The Doctor Is In... Your Living Room?
Telehealth and the Future of Parkinson’s Care

Could we be returning to the tradition of seeing our doctors at home? We might be, but in this more modern version, the doctor may very well pop up on your computer screen instead of at your front door.

This is the concept of telehealth. Also referred to as “virtual” office visits, it means being able to see your doctor and health care professionals remotely via your computer, your tablet or even your smartphone.

The idea of telehealth — pioneered in stroke and other disease communities — is coming up with increasing frequency in conversations at the Parkinson’s Disease Foundation (PDF). This is because of the benefits it can potentially provide to the PD community. For one thing, it may offer access to care — particularly to specialists and complementary care — in locations that are remote or poorly served by medical resources. For another, it may make it easier for people with PD to participate in clinical trials, which could speed up the development of new treatments.

Currently, a few institutions offer telehealth care for people with Parkinson’s. These include the Veterans Health Administration (VHA), the Medical University of South Carolina (MUSC), The Johns Hopkins University and the University of Rochester. From these programs, we have learned how to create new models of care and how to negotiate barriers to access, including insurance restrictions and the risk of privacy violations.

For the full article and more on the potential impact of telehealth on access to care, quality of care, research, and the future of virtual healthcare, please visit www.pdf.org/winter14_telehealth.

To contact MUSC about telehealth, please call the Neurology scheduling department at 843-792-3223.
Though it has been a cold winter for most of us, it is always reassuring to know that spring is right around the corner. With great anticipation we await the warmth of the sunshine, the blooming flowers, and the time in which we are able to come out of our homes and enjoy our friends and neighbors. With all of this excitement, this makes April a perfect time of year to celebrate Parkinson’s Awareness Month.

It’s important to take time this month to reach out to the larger community and help them to better understand Parkinson’s disease. With nearly one million Americans living with Parkinson’s disease, which is more than the combined number of people diagnosed with multiple sclerosis, muscular dystrophy and Lou Gehrig’s disease, there is a great need to educate the community about the Disease.

Experts anticipate this number will only continue to grow. Most people start to develop Parkinson’s disease in their 60’s and it is estimated that hundreds of thousands of baby boomers are likely to be diagnosed over the next several years.

Of the nearly one million Americans with Parkinson’s disease, each one has a different face and the symptoms of the disease look different in everyone. Therefore we must begin to educate the community about the many different aspects of the Disease and spread the word that Parkinson’s is more than just a tremor. There are several ways in which you can help raise awareness during the month of April. We encourage you to take a look at an awareness tool kit that the Parkinson’s Disease Foundation has assembled. They have done an excellent job in providing ideas and tips to help each of us in our awareness efforts. You can view the full kit at http://www.pdf.org/en/parkinson.awareness.spread

Let’s also use this time of year to celebrate the work of the entire Parkinson’s community. Help us to celebrate: Volunteers who organize educational events and workshops; Support Group Leaders who work so hard to put together helpful meetings; physicians, nurses, physical and occupational therapists and all allied health providers for their service and support; Researchers who are working to find a cure; care partners, families and friends who make up the support system of people with Parkinson’s disease; and most importantly, let’s celebrate people with Parkinson’s disease who work to overcome daily challenges while remaining positive and hopeful for the future.

Join the Parkinson Association of the Carolinas in celebrating Parkinson’s disease Awareness Month.

Sincerely,

Marie Jaffe
Executive Director
Another issue of critical importance is the annual problem of eliminating the $1950.00 Medicare Therapy Cap. We are asking our Legislators to permanently eliminate the Therapy Cap altogether because physical therapy and occupational therapy are so essential for those with a degenerative disease for which there is no cure. Without physical therapy a person with Parkinson's could find themselves unable to walk or move without experiencing immobilizing stiffness and slowness. Without Occupational therapy for the soft, diminished voice and swallowing issues a person with Parkinson's could choke! But isolation and depression is our biggest threat to wellbeing.

The Parkinson’s Action Network is a Grassroots Advocacy Organization, advocating for better treatments and a cure! We are advocates, not lobbyists! We write letters to the editor. We tell our stories. We educate the public about our disease. Our legislators want to hear from us. And they are tremendously welcoming to those who travel to visit them. One important thing I’ve learned is that they appreciate our efforts to inform them with the kind of information that enables them to make knowledgeable decisions. we like to say “When constituents speak, Congress listens”.

