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Please visit pdfrontline.com/en to learn more

Issue 11 | July 2026

# SUMMER SUMMARY

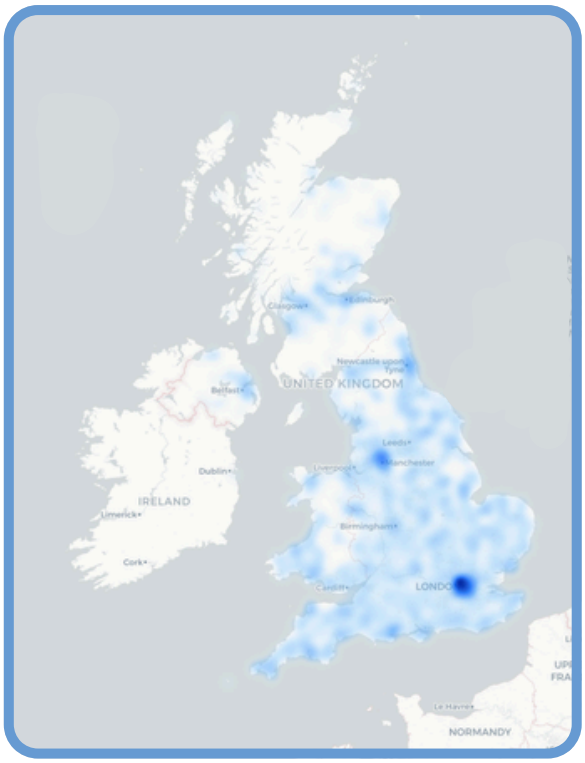
## Welcome to the summer issue of the PD Frontline Newsletter

**Welcome to the summer issue of the PD Frontline newsletter. We would like to share some information about why we focus on genetics and how we approach sharing news of genetic changes. We will also provide an update on some of our associated trials, spotlights on our ambassadors and a new collaboration to support you!**

## STUDY UPDATE

As of July 2026, the PD Frontline study has over 8120 participants and remains the largest study of its kind in Parkinson's research. Your participation is essential to the success of our study and we cannot thank you enough for your engagement and support!

We currently have 58 sites recruiting from 39 NHS Trusts, all helping us provide access to research across the UK!

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# Spread the Word

**We are a growing study and your help is essential to its success!**

## Engagement with Parkinson's Research

**There are lots of reasons someone might choose to either join or not join research.**

A key barrier to joining Frontline is the lack of general awareness that our research exists. We hope to rectify this.

We share the opportunity to learn more about Parkinson's research and join PD Frontline in lots of places:

- Social Media
- Parkinson's charity events
- Via Parkinson's consultants working at hospitals across the UK
- National Insititute of Health Research Database

Many of our research projects are dependent on people with PD participating. The more engagement with research the better our understanding of Parkinson's, and the more likely we are to make a difference.

If you know anyone with Parkinson's who wants to get involved with research or join our study, we would be happy to see them join our research efforts:

@PDfrontline

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**Help us engage people with Parkinson's Disease Research!**

We would love to hear your opinions on how we can engage more people with Parkinson's Research. If you have a few minutes spare, we would be grateful for your insight via this short form!

*Click here to complete our short survey!*

**166,000**

**people in the UK live with Parkinson's Disease**

**8,122**

**people with Parkinson's have joined our study**

**Less than 5%**

**have accessed our research into Parkinson's**



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# Ambassador Spotlight

## Saul Letourneau

I'm a public library worker in Sheffield; with a motivation to understand how I can identify the cause/causes of my Parkinson's and see if I can do more than treat the symptoms. Like many others I volunteer with, I would like to be able to find a cure or prevent the causes for myself and others. My broader interests are in working with community organisations: mostly cooperative housing for over 12 years and Friends of the Earth more recently. So, I come from a strong belief that real change for people comes from grassroots engagement.

**Saul's Journey:**

The first indications that my body was not working as it had been for the first 50 years of my life, showed up as symptoms I was not aware were classically Parkinson- like. These included less control of my breathing while swimming, feeling zapped earlier in the day, erratic shivers in my left leg, increasing thoracic tightness, and a lack of gait flexibility. My GP referred me to see an NHS neurologist, but after 6 months, my partner paid for me to see a neurologist privately. He did a thorough clinical motor examination. Matter-of-factly he asked if we had any suspicions, we blanked and he said it was doubtless Parkinson's. We were naively astounded but two research months later, felt more informed and with the benefits of Beneldopa and an agonist drug kicking in, this meant a return to me feeling mostly normal.

Since then, I've been inspired to link up with both Parkinson's UK in Sheffield and Edmond J Safra, Accelerating Clinical Trials in Parkinson's Disease (EJS ACT-PD). In the last few weeks, I received my genetics results from PD Frontline. Although my Parkinson's is unrelated to the genes tested, I'm suggesting another lifeline for people with Parkinson's may be support resources in the PD Frontline FAQ, with a decision tree to highlight varied pathways Parkinson's people can continue on to engage other research and life choices. This is being developed and will hopefully simplify our steps forward. I'm also kickstarting a reading group in Sheffield libraries for people with the early onset variety.

