

# In Touch Newsletter May/June 2024

## Cough medicine could be used in new treatment for Parkinson's

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 University College London (UCL) Queen Square Institute of Neurology identified ambroxol as a candidate drug to slow the progression of Parkinson's.

A Phase 2 clinical trial by Professor Schapira was performed at UCL to test ambroxol in people with Parkinson's.

It found that ambroxol was able 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, will also be led by Professor Schapira in partnership with U.K. charity Cure Parkinson's and the Van Andel Institute following eight years of work with the Parkinson's community.

The trial will involve 330 people with Parkinson's across 10 to 12 clinical centres 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 Medicines and Healthcare products Regulatory Agency (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 prioritised research into the drug.

Created and operated by Cure Parkinson's and the 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 clinic for 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."

#### Sources

<u>Neuroscience News</u> <u>University College London (UCL)</u>

## A good diet can help with anxiety and panic disorders

People with Parkinson's can often experience non-motor symptoms such as anxiety and panic disorders.

Anxiety is a condition that causes fear, worrying, and/or nervousness. The fears may or may not be based on reality.

Anxiety can have severe effects, causing feelings of fatigue, and can affect sleep, work, and even relationships. Some people with Parkinson's avoid social engagements, for example, for fear of being criticised or judged by others.

Panic disorder is another kind of anxiety, in which a person has a sudden attack of uncontrollable terror. It can cause shaking, panting or trouble breathing – each of which can also present as Parkinson's symptoms. Panic attacks make Parkinson's symptoms much worse and can even stop medications from working.

## What causes anxiety and panic disorders?



For some people, low blood levels of nutrients such as iron, vitamin D, and vitamin B6 are related to anxiety and panic disorders. And, for reasons not entirely clear, many people with Parkinson's have been found to have low levels of these nutrients.

Iron is involved in the production of some neurotransmitters, including dopamine. In one study<sup>1</sup>, iron-deficient patients were given iron supplements, and found a reduction in their anxiety.

Additionally, in a review of preclinical and clinical studies<sup>2</sup>, researchers found that, among other nutrients, low iron levels were involved in people experiencing anxiety<sup>3</sup>.

In a study related to vitamin D deficiency, researchers studied over 7,000 individuals with regard to depression, anxiety, panic, and phobia, and found that vitamin D deficiency was associated with depression and panic<sup>4</sup>.

Other researchers have found widespread deficiency of vitamin D among people with Parkinson's; deficiency is also associated with depression, falls, and bone fractures.

Some people who have panic attacks have a low level of serotonin, a neurotransmitter found in the nervous system and in blood platelets. Serotonin is produced by vitamin B6 and iron from the amino acid tryptophan.

Researchers studied individuals who were having panic attacks and found that they had lower levels of both B6 and iron than patients in a control group who didn't experience panic attacks<sup>5</sup>. This suggests that B6 and iron levels in the blood may be factors in panic attacks.

## How do you know if you have nutrient deficiencies?

If you experience anxiety or panic attacks, your doctor can test your blood for levels of iron (blood levels of ferritin, hemoglobin, and hemocrit), vitamin B6 (pyridoxine) and vitamin D (25[OH]D). If levels are very low, the doctor may prescribe supplements or even injections, to bring your blood levels back to normal.

It will also be important for you to be sure to get enough of these nutrients in your daily meals. Supplements are helpful, but foods have supporting nutrients that work together to provide much greater benefit than a supplement.

Also, iron is found in elevated amounts in the brain of people with Parkinson's – it is a pro-oxidant and can be inflammatory in the large amounts found in supplements, so foods are a better choice.

## Seeking advice

If you experience anxiety and/or panic attacks, first ask your doctor to rule out deficiencies of iron and vitamins B6 and D. If you are deficient in one or more of



these, your doctor can decide whether you need supplements, injections, or simply an improved diet.

When your blood levels return to normal, you may find the anxiety and panic attacks have stopped. If not, there are medications your doctor can prescribe to treat anxiety and panic disorders.

However, not everyone responds equally well to them, and for some, the side effects can be an additional problem. Your doctor can help determine the best course of action for you.

#### Source

Kathrynne Holden, former National Parkinson Foundation dietician (UK) Visit her website, <u>nutritionucanlivewith.com</u>, for more Parkinson's-related nutrition information

For more evidence-based information and advice call the Parkinson's NSW InfoLine: 1800 644 189

### Exercise needs to be fun!

The process of getting fit doesn't have to be feared; it only requires you to be consistent.

It also doesn't need to be vigorous or done for long periods to improve your quality of life and health. So let's get moving!

Start with small, achievable goals. Setting lofty goals will become overwhelming very quickly and have you thinking it's all too hard.

A small goal could be: "I'm going to go for a walk once a week". However, if you say: "I'm going to walk every single day of 2020" the chances of failure are high.

Start by spending some time thinking about what exercise or activity makes you happy? Something you find fun or social.

If you can't stand the gym and love being outdoors, start by looking into some short bush walks in your area. Is dancing your thing? Commit to a weekly class and increase from there.

Do you like to chat whilst you are exercising? Ask a friend to go for a walk or come to a class with you. You'll be doing them a favour as well as yourself. Or join an exercise group if your friends aren't available.

If you enjoy peace and quiet and some alone time, then swimming may well be your thing. Tailoring what exercise you do, to what you enjoy is vital.