Featured in this article are photographs of our visits with Senator Lindsay Graham and Senator Tim Scott. We also met with our newly elected District 1 Representative, Mark Sanford. All of our meetings were positive and encouraging and we are already looking forward to next year’s visit!

It is an honor to represent the Parkinson’s Community of South Carolina in this important mission.

Sincerely,

Adrienne O’Neill
<table>
<thead>
<tr>
<th>Find Your Area</th>
<th>Find Your Way To Move It!</th>
</tr>
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<tbody>
<tr>
<td>Brevard/Hendersonville, NC</td>
<td>Tai Chi is held during every meeting as well as a monthly class at instructor’s studio. Call 828-862-8820 for more information.</td>
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<tr>
<td>Brevard/Hendersonville, NC</td>
<td>‘Big and Loud Crowd’ facilitated by certified LSVT therapists on the 3rd Tuesday of each month from 4:15 PM to 5:15 PM. Contact Lucy Butler at 828-698-6774 for more information.</td>
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<tr>
<td>Chapel Hill, NC</td>
<td>Yoga. Call Jessica Katz 919-843-1657 for more information.</td>
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<tr>
<td>Charlotte, NC</td>
<td>Gentle Yoga for Movement Disorders: Saturdays: 12:15 PM – 1:15 PM at Harris Express YMCA. Call 704-248-3722 for more information.</td>
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<tr>
<td>Charlotte, NC</td>
<td>Tai Chi Classes in Pineville and Matthews, NC for $5 or FREE for SilversSneakers members. Call Ioana 704-681-248</td>
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<tr>
<td>Durham, NC</td>
<td>Tai Chi/General Exercise for PD. 8 week sessions. Call Anna Martin 919-660-6810 for more information.</td>
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<tr>
<td>Kill Devil Hills, NC</td>
<td>Dancing with Parkinson’s (The Doowaps) FREE Mondays (Oct-May): 10:30 AM – 11:30 AM, Drop-ins welcome Tuesdays (May-Aug): 11:00 AM., Water Balance @ YMCA Thursdays (Apr-Oct): 3:00 PM., Yoga @ Spring Arbor For more information call 252-209-7704</td>
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<tr>
<td>Wilmington, NC</td>
<td>Exercise classes with Certified Personal Trainer Tuesdays &amp; Thursdays, weekly 2:00 PM -3:00 PM Registration is required prior to participation in exercise classes. Please call 910-791-0353 for more information or to register.</td>
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<tr>
<td>Winston-Salem, NC</td>
<td>Dance Improvisation and Parkinson’s class is held every Wednesday from 9:00 AM to 10:00 AM. For more information call Christina at 336-758-4460. If you are interested in A Pedaling for Improvement Parkinson's Cycle class please call Jordan at 336-661-1093.</td>
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<tr>
<td>Anderson, SC</td>
<td>Dance Class is held the 1st and 3rd Thursdays at 3:00 PM; Support group meetings are held at 2:00 PM the 3rd Thursday prior to the Dance class. Loud Talkers practice LSVT homework at 1:00 PM before the Support group meeting on the 3rd Thursday of the month. Call 864-716-2643 for more information.</td>
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<tr>
<td>Bluffton, SC / Hilton Head, SC</td>
<td>Gentle Yoga with Tai Chi at Jiva Yoga every Tuesday at 1:00 PM for $5 per session. Call 843-505-0175 for more information. Dance for Joy is the 2nd &amp; 4th Wednesdays from 11:00 AM to 12:00 PM – $10 per session. Call Madonna 843-422-0971.</td>
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<tr>
<td>Hilton Head, SC</td>
<td>Parkinson’s Movin’ and Groovin’ is the 1st and 3rd Wednesday at 2:00 PM for $5 per session. Call Dr. Joanne Smith 843-836-3640.</td>
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<tr>
<td>Easley, SC</td>
<td>Baptist Easley Hospital Arthritis Foundation Exercise classes in place. This program is very suitable for PD patients and families. Call 864-442-7791 for more information.</td>
</tr>
<tr>
<td>Greenville, SC</td>
<td>Walk BIG into Yoga on Tuesdays 10:30 AM – 12:00 PM  $10 per class. Call 864-241-9839 for more information or to register.</td>
</tr>
<tr>
<td>Spartanburg, SC</td>
<td>Dance /Movement Class on 2nd and 4th Thursdays, at same location as support group meeting @ 1:30 PM. (No meetings Jul or Aug). Call 864-579-1002 for more information.</td>
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Move It! Exercise Tip

