



BRAIN N' MOTION

PARKINSONS NEWS TO MOVE YOU FORWARD

1st QUARTER 2018

GAINING AN EDGE THROUGH ENGAGEMENT

BY ANISSA MITCHELL, LCSW
FLORIDA HOSPITAL PARKINSON OUTREACH CENTER

Patient engagement is a term that is used in a variety of ways and can be a bit misleading. However, what is being referred to in this article is the act of patient empowerment through education, disease management and connection to the Parkinson's community.

Person's with Parkinson's (PWP) may go through a series of doctor visits and tests before a diagnosis is made. Once diagnosed many still may not see a neurologist or receive education and direction in how to best treat their disease. According to a survey of 1,500 PWP's that was done through the Michael J Fox Foundation and Abbvie's Partners in Parkinson's, more than half of the people surveyed (57%) did not know where to turn to for Parkinson's information and support. Only 28% of these patients were currently seeing a movement disorder specialist and 45% never saw a movement disorder specialist-a sub-specialty of neurology with 1-2 years of additional fellowship training in Parkinson's and movement disorders (Partners in Parkinson's, 2014). People with Parkinson's who play an active role (are engaged) not only improve their own health outcomes, but contribute to the outcomes of the greater community. To be active and engaged, one must have the knowledge necessary to understand how to achieve their optimal health. (Story continued on page 4)

WHAT'S HAPPENING?

Brain and Beyond Conference

Walk for Parkinson 2018

New Program PD CARE

- INSIDE -

Engage in Walk Fundraising.... Page 3

Gaining an Edge through Engagement... Page 1 & 4

Engagement Opportunities... Page 4

When Your Get Up and Go... Page 7

Florida Hospital Program News.... Page 8 & 9

Parkinson's Research News.... Page 11, 12 & 13

Bioclinica Research News... Page 14 & 15

Walk for PARKINSON

A BRIGHTER FUTURE IS ON THE HORIZON



Saturday, April 14, 2018

Registration & booths open at 8am, Walk begins at 9am.

Cranes Roost Park

274 Cranes Roost Blvd,

Altamonte Springs, FL 32701

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TO REGISTER OR CREATE A FUNDRAISING TEAM
VISIT WWW.PARKINSONCF.ORG

ENGAGE IN WALK FUNDRAISING

BY EMILY RINEHART, DEVELOPMENT COORDINATOR, PACF

The Walk for Parkinson is more than just a Walk. It highlights the importance of movement, exercise, socializing and raises awareness and funds for research towards finding a cure. This event brings family and friends together joining in support for a brighter future for those with Parkinson's. Whether you create a team, join as an individual, donate or attend the Walk, you'll get the chance to associate with hundreds of supporters who share a common goal to beat Parkinson's. If you're new to fundraising or want to get involved, here's an outline of ways we can achieve our goals.

CREATE A TEAM

Anyone is welcome to create a Walk team. We encourage the use of teams and enjoy cheering on those who are achieving their goals. To ensure your team is successful engaging those in your community by contacting organizations such as schools, businesses, clubs, churches and many others are great sources of support systems. Simply reaching out can generate awareness and create connections between individuals.

When it comes to successful fundraising, think outside of the box. Do you have a runner or cyclist in your family or possibly like to bake? Many people raise funds through various events such as charity rides or runs, or bake sales. A benefit to hosting fundraising events in the community is to engage a different audience as well as educate people on the symptoms of Parkinson's. By incorporating your personal talents or hobbies, you have a fun and easy way to engaging others to donate. Visit the Parkinson Association of Central Florida's website (www.parkinsoncf.org) to learn more on fundraising A-Z to spark some additional ideas.

JOIN A TEAM

Joining a team shows support to your loved ones. Becoming involved and active on a team makes the team even stronger. You want to join a team if you know someone on a team or have been invited to join a specific team. Once you join the team you create a personal page and ask people to make donations on your page.

For those who have created a team, another fundraising key is to invite people to join your team and have them create their own page and fundraise on your behalf. Utilizing the fundraising site to recruit your fundraising team will help gain more team members and have a greater chance of raising more funds.

DONATE

Participation through a donation is a generous way of showing support even if you are unable to attend the Walk. Any type of participation helps to reach our goal and is a part of making a difference in the community.

SHARE

There are more ways to engage in helping fundraise for the Walk other than donations or creating team pages. Ways you can help would be to, SHARE! Share our printed flyers, brochures, and information. Share our posts on social media so your friends on Facebook can "like" us. Share your Walk fundraising page in email's to friends and family members letting them know what you are involved in. Be a voice for the Parkinson's community and help reach those who are unaware of the resources available in their community. Word of mouth is one of the most successful ways of promoting others to participate in programs offered in the community.

Engagement key to reaching the thousands of people in Central Florida who have Parkinson's. Help us make a difference and reach our goals to help those who are affected by Parkinson's. Your donations and fundraising efforts for the Walk helps fund programs and services to those living with Parkinson's, their care partners and families in Central Florida. With your support and dedication to meeting your fundraising goals, we can provide the best care possible for those with Parkinson's and their loved ones.



MEET MARY TABLER

Mary Tabler, Team Captain of MaryE Movers found it was easy to keep track of donations because she would receive an email each time someone had contributed to her team.

Each donation was also posted to her team page listing those who showed their support. Each time she received a donation she used the built in email feature to send a quick thank you, then followed up with a phone call or was able to thank them in person. Last year, Mary Tabler was ranked 4th on the top teams list and raised a little over \$3,000! This year Mary has set her goal at \$5,000 and has already created her team.

