



The PADRECC Post

Department of Veterans Affairs
2016

THE PHILADELPHIA PARKINSON'S DISEASE RESEARCH, EDUCATION & CLINICAL CENTER at
THE CORPORAL MICHAEL J. CRESCENZ VAMC

Stem Cell Therapies: Buyer Beware

By: Dr. John Duda, PADRECC Director



Stem cell therapies are one of the true revolutions in medicine over the last few decades. The potential that they hold for treating and preventing illness are enormous. However, as with most new therapies, it is a long, complicated process to complete the testing required to prove that it works better than a placebo treatment (basically the same as taking a sugar pill), and that the side effects justify the benefits. The testing required by the FDA to assure that a new therapy meets these requirements, while expensive and time-consuming, do protect consumers from wasting their money on ineffective treatments or worse, being harmed by unsafe treatments. Unfortunately, in their rush to bring these therapies to a market that is desperate to realize the promise that these therapies hold, some businessmen and companies, have exploited a few loopholes in FDA regulations, and are already offering these therapies to patients with Parkinson's disease. This article is an attempt to make you a better educated consumer of these therapies.

There are many questions to consider when deciding whether to pay for these expensive (\$5,000-\$50,000) therapies, that are almost never covered by insurance. Here are a few:

Question 1: Are they safe and effective?

While there are many excellent researchers developing these therapies and numerous scientifically rigorous trials have been concluded, there are no stem cell therapies for Parkinson's disease that have been shown to be safe and effective enough to receive FDA approval.

Question 2: Do I have anything to lose, other than my money, if I try these therapies?

Yes, because these therapies are poorly regulated and tested, it is difficult to determine exactly what the short and

long term consequences will be after getting these treatments. Some patients who have gotten stem cell treatments have developed tumors from the uncontrolled growth of the stem cells. Even cells taken from your own body and returned to you are not automatically safe. In addition, having these therapies might make a patient with Parkinson's disease ineligible for enrollment in other clinical trials of stem cells or new therapies.

Question 3: But what about all the patients who have had great results?

Many of the companies offering stem cell therapy offer convincing patient testimonials about how well the treatment has improved their health or even cured their disease. Unfortunately, in Parkinson's disease, because of poorly understood mechanisms in the brain, placebo effects are particularly strong. There are too-numerous-to-count treatments that have been shown to be effective in open-label, unblinded trials (when both the patient and doctor know what the patient is getting and expect it to work), but have failed when tried in double-blinded placebo-controlled trials (when a placebo treatment is compared to the real treatment, and neither the patient or physician know which therapy is given). Typically, these placebo effects will disappear after a few months and there are no published studies demonstrating long-term benefit from stem cell therapies.

There are indeed many other factors to consider, and becoming an educated consumer is the best preparation when deciding whether or not to accept any medical therapy. Fortunately, there is a highly reputable source to help educate you from the International Society for Stem Cell Research: www.closerlookatstemcells.org/

As always, it is highly recommended that you speak with your own physician about any planned medical therapies.

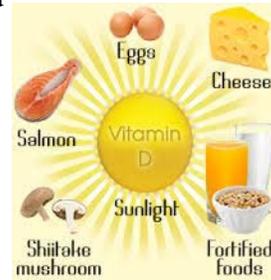
Vitamin D and Parkinson's Disease

By: *Michelle Fullard, MD-Movement Disorders Fellow*

Vitamin D has long been known to play a role in bone health, but more recent studies have shown connections between low vitamin D levels and cancer, heart disease, diabetes and neurodegenerative disorders, including Parkinson's disease (PD). Vitamin D is an important vitamin that is obtained through exposure to sunlight and through the diet. Examples of dietary sources include wild salmon, tuna and milk, as well as vitamin D supplements.

Vitamin D deficiency is common in people over the age of 50 years old, and recent studies have shown that it is even more common in those with PD. In multiple studies, low vitamin D levels or low sun exposure early in life increased the risk of developing PD many years or even decades later. Additionally, vitamin D levels are often lower in those with early and more advanced PD. There is evidence that vitamin D is active in the substantia nigra (part of the midbrain that contains dopamine producing cells), which is one of the main areas in the brain affected by PD. In animal studies, vitamin D may reduce the toxicity of agents that are used to produce Parkinson's symptoms.

