In Touch Newsletter
June 2026

New biomarker improves diagnosis of Parkinson's and Lewy body dementia

An international consortium has achieved a major breakthrough in the diagnosis of neurological diseases. In a recent publication, they described the discovery of a new quantitative biomarker in lumbar fluid (cerebrospinal fluid) that is helping doctors to diagnose Parkinson's disease and Lewy body dementia more accurately.

The researchers published their findings in the scientific journal *Nature Medicine*.

The consortium, led by Dr Katharina Bolsewig and Prof Charlotte Teunissen of the Laboratory of Neurochemistry at the UMC in Amsterdam, with the essential contribution of Dr Sebastiaan Engelborghs, Professor at the Vrije Universiteit Brussel (VUB) and Head of the Department of Neurology at UZ Brussel, focused on the protein DOPA decarboxylase.

This protein plays a crucial role in the production of dopamine in the brain. The study shows that the concentration of DOPA decarboxylase in cerebrospinal fluid is significantly higher in patients with Parkinson's disease or Lewy body dementia.

This difference is even clearly measurable compared with patients suffering from Alzheimer's disease, making the test highly specific.

"The importance of this discovery for clinical practice is considerable, as dementia with Lewy bodies is often difficult to diagnose correctly at present," said Professor Engelborghs.

"Because of the strong overlap of symptoms with other forms of dementia, patients are regularly misdiagnosed. Misdiagnosis can lead to less effective or, in some cases, harmful treatment. The new measurement method provides doctors with an objective tool for determining the right course of action at an early stage".

In the course of the study, the consortium developed two highly sensitive laboratory tests to reliably record the presence of DOPA decarboxylase. The results show that values in the target group are up to two and a half times higher than in healthy control subjects. In addition, a higher concentration of the biomarker correlated directly with the degree of pathological changes in the brain, underlining the biological relevance of the test.

Although these results represent a significant step towards everyday application in healthcare, the consortium stresses that further standardisation is required.

"We can speak of a fruitful international collaboration. This publication brings a crucial biomarker closer to the patient, precisely in cases where diagnosis is still too often associated with uncertainty," concluded Engelborghs.

Source:
Vrije Universiteit Brussel

New possible cause of Parkinson's discovered

Scientists have proposed a concerning new theory to explain the surge in Parkinson's disease, which suggests nearly everyone could have a more increased risk.

While the illness has long been linked to genetics and the environment, researchers in China now believe microplastics may also play a role.

In a review of more than 100 studies, the researchers said the tiny plastic fragments that enter the body daily through food and water could accumulate in the brain.

Once there, they warned the plastic could trigger the accumulation of toxic protein clumps linked to Parkinson's.

Writing in their review, they said: 'With the intensification of global plastic pollution, the potential threats posed by micro- and nanoplastics to human health have become a major concern.

'[Microplastics] enter the organism through ingestion, inhalation, and skin contact, subsequently accumulating in multiple organs – particularly the brain.'

The warning comes as Parkinson's cases have more than doubled globally in the last 25 years, with an estimated 8.9 million people now living with the disease.

In the US, about 1.1 million people are estimated to have been diagnosed with Parkinson's disease, a number that is set to double by 2040.

At the same time, plastic levels in the environment have surged.

Plastic debris first appeared in significant amounts in the 1960s, and is now virtually ubiquitous in the US environment.

Today, researchers estimate that the average American consumes about five grams of microplastics every week, the equivalent of a spoon full, 21 grams every month, the same as the weight of five casino die, and 125 grams every six months, or enough to fill a standard bowl of cornflakes.

Studies have already linked exposure to these plastics to numerous harmful effects, including infertility, cancer, and developmental delays, which experts say is because they can damage cells or interfere with hormones.

Microplastics in the environment come from the degradation of larger plastic items that takes place during use or in the environment.

In their study, the scientists — led by Gannan Medical University in southern China — noted that a microplastic is a plastic fragment smaller than five millimetres, while a nanoplastic is smaller than a thousandth of a millimetre.

