

**PARKINSON'S<sup>UK</sup>**  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.

# Every Parkinson's Journey October 2024

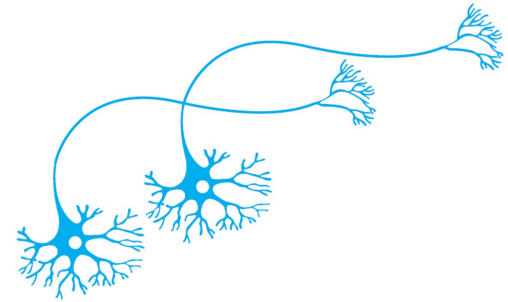
**Caroline Russell**  
CEO

# What do we know about Parkinson's?

Parkinson's is a condition that **affects the brain**. The area that is worst affected is called the '**substantia nigra**' and is involved in the coordination of movement.



People with Parkinson's don't have enough of a chemical called **dopamine** because some **nerve cells in their brain** have died



## What causes Parkinson's

- The majority of people have Parkinson's with no known cause.
- For a small minority there will be inherited genetic changes that increase their risk of developing the condition.
- The exact causes of Parkinson's are unknown and researchers believe that it is a complex mix of genetic and environmental factors.

# Impact of Parkinson's

153,000 in the 4 nations diagnosed

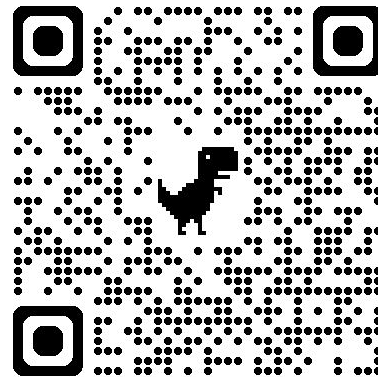
18,000 newly diagnosed each year

60:40 men:women

Increasing number of people under 50 (Young Onset being diagnosed -including many in their 20's)

New Study concluding in 2025 (using 16m GP records)  
looking more closely at numbers, date of diagnosis, ethnicity,  
sex, location

# Parkinson's UK



Parkinson's UK is a membership charity and has 40,000.

We encourage everyone to become a member as it:

- Allows us to “talk”, campaign and represent an increasing number of People Affected by Parkinson's
- It is free
- You can be kept (if you choose) informed of latest research and developments, events (magazines produced - Progress, The Parkinson's)
- You can (if you choose) become more involved in the running of the Charity by our members meetings (AGM) or becoming putting yourself forward to be a trustee

# Parkinson's UK - Overview

We are the largest charitable funder of research in Europe

Our website has over 220,000 users

We are about to launch a tech “which” guide - (apps and devices rated by you)

Our helpline takes over 28,000 calls per year - more to follow

We have over 3,500 volunteers who support the charity

We campaign and raise awareness on behalf of the Parkinson's community  
(heard of the Parky Charter?)

All of these activities are funded by donations, fundraising and legacies - we receive no government funding - THANK YOU

# Every Parkinson's journey

Our strategy for  
2023 to 2026

# Our Strategy

Together we will find a cure and improve life for the Parkinson's community. Until then, we're here for everyone affected by Parkinson's. Fighting for fair treatment and better services.



# Pushing for Excellence in Health and Care



- We fund Parkinson's Specialist Nurses (we have funded circa 70% - 300)
- We fund Physios, OTs and S&L Therapies
- We fund Clinical Fellowships - neurologist becoming Parkinson's specialist
- We run a Learning Hub for professionals
- We lead National Programmes - including Get It On Time

# Building Your Community of Support

Whatever your journey with Parkinson's, you're not alone. We're here for you with free information and support. From the moment you or someone you care about is diagnosed, or whenever you're ready, you can:

- **Call our confidential helpline on 0808 800 0303 to speak to one of our friendly expert advisers, including specialist Parkinson's nurses, care advisers, and benefits and employment advisers.**

We've got information and advice on all aspects of living with Parkinson's. Symptoms, medication, work, money issues, local activities and services, relationships and family life, emotional support: whatever it is, we can help. And we can signpost you to other support too.

- **Speak to your Parkinson's local adviser**

Our team of over 100 local advisers can give you more in depth and personal support wherever you live in England, Wales, Scotland and Northern Ireland. We can advise on everything from Blue Badges to benefits advice to accessing local services.

# Our Support Services

- **Get help managing your diagnosis**

Our information packs, webinars, courses and support groups can help you and your loved ones understand your Parkinson's diagnosis and better manage your symptoms.

- **Read our up to date, reliable health information**

Our website, booklets and magazines can help you better understand Parkinson's. They're full of tips and advice on managing your condition and supporting a loved one.