GAINING AN EDGE THROUGH ENGAGEMENT

BY ANISSA MITCHELL, LCSW FLORIDA HOSPITAL PARKINSON OUTREACH CENTER

(Continued from cover page)

Engagement through education is vital in positive outcomes in managing Parkinson's disease. On a personal level, people who receive education about the disease understand the steps they must take to optimize their health and manage their symptoms. They are more likely to recognize symptoms or concerns that need to be addressed in their treatment plan and can proactively begin a dialogue with their physician. According to the Partners in Parkinson's survey, "only about half of patients feel "informed or very informed" about living with Parkinson's disease (53%) and how to understand if their disease is progressing (51%). Further, only 48 percent of Parkinson's patients and 38 percent of caregivers reported feeling informed about where to turn for support or information, and even fewer (43% of patients and 36% of caregivers) felt informed of ways to get connected with their local Parkinson's community" (Michaeljfox.org 2014). Conversely, people who see a specialist report that their physician addressed how they felt physically (91%), the importance of exercise (78%) and how PD was impacting their life (75%). There was also noted a considerable number of PWP's who reported that their physician helped them to address problems such as balance and mood issues.

So, how do you improve education when there appears to be such a lack, but obvious benefit in your health outcome? By getting involved now that you have been made aware of the issue and helping to raise awareness. Start by learning more about Parkinson's disease. There are a variety of tools available including online resources and local programs. If you have been newly diagnosed, consider taking a PD 101 class to gain a general knowledge about what Parkinson's is, how it's diagnosed, common treatment options and who should be managing it from a physician and multi-disciplinary team perspective.

If you are not seeing a neurologist, now is the time to change that! Another study published in *Neurology*

(2011) reported that 32% of patients with Parkinson's are not seeing a neurologist but are managed by a primary care physician. While you may have limited access to a movement disorder specialist neurologist, seeing a general neurologist improves patient outcomes versus treating through a primary care physician. In fact, the study found that PWP's who are managed by a neurologist live longer, are less likely to be placed in a nursing home and less likely to break a hip than those managed by a PCP.



Engagement also means optimizing your health through disease self-management. This means taking charge of managing your PD through recognizing and monitoring symptoms, proper medication management, communication of your symptoms and health status with your provider, exercising, eating well and being proactive in your care. Patient engagement in chronic disease management is increasingly recognized as a key factor in improving patient's health outcomes, quality of life, health care experience and reduction in healthcare costs (Aseltine, et al. 2016). This is achieved through health literacy, which means a person's ability to seek, understand and utilize health information enabling them to participate in decisions about their health, as well as identify their coping ability and access resources (Jordan, et al. 2008). More than ever before, access to information to improve patient engagement has been made available.

However, it can be overwhelming trying to find reliable information that is organized, concise and offers the ability to ask questions and interact with others. While support groups can offer a great deal of education, the educational needs of the PWP may not be fully met. That is why Parkinson's specific self-management programs are helpful. A new program, PD CARE is soon to be offered to PWP's that helps them understand their disease, how to cope, advocate for themselves, relate to others and get engaged. This program will be available starting in April.

A final way that people can be more engaged is through community awareness activities and research.

Joining with local PD associations such as Parkinson Association of Central Florida helps to promote awareness of Parkinson's and supports funding for programs that help the PWP and the family cope with the disease. Activities such as walks and other fundraising and awareness promotion events are crucial in educating the community.

There is a huge need for participation in research for Parkinson's. 85 percent of all clinical trials are delayed, and 30 percent never get started due to lack of participation. But, volunteering in research provides the PWP opportunity to give back to the greater PD community through contributing to new treatments in the future (michaeljfox.org, 2014).

To learn more about how to become more engaged through education, self-management and community involvement, check out the information below or call the Parkinson Outreach Center at 407-303-5295.

Source: <https://www.michaeljfox.org/foundation/publication-detail.html?id=556&category=7> retrieved February 14, 2018

Seeing a neurologist helps people with Parkinson's live longer, study suggests. *www.sciencedaily.com* August 15, 2011.

Jordan, Joanne, Briggs, Andrew M., Brand, Caroline A., and Osborne, Richard H. (2008) Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach. *MJA*, volume 189, Number 10, November 7.

Aseltine, Robert H, Sabina, Alyse, Barclay, Gillian, Rappoport, Daniel and Graham, Garth. (2016). Engaging patients in managing chronic disease: an analysis of data from the Connecticut health care survey. *Society for Participatory Medicine*.

ENGAGEMENT OPPORTUNITIES

EDUCATION

The Parkinson Outreach Center offers several levels of education for the person with Parkinson's and their family. Tier I is for beginners, Tier II is a deeper level of education and equips the PWP's and caregivers to proactively manage the disease and plan for the future through patient self-management and caregiver training classes. Tier III is ongoing education through opportunities such as the Parkinson's Brain and Beyond conference, educational lectures at the support groups and the quarterly newsletter.

TIER I

PD 101 WHAT YOU AND YOUR FAMILY SHOULD KNOW-This is a free class for anyone who would like to learn some general information about symptoms, diagnosing and treating PD. Classes are offered at various locations and times, contact the Parkinson Outreach Center for more information call 407-303-5295.

