

In Touch Newsletter May 2025

Combined DBS approach found safe, feasible in Parkinson's

Data suggest more DBS-Plus study warranted, researchers say

Inserting a piece of nerve tissue from a patient's ankle into the brain during deep brain stimulation (DBS) surgery appears a safe and feasible way to support damaged dopaminergic neurons in Parkinson's disease, with the goal of slowing symptom progression.

That's according to results from a Phase 1 clinical study watching for any side effects of that combined approach, called DBS-Plus, over the course of 15 years. The most common complaint during the first two years was pain or tingling in the foot or ankle, which eased over time and wasn't bothersome.

"The results from this study encourage us to perform more clinical trials on this procedure in the future," the researchers wrote.

The study, "[Two-year feasibility and safety of open-label autologous peripheral nerve tissue implantation during deep brain stimulation in patients with Parkinson's disease](#)," was published in the *Journal of Parkinson's Disease*. Craig van Horne, MD, PhD, a neurosurgeon and Professor of Neurosurgery at the University of Kentucky in Lexington, led the research team.

Parkinson's disease occurs when dopaminergic neurons in a part of the brain called substantia nigra are damaged. Dopaminergic neurons are responsible for producing dopamine, a chemical that signals for motor control, so their loss results in motor symptoms like tremor, slow or stiff movements, and problems with walking.

DBS and Parkinson's

The team is testing whether taking a piece of a patient's peripheral nerve tissue, found outside the brain and spinal cord, and inserting it into the substantia nigra while the patient undergoes DBS is a safe and feasible way to support damaged dopaminergic neurons.

Unlike neurons in the brain, peripheral nerves are likely to regenerate and may release chemicals that support the survival and function of dopaminergic neurons. This would be expected to stop or even reverse damage, slowing Parkinson's progression over time.

The study involved 13 men and five women with Parkinson's, with an average age of 62, who were planning to have DBS surgery. The procedure involves placing small

wires in the brain to send electrical signals to fine-tune the activity of specific parts of the brain to ease motor symptoms.

All 18 patients underwent DBS surgery in both sides of the brain. Then a small piece of the sural nerve, which runs just below the skin's surface in the back of the leg down to the ankle, was taken and implanted into one side of the brain, opposite the side with more severe motor symptoms.

The team aimed to check patients' motor symptoms at five visits over two years. Of the 18 patients, 17 completed all the follow-up visits within that time frame, the exception being a patient who completed the final visit 15 months later due to medical and personal issues unrelated to the study. Of a total of 90 visits, patients attended 83 (92%). Patients "were willing to return for study visits and exams," the researchers wrote.

No abnormalities revealed

MRI scans didn't reveal any abnormalities potentially related to the implant or the implant procedure. Consistent with the safety profile reported during the study's first year, the most common side effect was loss of sensation in the foot or ankle (71%), followed by extreme sensitivity (14%) and wound infection (14%) in the ankle.

"No additional study-related adverse events were reported beyond the results presented in our one-year interim report," the researchers wrote. Likewise, "MRI scans conducted at the two-year mark did not identify any indication of anomalous growth or signs of infection," suggesting that DBS-Plus is safe, they wrote.

Patients also underwent neurocognitive assessments. Despite changes in working memory and colour naming, reductions were small and typical of DBS. All scores remained in the normal range, suggesting DBS-Plus didn't "add incremental risk of cognitive changes beyond those expected following standard of care DBS."

The Unified Parkinson's Disease Rating Scale (UPDRS) Part 3 measures motor symptoms, with lower scores indicating less severe symptoms. Beginning at six months, there was a significant, 9.4-point reduction, which remained stable, suggesting no decline in motor function.

Results also showed a reduction in dyskinesia, involuntary movements that occur in Parkinson's patients.

The study "met its primary endpoints of feasibility and safety," and the results "encourage additional work and support the concept of future blinded clinical trials," the researchers wrote.

Sources:

Original article by Margarida Maia, PhD.

[Parkinson's News Today](#)

[Journal of Parkinson's Disease](#)

Support Group Round-up

By Stacey Foster, Support Group Coordinator

Welcome to the May Support Group round-up.

It's been another busy month in Support Group land. Several support groups participated in Awareness Month in April as well as our annual Community Heroes initiative.

What is a Community Hero? Each year, support groups are invited to nominate an individual or organisation in their local community that has provided significant or meaningful support to their group. When Parkinson's NSW receives those nominations, we create certificates for the Heroes and pass them onto the Support Group to present at a special time of their choosing.

