

## In Touch Newsletter March 2026

### Parliamentary Friends of Parkinson's Launched in Sydney

The Parliamentary Friends of Parkinson's was officially launched on Thursday 6 February at a function for more than 70 people at NSW Parliament House.

The initiative aims to strengthen understanding of Parkinson's and support better access to services for people living with Parkinson's, their families and carers.

Phil Donato, Member for Orange, and Dr Joe McGirr, Member for Wagga Wagga, are Co-Chairs of the group and Robert Dwyer, Member for Port Macquarie, is Vice Chair.

Parkinson's NSW CEO Mary Kay Walker was MC for the event and also gave the keynote presentation. The audience included the Minister for Mental Health, Rose Jackson who also spoke to the gathering, Members of Parliament, parliamentary staffers, people living with Parkinson's and family members from across the state, movement neurologists, researchers, Parkinson's Specialist Nurses, allied health practitioners and Parkinson's NSW Board Members and staff.

The Parliamentary Friends of Parkinson's launch event can be viewed on the Parkinson's NSW YouTube channel by clicking on this link: [Parliamentary Friends of Parkinson's](#)

---

### Two New Parkinson's Therapies Enter Final Stages of Clinical Trials

#### *New treatments on the horizon for Parkinson's*

Two new therapies are entering the final stages of clinical trials before potential U.S Food and Drug Administration (FDA) approval.

One is a new dopamine-based therapy for motor symptom management, and the other is a stem cell therapy poised to replace the lost brain cells of Parkinson's disease. Together, they represent two very different but complementary paths forward in the fight against Parkinson's.

These two potential therapies are important indicators of significant progress when it comes to Parkinson's therapy research.

## **Tavapadon: A Next-Generation Dopamine Therapy**

The pharmaceutical company AbbVie recently announced that it has submitted a new drug application (NDA) to the FDA for **tavapadon**, a once-daily pill designed to help manage PD symptoms such as stiffness, [tremor](#), and slowness of movement.

Tavapadon shows fewer side effects than existing medication.

Dopamine is the chemical messenger in the brain most affected in Parkinson's. A class of Parkinson's drugs called dopamine agonists (pramipexole, ropinirole, rotigotine) act by binding and activating the dopamine receptors in the brain.

Dopamine agonists that are currently available can sometimes cause unwanted side effects such as excessive daytime sleepiness, compulsivity, and psychosis.

*Tavapadon is a partial agonist of the D1 and D5 dopamine receptors in the brain, whereas current dopamine agonists primarily target D2 and D3 dopamine receptors. Because of its different binding profile, tavapadon tends to have fewer side effects than traditional dopamine agonists.*

In clinical studies known as the TEMPO trials, tavapadon showed meaningful improvements in motor control and daily function for people both newly diagnosed and those already on levodopa as compared to those taking a placebo. When tavapadon was added to levodopa, patients gained about an extra hour of improved 'on' time per day without negative side effects.

Tavapadon appeared to be well tolerated, with most side effects described as mild to moderate. Because of the positive results of the clinical trials, Abbvie submitted a new drug application (NDA) for tavapadon to the FDA in September 2025.

It takes about 10 months for the FDA to review an NDA and potentially approve it. If approved, tavapadon could become a valuable new option that smooths out motor symptoms and may reduce the need for more frequent levodopa dosing, with fewer side effects overall.

## **Bemdaneprocel: A Cell Therapy for Parkinson's**

The pharmaceutical company Bayer is taking a much bolder approach to novel therapies in Parkinson's – a stem cell-based therapy designed to replace the brain cells that degenerate in Parkinson's.

The treatment, called **bemdaneprocel** uses dopamine-producing neurons derived from stem cells. These are implanted directly into the part of the brain affected by Parkinson's, with the hope that they will connect correctly within the brain and start restoring dopamine production naturally. This therapy was developed by Blue Rock Therapeutics which is now a Bayer subsidiary specializing in regenerative medicine.

