do I send a donation, and my favorite “you guys are doing a terrific job.” To them I say thank you, and a huge thank you to everyone on the Board and everyone who lends a hand to keep us going month after month. I certainly don't do this by myself. I am only as good as the people around me.

That's our situation in a nutshell. Now let's hunker down for a while more and wait for the first signs of Spring. As always my phone line is open and my e-mail is available 24/7 so if you want to talk, have any ideas, suggestions or any concern, let me know. Happy 2015!



High-intensity Strength Training Shows Benefit for Parkinson's Patients

By Bob Shepard

BIRMINGHAM, Ala. – Researchers at the University of Alabama (UAB) at Birmingham say that high-intensity strength training produced significant improvements in quality of life, mood and motor function in older patients with Parkinson's disease. The findings were published Jan. 9 online in the *Journal of Applied Physiology*.

Fifteen subjects with moderate Parkinson's underwent 16 weeks of high-intensity resistance training combined with interval training designed to simultaneously challenge strength, power, endurance, balance and mobility function. Before and after the 16 weeks, the subjects were compared to age-matched controls who did not have Parkinson's and did not undergo the exercise regimen.

"We saw improvements in strength, muscle size and power, which we expected after rigorous weight training; but we also saw improvement in balance and muscle control," said Marcos Bamman, Ph.D., professor in the Department of Cell, Developmental and Integrative Biology and lead author of the study. "We also saw improvement in cognition, mood and sense of well-being."

Parkinson's disease is a debilitating, neurodegenerative disease that dramatically affects mobility function and quality of life. Patients often experience weakness, low muscle power and fatigue.

Bamman, who heads the UAB Center for Exercise Medicine, devised a strenuous exercise regimen for the participants. Subjects performed three sets of eight to 12 repetitions of a variety of strength training exercises, such as leg or overhead presses, with a one-minute interval between sets for high-repetition, bodyweight exercises, such as lunges or pushups.

"We pushed these patients throughout the exercise period," said Neil Kelly, M.A., a graduate student trainee and first author of the study. "We used a heart rate monitor to measure exercise intensity — keeping the heart rate high through the entire 40-minute session."



Bamman says this was the first study of its kind to look at the biology of the muscles. Biopsies of muscle tissue were collected before and after the 16 weeks.

"We found favorable changes in skeletal muscle at the cellular and subcellular levels that are associated with improvements in motor function and physical capacity," Bamman said.

Physicians who treat Parkinson's patients, such as UAB's David Standaert, M.D., Ph.D., chair of the Department of Neurology, say they have long believed that exercise is beneficial to their patients.

"What we do not know is what kind of exercise and how much exercise will prove best for individual patients with Parkinson's," Standaert said. "This study is concrete evidence that patients can benefit from an exercise program and can do so rapidly in only 16 weeks."

Standaert says he hopes this study will open the door to a more complete understanding of the role of exercise in this patient population.



ng



“My patients who participated in the study told me that they enjoyed the exercise regimen and that they saw distinct improvement in their health and physical condition,” he said. “Future studies should be able to help answer questions such as optimal frequency, intensity and type of exercise.”

Study participants showed significant improvement of six points on average on a measure called the Unified Parkinson’s Disease Rating Scale. On another measure, a seven-point fatigue scale, the group improved from a score above the clinical threshold for undue fatigue to a score below this threshold.

A sit-to-stand test showed that, after strength training, participants dropped from requiring 90 percent of maximum muscle recruitment to rise to a standing position to just 60 percent, which put them on par with their same-age, non-Parkinson’s peers.

“These are all indications that strength training produced a major improvement in the ability to activate muscles, to generate power and to produce energy,” Bamman said, “all of which can contribute to improved quality of life and reduction of injury risk from falls.”

The study was funded by the UAB School of Medicine and the Department of Neurology, along with the UAB Center for Exercise Medicine. Bamman hopes the findings will pave the way for larger studies to define optimal exercise doses for Parkinson’s patients across the disease spectrum.

“This is the first step in an important direction to maximize the therapeutic benefits of exercise training for people with Parkinson’s disease,” he said.

FYI FOR YOUR INFORMATION

Exercise Class Created by a Parkinson’s patient may slow the disease’s progression

On December 17, 2014 WTNH Channel 8 News featured a segment on the BeatPD Today exercise program. Michelle Hespeler, a physical education teacher living with young onset Parkinson’s, developed a specifically designed BeatPD Today class for people living with Parkinson’s disease.