The Community Heroes for 2025 are:

The Australian Chinese Charity Foundation (ACCF), nominated by Chinatown Bilingual Support Group. The ACCF has been supporting the Group's annual events for many years. This year, they donated \$6500 for their support group activities that promote the mental health of people living with Parkinson's.

Tim Ayers, nominated by Lismore Support Group. Tim is one of the Parkinson's nurses in Northern NSW. He regularly attends the Group, providing information and expertise, taking time to chat with members one-to-one. Tim has been involved with the Group for over three years, and "...we have appreciated every moment," say the leaders of the Group.

Faddi Azzi, nominated by St George Sutherland Support Group. For the past two years, Faddi has donated two fruit boxes each month for the Group's raffle with proceeds supporting the Group as well as Parkinson's NSW.

Tina Boger, nominated by Eastern Suburbs Young Onset Support Group. The leaders said in their nomination: "In 2021, Tina, on behalf of Wolper Jewish Hospital encouraged us to form a support group dedicated to helping younger people with Parkinson's Disease and, more importantly, offered and continues to offer free room and refreshments to accommodate it on a monthly basis. Tina and Wolper have remained champions of the Group. Without their support, our Group might not exist and definitely would not be as wonderful and vibrant as it is. We are so grateful to Tina and Wolper Jewish Hospital."

Kiama Support Group nominated physiotherapist, **Matt Cooke**, who has had special interest in Parkinson's. Their leader, Lesley, says of Matt, "He has been successful in getting many of our members into regular exercise programs & in encouraging his

clients with Parkinson's to join our Support Group. Matt takes exceptional care of his clients with Parkinson's. He is a regular at our Support Group monthly meeting, absorbing new information and providing us with an exercise segment."

Evans Head Support Group nominated former community nurse, **Paul Manning**. Diane Lymbury, leader of the Group, said Paul "...selflessly offered his assistance to our group immediately when this new Group was formed. He regularly attends meetings and sees what is needed, quietly working in the background offering support. Paul is always ready to assist to ensure the smooth running of each Group session and shares many valuable insights."

This year, Griffith Support Group nominated four community heroes! **Lauren Bortolin**, the group's gym instructor who runs the cardio exercise program and brings with her "...a lot of empathy and makes our classes very enjoyable and comfortable for everyone, regardless of the stage of Parkinson's. We have lots of laughs and we all leave the class with happy hormones."

Management and staff at **WIN Television Griffith**, for their assistance in promoting the group's activities such as their monthly meetings and exercise programs. They have promoted the Support Group for many years at no cost.

Management and staff at **Coro Club** were nominated for their continued support of the Group since 2013. They have supplied the venue for monthly meetings and Christmas parties, and supplied refreshments to all their meetings free of charge. The leader of the Group, Louisa Feltracco says, "...the staff are all very helpful and willing to help us out anytime."

Their last nomination was for the management and staff of **Griffith City Council**. The Council provides the venue for the carers meetings and exercise classes free of charge.

It is wonderful to see the outstanding support our groups have across the state. These connections and partnerships boost groups' sustainability and raise important awareness of Parkinson's in the local community. Thank you to all these Community Heroes for all you do for our support groups and your local Parkinson's community.

During April Awareness Month, several of our support groups held events in the community:

- Temora, Tumbarumba, Forster-Tuncurry, Albury, Armidale and Southern Highland Support Groups all ran information tables at their local shopping centres.
- Coffs Harbour Support Group leader, Graham Saxby, presented to the Chamber of Commerce on how businesses can support the Parkinson's community in Coffs Harbour.
- Port Macquarie Support Group ran a raffle as well as an information session at the local library, which was attended by Parkinson's Specialist Nurse, Jody Lloyd,

Parkinson's NSW CEO, Mary Kay Walker, and the local member for Port Macquarie, Rob Dwyer.

Well done to you all for being front and centre in your local community to raise awareness for Parkinson's!

Support Group Visits

In April and May, we visited and will visit:

- Eurobodalla Support Group
- Yass Support Group
- Crookwell Support Group
- Kiama Support Group

Upcoming visits include:

- Bathurst Support Group
- Chinatown Bilingual Support Group
- Manly Mosman Support Group
- Port Stephens Support Group
- Belrose Young Onset Support Group
- Evans Head Support Group
- Inverell Support Group

If you are a part of these Support Groups, we look forward to seeing you soon!

Study Adds to Evidence That Parkinson's Starts in the Gut

The conspicuous symptoms of Parkinson's disease – uncontrollable tremors, slowed down motions, and the feeling that one's feet are stuck to the ground – all stem from the loss of neurons in a region of the brain that helps control movement.