TIER II

PD CARE - Coping Advocating Relating and Engaging for Patients - This is a NEW patient self-management training and support program for those diagnosed with PD who want to better understand what it takes to fight back at the disease and live the highest quality of life possible. PD CARE provides a greater understanding of PD symptoms, treatments and common concerns while addressing: coping, with the disease, advocating for yourself, relating to others and engaging in the community. This program launches in April on two successive Mondays , April 23rd and April 30th from 1:00 pm to 5:00 pm at One Senior Place, Altamonte Springs. This class is a pilot program and is free, but seating is limited and registration is required. Call 407-303-5295 for more information or to register.

COPE - CARE OPTIMALLY PARKINSON EDUCATION FOR CAREGIVERS - If your loved one has been diagnosed with Parkinson's you may have many questions about symptoms, how to help them and be prepared. COPE is an educational program that discusses these issues as well as managing stress and maintaining a healthy relationship. This class is free but space is limited, call 407-303-5295.

ENGAGEMENT IN THE COMMUNITY

PD LINK - Talking to another person who is in a situation like yours can often provide the meaningful connection you may not find with someone who isn't going through this journey. PD Link Central Florida is a program in which volunteers who are also living with Parkinson's or caring for someone with it can share knowledge, emotional support, practical ideas and tips all with an attentive, compassionate ear to those who need a little help navigating the disease from various viewpoints and stages. No one is ever prepared for the diagnosis of Parkinson's and the journey that comes along with it so who better to offer guidance and support than those who live with Parkinson's every day; either themselves or as a care partner. The goal of PD Link is to create a supportive connection, on a limited basis, for those with Parkinson's or care partners to those with Parkinson's who would benefit from one-on-one interaction by phone or email. The connection created is based on respect and trust which can be empowering and positive for both the client and volunteer through the sharing of ideas, insights and stories. We recognize that not everyone has access to support groups but everyone needs support and that is why you have PD Link. If you would like to be connected to someone, please call the Parkinson Outreach Center where we will talk with you and help you determine a good volunteer match. If you are someone who has Parkinson's or a caregiver who would like to give back through volunteering for PD Link, please call and we will give you the information on how to get involved. For more information call 407-303-5295



PARKINSON'S: BRAIN AND BEYOND CONFERENCE

HOPE IN ACTION



Join us for the 2018 Brain and Beyond Conference as we seek to educate, empower and equip patients, caregivers and family members with news on the latest trends in managing Parkinson's symptoms and improving quality of life.

Thursday, April 12, 2018

9:00 am | Registration and Vendor Exhibits

10:00 am - 4:00 pm | Speaker Presentations

Marriott Lake Mary

1501 International Parkway

Lake Mary, FL, 32746

Seating is limited.

For more information or to RSVP, call (407) 303-1700 or visit ParkinsonsBrainAndBeyondConference.eventbrite.com

When calling to RSVP, please let us know if you have any special needs and/or your meal preference (boxed lunch options include turkey and brie wrap or greek vegetarian wrap). Continental breakfast also provided. Please make sure to bring a sweater or jacket if you get cold.

This program is free, however, donations are appreciated. You can donate by visiting FloridaHospital.com/ParkinsonOutreach.

Speaker Presentations

MORNING SESSION

Opening Remarks

Florida Hospital and Parkinson Association of Central Florida

Waging War on Parkinson's

Ramon Gil, MD, Parkinson Treatment Center of Southwest Florida

Complementary and Alternative Treatments in Parkinson's

Laurie Mischley, ND, PhD, MPH

Be a PD Ninja!

Jimmy Choi, American Ninja Warrior Contestant, Ultra Marathoner and Team Fox Fundraiser, Person with Parkinson's

AFTERNOON SESSION

Does it Matter What I Eat? Nutrition in Parkinson's

Laurie Mischley, ND, PhD, MPH

A Couple's Perspective on Living with Parkinson's

Chad and Tonya Walker

Presented by



WHEN YOUR GET UP AND GO HAS GOT UP AND WENT-FIGHTING APATHY

BY ANISSA MITCHELL, LCSW FLORIDA HOSPITAL PARKINSON OUTREACH CENTER

Have you noticed that you or your loved one struggle with the motivation to get moving and participate in daily activities? Have you seen a decline in the interest in socializing with friends or participating in hobbies? If so, you might be dealing with apathy. Studies indicate that up to 42 percent of people with Parkinson's experience apathy (Pluck, Brown, 2002). Apathy is a neuropsychological symptom of Parkinson's characterized as the lack of interest and participation in purposeful behaviors, difficulty with initiating, sustaining and completing tasks, and lack of concern for yourself and those around you (Simpson, 2013). These characteristics encompass behavior (treatment compliance, effort), cognition (lack of engagement) and emotion (lack of responsiveness). While apathy can be a symptom of depression, it can exist alone with unique symptoms including a flat affect, generalized indifference, poor social engagement, reduced initiation of activities and poor persistence. While loved ones might perceive the person with Parkinson's as lazy or uninterested, what is happening is related to physiological changes in the brain related to an impaired dopamine pathway and processing of reward

Have you been touched in some helpful way by the Parkinson Outreach Center? Would you like a way to give back or even a way to honor someone in your life with PD? Consider a gift to the Parkinson's Outreach Center. Your tax-deductible gift in any amount goes directly towards programs that are free in the community. Please visit our donation page through Florida Hospital Foundation: FloridaHospital.com/ParkinsonOutreach

which is hindered in patients with Parkinson's (Pluck, Brown, 2002).