*In earlier smaller trials, bemdaneprocel was shown to be safe and potentially beneficial, with patients tolerating the treatment well, and imaging suggesting that*

*the transplanted cells survived and integrated into the brain. Now, the company has launched a phase 3 trial called exPDite-2 that will be the first large study of its kind to test a stem cell therapy for Parkinson's in people on a global scale.*

If successful, bemandeprocel could represent the first therapy to repair the underlying damage caused by the disease and not just mask its symptoms. Bayer expects early results in the next few years, though final outcomes will take time to confirm.

### **Why These Two Therapies Matter**

These two therapies highlight how Parkinson's research is pushing forward on two fronts: improving quality of life now and pursuing long-term solutions.

Tavapadon, as an advanced oral medication, could reach patients relatively soon if approved by the FDA, offering more consistent symptom relief and fewer side effects. Bemandeprocel represents the frontier of regenerative medicine, and although it will take a bit longer to validate in trials, it could be the first therapy to restore what Parkinson's takes away.

Neither has a sure path to approval, as late-stage trials face many challenges, including safety and long-term benefits that both must be proven. Regardless, the fact that two very different therapies have reached the phase 3 stage of clinical trials marks genuine progress in the field and may provide PD patients with much needed options in the future.

#### **Source:**

[American Parkinson's Disease Association](#)

---

### **First table tennis tournament classified by Parkinson's symptoms**

The first table tennis tournament in NSW to offer classification in relation to the symptoms of Parkinson's is being held on 4 April.

The PingPong Parkinson Sydney Open is open to players with a Parkinson diagnosis with any level of table tennis skills. Players can participate in singles and doubles in categories that take into account table tennis skills and level of Parkinson symptoms.

The focus will be on celebrating participation: the joy of playing, feeling better and being part of a supportive community.

Forestville Table Tennis Club is the event host. See the accompanying poster for full details.

In other news, the 7th PingPong Parkinson World Championship, to be held in Hanover from 26 to 30 September 2026, has an Australian entrant, who is also a member of the Forestville PPP chapter.

The Championship expects 600 to 800 players from at least 30 countries. It will be the first time an Australian has entered.

---

## **My [Parkinson's] Life**

### **Pamela Tilbrook on Deep Brain Stimulation**

Recently I was telling anyone who would listen how much I enjoyed the company of others while I drank a good cup of coffee plus how happy I was that I could still participate at Pilates, gym and PD Warrior classes. But this was about to change.

At my six-monthly visit to the neurologist in January 2025, it became evident that an increase in my medication, especially levodopa would be necessary. Levodopa is a neurotransmitter, which helps to alleviate symptoms like tremors, stiffness, and slow movement. The time was coming when I had to consider alternatives to taking the levodopa orally in tablet form.

One alternative was Deep Brain Stimulation (DBS). I had heard of this treatment but had never seriously considered it for myself. In fact it horrified me!

However, my Parkinsons was now at that stage that I needed to consider it because my body was reacting to the levodopa resulting in quite noticeable dyskinesia (involuntary, uncontrolled body movements).

I investigated other non-tablet oral methods, two of which involved wearing a bag.

One meant I would have to inject myself in the tummy every day, the other required a shunt to be inserted in my tummy. Neither of these alternatives appealed to me so I started investigating the DBS procedure.

I mentioned to my GP and all my specialists what I was thinking of doing and I didn't hear any negativity. I was referred to a neurologist who has a team of three to carry out these procedures at North Shore Private Hospital.

He arranged for me to attend a number of appointments and sessions with the team members. For example I had several sessions with the neurologist himself, about an hour each in length, another hour with the neurosurgeon and two separate sessions with a psychiatrist.

The psychiatrist even evaluated me for dementia! (And no, I don't have dementia, thank goodness). At the same time I was reading up on various sites on Google and also found two other women through the Parkinsons Support Group that I attend,

who had been through the surgery themselves. One of these women was particularly enthusiastic and assured me it was the right thing to do.

I made up a list of pros and cons based on the information I had after nearly six months of investigation and research to help me make a decision. One con mentioned to me, was my age.

Anyone over 80 years old, would have to make a very strong case to be eligible. I am now 77 years old, and I was reminded that if I was going ahead with the procedure that I should have it 'sooner rather than later'.

The decision was made to go ahead with the surgery. Everyone, professionals and friends, were excited for me and I couldn't wait for the surgery to be completed.