Only one study to date has tested the effects of vitamin D supplementation on Parkinson's symptoms.

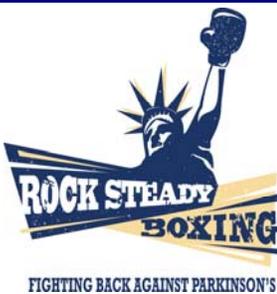


The results of this study suggested that for those with vitamin D deficiency, supplementation may delay progression of PD symptoms. However, this was only true for people with specific types of vitamin D receptor genes, and more studies are needed to determine if supplementation is effective.

Vitamin D levels have also been associated with memory and mood. In one study, people with PD who had higher vitamin D levels were less likely to be depressed and scored better on memory testing.

While all of these studies suggest that there may be a link between PD and vitamin D, more studies are needed to determine if vitamin D supplementation is effective in slowing the progression of PD, and there are several ongoing in the United States. Therefore, it is important to talk with your doctor about the risks and benefits of vitamin D supplementation if your vitamin D level is low and to have your vitamin D level checked regularly if you start supplementation, since too much vitamin D can cause side effects. The American Geriatrics Society recommends that adults 65 and older consume at least 1000 IU of vitamin D daily to prevent fractures. However, in our experience, we have found that higher doses of vitamin D are often needed in those with PD to reach an adequate level.

Rocky Steady Boxing Program



Rock Steady Boxing is a non-contact boxing exercise program that promotes fitness and function in people with Parkinson's disease.

The Dan Aaron Parkinson's Rehabilitation Center at Pennsylvania Hospital offers Rock Steady Boxing. Recent studies suggest that intense exercise programs like Rock Steady Boxing may delay the progression of PD symptoms. Rock Steady-certified physical therapists lead one-on-one sessions and group classes. Participants train on boxing equipment, including speed/heavy bags, heavy/jump ropes, gloves and focus mitts. In addition to providing fitness, the program has been shown to improve confidence, quality of life and energy levels.

COME CHECK IT OUT! Joellyn Fox, Lead PT at The Dan Aaron PD Center will be presenting information on Rock Steady and do a live demonstration at the PADRECC PD Support Group on **June 6, 2016 1:30p-2:30p** in the **CMCVAMC 7th Fl. Multipurpose Room-7A141-back**. You can also learn more by calling **The Dan Aaron PD Center at: 215-829-7275** or checking the program out on the web at: **www.rocksteadyboxing.org/**

Research Happenings at PVAMC PADRECC

Parkinson's Disease & Motor Symptoms

Dr. James Morley, Associate Research Director of the PADRECC, continues to study whether computerized movement tests can help identify early signs of PD and make the diagnosis of movement disorders more accurate. Data is being analyzed from patients who performed several movement tests using electronic monitoring devices. This included walking on a mat with sensors and moving their fingers and feet while wearing movement monitors.

Medication-Induced Parkinsonism

Dr. James Morley is conducting a study to understand how Parkinson's-like symptoms caused by medications are related to PD. Symptoms of PD can be mimicked by certain medicines (usually used for schizophrenia and some other psychiatric conditions) that block dopamine—the major brain chemical missing in PD. Not everyone's symptoms improve after the medicines are switched or stopped, so it is possible that the medicines uncover very early PD in some cases. Dr. Morley's team is comparing medication-exposed patients with and without Parkinson's symptoms using questionnaires, physical exam, blood tests and a brain scan in addition to following patients with symptoms after the medication is switched or stopped. Their goal is to determine whether any of these tests can predict which patients are at higher risk of developing PD. For patients with abnormal brain scans suggesting they may have early PD, Dr. Morley is beginning a new study to test whether exercise can improve movement symptoms and disease progression on the brain scan.