But many researchers believe that the neurodegenerative disorder may get started far away from the brain – in the gut – and years before the first neurological signs appear.

New findings by Columbia researchers David Sulzer, PhD, and Dritan Agalliu, PhD, and two of their graduate students are adding to evidence backing this hypothesis – and showing that what triggers initial gastrointestinal changes in Parkinson's could be a misdirected immune attack.

"If this is the beginning of Parkinson's in many people, we could potentially identify who has the disease before it ever reaches the brain and hopefully stop it in its tracks," Sulzer says.

Autoimmunity and the gut

The gut-first theory of Parkinson's, originally proposed 20 years ago, started to intrigue Sulzer after his own research pointed toward the role of an autoimmune response in Parkinson's.

In Parkinson's, a protein called alpha-synuclein becomes misfolded, accumulates inside neurons, and slowly poisons the cells.

Sulzer's lab, in collaboration with immunologists at the La Jolla Institute of Immunology, has shown that small portions of the misfolded alpha-synuclein also can appear on the outside of neurons. This makes the neurons vulnerable to attack from the immune system.

The immune attack could be doing more acute damage to the neurons than the internal deposits of alpha synuclein.

"The blood of Parkinson's patients often contains immune cells that are primed to attack the neurons," Sulzer says, "but it's not clear where or when they are primed."

The gut was an intriguing possibility because it contains the same neurons and because most Parkinson's patients experience constipation years before brain symptoms emerge and the disease is diagnosed. To pursue this hypothesis, Sulzer teamed up with Agalliu, a neuroimmunologist with expertise in mouse models of another neurological disorder (multiple sclerosis) that has autoimmune features.

Immune response to alpha synuclein leads to gut symptoms

To find out if an immune reaction to alpha-synuclein can kick-start the disease and where, Francesca Garretti and Connor Monahan – graduate students directed by Agalliu and Sulzer – first created a mouse capable of displaying pieces of misfolded alpha-synuclein on cell surfaces (natural mice do not have this ability).

They then injected the mice with alpha-synuclein and monitored what happened in the brain and the gut.

The researchers did not see any signs resembling Parkinson's disease in the brain, but they did see that an immune attack on neurons in the gut produced constipation and other gastrointestinal effects resembling those seen in most Parkinson's patients years before they are diagnosed with the disease.

"This shows that an autoimmune reaction can lead to what appears to be the early stages of Parkinson's and is strong support that Parkinson's is in part an autoimmune disease," Sulzer says.

The findings also raise the possibility that early detection – and then interruption – of an immune response in the gut could prevent a later attack on the brain's neurons and stop Parkinson's in its tracks.

Wanted: A mouse with Parkinson's disease

Right now, though, it's not clear how big a role the immune system plays in the Parkinson's brain. The answer to that question may become clearer if the researchers find out why the brains of their mice did not develop any signs of Parkinson's.

The team hypothesises that the immune cells in their mouse model may not be reaching the brain because the animals are young, and age has not yet weakened the blood-brain barrier sufficiently to let immune cells squeeze through. Opening the barrier or accelerating the aging process may lead to mice that develop gastrointestinal and brain symptoms.

"Our ultimate goal is to develop a model of Parkinson's disease in mice that recreates the human disease process, which doesn't exist right now," Sulzer says. "That will be critical in answering questions about the disease that we can't explore in people and eventually developing better therapies."

Sources:

[Neuron](#) journal

[Columbia University Irving Medical Center](#)

David Sulzer, PhD, is Professor of Neurobiology (in psychiatry, neurology, and molecular pharmacology & therapeutics) at the Columbia University Vagelos College of Physicians and Surgeons.

Dritan Agalliu, PhD, is Associate Professor of Pathology & Cell Biology (in neurology) at Columbia University Vagelos College of Physicians and Surgeons.

How to Adapt Your Hobbies to Parkinson's

Art, craft and music

Keep small items in trays or baskets so they're less likely to be knocked onto the floor. Or use non-slip mats to keep things in place while you're working on them.