In the brain, they said they could cause toxic alpha-synuclein protein clumps to form, which are typically found in Parkinson's patients.

In their review, the team cited evidence that the plastic particles could also cause neuroinflammation, disrupt cell communication and carry metals into the brain, which they said may also raise the risk of the disease.

Published in the *Nature* journal npj Parkinson's Disease, researchers analysed more than 100 studies based on animal testing or lab experiments

The scientists noted that they had only detected an association and said more research was needed to back up their claim.

Parkinson's disease is caused by the loss of dopamine-producing cells in the brain, triggering irregular brain activity and the symptoms linked to the disease.

It is not clear why this happens, but previous research suggests these cells may be eliminated by the immune system misfiring. This could be caused by genetics and exposure to certain toxins, pesticides and even well water.

People at the highest risk of Parkinson's are individuals aged over 60 years old and men, who are 50 percent more likely to develop the condition than women.

Source:
Original article by Luke Andrews, U.S. Senior Health Reporter, MSN.com

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Why Michael J. Fox Sees Parkinson's as a 'Gift That Keeps on Taking'

When Michael J. Fox was diagnosed with Parkinson's disease at age 29 in 1991, "…it was an old person's disease," he says. "It was not a disease that got much attention."

But now that it was *his* disease to deal with for the rest of his life, Fox got busy learning everything he could about the state of scientific progress and the realities of

living with Parkinson's. He quickly saw what was missing – and what he could help provide.

"I was motivated by what I heard from the science people who said that the science is ahead of the money," says Fox. "They said, 'If you can direct money toward the right research, we can speed things along.' And then I was touched and motivated by the patient community. They just needed someone to step in and push things along."

Fox co-created the Michael J. Fox Foundation for Parkinson's Research with Deborah Brooks, formerly of Goldman Sachs, in 2000 essentially "to be a noodge; I wanted to push things along," he says.

He went where the money is – to businesses and hedge funds – and appealed to the "ego side of them, to the winners who wanted to win, and I said, 'Let's win [against this disease].'" He brought with him his trademark charm. Fox's philosophy: "I'll come in your office, I'll take pictures with all of your employees, and I'll pound you for money," he says.

Key role

The organisation's key role, more than 25 years later, is to convene scientists, policy makers, and advocates to address barriers standing in the way of better understanding Parkinson's and developing new treatments – and ultimately a cure.

"Our goal was to put ourselves and the capital we would raise into the perspective of the patients: what are their unmet needs, and what could be done?" says Brooks, who oversees the foundation's fundraising and marketing efforts. "What we saw at that time was not much in the way of novel targets for drug development. And I think today there are 175-plus therapeutic interventions being tested in humans."

Since its creation, Fox and Brooks have built the foundation from a startup into the largest nonprofit funder of Parkinson's research, surpassing even the U.S. government, with more than $2 billion provided to scientists to date.

One of the projects the foundation supports is to find ways to identify and track the progression of Parkinson's, a critical step toward identifying patients early and allowing doctors to monitor the progression of the disease and the effectiveness of new treatments.

The Parkinson's Progression Markers Initiative is a study involving scientists from around the world to identify the key biological signals of the disease; since its launch in 2010, the study has tripled the number of Parkinson's patients enrolled and led to a breakthrough test of spinal fluid for a key abnormal protein of the disease, years before the first symptoms appear.

Way to diagnose the disease

The test provides a scientifically validated way to diagnose the disease, improving on the symptoms-based criteria on which doctors had previously relied.

Sharing his diagnosis, as well as being open about how it was affecting him, wasn't an easy choice, Fox says. It took about seven years after his diagnosis to disclose it publicly, but once he did, he saw the impact.

"I went online and into Parkinson's chat rooms, and I would go in anonymously, and would ask, 'What do you think of this Michael Fox thing?' And they would say, 'It's great.' I would think, 'You're celebrating my having Parkinson's.' But then I got it, and realised these people were stuck in the rocking chair on the porch for all this time to just whittle away until they can't move, and never had a part in solving their problems."