Overhead Arm Raise

1. You can do this exercise while standing or sitting in a sturdy, armless chair.
2. Keep your feet flat on the floor, shoulder-width apart.
3. Hold weights at your sides at shoulder height with palms facing forward. Breathe in slowly.
4. Slowly breathe out as you raise both arms up over your head keeping your elbows slightly bent.
5. Hold the position for 1 second.
6. Breathe in as you slowly lower your arms.
7. Repeat 10-15 times.
8. Rest; then repeat 10-15 more times.

As you progress, use a heavier weight and alternate arms until you can lift the weight comfortably with both arms.

This exercise will strengthen your shoulders and arms. It should make swimming and other activities such as lifting and carrying grandchildren easier.

Always consult your physician before starting a new exercise regimen.
NORTHERA Approved For Orthostatic Hypotension

February 18, 2014 | CHARLOTTE, N.C. | (BUSINESS WIRE)
Chelsea Therapeutics Announces FDA Accelerated Approval of NORTHERA™ (Droxidopa) for the Treatment of Symptomatic NOH. First New Treatment Option for Symptomatic NOH in Nearly Two Decades. First and Only FDA Approved Therapy to Demonstrate Symptomatic Benefit in Patients with NOH.

Chelsea Therapeutics International, Ltd. (Nasdaq: CHTP) today announced that the U.S. Food and Drug Administration (FDA) granted accelerated approval of NORTHERA™ (droxidopa) for the treatment of symptomatic neurogenic orthostatic hypotension (NOH). NORTHERA is the first and only therapy approved by the FDA which demonstrates symptomatic benefit in patients with NOH.

NORTHERA is indicated for the treatment of orthostatic dizziness, lightheadedness, or the "feeling that you are about to black out" in adult patients with symptomatic NOH caused by primary autonomic failure (Parkinson's disease, multiple system atrophy and pure autonomic failure), dopamine beta hydroxylase deficiency and non-diabetic autonomic neuropathy.

Symptomatic NOH is an autonomic nervous system disorder caused by failure to produce and or release adequate amounts of norepinephrine upon standing. Norepinephrine deficiency results in an inability for a person to maintain adequate blood pressure and blood flow to the brain when upright, frequently resulting in dizziness, lightheadedness, blurred vision, fatigue, poor concentration and fainting episodes. These symptoms often severely limit a person’s ability to perform routine daily activities that require standing or walking for both short or long periods of time. The disorder affects an estimated 80,000 to 150,000 individuals in the United States.

“Symptomatic NOH is a commonly debilitating disorder with limited treatment options and no new therapeutic choices introduced in nearly two decades,” commented Dr. Robert A. Hauser, Professor of Neurology, Molecular Pharmacology, and Physiology, and Director of the Parkinson’s Disease Movement Disorders Center, University of South Florida. “NORTHERA has a distinct mechanism of action affecting the root cause of NOH and represents an important new treatment choice for patients. It is the first and only therapy approved to address specific underlying symptoms of NOH, namely orthostatic dizziness, lightheadedness, or feeling like you might black out. I look forward to offering this new and novel treatment approach to patients who may benefit from it.”

The NORTHERA approval was granted under the FDA’s accelerated approval program, which allows for conditional approval of a medicine that fills a serious unmet medical need, provided additional confirmatory studies are conducted. The package insert indicates that effectiveness beyond 2 weeks of treatment has not yet been demonstrated, therefore the continued effectiveness of NORTHERA in patients should be assessed periodically. A multi-center, placebo-controlled, randomized study, which includes a 4 week randomized withdrawal phase preceded by a three month open label run-in phase, designed with the goal of definitively establishing the durability of the clinical benefits of NORTHERA, has been preliminarily agreed to with the FDA. Based on the contemplated study design, the trial would include approximately 1,400 patients, which the FDA has agreed may be enrolled over a six year period.