Apathy can have a negative impact on the person's treatment compliance, social participation and even disease outcome. But apathy doesn't just affect the person with Parkinson's, it has a significant impact on the caregiver as well. Stress in the caregiver has been found to be higher in those who care for someone less motivated as the caregiver often takes on more responsibilities, must prompt or remind their loved one to do necessary things and often leads to reduced socialization outside the home and even within the relationship if there is a reduction in conversation. However, many PWP's who experience apathy are not concerned or bothered by it and are content to not do anything about it. But for some, there is a recognition of the loss of desire and they do want to do something about it, but are not sure how to make themselves feel something they don't.

If you, or your loved one are experiencing apathy, discuss this with your physician. Treating the non-motor psychological features, such as apathy, depression and anxiety which have a significant impact on quality of life, is just as important as treating the motor symptoms. While there are limited pharmacological treatment options for apathy specifically, aside from dopaminergic medications, there are some things that you can do to manage it.

Increasing engagement in activities has been related to decreases in apathy and depression. Scheduling or having someone assist you in scheduling a daily plan of activities (goals) with set times helps to increase success in completing your goals. Having accountability such as task lists, calendars, and verbal or other types of reminders helps to keep you on track and

documents progress. Giving yourself a reward for completing a task-such as watching your favorite TV show-helps to reinforce the behavior of engaging in and completing your goal. Having accountability for engaging in and completing activities is key to success, reinforces the behavior and provides social interaction. Whether it is a family member, buddy or even a counselor, having to share your goals and accomplishments with another is often a motivator to follow through even if you do lack interest in doing so.

Exercise is another great motivator. Daily physical activity can not only help slow progression of symptoms, the chemical reactions in the brain from strenuous exercise elevates mood and increases motivation.

Lastly, support groups and other social outings can help to encourage and motivate you while providing you the chance to connect socially with others. The Parkinson's Outreach Center offers several programs including PD Link, support groups, CHEER>UP drama therapy, Movement as Medicine and other Parkinson's programs in the community that have been designed to promote wellness, socialization and most of all encouragement and motivation. For more information about how you can get involved, call the Parkinson Outreach Center at 407-303-5295.

This article is a revised reprint from the Staying in Step 2014 newsletter by same author.

Sources: G C Pluck, R G Brown (2002) Apathy in Parkinson's disease. J Neurol Neurosurg Psychiatry 2002;73:636-642

<http://movementdisorders.uchicago.edu/2013/11/26/apathy-and-parkinsons-disease/>

<http://jnnp.bmj.com/content/73/6/636.full>

EDUCATIONAL PROGRAMS OFFERED BY THE PARKINSON OUTREACH CENTER

PD 101 WHAT YOU AND YOUR FAMILY SHOULD KNOW

PD 101 is a quarterly education class that provides a general overview of Parkinson's disease for you and your family. To find out when the next program is being held, contact the Parkinson Outreach Center at 407-303-5295.

COPE-CARE OPTIMALLY PARKINSON EDUCATION

Cope is a caregiver training and small group experience for those who are caring for a loved-one with Parkinson's. Learn about the symptoms, stages of the disease and care needs at each stage, relationship issues including intimacy, coping with stress and more. Space is limited and registration for this program is required. Call the Parkinson Outreach Center for dates, locations and to register 407-303-5295.

PARKINSON'S CARE CONSULTING

The Parkinson Outreach Center offers free consultation with a Parkinson's clinical social worker for individuals and family to help guide you towards your goals of understanding the disease and ways to help you manage it. The social worker can guide you to resources and programs that will help you live well today. To learn more or make an appointment call 407-303-5295.

YOUNG ONSET PARKINSON'S

Did you know we have a program for those diagnosed with Parkinson's under 50? Starting in 2018, this program will be offered monthly on the 1st Thursday at 6:30 pm at the Parkinson Outreach Center office, 1685 Lee Rd., Ste. 110, Winter Park. If you would like to join, contact the POC at 407-303-5295.

PD CARE

Is a NEW patient self-management training and support program for those diagnosed with PD who want to better understand what it takes to fight back at the disease and live the highest quality of life possible. PD CARE provides a greater understanding of PD symptoms, treatments and common concerns while addressing: coping, with the disease, advocating for yourself, relating to others and engaging in the community. This program launches in April on two successive Mondays, April 23rd and April 30th from 1:00 pm to 5:00 pm at One Senior Place, Altamonte Springs. This class is a pilot program and is free, but seating is limited and registration is required. Call 407-303-5295 for more information or to register.

PROGRAMS OFFERED AT CELEBRATION HEALTH

PEDALING FOR PARKINSON'S

Pedaling for Parkinson's an indoor cycling program that provides a safe and effective way for Parkinson's patients to combat symptoms and improve motor function. Under the supervision of an Exercise Physiologist, patients will be coached to maintain a cycle speed of 80-90 RPM's, to increase cardiovascular fitness and improve motor control. This program is now being offered at Celebration Health on Tuesdays and Wednesday at 1:30 pm in the Group Fitness Studio. If you would like to join please call 407-33-4400 or email Adam.Daniel@flhosp.org.

PWR! MOVES

This group class starts with the repetitive training of four foundational skills that make up everyday function. The class emphasizes learning what optimal function should feel like so you can move more quickly and freely during daily activities. This class is Mondays and Thursdays 10:00-11:00 am. To register, call 407-303-4400

PARKINSON SUPPORT GROUP AT CELEBRATION

Starting in 2018, this support group will meet monthly in the Palms Conference Room at Florida Hospital Celebration Health and will offer educational presentations and group meetings. For more information, call 407-303-5295.