Numerous studies such as the one out of the University of Alabama at Birmingham say that high-intensity strength training significantly improves quality of life, mood and motor function in Parkinson’s patients.

Currently there are beginner and intermediate BeatPD Today classes offered in New Britain, Marlborough, and Glastonbury, and plans to expand the program to Granby and other areas in the state.

Michelle will be presenting a demonstration class at the May 16 CPWG meeting. Be sure not to miss this opportunity to participate in a BeatPD Today class! Visit <http://www.beatpdtoday.com/> to learn more.

Go to <http://wtnh.com/2014/12/17/exercise-class-created-by-parkinsons-patient-may-slows-the-diseases-progression/> to view the channel 8 news BeatPD Today video.

Mama Said There'll Be Days Like This

Decades ago, before the timeless children's book *Alexander and the Terrible, Horrible, No Good, Very Bad Day*, by Judith Viorst, was made into a movie, the story's theme struck a harmonious chord with my children. Just like most youngsters mine occasionally felt that life was picking on them. So naturally Alexander's terrible day brought it all into perspective for them with humor. Now it is my turn to relate to Alexander's plight, because when you live with Parkinson's disease you inevitably have a few terrible, horrible, no good, very bad days along your voyage. I have often thought if I could just run away, bad days would magically disappear.

Poor Alexander's jinxed exploits began when upon rising one morning he discovered the chewing gum he had left in his mouth the night before was now stuck in his hair. Next he jumped out of bed and tripped over his skateboard. That is when our protagonist sensed his day would undoubtedly be heading downhill. His solution, move to Australia

Occasionally in the middle of the night I awake screaming, the result of a vivid dream, and discover that I'm entangled in the sheets unable to move. Then I painstakingly watch the fluorescent green digital time blink incessantly towards dawn. With my blurry eyes wide open and feeling exhausted, I know the day ahead is going to have a few rough spots. I too wish I could flee to Australia.

As Alexander's day continued he couldn't catch a break. His brothers found prizes in their cereal boxes; Alexander only found flakes. He didn't get a window seat carpooling to school; he almost got car-sick. His mom forgot to include dessert in his lunch box; everybody at the lunch table had a great dessert. His teacher criticized his invisible castle picture.



Duh...it was invisible, so what's not to like? The dentist found a cavity and scheduled another appointment the following week. "I'll be in Australia next week," Alexander replied. No one cared that he was having a bad day.

As Alexander's day came to an end, things did not improve. They had lima beans with dinner, there was kissing on the television, soap got in his eye while bathing and his marble was sucked down the drain. Mom selected railroad-train pajamas from the bureau; he hated railroad-train pajamas. The cat refused to sleep with him and the night light burned out. While mom tucked him into bed he voiced the trials and tribulations of his terrible, horrible, no good, very bad day. She replied "some days are like that, even in Australia."

Parkinson's poses obstacles for all who live with the disease, and some days the hurdles are very high. The waxing and waning of the wide-ranging symptoms can be arduous, making one believe the impediments of living with Parkinson's are exclusive to them. And just like children learn, people with Parkinson's come to recognize that no one individual holds the patent on having a bad day.

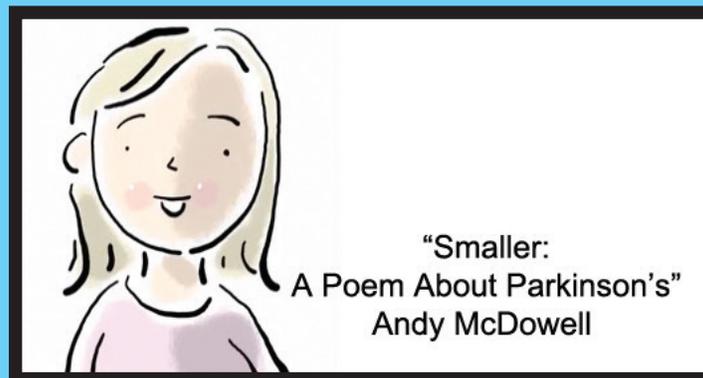
In spite of that, I would still like to journey to Australia! (Okay, I'm taking poetic license here, and must substitute neighboring New Zealand for my getaway destination.) Not to escape, but to meet a special inspirational person with Parkinson's named Andy McDowell who lives in New Zealand with his wife Kate and daughters Lily and Pearl. Andy won