Chelsea Therapeutics anticipates delivering NORTHERA to patients with NOH in the US in the second half of the year. Please see NORTHERA full Prescribing Information including Most Serious Side Effects for additional Important Safety Information at http://www.chelseatherapeutics.com.

For product information, or to report SUSPECTED ADVERSE REACTIONS, contact Chelsea Therapeutics, Inc. at 1-855-351-2879 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch

About NORTHERA: NORTHERA is indicated for the treatment of orthostatic dizziness, lightheadedness, or the “feeling that you are about to black out” in adult patients with symptomatic NOH caused by primary autonomic failure (Parkinson’s disease, multiple system atrophy and pure autonomic neuropathy).
failure), dopamine beta hydroxylase deficiency and non-diabetic autonomic neuropathy. Effectiveness beyond 2 weeks of treatment has not been demonstrated. The continued effectiveness of NORTHERA should be assessed periodically. Droxidopa was initially developed by Dainippon Sumitomo Pharma Co., Ltd. (DSP) and first commercialized in Japan in 1989.

About Chelsea Therapeutics
Chelsea Therapeutics (Nasdaq:CHTP) is a biopharmaceutical development company that acquires, develops and commercializes innovative products for the treatment of a variety of human diseases, including central nervous system disorders. Chelsea acquired global development and commercialization rights to droxidopa (L-DOPS), or NORTHERA, from Dainippon Sumitomo Pharma Co., Ltd. in 2006, excluding Japan, Korea, China and Taiwan. *

Spinal Cord Stimulation Could Stall Symptoms of Parkinson’s-like Disease
Rachel Harrison | DURHAM, N.C. | Duke University Medical Center

Researchers at Duke Medicine have shown that continuing spinal cord stimulation appears to produce improvements in symptoms of Parkinson’s disease, and may protect critical neurons from injury or deterioration.

The study, performed in rats, is published online Jan. 23, 2014, in the journal Scientific Reports. It builds on earlier findings from the Duke team that stimulating the spinal cord with electrical signals temporarily eased symptoms of the neurological disorder in rodents. “Finding novel treatments that address both the symptoms and progressive nature of Parkinson’s disease is a major priority,” said the study’s senior author Miguel Nicolelis, M.D., Ph.D., professor of neurobiology at Duke University School of Medicine. “We need options that are safe, affordable, effective and can last a long time. Spinal cord stimulation has the potential to do this for people with Parkinson’s disease.”

Parkinson’s disease is caused by the progressive loss of neurons that produce dopamine, an essential molecule in the brain, and affects movement, muscle control and balance. L-dopa, the standard drug treatment for Parkinson’s disease, works by replacing dopamine. While L-dopa helps many people, it can cause side effects and lose its effectiveness over time. Deep brain stimulation, which emits electrical signals from an implant in the brain, has emerged as another valuable therapy, but less than 5 percent of those with Parkinson’s disease qualify for this treatment. “Even though deep brain stimulation can be very successful, the number of patients who can take advantage of this therapy is small, in part because of the invasiveness of the procedure,” Nicolelis said. In 2009, Nicolelis and his colleagues reported in the journal Science that they developed a device for rodents that sends electrical stimulation to the dorsal column, a main sensory pathway in the spinal cord carrying information from the body to the brain. The device was attached to the surface of the spinal cord in rodents with depleted levels of dopamine, mimicking the biologic characteristics of someone with Parkinson’s disease. When the stimulation was turned on, the animals’ slow, stiff movements were replaced with the active behaviors of healthy mice and rats.

Because research on spinal cord stimulation in animals has been limited to the stimulation’s acute effects, in the current study, Nicolelis and his colleagues investigated the long-term effects of the treatment in rats with the Parkinson’s-like disease.

For six weeks, the researchers applied electrical stimulation to a particular location in the dorsal column of the rats’ spinal cords twice a week for 30-minute sessions. They observed a significant improvement in the rats’ symptoms, including improved motor skills and a reversal of severe weight loss.