FLORIDA HOSPITAL PARKINSON OUTREACH CENTER

The Florida Hospital Parkinson Outreach Center offers support programs for people with Parkinson's disease and their loved ones. All meetings are free to attend!

Call the POC for more information 407-303-5295

[Longwood/Altamonte Support Day Programs](#) - 2nd and 4th Tuesday each month from 10:00 am to 12:45 pm at St Stephen's Church Parish Hall, 2140 W State Rd 434, Longwood, FL 32779. FREE

[Orlando Support Day Programs](#) - 2nd and 4th Thursday each month from 10:00 am to 12:45 pm at Florida Hospital Church, 2800 N Orange Ave, Orlando, FL 32804. FREE

[Lake County Support Group](#) - 2nd Monday each month from 1:00pm to 3:00 pm, at Florida Hospital Waterman, 1000 Waterman Way, Tavares, FL. FREE

[Celebration Support Group](#) - Every-other month from 3:00-4:00 pm at 400 Celebration Pl, the Palms Conference Room, Kissimmee, FL 34747. FREE

[Movement as Medicine](#) - 1st and 3rd Thursday of each month from 2:00-3:15 pm at Florida Hospital Church, 2800 N Orange Ave, Orlando, FL 32804. FREE

[COPE-Care Optimally Parkinson Education for Caregivers](#) - Offered quarterly in several locations/times. For caregiver's only. FREE Call the POC for details 407-303-5295.

[YOPD Meetings](#) - Offered every-other month to those 50 and under. For days and times, call the POC office 407-303-5295. FREE

[CHEER>UP Drama Therapy Group](#) - 3rd Tuesday of each month from 2:00 pm to 3:00 pm, at Florida Hospital Church, 2800 N Orange Ave, Orlando, FL 32804 FREE



PWR! Parkinson Wellness Recovery Exercise Classes Offered in SEVEN locations:

Altamonte Springs - 407-303-5465

Apopka - 407-889-1039

Celebration - 407-303-4400

Orlando - 407-303-8041

Winter Park - 407-646-7711

Lake Mary - 407-323-0399

East Orlando-407-303-8626

Florida Hospital Waterman-352-253-3892



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HELP WANTED



PD Link Central Florida is looking for Volunteers!

Here is your chance to give back! Help others by offering support from the comfort of your own home.

Requirements:

- Have been diagnosed with Parkinson's or have been caring for someone with Parkinson's at least one year
- Able to talk by phone or email
- Complete Short Orientation

Apply TODAY!

Contact Parkinson Outreach Center 407-303-5295 or Email: Alissa.Taylor@flhosp.org

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visit: smile.amazon.com/ch/45-5464483

NIH SCIENTISTS MODIFY NEW RT-QUIC ASSAY TO DETECT PARKINSON'S, DEMENTIA WITH LEWY BODIES

National Institutes of Health scientists developing a rapid, practical test for the early diagnosis of prion diseases have modified the assay to offer the possibility of improving early diagnosis of Parkinson's disease and dementia with Lewy bodies. The group, led by NIH's National Institute of Allergy and Infectious Diseases (NIAID), tested 60 cerebral spinal fluid samples, including 12 from people with Parkinson's disease, 17 from people with dementia with Lewy bodies, and 31 controls, including 16 of whom had Alzheimer's disease. The test correctly excluded all the 31 controls and diagnosed both Parkinson's disease and dementia with Lewy bodies with 93 percent accuracy.

Importantly, test results were available within two days, compared to related assays that require up to 13 days. The group conducted the tests using Real-Time Quaking-Induced Conversion (RT-QuIC), an assay developed and refined over the past decade at NIAID's Rocky Mountain Laboratories. Scientists from the University of California San Diego, University of Verona in Italy, Indiana University School of Medicine, Indianapolis, and the Case Western Reserve University

School of Medicine, Cleveland, collaborated on the project. The research findings were published in *Acta Neuropathologica Communications*.

Multiple neurological disorders, including Parkinson's disease and

about 1,000 times more common than prion diseases, affecting up to 1 million people in the United States, with 60,000 new cases diagnosed each year. Lewy body dementia affects an estimated 1.4 million people in the United States, according to the Lewy Body Dementia Association.

Early and accurate diagnoses of these brain disorders is essential for developing treatments and identifying patients eligible for clinical trials. The diseases typically progress for years before symptoms appear, and once they do, distinguishing one disease from another can be difficult.

The NIAID group continues to adapt the RT-QuIC assay to detect additional types of neurological diseases with greater accuracy using the least invasive patient sample possible--whether that is blood, skin, nasal brushings, or other samples. The group also has trained many international colleagues to use and advance the test

Source: <https://www.niaid.nih.gov/news-events/nih-scientists-adapt-new-brain-disease-test-parkinsons-dementia-lewy-bodies>



dementia with Lewy bodies, involve the abnormal clumping of a protein called alpha-synuclein into brain deposits called Lewy bodies. The pathological processes in these diseases resembles prion diseases in mammal brains. Like prion diseases, Parkinson's disease and dementia with Lewy bodies result in progressive deterioration of brain functions and, ultimately, death. Parkinson's disease is

RESEARCHERS UNCOVER HOW EXCESS CALCIUM MAY INFLUENCE DEVELOPMENT OF PARKINSON'S DISEASE

Researchers have found that excess levels of calcium in brain cells may lead to the formation of toxic clusters that are the hallmark of Parkinson's disease.