Parkinson's Disease & Blood Pressure Medication

Dr. James Morley is currently conducting a study to demonstrate the effects of a medication that increases blood pressure on symptoms of dizziness in patients with Parkinson's disease. This study is based on a prior study conducted at the PADRECC by Dr. Amy Hellman using continuous non-invasive arterial pressure monitoring to show abnormal control of blood pressure responses in some PD patients. It is hoped that the results of this study will be able to provide additional options for the treatment

of disabling dizziness to patients with Parkinson's disease.

Neurorestoration in Parkinson's Disease

Dr. John Duda and his colleagues Kacy Cullen, PhD, and James Harris, PhD from the recently established Center for Neurotrauma, Neurodegeneration, and Restoration (CNNR) at the Crescenzo VA Medical Center, were awarded a two-year grant from the Michael J. Fox Foundation for Parkinson's Research to investigate experimental reconstitution of the nigrostriatal pathway (the pathway that degenerates in PD and causes the motor symptoms) in animal models of PD in a grant entitled, 'Restoring the nigrostriatal pathway with living micro-tissue engineered axonal tracts'.

Traumatic Brain Injury

Dr. John Duda, PADRECC Director, and his colleagues, Drs. Kacy Cullen and John Wolf, continue studies funded by the Rehabilitation Research and Development Service of the Department of Veterans Affairs to develop animal models of Chronic Traumatic Encephalopathy (CTE) that sometimes develops years later in people such as football players and war fighters who have had traumatic brain injuries. The goal of these studies is to develop models of these changes in the brains of animals so that novel treatments and preventive strategies can be tested. It is hoped that these studies will lead to treatments to prevent the development of these neurodegenerative diseases in Veterans and others who have suffered head injuries.

Bacteria and Parkinson's Disease

Dr. Fullard and Dr. Duda, in collaboration with Dr. Noam Cohen from the Ear Nose and Throat Department, are starting a new study to help understand how the bacteria that colonize our body might contribute to the risk of Parkinson's disease. It has been shown that these bacteria are different in people with Parkinson's disease compared to people without Parkinson's disease. This study will try to understand if there are genetic reasons why some people have certain types of bacteria in the hopes of developing new therapies in the future.



Parkinson's Disease and Melanoma

By: *Delaram Safarpour, MD-Movement Disorders Fellow*

Melanoma is the most serious form of skin cancer and the sixth most common cancer in North America. Despite the fact that melanoma only accounts for 4-5% of all skin cancers, it is associated with 75% of the deaths from skin cancer.

Some risk factors for melanoma such as skin color, hair color and gender have been well known for decades. More recently, other risk factors such as ultraviolet (UV) exposure have been linked to melanoma. Those with lighter skin tones are considered to have a higher prevalence of melanoma than those with darker skin tones and the prevalence is higher in men than in women.

Melanin is the primary determinant of skin and hair color in humans and more melanin pigment means darker skin color. Melanin also exists in neurons of the brain known as neuromelanin and is a protective factor that can save neurons from oxidative stress, a possible source of neuronal injury and death, that may also play a role in Parkinson's disease (PD). Abnormalities in melanin can cause various skin cancers, including melanoma. Several studies have looked at the relationship between PD and melanoma.

Studies suggest that people with PD have a decreased risk of almost all cancers. However, the occurrence of melanoma is higher in patients with PD than in the general population.

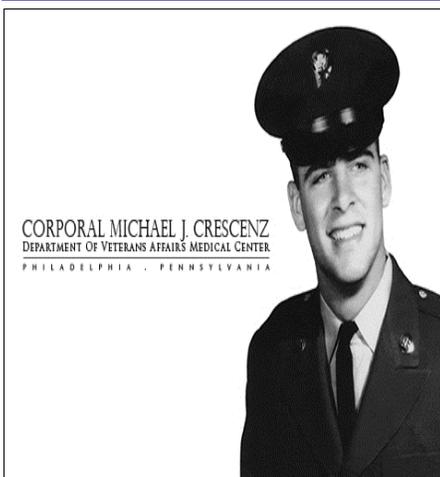
Several studies have also shown a genetic correlation between PD and melanoma; based on these studies it is possible that changes in certain genes may increase the risk for both PD and melanoma. However, both PD and melanoma are complex diseases caused by many factors including genetic and environmental risk factors.