When you have decided what activities you enjoy, the secret is to physically schedule it into your diary, like you would a doctor's appointment. Setting aside time in your diary and planning days and time when you will exercise is a much more effective than "...I'll start my exercise sometime tomorrow or Monday".

We all have busy lives and there is always something else that needs to be done, but this is your health, wellbeing, and quality of life we are talking about.

What is really more important than that?

Schedule your exercise like it's an important meeting and you'll be more likely to stick to it.

## Managing heartburn and reflux

People living with Parkinsons can experience heartburn or oesphageal reflux – and hiatus hernia (where your stomach bulges up into your chest through an opening in your diaphragm) and ulcers may also be problematic.

Parkinson's medications can cause heartburn and it is a common problem with ageing. Heartburn is an annoying and painful burning sensation.

Oesophageal reflux is a condition in which the valve closing off the stomach from the oesophagus fails to close properly allowing stomach acid contents to flow upwards towards the throat causing the painful burning sensation.

Stomach acids are very strong and can damage and scar the valve or oesphageal sphincter as well as the base of the throat. The condition is called oesphagitis and can make it increasingly difficult to swallow or to keep the valve closed.

Acid reflux can also be accidentally inhaled into the lungs causing aspiration pneumonia, which is a very dangerous, sometimes fatal condition needing expert management.

Not all foods affect people in the same way and so some investigative work may need to be undertaken to decide which foods are problematic. Taking an accurate record of foods eaten prior to the attack is recommended.

Some foods known to be problematic are tomatoes, citrus juices, pepper, decaffeinated coffee, chocolate, caffeine, peppermint, spearmint, garlic, onion, carbonated drinks, and alcohol.

Foods high in fats stay longer in the stomach and are more likely to cause issues particularly if eaten later in the evening. Very hot or very cold foods can also cause reflux.

Keeping a list of foods eaten, timing of medications, time of meals, amount eaten may assist in identifying the issues.



The amount of food eaten is just as important as the type of food; reflux is more likely to occur when the stomach is full as it causes the contents to push upwards putting pressure on the valve.

It is best to eat smaller meals with snacks in between and to eat your evening meal earlier rather than later. This allows the stomach to empty prior to lying down in bed where the stomach contents can push upwards, thus causing discomfort.

Tips on managing reflux

- Eat smaller meals
- Have small nutritious snacks between meals
- Eat your evening meal early
- Slightly elevate the head of the bed
- Wear loose fitting clothing
- Avoid smoking
- Avoid or reduce stress

#### Source

Eat Well, Stay Well with PD By Kathryn Holden

## How singing helps with Parkinson's

Communication impairment in voice and speech changes affects most people living with Parkinson's eventually.

The most common communication disorder is hypokinetic dysarthria, which causes rigidity and slowness of communication systems, including breathing, swallowing, voice, and speech. It can lead to reduced voice volume, hoarseness, imprecise articulation, and tremors.

Studies have shown that singing offers an engaging way to enhance voice and communication for people living with mild to moderately severe Parkinson's. Intensive singing can increase vocal loudness, respiratory muscle strength, and voice-related quality of life.

Jenny Yoston is a neurological music therapist and founder of the Music Affect Centre in Canada. She uses music in her work with residents in a senior long-term care facility and in her private practice. She has found that music connects with people emotionally and socially, and she has seen its physical benefits.

"Singing is a great way to slow the progression of Parkinson's. It's particularly beneficial for speech and swallowing, and the sooner you start, the better."

She notes the rise in research using music and its elements for people with neurological disorders.



"Scientists and neurologists are collaborating with those in the music psychology and music therapy fields. I'm excited about these collaborations and their future findings. There is so much more to music. We just need to learn to share how to use its power!"

When the pandemic began, she saw that many of her Parkinson's patients were isolated and unable to come to appointments, so she developed a DVD people could use at home.

*"ParkinSing* is a music and fun scientific approach to vocal exercises and respiratory maintenance for people with Parkinson's. With the DVD, they can still maintain where they were during their in-person sessions in a fun way."

## **Choral Singing**

Paula Wolfson is an award-winning performer with a long career in professional theatre. She also works with vulnerable populations using music and is a certified artist-educator.

Paula became involved with a new choir through a study conducted by Dr. Frank Russo and Esztella Vezer of Ryerson University's Smart Lab in Toronto to see if "emotional" singing would impact the Parkinson's mask (the difficulty some people with Parkinson's have in producing facial expressions).

The results are still being finalised but showed that overall, the effects of ongoing group singing are beneficial on many levels, as Paula indicates.

"Voices, both speaking and singing, grow stronger; breath is better controlled as the expressive muscles of the face are exercised; there is a deep sense of belonging and communal support; there is pride and a feeling of accomplishment as the brain is engaged with learning new songs and vocal techniques."

Paula has continued to lead the Singing With Parkinson's choir. She emphasises that participants don't need any prior group singing experience.

"Partners and caregivers are welcome to join. Our choir participants tell us that the social hour after the singing session is equally as important as the singing because it provides a safe community where they can speak openly."

## For evidence-based information and advice call the Parkinson's NSW InfoLine

1800 644 189 Parkinson's NSW InfoLine Email: pnsw@parkinsonsnsw.org.au Web: www.parkinsonsnsw.org.au