The international team, led by the University of Cambridge, found that calcium can mediate the interaction between small membranous structures inside nerve endings, which are important for neuronal signaling in the brain, and alpha-synuclein, the protein associated with Parkinson's disease. Excess levels of either calcium or alpha-synuclein may be what starts the chain reaction that leads to the death of brain cells.

The findings, reported in the journal *Nature Communications*, represent another step towards understanding how and why people develop Parkinson's.

Parkinson's disease is one of a number of neurodegenerative diseases caused when naturally occurring proteins fold into the wrong shape and stick together with other proteins, eventually forming thin filament-like structures called amyloid fibrils. These amyloid deposits of aggregated alpha-synuclein, also known as Lewy bodies, are the sign of Parkinson's disease.

Curiously, it hasn't been clear until now what alpha-synuclein actually does in the cell: why it's there and what it's meant to do. It is implicated in various processes, such as the smooth flow of chemical signals in the brain and the movement of molecules in and out of nerve endings, but exactly how it behaves is unclear.

"Alpha-synuclein is a very small protein with very little structure, and it needs to interact with other proteins or structures in order to become functional, which has made it difficult to study," said senior author Dr Gabriele Kaminski Schierle from Cambridge's Department of Chemical Engineering and Biotechnology.

Thanks to super-resolution microscopy techniques, it is now possible to look inside cells to observe the behavior of alpha-synuclein. To do so, Kaminski Schierle and her colleagues isolated synaptic vesicles, part of the nerve cells that store the neurotransmitters which send signals from

one nerve cell to another.

In neurons, calcium plays a role in the release of neurotransmitters. The researchers observed that when calcium levels in the nerve cell increase, such as upon neuronal signaling, the alpha-synuclein binds to synaptic vesicles at multiple points causing the vesicles to come together. This may indicate that the normal role of alpha-synuclein is to help the chemical transmission of information across nerve cells.

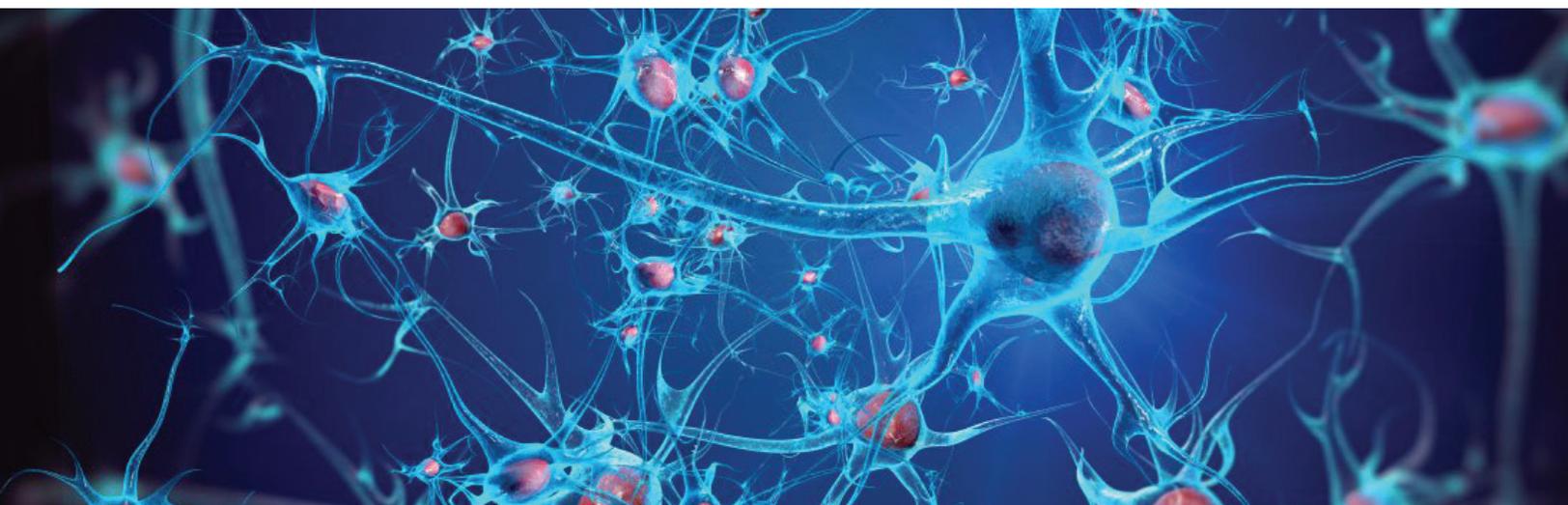
"This is the first time we've seen that calcium influences the way alpha-synuclein interacts with synaptic vesicles," said Dr Janin Lautenschlager, the paper's first author. "We think that alpha-synuclein is almost like a calcium sensor. In the presence of calcium, it changes its structure and how it interacts with its environment, which is likely very important for its normal function."

"There is a fine balance of calcium and alpha-synuclein in the cell, and when there is too much of one or the other, the balance is tipped and aggregation begins, leading to Parkinson's disease," said co-first author Dr Amberley Stephens.

The imbalance can be caused by a genetic doubling of the amount of alpha-synuclein (gene duplication), by an age-related slowing of the breakdown of excess protein, by an increased level of calcium in neurons that are sensitive to Parkinson's, or an associated lack of calcium buffering capacity in these neurons.