In addition to Nicolelis, study authors include Amol P. Yadav of Duke University; Hao Zhang, Thais Vinholo and Chi-Han Wang of Duke University School of Medicine; and Romulo Fuentes and Marco Aurelio M. Freire of the Edmond and Lily Safra Institute of Neuroscience of Natal in Brazil.

This research was supported by a National Institutes of Health (NIH) Transformative Award (R01-NS073125-03), an NIH Director’s Pioneer Award (DP1-OD006798), and the grant “Plano de Acao Brasil Suica CNPq 590006/2010-0” awarded to Nicolelis. *
Coping Skills for Parkinson’s Care Partners

By Julie Carter, R.N., M.S., A.N.P.

A diagnosis of Parkinson’s disease (PD) is a lifechanging experience not only for the person with PD, but also for the spouse, child, parent or friend who becomes the person’s primary care partner.

Care partners take on many different responsibilities. Some of these may seem matter-of-course - for example, accompanying a loved one on visits to doctors, or doing the grocery shopping. Others, such as providing physical care, are more demanding. Whatever may be the nature of the task, the work of the care partner is essential to the well-being of a person with PD. Because PD progresses slowly, the care partner’s role can last for decades. This journey can certainly bring rewards, but it can also bring difficult times. It is important for every care partner to remember that taking care of oneself is not the same as being selfish. By renewing your own energy and staying healthy, you can better support your loved one who lives with PD.

Health of the Care Partner

As a care partner, you are likely focused on your loved one. Yet research shows that care partners — in general, not just those who care for loved ones with PD — face risks to their own physical and emotional health. This elevated risk can show up in a higher-than-average incidence of heart disease, high blood pressure and visits to the emergency room. Care partners have been shown to experience decreased immunity and sleep deprivation. Lack of sleep can lead to irritability and frustration. In addition, care partners experience higher-than-average rates of depression, anxiety and grief.

Practicing the Art of Self-Compassion

In spite of all that care partners do for their loved ones, it is still easy to be self critical and to feel guilty for not doing more. I encourage you to be forgiving, and to treat yourself with the same kindness you would extend to a friend who had a concern or problem. Selfcompassion is not an act of self-pity or self-indulgence, and research backs this up. It will prevent burnout and will allow you to move forward with the things you need to do every day.

A Toolbox for Self-Care

Here are some tools for practicing self-compassion so you can maintain your physical and emotional health.

Identify Stress Triggers: A first step in self-care is identifying and acknowledging the sources of one’s stress. A PD care partner once told me that she always felt irritable, and she felt bad about this. But when she kept a diary to record her emotions throughout the day, she was surprised to find that her irritability was not continuous throughout the day. Instead, it seemed to be triggered by certain specific situations - for example, having three things to do at once, or trying to get out the door and finding her spouse was not keeping pace, or when she was sleep deprived. Recognizing these triggers helped her find solutions to reduce stress.

Build Support Networks: You may feel that you do not want to burden others, but in fact most people are willing to help if asked; they just need help in knowing what to do. Families, friends and caregiver support groups provide a network of people who can help. If you cannot think of a specific task at the time when a person offers help, write down his or her name and ask if you can tell him or her later when a need arises.

In addition, consider talking with a counselor or therapist. Support groups also can
be useful. Beyond being a place where people can express their emotions, support groups are a forum for exchanging resources.

If it fits your budget, hiring paid help can free up your time, so you can spend it meaningfully with your loved one. Often, in the rush of errands and medication schedules, quality time gets pushed to the bottom of the to-do list. One tip: make a priority list of caring responsibilities, then: (i) take on the most important ones yourself, and (ii) try to find someone else — paid or unpaid — to help out with the less important ones.

Finding paid help also can allow you to schedule guilt-free respite time. This should be a priority. Personal time promotes emotional health and rejuvenates energy to do the work of caregiving. I know one spouse caregiver who brings in someone to stay with his wife three days a week for two hours, to provide him the time he needs to exercise. While finding paid help is ideal, it is easier said than done for families who are already under financial strain due to Parkinson's. In such situations, consider consulting a social worker or the state's Area Agency on Aging to learn about assistance that may be available.