"Now I create digital art. I've had to give up the majority of my painting, but it hasn't stopped me being creative. Adapting to the digital realm of art has been a lifesaver. There are no rules in art. You can't make bad art. Everyone's an amateur." **Alex**

"I get bad cramps in my right hand. The first time it happened I couldn't hold my guitar plectrum properly as my hand had curled up. But I chatted to the crowd until it passed, and I've since found plectrums that you can attach to your finger." **Laz**

Sport

"I have been an avid weight trainer for over 30 years. I can highly recommend the use of figure-of-8 lifting straps. They're simple to put on and off and allow me to keep exercising pretty much as before, despite my tremor." **Richard**

"I can no longer play golf, as I can't maintain the same swing with my tremor. Instead, I've taken up ten-pin bowling. The weight of the ball means my hand doesn't shake." **Karl**

"In walking tennis, the ball doesn't move as fast or need to be hit as hard. I've just taken up pickleball as well, which is a combination of badminton, table tennis and normal tennis, and is great fun!" **Sharon**

"I bought a table tennis trainer, which is a ping pong ball on a swing-ball that you can use at home. It meant I could still practise and keep my skills up, like maintaining a good swing with my arm. It helped keep my motor skills going." **Paul**

Writing

Use pens and pencils with a thick or padded cover to help you get a better grip.

If you have a tremor, a weighted cuff may give you more control. This is a heavy padded strap that you wear around your wrist.

Use a clipboard or a non-slip mat to stop your paper slipping.

Write on lined paper, so it's easier to keep your writing straight.

Take your time to write, or dictate into a smartphone or voice recorder.

Cooking

If chopping food is difficult, a mini food processor can help you chop things like garlic, ginger and spring onions finely. Then you can freeze the ingredients until you need them.

If you have difficulty gripping things, a curved-handled or rocking-action knife can be used for chopping food.

A kettle tipper lets you pour boiling water out of the kettle without lifting it up. This reduces the risk of spills and burns.

You can place a non-slip mat under a plate or bowl to stop it from moving around. This can be useful if you have limited mobility in one arm and find yourself chasing plates and bowls across the table.

Source:

[Parkinson's UK](https://www.parkinsonsuk.org/)

Managing Apathy if Your Loved One has Parkinson's

Apathy is a loss of motivation for doing things. It can appear in different ways, such as not being interested in activities someone used to enjoy, difficulties planning tasks, or even having trouble thinking of what to do.

Feelings of apathy can be temporary, but frustrating if you're caring for someone who experiences it. Here are some tips for managing if your loved one has apathy.

1. Remember apathy is a symptom of Parkinson's

It can be frustrating if your loved one doesn't seem interested in activities or socialising. You might feel they don't want to help themselves or just don't care.

Try to remember that apathy is a symptom of Parkinson's and if your loved one doesn't engage, they're not being lazy or difficult on purpose.

2. Offer encouragement

If someone is experiencing apathy, it can be easy to cancel plans or decide they don't want to do something. Keep encouraging your loved one to take part in activities or visiting friends, for example. They may be reluctant, but engaging with something can have a positive effect on their mental health.

3. Stick to a routine

Establish a regular routine where your loved one has to do tasks at certain times. Make these non-negotiable.

4. Set a goal

Support your loved one to set a goal. Help them to break the goal down into smaller, manageable tasks so they are more likely to achieve what they have set out to do.

5. Offer encouragement

You may need to prompt your loved one to start an activity and then offer support as they progress with the task. Try to be positive and focus on what they've achieved.

6. Look after yourself

Looking after someone with apathy can also affect your own mental health, so it's important you look after yourself.

Take regular breaks if you can and talk to people who may be in a similar situation to you. This could be through a local Parkinson's group or our [forum](#).

For more advice and to connect with a Counsellor, phone the Parkinson's NSW InfoLine on 1800 644 189.

Source:

[Parkinson's UK](#)

Mid North Coast Movement Disorders Neurology

Service improving patients' quality of life

It has been two years since the Mid North Coast Local Health District Movement Disorders Neurology Service was established and patients are praising the benefits of the highly specialised care they are receiving.

The service was launched in April 2023 and provides patients with a blend of face-to-face appointments in Coffs Harbour and telemedicine appointments with a movement disorder specialist neurologist in either Port Macquarie or Coffs Harbour.

It is a collaboration between Mid North Coast Local Health District, Westmead Hospital in Western Sydney Local Health District, the NSW Rural Doctors Network and Parkinson's NSW. The service is led by Movement Disorder Specialist Neurologists Dr Victor Fung and Dr Hugo Morales Briceno, and Parkinson's Specialist Nurse Vince Carroll.

Paul Grant was diagnosed with Parkinson's in 2007 and had Deep Brain Stimulation surgery at Westmead Hospital in 2020. The service in Coffs Harbour has removed the need for him to travel to Sydney for treatment.