Understanding the role of alpha-synuclein in physiological or pathological processes may aid in the development of new treatments for Parkinson's disease. One possibility is that drug candidates developed to block calcium, for use in heart disease for instance, might also have potential against Parkinson's disease.

Source: <http://www.cam.ac.uk/research/news/calcium-may-play-a-role-in-the-development-of-parkinsons-disease>



SCIENTISTS ELUCIDATE WHY EXERCISE SLOWS PROGRESSION OF PARKINSON'S DISEASE

While vigorous exercise on a treadmill has been shown to slow the progression of Parkinson's disease in patients, the molecular reasons behind it have remained a mystery.

But now scientists at the University of Colorado Anschutz Medical Campus may have an answer. For the first time in a progressive, age-related mouse model of Parkinson's, researchers have shown that exercise on a running wheel can stop the accumulation of the neuronal protein alpha-synuclein in brain cells.

The work, published in the journal PLOS ONE, was done by Wenbo Zhou, PhD, research associate professor of medicine and Curt Freed, MD, professor of medicine and division head of the Division of Clinical Pharmacology and Toxicology at the CU School of Medicine.

The researchers said clumps of alpha-synuclein are believed to play a central role in the brain cell death associated with Parkinson's disease. The mice in the study, like humans, started to get Parkinson's symptoms in mid-life. At 12 months of age, running

wheels were put in their cages. "After three months," Zhou said, "the running animals showed much better movement and cognitive function compared to control transgenic animals which had locked running wheels."

Zhou and Freed found that in the running mice, exercise increased brain and muscle expression of a key protective gene called DJ-1. Those rare humans born with a mutation in their DJ-1 gene are guaranteed to get severe Parkinson's at a relatively young age.

The researchers tested mice that were missing the DJ-1 gene and discovered that their ability to run had severely declined, suggesting that the DJ-1 protein is required for normal movement. "Our results indicate that exercise may slow the progression of Parkinson's disease by turning on the protective gene DJ-1 and thereby preventing abnormal protein accumulation in brain," Freed said. He explained that his animal experiments had very real implications for humans.

"Our experiments show that exercise can get to the heart of the problem

in Parkinson's disease," Freed said. "People with Parkinson's who exercise are likely able to keep their brain cells from dying."

Parkinson's is a disease caused by the death of brain cells that make a critical chemical called dopamine. Without dopamine, voluntary movement is impossible. Most people with Parkinson's disease take a drug called L-DOPA to treat their symptoms. The oral drug is converted into dopamine in the brain allowing patients to get up and move.

In 1988, Freed and his colleague Robert Breeze, MD, performed the first transplant of human fetal dopamine cells into a Parkinson's patient in the United States. His lab is currently working to convert human embryonic stem cells to dopamine neurons. These techniques should make it possible to produce unlimited quantities of dopamine cells for transplant.

Source: <http://www.ucdenver.edu/>

ACORDA ANNOUNCES FDA ACCEPTANCE OF NEW DRUG APPLICATION FOR INBRIJA™ (LEVODOPA INHALATION POWDER)

Acorda Therapeutics, Inc.) announced that the U.S. Food and Drug Administration (FDA) has accepted for filing its New Drug Application (NDA) for INBRIJA. INBRIJA is an investigational inhaled levodopa treatment for symptoms of OFF periods in people with Parkinson's disease taking a carbidopa/levodopa regimen. Under the Prescription Drug User Fee Act (PDUFA), the FDA has set a target date of October 5, 2018.

The NDA for INBRIJA includes data from a Phase 3 safety and efficacy study (SPAN-PD), as well as results from two long-term safety studies in people with Parkinson's disease. Findings from these studies support the filing of INBRIJA for use on an as-needed basis to address symptoms of OFF periods in patients on a carbidopa/levodopa regimen. Data from the SPAN-PD trial were presented at the International Congress of Parkinson's

Disease and Movement Disorders (MDS) in June 2017.

"People with Parkinson's and physicians need more options to manage this disease," said Todd Sherer, Ph.D., CEO of The Michael J. Fox Foundation. "Inhaled delivery of levodopa could help the many people living with Parkinson's facing the complication of OFF periods as their disease progresses."

Parkinson's is a progressive neurodegenerative disorder resulting from the gradual loss of certain neurons responsible for producing dopamine. It causes a range of symptoms including impaired movement, muscle stiffness and tremors. As Parkinson's progresses, people will experience OFF periods, which are characterized by the re-emergence of Parkinson's symptoms. This re-emergence can occur even when an individual's treatment regimen

has been optimized. INBRIJA is a self-administered, orally inhaled levodopa (L-dopa) therapy in development for the treatment of symptoms of OFF periods in people with Parkinson's disease taking a carbidopa / levodopa regimen. INBRIJA utilizes Acorda's investigational ARCUS® platform for inhaled therapeutics. INBRIJA was designed to deliver a precise dose of a dry powder formulation of L-dopa to the lung. Oral medication can be associated with variable onset of action, as the medicine is absorbed through the gastrointestinal (digestive) tract before reaching the brain. Inhaled treatments enter the body through the lungs and reach the brain, bypassing the digestive system.

Source: <https://www.businesswire.com/news/home/20180220005557/en/Acorda-Announces-FDA-Acceptance-New-Drug-Application>

DO YOU HAVE PARKINSON'S DISEASE AND IS EXCESSIVE SLEEPINESS SLOWING YOU DOWN?

You may be able to take part in a clinical research study.