The big day came – 24 June 2025, a Wednesday. I had been admitted two days prior for a number of tests in preparation for the procedure. The first thing that occurred after I was wheeled to theatre was also the last thing I remember of that day.

I had to have my head shaved, so as my head could be contained in a structure that was stapled to it in order to keep my head still. Hence all hair had to go. Oh well it wasn't as if I had beautiful blond locks cascading down my back!

Hours later, I woke in ICU feeling terrible. It was nighttime with only one nurse and one patient (me) as far as I could see.

Before I left ICU I was alerted to the fact that I wouldn't be returning to the same room. Why didn't someone tell me. I wasn't happy about this, and it meant that someone else had to pack my belongings. For the next couple of days I found belongings in unexpected places.

The first thing that everyone noticed about me, was my baldness. I felt like DBS had taken over my life. I didn't exist. Everyone I met, the first question after they enquired about how I felt, was how much my hair had grown back. Is it going to grow back curly or grow back the same colour? Are you going to colour your hair if it grows back grey?

Every day I became super-aware of the stimulator below my right clavicle and how important it is to my well-being. Every day there is a new symptom which becomes of heightened importance. Every day I am told to rest, that I have had major surgery, stay home, don't do too much. And I am bored!

For at least 12 weeks after surgery both the hospital physiotherapist and the neurologist agreed that I could not do any exercise apart from walking. Nothing from the waist up!

I wanted to be able to go to the gym and really move again. I didn't want to look or act like a silly old woman, but unwittingly that is what I am becoming. I see my reflection in a mirror or shop front and that is what I am – slightly bent over one side, fiddling with something in my bag, (probably getting out my bus ticket) and trying to juggle everything with a walking stick stuck under my arm.

And now, present day? How do I feel? It is six months since I had surgery and everyone (and I mean everyone) is impressed with my lack of movement and swaying due to dyskinesia.

Perhaps I don't appreciate it as much because I couldn't see myself continually moving and swaying. Areas which haven't improved or even deteriorated include my balance (as foretold by the neurologist).

Another unexpected occurrence was my habit of leaning over to the left, so I am stooped with my head following. As a result, I have just started using a walker to help with my posture.

I am coming to grips with my body which is slowly functioning differently. I am trying to look at this phase of the disease as a preparation for the future. However, DBS has reduced my dyskinesia by at least 85% which on its own was very debilitating.

What I have learned over the last six months, like any big decision, is that always some bad gets mixed in with the good.

My conclusion is that DBS has done what it was supposed to do. That may not be saying much but being objective that is the truth.

### **Advice from a Parkinson's NSW InfoLine Registered Nurse**

Like any procedure, both the positives and negatives of Deep Brain Stimulation (DBS) need to be weighed up closely with your Neurologist.

As with any procedure your response to it will be different to someone else's. Every person is an individual and will respond differently to every treatment regime.

Your Neurologist will always weigh up the best option with the best outcome for you in mind. DBS is not an appropriate treatment for everyone and is not an option in the treatment plan for everyone.

Discussion needs to be had with your own Neurologist in which the benefits to you are clearly outlined. Similarly, symptoms which may not necessarily improve will be discussed.

We recommend videoing yourself pre- and post-DBS to fully understand and acknowledge the changes this treatment has made to your symptoms and life.

Remember you are not alone in this decision-making process.

The Info Line is here to support and advise you and can provide you with accurate information and connections to others who have experienced this treatment option.

**For more information call the Parkinson's NSW InfoLine on 1800 727 567**

## Spotlight on Port Macquarie Support Group

Kim Dahler has led the Port Macquarie Support Group for the past six years. The group was established in the mid-1980s. When asked what makes an effective Parkinson's support group she doesn't hesitate:

"I think an effective support group needs to have an active Committee which leads proactive engagement with support group members and strives to establish a sense of camaraderie between everyone involved.

"It's also important to create a safe environment where everyone feels supported and cared for," she said.

The Port Macquarie group has 150 people on its distribution list, and a good meeting attracts 50 participants while the average attendance is 35.