It is important to know that studies have not reported any relationship between Levodopa treatment for PD and melanoma and therefore treatment choices for patients with PD have little or no effect on the development or progression of melanoma.

Screening guidelines suggest that physicians and PD patients should be made aware of the relationship between PD and skin cancer. Sun protection, self-surveillance and routine skin check-ups by a Dermatologist, to identify melanoma at an early stage, are commonly recommended by many movement disorder specialists.

Philadelphia VA Medical Center Renamed:

Corporal Michael J. Crescenz VAMC



On May 2, 2015 the Philadelphia VAMC was renamed the Corporal **Michael J. Crescenz VAMC** in recognition of Vietnam War Medal of Honor Recipient Michael J. Crescenz. Corporal Crescenz, a native of the West Oak Lane neighborhood, was 19 years old when he was killed in action on Nov. 20, 1968, while charging multiple North Vietnamese machine-gun bunkers during an ambush. If not for his incredible bravery, the Corporal's entire squad might have perished that day. Corporal Crescenz is the only Philadelphia native to receive the Medal of Honor. The Philadelphia PADRECC is proud to be supported by this facility and continues to provide state-of-the-art clinical care, research and education to Veterans with movement disorders in the Northeast corridor of the United States.

PADRECC Resources

Patient Education Video Series

The PADRECCs developed the "My Parkinson's Story" Film Library Video Series. The videos provide information about common concerns related to PD. Each segment explores a specific issue related to PD from the perspective of the patient, his or her family and his or her healthcare team. All videos are available for viewing on the National PADRECC & VA PD Consortium website:

www.parkinsons.va.gov/patients.asp

Parkinson's Disease Hospital Kits



According to the National Parkinson's Foundation (NPF), people with PD face greater risks and challenges when hospitalized. The best way to avoid complications while hospitalized is to be prepared. The PADRECC **Parkinson's Disease Hospital Kit** and the **NPF Aware in Care Kit** were developed to help you with this process. If you are interested in obtaining a Parkinson's Disease Hospitalization Kit and/or the NPF Aware in Care Kit ask your PADRECC clinician or Social Worker.

Patient Education Brochures

Patient Education Brochures were developed to provide patients and families with information on the most common topics concerning Parkinson's disease: **Fall Prevention, Exercise and Physical Activity, Medications, Agent Orange, Motor and Non-Motor Symptoms of PD.**

The brochures are available in the Philadelphia VA PADRECC Clinic or can be downloaded from the National PADRECC & VA PD Consortium website:

www.parkinsons.va.gov/patients.asp

VA "At-Home" Telephone Education & Support Group

The Southwest PADRECC in West Los Angeles sponsors a Telephone Education/Support Conference on the **2nd Tuesday of every month, 1-2 pm Eastern Time**. Participate in the convenience of your home. Simply dial toll-free **1-800-767-1750 and enter code 54321#**. For more info, contact West LA PADRECC at 1-800-952-4852 or (310) 478-3711 x 48041.

National PD Web-Based Resources

Michael J. Fox Foundation: www.michaeljfox.org

◆ **Fox Feed Blog:** the latest reporting of progress in PD research & issues that matter to you. Features webinars, podcasts and blog posts on topics related to PD.

Parkinson Disease Foundation (PDF): www.pdf.org

◆ **PD Expert Briefings:** 1 hour online seminars that offer practical tips and tools. Seminars are broadcasted live and archived for later viewing.

◆ **Educational Publications:** factsheets, brochures and booklets on various PD topics are available for viewing and download on the PDF website.

National Parkinson Foundation: www.parkinson.org

◆ **Parkinson's Today Blog:** Up-to-date information on the latest PD research, news, and caregiving tips.

◆ **Educational Publications and Webcasts:** factsheets, newsletters, handbooks, videos and archived webinars on various PD topics and are available for viewing and download on the NPF website.