**Communicate:** The first step in being able to communicate effectively - with a loved one, with a support network or in other social situations — is finding a way to understand and express emotions. Being a care partner can stir many, often conflicting feelings, such as guilt or frustration — as well as pride. Talk to a counselor, to members of a support group, or to trusted friends. Try writing in a journal or making art — both of which can be therapeutic ways to express emotions. An outlet of this kind can ease communication with a loved one, making it less charged and more meaningful.

Next, remember that communication changes when someone lives with PD. Because of the disease itself, people with PD often have difficulty showing facial expressions, and their voices can become more monotone. They may respond more slowly than they used to, and gesture less often. It is important to really look at the person with PD when speaking and ask, if unsure, what he or she is feeling and thinking. It may also help your partner to talk about his or her own feelings.

Another important area of communication is with the health care providers of your loved one. By being observant and well organized, and by making a habit of writing down questions, you will get more information and support from health care providers.

**Focus on the Positive:** This may sound unrealistic in the midst of a difficult situation. However, we all harbor some degree of optimism, and there are proven techniques for nurturing it.

**Be Flexible:** Especially when we are busy, it is easy to fall back on routines — even ones that no longer work. If this happens, the smart move is to step back, to identify the problem, to think up alternative solutions ... and then to try them out. Being a creative problem solver is a key to decreasing stress.

**Treat Yourself With Care**

Treating yourself with care is simply not a luxury; it is a necessity. It helps us rediscover the purpose and meaning in our lives. Doing the things that bring us pleasure - whether they are small rituals like enjoying a morning cup of coffee, following an exercise routine, practicing meditation, or simply spending time with positive friends — replenishes reserves of love, improves our health and adds depth to our experience of caring for a loved one.

Ms. Carter is Professor of Neurology at Oregon Health & Science University.
Parkinson’s Disease and Social Security Disability Benefits

By Ram Meyyappan

Social Security Disability Help
When you are diagnosed with a serious health condition, you shouldn’t have to worry about how you will keep a roof over your head or put meals on the table. Unfortunately, that’s exactly what happens to many disabled individuals when their conditions result in the inability to maintain gainful employment. The good news is that in some cases, Social Security Disability benefits can offset some of the financial strain caused by a disabling condition.

The Social Security Disability Programs
There are two different disability programs offered by the Social Security Administration (SSA) including Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). In addition to meeting the SSA’s disability criteria, each program requires you to meet specific eligibility criteria in order to receive benefits.

To be eligible for SSDI benefits, you must have earned enough work credits through prior work history. The exact number of credits needed to qualify for benefits will vary depending on your age. Household income is not considered when qualifying for SSDI benefits, although your past income will impact how much you are eligible for in monthly SSDI payments.

You do not need any work credits to qualify for SSI benefits. Instead, your eligibility will be based on your household income and assets. As of 2014 you cannot have more than $721 in household income as an individual or $1,082 as a couple in order to qualify for SSI benefits. You may also not have more than $2,000 in household assets as an individual or $3,000 as a couple. You can learn more about the disability programs here: http://www.ssa.gov/disability/

Medically Qualifying for Social Security Disability Benefits with Parkinson’s Disease
In order to qualify for Social Security Disability benefits, you must meet the disability criteria that has been set forth by the SSA. The SSA has published what is referred to as the Blue Book. This publication lists all of the conditions that could possibly qualify an individual for disability benefits, along with the criteria that must be met under each condition. Parkinson’s Disease is covered under Section 11.06 of the Blue Book, which covers Parkinsonian Syndrome. According to this section of the publication, you can qualify for disability benefits if you can prove that you suffer from significant rigidity, bradykinesia, or tremor in two extremities and the condition has resulted in a sustained disturbance of gross dexterous movements or gait and station. For more information on medically qualifying with Parkinson’s Disease visit: http://www.disability-benefits-help.org/disabling-conditions/parkinsons-disease-and-social-security-disability

Preparing for Your Social Security Disability Application
When preparing to apply for Social Security Disability benefits, you will want to gather enough medical evidence to prove that you meet the criteria of the SSA’s Blue Book listing. This means gathering copies of your medical records including a copy of your clinical history, lab results, and treatment history. A written statement from your treating physician (or physicians) can also significantly help your disability claim. After you have gathered the necessary medical evidence, you can apply for benefits online at the SSA's website (http://www.ssa.gov/pgm/disability.htm) or in person at your local Social Security office. When applying, you will be asked to fill out a number of forms. Be sure to fill out each of these forms in their entirety and with very detailed answers. The more detail you can provide in your answers, the easier it will be for the SSA to understand how your condition prevents you from performing any type of gainful work activity. You should receive a decision regarding your claim within two to four months of the date of your initial application.