"The more I thought about it, the more I thought it was a privilege, and in a way, a gift," he says. "It's a gift that keeps on taking, but if I look at the positive side of it… this is a role that I fell into and I found myself uniquely qualified to fulfill. Now people say, 'I have what Michael Fox has.' Parkinson's patients now have an identity, and they don't have shame."

Fox says advances in genetics and the progress in identifying biological markers of Parkinson's are only the beginning. "I know we've done a lot, but we haven't cured Parkinson's," he says. "I'm always pushing and never happy until we get this done. We've changed the way people think about the disease, and we know there's an end, and we'll find it."

That requires continuing to build on what the foundation has started so that promising treatments can come to fruition. "I was always a small guy; I was bullied and pushed around, and I would overcome that and push through it. [Parkinson's] is the biggest bully there is for me. And I'm not just going to let it get its way. We're going to have a fight and I'm going to get a few punches in. I may get beat up in the long run, but we'll get it done. I'm a – pardon my language – tough son of a bitch and I'm going to get it done."

Ultimately, he says, "I'd like to see a world without Parkinson's, and I think that will happen. I think in 30, 40 years, this will be done. Optimism is a powerful thing."

Source:
Original article by Alice Park, Senior Correspondent, TIME Magazine

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Excessive daytime sleepiness

Some Parkinson's medications can cause excessive daytime sleepiness or sudden onset of sleep.

What causes excessive daytime sleepiness?
Excessive daytime sleepiness is a non-motor symptom of Parkinson's, but researchers aren't sure whether it's part of how Parkinson's progresses or if it's caused by Parkinson's medication.

Evidence suggests that it's more common if you are taking Parkinson's drugs, especially dopamine agonists. It can also be common in people taking levodopa. Amantadine, another Parkinson's drug, can cause insomnia, which can cause tiredness the following day.

There are also other factors that can contribute to excessive daytime sleepiness. People with Parkinson's who experience night-time sleep disturbances are more likely to experience excessive daytime sleepiness. If you have fatigue, another common Parkinson's symptom, you may also have daytime sleepiness.

How can excessive daytime sleepiness be managed?
If you experience daytime sleepiness, it's important to speak to your specialist or Parkinson's nurse.

One way of managing it is to reduce the amount of medication you are taking that may be causing the symptom. But that may mean your Parkinson's symptoms aren't as well controlled.

For mild to moderate excessive daytime sleepiness, things that can help include:
- Regular, daily physical activity, such as walking
- Taking a short daytime nap
- Playing board games or electronic games when you begin to feel tired
- Eating healthy food and avoiding alcohol

At night, good sleep hygiene can be helpful – having a good night's sleep can help reduce feeling tired during the day. Sleep hygiene 'rules' include keeping to a regular routine and reducing noise and light in your bedroom.

It is also a good idea to avoid drinking too much tea or coffee, which can result in urinary frequency and disturb your sleep.

Source:
Original article by Parkinson's Nurse Lee Kieft
Parkinson's UK

Take 5 June

A monthly review of the top five issues raised in calls to the Parkinson's NSW InfoLine team (call 1800 727 567).

1. Bone Health and Parkinson's

Falls and bone health often go hand-in-hand in Parkinson's. People living with Parkinson's have a higher risk of falls and are more likely to develop osteoporosis, increasing the risk of fractures. Reduced mobility, balance difficulties, and changes in posture can all increase the likelihood of fractures.

There are several ways to support bone health, including regular weight-bearing exercise, adequate calcium and vitamin D intake, and discussing bone density scans with your GP. Strength and balance exercises can also help reduce falls risk. If you're concerned about your bone health, speak with your healthcare team about prevention strategies before problems arise.

2. Alcohol and Parkinson's

Many people ask whether they need to give up alcohol completely after a Parkinson's diagnosis. For most people, moderation is the key rather than complete avoidance.

Alcohol can sometimes worsen symptoms such as balance difficulties, sleep disturbances, dizziness, and low blood pressure. It may also interact with certain medications. If you choose to drink, it's worth discussing what is appropriate for your individual circumstances with your GP or neurologist. The goal is to make informed choices while still enjoying life's pleasures where possible.