"To have the Movement Disorder Service come here to Coffs Harbour is fantastic, it saves energy and time," he said.

"When you have a movement disorder getting from A to B is sometimes very difficult. When I travel to Sydney for appointments I get very tired, it takes a lot out of me. So having the Movement Disorder Service here in Coffs Harbour is so much easier."

Dr Fung said the program had been embraced at both Westmead and on the Mid North Coast.

"Our Movement Disorders Specialist Dr Morales Briceno works closely with expert movement disorders nurses who are an integral part of the service," said Dr Fung. "We have also expanded the service to the NSW North Coast."

Parkinson's Specialist Nurse Vince Carroll – a key advocate for the service – said that the care being provided to local patients is equal to that provided to metropolitan patients.

"More than 90 percent of specialists reside in the metropolitan areas, leaving only seven percent in rural and regional Australia," he said. "We are achieving what we set out to do in bridging the gap in bringing world class care to the Mid North Coast of NSW."

A recent survey has highlighted the ongoing positive impact of the service:

- 95 percent of patients are satisfied with the level of care and coordination.

- 90 percent report a reduction in travel burden, with fewer trips required to Sydney for specialist consultations.
 - GPs overwhelmingly support the clinic, with many now expressing interest in directly participating in virtual consultations with their referred patients.
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Turning when walking with Parkinson's

If you have Parkinson's, you may have problems making movements that include an element of twisting your body, such as turning when walking.

Stiffness and slowness of movement are common symptoms in Parkinson's. Often, they will affect one side of the body more than the other.

Anyone who has sat in one position for a long time will feel stiff and find their movements are slower when they first move, especially if the action involves turning.

When you have Parkinson's, this can happen while making everyday movements, including walking. This is because a level of speed is needed to start moving or to keep a movement going. If you have to twist your body as part of the movement, this can make it even harder to move.

Why might I find it difficult to change direction when walking?

Over time, the length of your steps may become smaller when you are moving about. The muscles around your hips and up your spine can also become weaker and stiffer.

This can affect how well you can control and move your upper body, particularly if you're turning. This is because when you turn, your head, body and legs are all twisted relative to one another. This needs more balance to achieve the movement.

If you are doing something else as you walk, such as talking or carrying an object, you may notice you shuffle more as you turn, especially if your feet are too close together at the start of the movement.

Freezing as you walk is a common symptom of Parkinson's and can stop you from turning while you walk. If you experience freezing, you may find it hard to start walking or come to a halt for several seconds or minutes as you are moving forward.

You might feel like your lower half is stuck yet the top half of your body is still able to move. Sometimes this can lead to you falling. You need to focus more on turning safely if this happens to you.

Not everyone with Parkinson's will have problems turning when they walk. It may only be an issue if you experience 'off' periods, such as when your medication is not working fully, or at night when you're more tired and stiff.

How can I turn more easily when I walk?

- Think about the way you are turning. Imagine your feet following two curved tracks going in the direction and at the angle you want to turn.

Make sure that your foot on the side you are turning towards takes a smaller step than the other foot. You will need to take a larger step with your other foot, so this foot keeps coming forward, level with the inner foot as you are turning.

This is more important if you have a 'Parkinson's side' (where one side of your body is more affected by the condition than the other).

It will make turning in the opposite direction harder as the Parkinson's side will naturally take smaller steps but will be the outside foot. Your focus is on taking even bigger steps each time you move forward into the turn so the outside leg doesn't lag behind.

- Avoid pivoting round on your toes if you have poor balance when moving. Instead, imagine a larger circle to walk round than a small circle.
- Some people prefer to visualise an object, like the face of a clock, and imagine they are stood in the middle of it. Your feet form the hands of the clock, and each step turns into the next number round on the clock face until you are facing the direction you need.
- If you find it difficult to visualise something, you could try putting masking or electrical tape on the floor. Space it just under a foot length apart so you can follow the angle of the turn. As you walk into the turn, use the taped markers as a cue for where to place your feet and let them guide you into the turn. One to three strips is usually enough for a good turn.
- Alternatively, you may find it more helpful to step into a turn using the rhythm of a piece of music, a metronome beat or by counting out loud.

A physiotherapist or occupational therapist can visit you at home and help you choose which method will work best for you.

Sources:

Original article by Bhanu Ramaswamy, Specialist Physiotherapist

[Parkinson's UK](#)

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

(02) 8051 1900

Parkinson's NSW InfoLine

Email: pnsw@parkinsonsnsw.org.au

Web: www.parkinsonsnsw.org.au