Appealing a Denial
If you are denied benefits during the initial stage of the application process, do not give up hope. The truth is that the majority of disability claims are denied during this stage of the application process. You have 60 days from the date of the denial notice to file an appeal with the SSA. The hearing stage of the appeal process is when you will have the best chance of overturning the SSA’s decision to deny your benefits. Nearly two-thirds of all disability hearings are decided in favor of the disability applicant. If you have not yet applied for benefits, you may want to consider retaining the services of a disability attorney prior to filing your claim. These professionals work on a contingency basis, only collecting a percentage of your back pay if you win your disability case.

“Nearly two-thirds of all disability hearings are decided in favor of the disability applicant.”
PAST EVENTS

Dance for Joy Christmas Show

Dance for Joy dancers from The Beaufort County Coalition of PD Support Groups performed their debut performance “Christmas on Broadway” this December. Dance for Joy is a program initiated by Madonna Muller in collaboration with Adrienne O’Neill, SC Director of the Parkinson’s Action Network. The dance class combines elements of ballet, jazz, lyrical, and ballroom dance in a format that accommodates people with Parkinson’s disease and enables the participants to work on balance, coordination, musicality and improving their mobility by performing dance sequences. Dance for Joy is grateful to Mr. Virag and Armando Aseneta for their outreach to the Parkinson’s community and giving the program a home at the Fred Astaire Dance Studio. Dance for Joy is offered every 2nd and 4th Wednesday from 11AM to 12PM for $10 per class. Call Madonna at 843-422-0971 for more information.

Parkinson’s Research Panels

PAC hosted two Parkinson’s Disease Research Panels in Burlington, North Carolina on February 6 and one panel in Fayetteville, North Carolina on February 7, 2014. The Research Panel provided attendees with an update on the progress being made to find a cure as well as updates on new treatment options and studies underway that are exploring ways to slow the progression of the disease. Nearly 200 people attended these research panels. Attendees received an update on research underway internationally and nationally from The Michael J Fox Foundation. Researchers from Duke University, University of North Carolina and Wake Forest Baptist Medical Center shared an update on local studies being conducted. A Parkinson’s Advocate in Research (PAIR) also provided a patient’s perspective into research.
Here is a list of upcoming webinars and events. Please visit our website www.parkinsonassociation.org for a full calendar of events and updates!

If you would like information about your local support group or would like to receive our monthly e-newsletter, you can visit www.parkinsonassociation.org or call our office at 1-866-903-7275.

If you need additional assistance or do not have internet access, please call us.

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<thead>
<tr>
<th>DATE</th>
<th>EVENT</th>
<th>LOCATION</th>
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<tr>
<td>April 22, 2014</td>
<td>NPF Webinar: Stem Cells for Parkinson’s Disease: Fact or Fiction</td>
<td>Online</td>
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<tr>
<td>April 26, 2014</td>
<td>Taste of Italy and Silent Auction</td>
<td>Charlotte, NC</td>
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<td>April 26, 2014</td>
<td>20th Annual Parkinson’s Unity Walk</td>
<td>Central Park</td>
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<td>May 15, 2014</td>
<td>MJFF Hot Topics Webinar: Taking Inventory of Parkinson’s and Alzheimer’s Diseases.</td>
<td>Online</td>
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<tr>
<td>June 24, 2014</td>
<td>PDF PD ExpertBriefing: Parkinson’s Interferes with Gastrointestinal Function</td>
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Get Involved!

Who is finding the cure for Parkinson's?

They all are.

Parkinson's Advocates in Research

Find out more: www.pdf.org/pair

Public Officials Declare Parkinson’s Awareness Month

One of the many ways you can create awareness is to work with your local public officials to obtain a proclamation declaring the month of April Parkinson’s Awareness Month. Receiving a proclamation from a mayor or governor can increase awareness about Parkinson's and the continued need for research for better treatments and a cure.