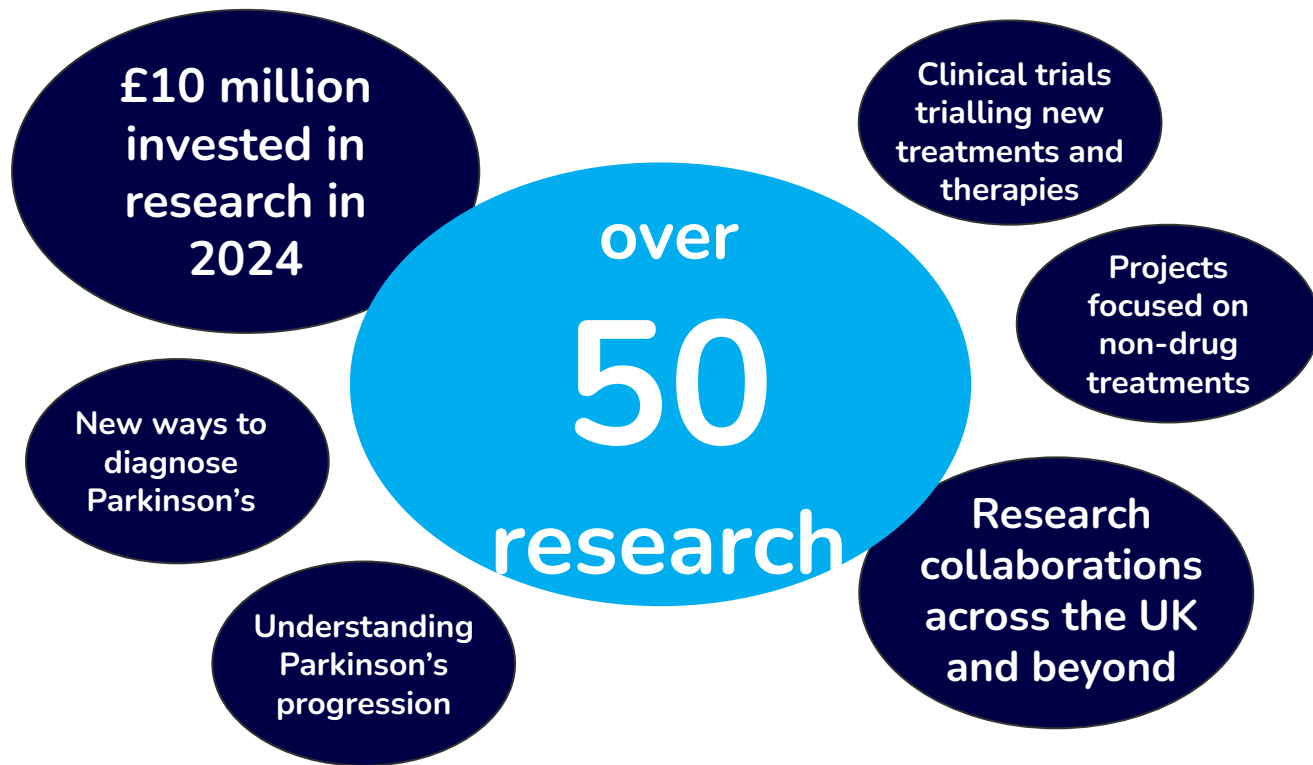
- **Find ways to get active, stay active and live well with Parkinson's**

Whatever your fitness level, we'll help you find the right activities for you, from Parkinson's dance classes to videos of exercises you can do sitting down at home.

- **Connect with other people with Parkinson's, families, friends and carers**

Across the UK, in your local area or online. We'll help you meet others who understand what you're going through, because they're going through it too.

# Getting You New Treatments, Faster



# Big steps forward

## New treatment available

Produodopa is now available for people with Parkinson's whose tablets no longer control their symptoms.

## Momentum is gathering in research

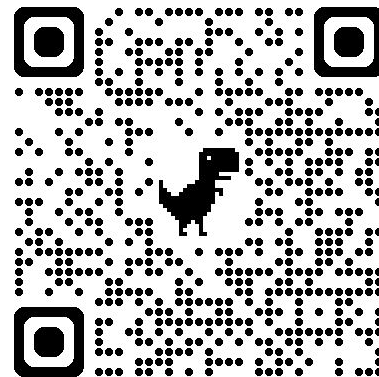
- We are playing a key role in drug development for Parkinson's. We are particularly excited to be funding a trial of an injectable form of a growth factor, with the potential to stop the progression of Parkinson's, for the first time in people with Parkinson's.
- There's been a flurry of news showing that we're close to developing simple tests for identifying Parkinson's earlier. This is vital in the search for better treatments.
- We have launched a project that will bring together Parkinson's UK, other funders, Imperial College London and a number of international pharmaceutical companies, to understand Parkinson's in unprecedented detail using AI and the brains in the Brain Bank which we fund.



**TOGETHER WE CAN MAKE A  
DIFFERENCE**

# Membership of Parkinson's UK

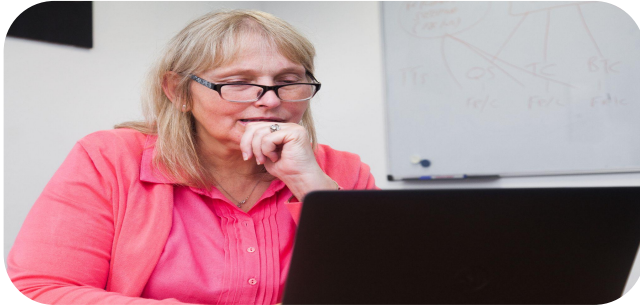
Our message to the Parkinson's community - When you need us, we're ready; when you're ready, we need you.



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<https://www.parkinsons.org.uk/get-involved/become-member>

# Take part in research



**Filling in questionnaires**



**Sharing your experiences**



**Testing a new device**



**Trialling a medication**

# Stay up to date

Join the **Research Support Network** to receive regular emails with the latest research news, events and opportunities.



Get in touch: 020 7963 3606 or [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk)

*Join Now!*

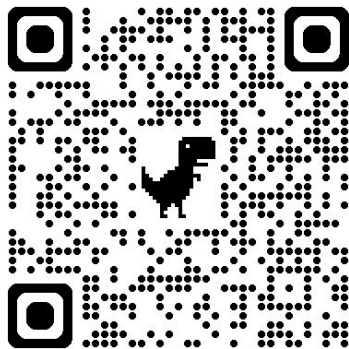


# Other Top Tips - Podcasts ....

## Movers and Shakers



## 2 Parkies in a Pod



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