

February 2023



Moving Along

A newsletter of the Waverly Area
Parkinson's Disease Support Group

UPCOMING MEETINGS

Parkinson's Support Group

Saturday, February 11 | 10 a.m. to Noon | Tendrils Rooftop Garden

We will start by getting everyone moving, then break into groups for discussion with those who have Parkinson's and those who are care partners. Park in the Red Lot and enter through the door marked "Tendrils" near the pharmacy drive-up window. This event is free and open to all. Masks are optional. Call (319) 352-4961 with questions.

Exercise Programs at The W

Delay the Disease: Exercise Program for People with PD | M, W, F | 10 to 10:50 a.m.
For more information or to sign up, call (319) 352-8311 or go to: the-w.org

WHC Parkinson's Singing Group

This group meets Mondays at 10 a.m. in Tendrils Rooftop Garden. For information on how to participate, contact Kara Rewerts by phone at (319) 483-4118 or via email at KRewerts@WaverlyHealthCenter.org

PD Essentials Class

Weekly on Wednesdays, 11 a.m. to 12 p.m. CST | February 22 - March 29

The class is open to any adult who has been diagnosed with Parkinson's disease within the last 5 years, their care partners and adult family members. Class will meet at On With Life, Ankeny, in person or login remotely via zoom. For more information and to register, go to:

<https://www.apdaparkinson.org/community/iowa/>

ADDITIONAL MEETINGS

Understanding Parkinson's Disease: A Virtual Series for Those Living with Parkinson's Disease

February 6, 13, 27, 28, March 6, 14, 15,
all at 7 p.m. CST

Please join us for the upcoming virtual Parkinson's disease (PD) series hosted by the University of Kansas Parkinson's Foundation Krupp Smith Family Foundation Center of Excellence.

For more information and to register, go to:
<http://bit.ly/3YhrVgf>

APDA Virtual Parkinson's Conference: Educate, Empower, Engage

February 15-16, 11 a.m. to 3:30 p.m. CST
each day

FREE two-day event designed to educate, empower and engage you! Perfect for people with PD, care partners, friends and family, and anyone who wants to learn more.

For more information and to register, go to:
<https://bit.ly/3jiBPQe>

Redefining Intimacy in Parkinson's Disease and Beyond

February 15, 12 to 1 p.m. CST

Join us to learn how others are navigating intimacy changes and challenges during this candid, virtual conversation.

For more information and to register, go to:
<http://bit.ly/40cqLVc>

NEW STUDY INDICATES THAT NEW CASES OF PARKINSON'S DISEASE ARE 50% HIGHER THAN PAST ESTIMATES

The results of a new study show that the incidence of Parkinson's disease (PD), or the number of new cases diagnosed per year, is 50% higher than previously estimated. Instead of past estimates of 60,000 new cases of PD diagnosed per year, the new study determined that there are approximately 90,000 new cases

of PD diagnosed in the US per year. In addition, the study looked at the geographical variation of diagnoses and found a higher incidence of PD in certain areas of the Midwest and South, as well as in southern California, southeastern Texas, central Pennsylvania and Florida.

This current finding builds on past work that updated the estimates of the prevalence of PD, or the total number of people diagnosed in a population. About four years ago, a crucial study determined the prevalence of PD to be approximately one million in the United States. The study estimated that the prevalence will increase to 1.3 million by 2030, which aligns with an increase in the incidence, or the number of cases being diagnosed.

The study results beg the question - why is the incidence so high? The answer is likely due to a number of reasons: 1) the clearest risk factor for being diagnosed with PD is age, and the population is aging, therefore more people are being diagnosed; 2) there is increased awareness of the disease, so people are more likely to go to a doctor for a symptom that in the past, may have been dismissed as normal aging. This increased engagement with the medical community can increase diagnoses as well; and 3) there may be factors in the environment that are increasing PD risk and therefore PD diagnoses. One such chemical is paraquat, a herbicide. Currently, there are efforts to advocate for a ban on paraquat in the US.

Knowing the accurate incidence and prevalence of PD are vital for the PD community. It is crucial to have accurate PD statistics since they inform lawmakers who make decisions concerning allocation of research funds about the true impact of the disease. They also inform public health officials who need to plan for the growing PD population. Currently, the National Plan to End Parkinson's Act is working its way through both houses of Congress and if passed will unite the federal government as well as all those impacted by PD to create ways to further prevention, medical care, treatment and



research for PD. Knowing the number of people in the US who have been recently diagnosed, the total number of people diagnosed, and the geographic locations of those affected, will be essential to these efforts.

Source: <https://www.apdaparkinson.org/article/new-study-indicates-parkinsons-disease-is-50-more-prevalent-than-previously-thought/>

COUGH MEDICINE COULD BE USED IN NEW TREATMENT FOR PARKINSON'S DISEASE

Ambroxol is a drug which is currently used to treat respiratory conditions. It promotes the clearance of mucus, eases coughing and has anti-inflammatory properties.