3. Word Finding Difficulties and Communication

Difficulty finding the right word can be a frustrating symptom for some people living with Parkinson's. It may lead to pauses in conversation, losing track of thoughts, or difficulty expressing ideas clearly.

Family and friends can help by allowing extra time for responses, avoiding finishing sentences unless asked, and reducing distractions during conversations. Speech pathologists can also provide practical strategies to support communication and confidence. Early intervention can make a real difference.

4. When Eating Becomes Messy

Eating should be enjoyable, but Parkinson's can sometimes make mealtimes challenging. Tremor, reduced dexterity, swallowing difficulties, excess saliva, changes in posture, and slower movements can all contribute to messy eating and make people feel self-conscious, particularly in social situations.

The good news is that there are practical strategies and supports available. Adaptive cutlery, non-slip plates, specialised cups, and seating adjustments can make eating easier. Speech pathologists can assist with swallowing difficulties and saliva

management, while occupational therapists can recommend equipment and techniques to support independence and confidence at mealtimes.

If eating is becoming frustrating or you're avoiding social situations because of it, speak with your healthcare team or contact the Parkinson's NSW InfoLine for advice and referral options.

5. Waking Early and Fragmented Sleep

Many callers report waking in the early hours of the morning and struggling to get back to sleep. Sleep disturbances are common in Parkinson's and can leave people feeling exhausted during the day.

Helpful strategies may include maintaining a consistent sleep routine, limiting caffeine later in the day, reducing screen time before bed, and keeping the bedroom comfortable and dark. It's also important to discuss sleep issues with your medical team, as medication timing, anxiety, pain, or overnight Parkinson's symptoms may be contributing factors. Good sleep is an important part of overall wellbeing and symptom management.

If any of these topics sound familiar, our Parkinson's NSW InfoLine team is here to provide further information, support, and referrals to help you live well with Parkinson's.

For information or personalised guidance on any of these topics, please contact the Parkinson's NSW InfoLine on 1800 727 567. We're here to support you every step of the way.

Communication tips for family and friends if your loved one has Parkinson's

If your loved one experiences speech and communication problems as part of their Parkinson's, there are ways you can support conversations. Here are some useful strategies to reduce frustrations and help make your conversations more successful.

1. Make sure you and the person with Parkinson's can see and hear each other. Facing someone with Parkinson's can be particularly important to help them communicate clearly and understand you. You don't need to shout.

2. Be patient. Give the person affected the opportunity to get involved in a conversation but don't pressure them to speak if they don't want to. They may need extra time to respond, so try not to interrupt or walk away.

3. Try to avoid speaking above noise, such as a TV or radio. Try not to be too far away – for example, in another room – when talking.

4. Be reassuring and help them to relax if you can see they're stressed.

5. If you don't understand what they say, ask them to repeat it more loudly and slowly. If it's just a key word you've missed ask them to repeat that word.

6. Try not to pretend you've understood if you haven't.

7. Try not to talk for the person, unless it's absolutely necessary.

8. Avoid finishing their sentences.

9. Don't accidentally ignore the person affected by asking someone to speak for them.

A speech therapist will be able to give you more advice on what you can do to make communication easier. Call the Parkinson's NSW InfoLine for more information on 1800 644 189.

Source:
Parkinson's UK

Eight New Books on Parkinson's

1. *Living Parkinson's: 7 Strategies for Living a Full Life with Renewed Purpose* by Steve Yellen

How can you live your best life with Parkinson's? This is what Steve Yellen, who lives with the condition, wants to help others achieve with his book, *Living Parkinson's*. It aims to provide a roadmap to help people with Parkinson's take control, find purpose and face the condition head-on. The book offers 35 "What You Can Do" actions to jumpstart change, and includes expert insights from neurologists, researchers, therapists and advocates from around the world – including Parkinson's Europe board member Cathy Molohan.

Available from Amazon in Kindle or paperback formats.