Every meeting starts with an ice-breaking exercise followed by one or more guest speakers, news updates and sharing of articles from the Parkinson's NSW *InTouch* newsletter, and the usual Treasurer and Secretary reports to members.

The local Parkinson's Specialist Nurse Jody Lloyd also tries to attend all meetings.

There are sometimes breakout groups set up to discuss upcoming events, as well as other opportunities for participants to get together at a boxing group on Friday mornings and a weekly exercise session at Ramsay Health.

The group also publishes a monthly magazine called *The Rattler* and undertakes fundraising in support of its local nursing service.

"However fundraising is on a case-by-case basis; we don't believe it's appropriate to make donation requests of group members all the time," said Kim.

"Also we try to be creative and offer meaningful returns for donors. For example, at the moment we are running a raffle, and the prizes include home-cooked meals for the winners. That enables support group engagement at the same time as providing a tasty benefit for the winning ticket holders."

---

## April is Parkinson's Awareness Month

At Parkinson's NSW, we are committed to supporting individuals and families affected by Parkinson's.

Through information, support services and community connection, we help people navigate the challenges of living with Parkinson's.

But we can't do it alone – we need your help to raise awareness and make a difference in the lives of those living with Parkinson's.

We are stronger together, so during Parkinson's Awareness Month in April we encourage everyone to start conversations about Parkinson's ... what it is, how it affects individuals, carers and families, and why awareness matters.

Because every conversation helps build understanding.

And every conversation counts for our community.

---

## **Take 5**

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

### **1. Feeling "Deconditioned" After the Holidays**

Early in the year we often receive calls from people who feel they've gone backwards. Routines changed over the holidays, exercise programs paused, and the heat didn't help. It's common to feel more stiff, slower, or less steady than before.

The key is not to panic. Start small and rebuild gradually. Gentle stretching, short walks, or returning to your usual Parkinson's-specific class can help you regain confidence and strength. Progress doesn't have to be dramatic; consistency is what matters. If you're unsure how to restart safely, our InfoLine can help connect you with appropriate exercise programs or physiotherapists.

### **2. Newly Diagnosed – Take a Breath**

We've spoken to many people newly diagnosed this month. The first message we often share is simple: take a breath. Parkinson's is a journey, and there is time to build your knowledge and your support team.

Early steps include connecting with a movement disorder neurologist, learning about treatment options, and reaching out for support. You don't need to navigate it alone. Our InfoLine team can help you understand what comes next and assist you in building your care team with confidence.

### **3. Sweating, Temperature Control & Electricity Rebates**

Changes in temperature regulation and excessive sweating are common in Parkinson's. Summer heat can make symptoms feel worse and increase fatigue. Staying hydrated, dressing in layers, and using cooling strategies at home can help.

For those needing increased air conditioning or cooling support, you may be eligible for electricity rebates or concessions. Our InfoLine team can guide you to the right state-based programs and help you understand what supports are available.

### **4. Denial, Sadness and Grief**

We've had important conversations this month about the emotional impact of Parkinson's. Sometimes people living with Parkinson's, or their carers, can feel stuck in denial, sadness, or grief. These feelings are normal and part of adjusting to change.

It's okay to acknowledge that Parkinson's brings loss as well as change. Talking to someone outside your immediate family can help. Our counsellors provide support at no cost, and the InfoLine can connect you to the right counsellor when you're ready.

### **5. My Aged Care – Register Early**

A common theme continues into the new year: don't wait until you're struggling to register with My Aged Care. The assessment process can take time, and having services approved before you urgently need them provides peace of mind.

You can apply online via the My Aged Care portal or call directly to begin the process. If you're unsure about eligibility or how to start, our InfoLine team is here to help guide you through the steps.

A new year often brings reflection and a reset. If any of these topics resonate with you, remember our InfoLine team is here to support you as you reconnect with routines, services, and the supports that help you live well.

**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.**

---

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

**1800 727 567**

**Parkinson's NSW InfoLine**

Email: [pnsw@parkinsonsnsw.org.au](mailto:pnsw@parkinsonsnsw.org.au)

Web: [www.parkinsonsnsw.org.au](http://www.parkinsonsnsw.org.au)