NATIONAL RESEARCH LINKS

Fox Trial Finder (FTF)

<https://foxtrialfinder.michaeljfox.org/>

Online matching tool that connects volunteers with PD clinical trials.

NIH Clinical Research Trials and You

<https://www.nih.gov/health-information/nih-clinical-research-trials-you>

An online resource to help people learn more about clinical trials, why they matter and how to participate.

ClinicalTrials.gov

www.clinicaltrials.gov

Is a registry and results database of federally and privately supported clinical studies conducted around the world.

PADRECC Parkinson's Disease Education Group

Group meets the **1st Monday** of each month at **1:30 pm** in the 4th Floor PADRECC Conference Room and at the **VA Burlington & Horsham Clinics** via video connection. If you are interested in attending the education group at the **VA Burlington or Horsham Clinics please contact Gretchen Glenn, 215-823-5934, as space is limited.**

**Topics and speakers are subject to change*

April 4

Speaker: Heidi Watson, BSN, RN-PADRECC

Topic: Tips for a Healthy Brain

May 2

Speaker: Dr. Daniel Weintraub, Psychiatrist

Topic: Depression & Anxiety in PD

June 6

Speaker: Joellyn Fox, Lead PT-Dan Aaron PD Center

Topic: Rocky Steady

****Please note: This group is only being held**

IN-PERSON at Philly VA 7th Fl. Rm 7A141-back.**

July 4

4th of July-NO GROUP

August 1

Speaker: Dr. Delaram Safarpour, PADRECC Fellow

Topic: Overview of PD Treatment Options

September 5 **Labor Day-NO GROUP**

October 3

Speaker: Gretchen Glenn, PADRECC Social Worker

Topic: Long Term Care Planning

November 7

Speaker: Dr. James Morley, PADRECC Neurologist

Topic: Research Update

December 5

Speaker: PADRECC Fellow

Topic: TBA

Brain Wellness Clinic

Want to learn more about lifestyle changes to improve your own health? Do you want to hear about how dietary choices can affect your brain health and how to include these into your own diet? Do you have a New Year's resolution to exercise that you haven't put into action? Are you highly motivated to make changes in your lifestyle to improve your brain wellness? If so, we would like to invite you to the Crescenz VAMC Brain Wellness Clinic. The Philadelphia PADRECC is proud to offer a new wellness program. Dr. John Duda and Heidi Watson, RN started a Brain Wellness Clinic on Mondays at the PADRECC offering patients a chance to be guided in improving their brain health.

The Brain Wellness clinic provides an opportunity to focus in-depth on wellness. We discuss your current brain wellness risks as assessed by looking at different lifestyle factors including sleep, nutrition, exercise, mindfulness/spiritual, cognitive and social. During the visit, we complete a thorough interview, several short written or web-based assessments of your health, and lab work if appropriate. We discuss wellness goals that are important to you. Together, we develop a plan that is individualized to your needs with realistic and achievable goals and help provide a support system to implement it. We continue to follow your progress and provide follow-up in person or through telehealth. Please talk to your PADRECC provider or Dr. Duda or Heidi if you are interested. Take control of your brain wellness and let us help you along the journey!

Here are a few testimonials from recent Brain Wellness Clinic attendees:

"I learned I had a vitamin deficiency that was affecting my sleep and learned a new strategy for my exercise plan. Overall, it was a great visit."

"My experience at the brain wellness clinic was very informative and I'm looking forward to implementing the changes we discussed"





Dr. John Duda



Dr. Jayne Wilkinson



Dr. James Morley

The Philadelphia PADRECC Team

- Dr. John Duda, Director
- Dr. Jayne Wilkinson, Associate Clinical Director
- Dr. James Morley, Associate Director of Research
- Dr. Branch Coslett, Acting Chief, Neurology Service
- Dr. Michelle Fullard, 2nd year Fellow
- Dr. Delaram Safarpour, 1st year Fellow
- Dr. Daniel Weintraub, Geriatric Psychiatrist
- Dr. Rasham Shah, Pharmacist
- Rebecca Martine, MSN, RN, PMHCNS, Nurse Coordinator
- Heidi Watson, BSN, RN, Nurse Coordinator
- Eileen Hummel, BSN, RN, Nurse Coordinator
- Gretchen Glenn, LCSW, Social Worker
- Stephanie Wood, Research Coordinator
- Dawn McHale, Program Specialist
- Tonya Belton, Program Support Associate
- Yolanda Robinson, Patient Services Assistant