2. *I Love You, Grandma Sharon!* by Dr George Ackerman and Brooke Ackerman

Written to explain Parkinson's to children aged six to 12, *I Love You, Grandma Sharon!* has been written by Dr George Ackerman, whose late mother Sharon Riff Ackerman, had Parkinson's, and his daughter Brooke. It details the journeys and adventures of a grandmother and her granddaughter during her grandma's journey with Parkinson's. It aims to help guide children through the emotions and questions they may have when they learn that a relative has the condition.

Available from Amazon in Kindle or paperback formats.

3. *The Kindness of Strangers: Coast to Coast to Coast in Sixty Days* by Lloyd Taylor

In *The Kindness of Strangers*, Canadian Lloyd Taylor documents his battle with Parkinson's, and the incredible journey he took on his bike across Canada one summer to fight it. From the rocky outcrops of the Maritimes to the frozen tundra of the Arctic, he recounts his adventure as part of the Spinning Wheels Relay to End Parkinson's on their journey to inspire hope and raise awareness.

The book tells how Lloyd and his fellow riders battled their condition with courage as they rode through storms and untamed wilderness, with intriguing encounters ranging from Inuit grandmothers at the edge of the North Pole to musician fishermen in Newfoundland.

Available from Amazon in Kindle or paperback formats.

4. *Oh Crap! It's Parkinson's: A Rebel's Guide to Taking Back Control of Your Life* by Sara Whittingham, MD

Written with clarity, compassion and lived authority, *Oh Crap! It's Parkinson's* is a guide for navigating the shock, fear and uncertainty that follow a Parkinson's diagnosis. Blending personal experience with accessible medical insight, it helps you understand what's happening in your body while also tackling how to rebuild your life.

As well as clearly explaining Parkinson's and what it means for daily life, it outlines practical ways to regain a sense of control and offers perspective on identity and how to move forward. Whether you are newly diagnosed, supporting someone you love, or trying to make sense of what comes next, this book is designed to help you take the next step.

Available on Amazon in Kindle format.

5. *Twitch: My Life with Parkinson's* by Annemarie O'Connor

In 2021, *Irish Examiner* columnist, stylist, author and podcaster Annmarie O'Connor was diagnosed with early-onset Parkinson's. In this memoir she outlines her journey from receiving a life-altering diagnosis to becoming an activist and agent of change for people with the condition.

Available on Amazon in Kindle or paperback formats.

6. *100 Exercises for Parkinson's Disease* by Dr Susha Thomas

The power of exercise to improve life for people living with Parkinson's is well known. Written by Dr Susha Thomas PT, DPT, C/NDT, a physical therapist and Parkinson's rehabilitation specialist, *100 Exercises for Parkinson's Disease* provides an easy-to-follow guide to improving strength, flexibility, balance, mobility and

confidence and slowing progression, with the exercises designed for lying, sitting or standing positions. The book also includes expert insight on combining therapy, nutrition, and medication for better outcomes.

Available on Amazon in Kindle or paperback formats.

7. *Long Straight Walk: A Parkinson's Story* by John MacPhee

After hitting an all-time low following his Parkinson's diagnosis, John MacPhee decided to do something positive: he walked the length of the UK from South to North in as straight a line as possible. *Long Straight Walk* follows John on his journey, as he recalls encounters with the people he met along the way, and details how he has come to terms with his diagnosis.

Available on Amazon in Kindle or paperback formats.

8. *This Wasn't the Plan: Exploring Health from a New Perspective* by Marta Crespo

For Marta Crespo, being diagnosed with early-onset Parkinson's not only changed her daily life – it led her to discover a new way of living, facing challenges, and finding purpose through movement and community.

In *This Wasn't the Plan*, Marta shares her personal journey, offering an inspiring account of acceptance and the key role that exercise, nutrition, and emotional support play in facing Parkinson's with dignity and determination. Through practical chapters and real-life stories, this is a life guide for those seeking hope, tools, and connection in the face of adversity.

Available on Amazon in Kindle or paperback formats.