Pre-clinical studies, led by Professor Anthony Schapira at the UCL Queen Square Institute of Neurology, identified ambroxol as a candidate drug to slow the progression of Parkinson's.

Results of the Phase 2 clinical trial by Professor Schapira and performed at UCL was published in January 2020 and tested ambroxol in people with Parkinson's. It found that ambroxol was able to effectively reach the brain and increase levels of a protein known as GCase (glucocerebrosidase). GCase allows cells to remove waste proteins, including alpha-synuclein (a protein that builds up in Parkinson's and is thought to be important in its cause), more effectively.

Additionally, the Phase 2 trial showed that ambroxol was safe for people with Parkinson's and was well tolerated.

The world-first Phase 3 trial, named ASPro-PD, is led by Professor Schapira and is in partnership with U.K. charity Cure Parkinson's and Van Andel Institute—following eight years

of work with the Parkinson's community.

The trial will involve 300 people with Parkinson's across 10-12 clinical centers in the U.K. It will be placebo controlled and participants will take ambroxol for two years.

The effectiveness of ambroxol will be measured by its ability to slow the progression of Parkinson's using a scale including quality of life and movement. Preparations for recruitment of trial participants have already started.

Professor Schapira said, "I am delighted to be leading this exciting project. This will be the first time a drug specifically applied to a genetic cause of Parkinson's disease has reached this level of trial and represents ten years of extensive and detailed work in the laboratory and in a proof of principle clinical trial..

"The study design is the result of valuable input from people with Parkinson's, leaders in the field of Parkinson's, trial design and statistics from the UCL Comprehensive Clinical Trials Unit (CCTU), the MHRA and a consortium of funders led by Cure Parkinson's, all operating as an effective team to ensure we have reached this stage.

"We look forward to working with all these groups to ensure successful completion of the study."

After the Phase 2 data from Professor Schapira's group at UCL found that ambroxol could increase the removal of alpha-synuclein, the international Linked Clinical Trials (iLCT) program prioritized research into the drug.

Created and operated by Cure Parkinson's and Van Andel Institute, the iLCT program's mission is to slow, stop and reverse the progression of Parkinson's. It aims to significantly reduce the time to bring disease-modifying treatments to the Parkinson's community by testing promising drugs that already have extensive safety data and, in some cases, have been approved by regulators for other medical conditions.

Will Cook, CEO of Cure Parkinson's, said, "This trial is a big step forward in the search to find new treatments for Parkinson's. Once the ambroxol trial is underway, it will be one of only six Phase 3 trials on public record of potentially disease-modifying drugs in Parkinson's, worldwide.

"We at Cure Parkinson's are working hard—through our efforts within the iLCT program and in our fundraising efforts—to increase this number significantly in the next few years, to accelerate our progress towards a cure for Parkinson's."

Source: <https://neurosciencenews.com/parkinsons-ambroxol-222271>

IMPACT OF PARKINSON'S DISEASE ON RELATIONSHIPS

If you have Parkinson's disease, you probably realize that all of your relationships – those with your spouse, partner, family, friends, colleagues and acquaintances – can change. They can change in a good way (you renew and deepen a connection) or in a bad way (you completely lose a relationship).

The most important thing to remember when reflecting on how Parkinson's influences your relationships is that you have some say in the matter. While you cannot control how people react to your condition, you can speak up when people start to treat you in ways that are incompatible with your dignity or independence.

Your Most Important Relationships: Your Spouse and Yourself

The most important relationship you will have throughout your Parkinson's is your relationship with yourself. You will need to find ways to nourish your spirit despite much

adversity. You will need to find an inner spiritual core that can sustain you while you struggle to maintain a normal life despite Parkinson's daily intrusions.

No one can tell you how to do this. No one but you knows what really recharges your batteries and imparts to you inner calm, strength and fierceness. Whatever that thing is, that thing that gives you strength and a zest for life, you will need to nurture it and rely on it both to fight the illness and to keep your other relationships healthy and nourishing.

The second most important relationship for you, if already part of your life, will be your 'significant other' – your spouse, partner or primary companion. This person is the one who will witness your hardest moments and your brightest. You have got to find ways to graciously accept all of the help your companion is willing to give you. You also need to learn the ropes of coping with Parkinson's together. As much as you can, help that person learn about Parkinson's, keep spirits up and remain intimate with you.

Your partner needs you and you need your partner. Rejoice in that fact. Believe it or not, Parkinson's disease and its challenges can actually deepen and strengthen your relationship.

Parkinson's disease can have an impact on the relationships you have – sometimes for the good, sometimes not. But there are things you can do to deal with the effects your condition can have on connections with those close to you and foster the continuation of healthy and happy bonds.

Source: <https://www.verywellhealth.com/impact-of-parkinsons-disease-on-relationships-2612111>

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