To learn more about the Philadelphia PADRECC and the National PD Consortium, please call: **215-823-5934 or 1-888-959-2323** or check us out on the Internet at: www.parkinsons.va.gov

The Philadelphia PADRECC Consortium Network



National VA PD Consortium Centers

The National VA Parkinson's Disease Consortium was established in 2003 as a means to broaden the impact of the Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) and encourage modern Parkinson's disease care across the VA Healthcare System. Together, the PADRECCs and Consortium Centers create a hub and spoke model of care, allowing effective and convenient services to all veterans, regardless of location. Veterans who cannot access services at a PADRECC facility can receive specialized care at the closest Consortium Center in their region.

Northeast Consortium Centers	
<p>White River Jct., Vermont</p> <p>Consortium Director: Timothy Cox, NP Referral Number: 802-295-9363 x5780</p>	<p>Pittsburgh, PA</p> <p>Consortium Director: Dr. David Hinkle Referral Number: 412-688-6185</p>
<p>Jamaica Plain, MA</p> <p>Consortium Director: Dr. Raymond Durso Referral Number: 617-232-9500 x4750</p>	<p>Baltimore, MD</p> <p>Consortium Director: Dr. Paul Fishman Referral Number: 410-605-7000 x7060</p>
<p>Syracuse, NY</p> <p>Consortium Director: Dr. Dragos Mihaila Referral Number: 315-425-3474</p>	<p>West Haven, Connecticut</p> <p>Consortium Director: Dr. Diana Richardson Referral Number: 203-932-5711</p>
<p>Bronx, NY</p> <p>Consortium Director: Dr. Ruth Walker Referral Number: 718-584-9000 x5915</p>	<p>Albany, NY</p> <p>Consortium Director: Dr. Donald Higgins Referral Number: 518-626-6373</p>





PD Organizations

National Parkinson Foundation (NPF)

www.parkinson.org (800) 327-4545

Parkinson Disease Foundation (PDF)

www.pdf.org (800) 457-6676

American Parkinson Disease Association (APDA)

www.apdaparkinson.org (800) 223-2732

Michael J. Fox Foundation

www.michaeljfox.org (212)509-0995

Davis Phinney Foundation

www.davisphinneyfoundation.org (866) 358-0285

Related Movement Disorder Organizations

CurePSP

www.psp.org

Lewy Body Dementia Association

www.lbda.org

Association for Frontotemporal Degeneration

www.ftd-picks.org

Huntingdon's Disease Society of America

www.hdsa.org

International Essential Tremor Foundation

www.essentialtremor.org

Veterans Affairs

National PADRECC & VA PD Consortium

www.parkinsons.va.gov 1-888-959-2323

Agent Orange Website

www.publichealth.va.gov/exposures/agentorange

VA Health Care Eligibility

www.va.gov/healthbenefits 1-877-222-8387

Veterans Benefits Administration

www.benefits.va.gov/benefits/ 1-800-827-1000

VA and Department of Defense

www.ebenefits.va.gov

My HealthVet

www.myhealth.va.gov

VA Caregiver Support

www.caregiver.va.gov 1-855-260-3274

State Veterans Affairs Offices

www.va.gov/statedva.htm

Veterans Crisis Line

1-800-273-8255 Press 1

With Sincere Thanks

The Philadelphia PADRECC would like to thank those who made charitable donations on behalf of loved ones followed in the clinic. The donations are used to support our education initiatives.

The PADRECC Post

Editors: Gretchen Glenn, LCSW, Becky Martine, MSN, RN PMHCNS & Dawn McHale

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