The PASSAGE Study is looking at an investigational medication for patients with Parkinson's disease who are very sleepy during the day. The study will look at whether the investigational medication can help patients feel more awake and alert throughout the day. It will also look at how safe the investigational medication is.

Would you like to take part?

You may be able to take part in the PASSAGE Study if you:

- are between 35 and 80 years of age
- have a diagnosis of Parkinson's disease
- experience unusual daytime sleepiness, despite spending 6 or more hours in bed.

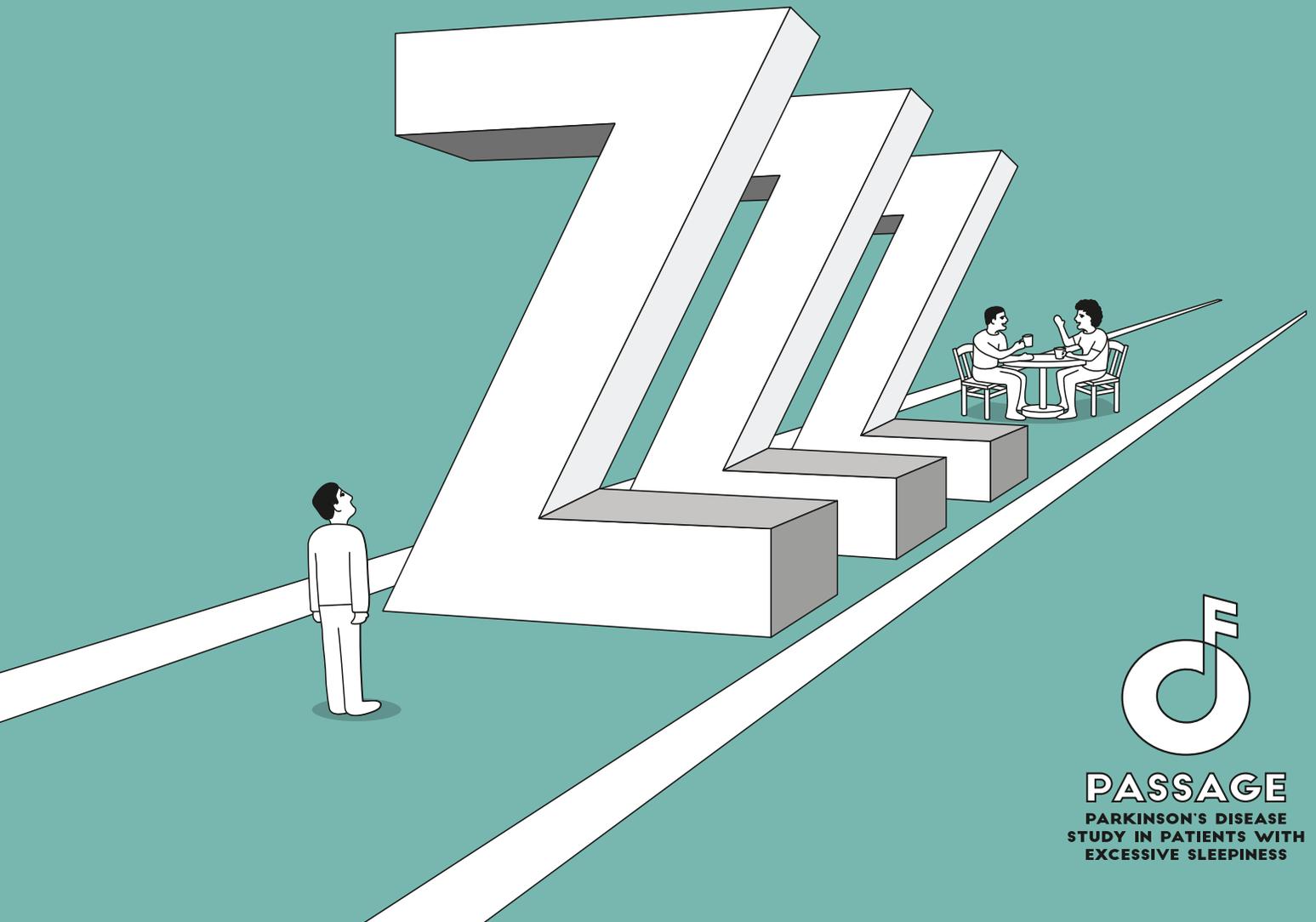
To learn more about this study, please contact

NEHA MAJID

407-210-1157

Neha.Majid@bioclinica.com

The study will last for about 9 weeks and will require 7 visits to the study center. All study-related medication and assessments will be provided at no cost, and you may be compensated for your time in the study.



PASSAGE
PARKINSON'S DISEASE
STUDY IN PATIENTS WITH
EXCESSIVE SLEEPINESS

HELP BE PART OF THE CURE!

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Bioclinica Research is currently enrolling volunteers with Parkinson's Disease for multiple clinical research trials. Research studies are available for all stages of Parkinson's Disease starting with early symptoms of loss of movement control.



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BRAIN N' MOTION

PARKINSONS NEWS TO MOVE YOU FORWARD

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Florida Hospital Parkinson Outreach Center, the Parkinson Association of Central Florida, and Compass Research are **committed** to raising awareness of Parkinson's disease, offering programs and **resources** for those living with the disease, and furthering the research of **new treatments**. We believe that combining our efforts to deliver **important**, breaking news in the PD community would help us reach more people **impacted** in the Central Florida community.