Support Group Update

Welcome to the June Support Group round up.

It's been a busy couple of months as we have visited several groups, meeting participants and sharing information.

In **May**, our Donor Development Manager visited **Eurobodalla Support Group** and there was a great group discussion around Parkinson's, the need for services, programs that are available, how Parkinson's NSW operates and is funded and how people can help.

One of our InfoLine staff, Margaret Howard, visited **Nepean Blue Mountains Support Group** to talk all about travel tips and shared many important resources and links, including making sure your immunisations are up to date, obtaining travel

insurance, mobility assistance, companion cards, and Parkinson's NSW information sheets and resources.

At the end of **May,** Christine McGee (Education Manager) and I travelled down to Merimbula to support the **Bega Valley Support Group** Parkinson's Information Seminar. It was a sold-out event and the guest speakers included movement disorder neurologist fellow, Dr Owen Chan, geriatrician Dr Janice Taylor, and local allied health professionals – speech pathologists, physiotherapist and dietitian. Congratulations to the support group and Christine for a successful event!

At the beginning of **June**, our InfoLine registered nurse, Melanie Ledbury visited **Manly Mosman Support Group** to speak about invisible symptoms. The meeting was well attended, and the group was very engaged, asking plenty of questions. Once the meeting concluded, Melanie joined the group for lunch where everyone took part in some important socialisation!

The following day, John Back (Communications Manager) and Terri Herlings (Community Engagement and Support Coordinator) attended the annual **Chinatown Bilingual Support Group's** Parkinson's Education Seminar at the Ultimo Community Centre, with about 70 members, volunteers, and community participants also attending.

Rosanna Ng, co-leader of the support group, notes, "The seminar featured two expert speakers:
• Professor Simon Lewis, who explained current treatment options for Parkinson's, including medications, deep brain stimulation, focused ultrasound, and emerging therapies.
• Speech Pathologist Abi Shi, who introduced the Speak Out! voice therapy program and demonstrated practical voice-strengthening exercises.

Cantonese and Mandarin interpretation was provided throughout, ensuring accessibility for all attendees."

It was also an opportunity for John and Terri to acknowledge and thank Rosanna Ng ang Wilson Ng who have been volunteering with the group since 2005, and leaders since 2019. Diana Ma, treasurer of the group was also acknowledged for her contribution since 2022.

Mirelle Brockett, Marketing and Digital Manager, visited **Griffith Support Group** and had a wonderful time with the group and chatting all about supporting, connecting and advocating for the Parkinson's community. Mirelle spoke about the NSW Parliamentary Friends of Parkinson's, the National Parkinson's Alliance and Action Plan; covered what PNSW has been working on over the past 12 months, including Parkinson's Awareness Month, Step Up for Parkinson's, GP and allied health education, collaboration and partnerships, and finished off talking about Parkinson's

NSW services and supports.

Last week, Mirelle and I travelled to Northern NSW and were warmly welcomed by **Lismore Support Group.** Thank you for having us! We also covered supporting, connecting and advocating for the Parkinson's community, how Parkinson's NSW is funded and the free services and supports we offer, made possible by the fundraising community, grants and gifts in wills.

After the meeting, we then had a lovely lunch with the leadership teams from **Lismore, Murwillumbah, Evans Head, Northern Rivers and Tweed Heads.** We all had a great time chatting and Mirelle and I appreciate everyone travelling to Ballina, juggling personal and professional duties.

A big thank you to Griffith and Lismore Support Groups for their contributions to the National Action Plan consultation, research participation, their strong support group leadership and their ongoing advocacy and awareness raising!

Upcoming SG visits:

Orange SG - Jayne

Fairfield-Liverpool SG - Terri

North Ryde SG - Terri

Murwillumbah SG

St George-Sutherland SG

If you would like us to visit your group later in 2026 or early 2027, please let us know!

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

1800 727 567
Parkinson's NSW InfoLine
Email: pnsw@parkinsonsnsw.org.au
Web: www.parkinsonsnsw.org.au