Continued on page 7

Mama Said ... *Continued from page 6*

the 2013 World Parkinson's Congress Video Competition Grand Prize and the People's Choice Award with his entry *Smaller: A Poem About Parkinson's*. His poem, narrated by his daughter Lily, touched my heart. This past July Andy underwent Deep Brain Stimulation (DBS). DBS is a surgical procedure which electronically stimulates a specific area of the brain to help control some Parkinson's symptoms. I believe Andy will persevere to live his life with Parkinson's savoring more good days than bad. And, if I do get the privilege to take a leisurely sojourn to New Zealand and meet the McDowell family it will definitely be a wonderful, fabulous, very good, totally great day!

To my children, mama said there'll be days like this, many totally great days like this, your mama said.



A Poem About Parkinson's, by Andy McDowell can be viewed at: <http://www.worldpdcoalition.org/?page=Top12Vide>

The documentary about Andy McDowell's DBS surgery can be viewed at: <http://attitudelive.com/documentary/andy-mcdowell-switched>

New Treatment ... *Continued from page 1*

researching Parkinson's disease. Parkinson's is a progressive neurodegenerative disease that occurs when there is significant loss of nerve cells in the area of the brain responsible for producing dopamine, a neuro transmitter linked to motor functions.

The Parkinson's Disease Foundation estimates that as many as one million Americans are living with the progressive neurological disease, and 50,000 to 60,000 new cases are diagnosed each year

Physically, the disease manifests itself in severe tremors, rigidity in limbs, mood swings, and "freezing" or "off" episodes. Although "off" episodes are temporary, they often become more severe over time. Patients are unable to speak or move their limbs. The non-motor symptoms of Parkinson's disease are also extremely debilitating and can significantly affect patients' quality of life. These complications can include cognitive, psychiatric, sleep and sensory disorders that might appear even before motor symptoms are first noticed.

For people with Parkinson's disease who are suffer-

ing from "off" episodes, a new method of relief is being developed by **Cynapsus Therapeutics, Inc.**, a specialty pharmaceutical company based in Toronto. It's studying a convenient, sublingual (under the tongue) thin film strip to rescue patients from "off" episodes. Cynapsus' drug candidate, APL-130277, is an easy-to-administer, fast-acting version of apomorphine, which is currently the only approved rescue therapy. As a testament to its groundbreaking technology and recent successes, Cynapsus has received two grants from the Michael J. Fox Foundation for Parkinson's Research, one in 2012 and one this year.

"Parkinson's patients have so much to deal with," says Anthony Giovinazzo, President and CEO of Cynapsus, "and 'off' episodes can be a real nightmare. We are determined to increasing the efforts of Parkinson's patients, their care-givers and neurologists help them regain control of their well-being and quality of life when these episodes occur."

Content by DGIwire



52 Princeton Drive
Middletown, CT
06457

Calendar

CPWG Activities:

Regular 3rd-Saturday-of-the-Month Meetings, 10:00 a.m.-Noon. Middlesex Hospital, Middletown, CT. Visit us at www.facebook.com/CPWG.org www.cpwg.org

January 17 –Dr. Raji Mulukutia from Middlesex Eye Physicians will speak about eye care and Parkinson's. This is a very special hard-to-get speaker so please don't miss this meeting.

February 21 – Pamela Atwood, Director of Dementia Services, Hebrew Health Care Services, Certified Laughter Leader, APDA CT Board of Directors member, Parkinson's support group facilitator

March 21 –Officer Anthony Knapp, from Middletown Police, Community Relations will join us.

Disclaimer: The content of this newsletter is offered to our readers solely on an informational basis and is not intended to support any medical treatment or advice. You are encouraged to review information regarding treatment with your physician. The opinions expressed are those of the writer or presenter and do not constitute an endorsement or approval by the CPWG Board or Newsletter staff.

April 18 – Dr. Ashish Adlakha, Medical Director, Middlesex Hospital Sleep Center.

May 16 – Michelle Hespeler, Beat PD Today Exercise Program (see page 5 for more information)

Events:

CT Advocates for Parkinson's (CAPs) will host a Gala Saturday, March 21, Glastonbury Country Club. There will be dinner, DJ, silent auction, dancing, etc. The proceeds will raise funds for new PD research and development. All are welcome. For tickets and information call 860.266.6040.

Rich Clifford, an astronaut with PD Spring. Talcot Mountain Science Center, Avon. More information to come.