We are excited to report that several volunteers and support groups have worked hard to secure proclamations from their local Public Officials including:

- Governor of South Carolina, Nikki Haley
- Mayor of Hilton Head, Drew Laughlin
- Mayor of the City of Port Royal, Samuel E. Murray
- Mayor of the City of Beaufort, Billy Keyserling
- Mayor of the Town of Bluffton, Lisa Sulka
- Mayor of Greenville South Carolina, Knox White

If your community received a proclamation from a local public official, please let us know so we can share the exciting news in our next issue.

On March 18, the Mayor of Hilton Head, Drew Laughlin (far left) held a ceremony and presented Tom Kurtz (far right) and Rusty Capers (middle) from the Hilton Head Support Group with a Proclamation declaring April to be Parkinson's Awareness Month.
Help us transform care for Parkinson disease across the country!

www.connect.parkinson.org

Connect.Parkinson is a national study examining the feasibility and effectiveness of using video calls to bring expert Parkinson disease care directly to patients’ homes. Around 200 people with Parkinson disease across the country will see a Parkinson disease expert via video calls on a computer, tablet, or smartphone, over the course of one year.

How does it work? Participants will be randomized, such that half will receive their usual care plus one video call with a specialist at the end of the study, while the other half will receive approximately four video calls with a specialist, in addition to their usual care. All participants will receive National Parkinson Foundation educational materials and tools to help them take charge of their care in their community. Educational materials and video calls with specialists are completely free to participants.

Why? Currently, over 40% of Medicare beneficiaries with Parkinson disease do not see a neurologist. Those who do are 20% less likely to break a hip, be placed in a skilled nursing facility, and die. Connect.Parkinson will connect you directly to a Parkinson disease expert in your home.

Who? To participate, you must:

- Have been told by a doctor that you have Parkinson disease.
- Have access to an internet-capable device, such as a smartphone, tablet, or computer, in a non-public location.
- Be physically located in a participating state when your visits take place. Please complete the survey (link below), and the investigators will contact you.

To learn more or to enroll:
Please complete the participant questionnaire online to find out if you are eligible.
Get started at: connect.parkinson.org
Call 800.4PD.INFO or Contact the NPF helpline at: helpline@parkinson.org

www.connect.parkinson.org

3,500 copies of this newsletter are printed and distributed to people with Parkinson’s disease and their families, as well as physicians, social workers, rehabilitation centers and other health care providers throughout North and South Carolina.

Why don’t you consider advertising with us?

Please contact Marie Jaffe at 704-248-3714 if you would like more information.

Advertising Opportunities Available!

Visit Highway 51 Publishing at www.hwy51.com to purchase it in print or for Amazon Kindle.

Available April 2014!

SHUFFLE: A WAY FORWARD, WHATEVER THE CHALLENGE

Have you recently been diagnosed with Parkinson's disease? Have you been on the PD path for a while and need some encouragement? Do you want to introduce others to what it means to live with PD?

Then check out Windy Woodall's warm and hope-filled book, Shuffle: A Way Forward, Whatever the Challenge—a look at his first thousand days with Parkinson’s and his plan for moving forward no matter what the obstacles.

Available April 2014!
Dignity and Respect are the hallmarks of our philosophy when caring for seniors. We receive great satisfaction in being included in our clients’ lives. Caring is the essence of our job. Our caregivers have been carefully screened, complete a rigorous skills validation process and are insured and bonded.

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Veterans and spouses with questions about VA benefits to contact us for assistance.

Tony Timmons, Sr NSO address PVA Columbia VARO Rm 1121 6437 Garners Ferry Rd. Columbia, SC 29209 ph # 803-647-2432.

Bill Pack, Sr NSO, PVA 251 N. Main St. Rm 424 Winston-Salem, NC 27155 e mail williamp@pva.org ph # 336-251-0836.

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Faces of Parkinson’s

Submit your face to our Faces of Parkinson’s Awareness Campaign.
www.parkinsonassociation.org

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Charlotte, NC 28210
Phone: 704-248-3722
Toll-Free: 1-866-903-PARK (7275)
www.parkinsonassociation.org

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