I'm glad to work as a Patient and Public Involvement and Engagement participant on the Trial Working Groups. Not being a scientist has meant I seek out plain English explanations in our meetings and in turn I get to emphasize the human side of clinical research. However, the research specialists have been very inclusive and acted on all our peer feedback to improve drug treatment trials for Parkinson's people and get us all to those goals of better treatment and maybe a cure.

***If anyone in the Sheffield area with young-onset Parkinson's is interested in joining Saul's reading group, please get in touch with us.***



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# PD Buddy

**PD Frontline has recently collaborated with PD Buddy, an easy-to-use app designed for people with Parkinson's and their carers to find support and shared experience!**

## Goals

- Help you stay in control of your symptoms
- Keep you connected with a community that understands

PD Buddy App

## Key Functionalities

- **Stay connected:** Built-in community features allow you to find and chat with others, including dedicated support and connection for carers.
- **Daily news and research:** Stay informed with the latest research, explained in simple terms so you know exactly what it means for your daily life.
- **AI-powered symptom tracking:** Easily log your symptoms and receive daily, personalised recommendations. Our AI analyses your data to suggest small adjustments to help you feel better each day.
- **All-in-one health hub:** Connect your smart wearables to keep all your health data (e.g. steps, sleep, and heart rate) in one convenient place.
- **Daily routines and habits:** Access habit tracking and daily routines specifically designed to meet the unique needs of people with Parkinson's.
- **Movement and mindset library:** Access a huge database of helpful exercises, daily cognitive challenges to keep the mind sharp, and guided meditations.
- **Parkinson's-friendly recipes:** Enjoy a collection of recipes tailored to support brain health and manage common nutritional needs.
- **Community hacks:** Learn practical tips from others on how to manage specific symptoms like insomnia, constipation, or "off" periods.
- **Web accessibility:** For those who prefer a larger screen or do not use a smartphone, some features are available via ***Parkinson's Insight*** on the web.
- **Entirely free:** Completely free app on the Apple App Store and Google Play Store

## Beatrice Zatorska: Behind the app

I am a technologist who built the app for my husband after his Parkinson's diagnosis. What started as a personal project to support my family has grown into a global community, with over 10,000 people already using the app to manage their journey. I continue to develop and improve the platform every day, ensuring it gets better and better for everyone who relies on it.

***CLICK HERE TO TRY OUT PD BUDDY***



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# Cure Parkinson's: The Tom Isaacs Award

**The Tom Isaacs Award recognises a researcher who is making a meaningful difference to people affected by Parkinson's by working with them, not just for them. Both researchers and people with Parkinson's are able to nominate individuals.**

In memory of former co-founder and President of Cure Parkinson's Tom Isaacs, who died in May 2017 aged 49, Cure Parkinson's and Van Andel Institute jointly present this annual award to a researcher who has shown the greatest impact on the lives of people living with Parkinson's and/or has involved people with Parkinson's in a participatory way in their work.

## Nominations will show:

- Meaningful collaboration with people affected by Parkinson's
- Evidence of impact, or strong potential for impact
- Ongoing commitment to partnership
- A clear spirit of working alongside people affected by the condition.

## Who can nominate:

- Anyone connected to Parkinson's
- People living with the condition
- Care partners
- Family members and friends
- Researchers, collaborators, and those involved in research or engagement activities.

*Nominate someone for the Tom Isaacs Award 2026 here*



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# Parkinson's and Genetics

**This section explores genetics, their relationship with Parkinson's Disease, genetic counselling and how your data has influenced practises for sharing GBA1 results in PD**

## Genes: What are they?

Genes are important parts of our DNA that act as recipes for proteins our body needs to function. We inherit one copy of a gene from our mother and the other copy from our father. Genes can influence traits such as eye colour. We have about 20, 000 genes in our body and when these have changes (variants), they can increase our risk for certain medical conditions. Several genes are associated with Parkinson's Disease, though at PD Frontline we are focussing on the GBA1 gene, as it is the most common genetic risk factor for developing Parkinson's.

Around 10 - 15% of people with Parkinson's have a variant in the GBA1 gene. In our cohort of ~8000 people with Parkinson's, there are just under 12% with a GBA1 variant. Understanding GBA1 variants better, through analysis of your data, helps to create accurate information about how common GBA1 changes are and how often certain variants are seen in the population.

Diversity within our cohort is incredibly important, as this helps accurately identify how common variants are and avoids over or understating the risk of a variant. For example, one research group has identified a genetic variant associated with African ancestry, which is almost completely absent from Asian and European populations. If no, or few individuals with African ancestry were included in Parkinson's research, this variant would not have been identified, even though it can contribute to risk for Parkinson's in a large number of people.

*African ancestry neurodegeneration risk variant disrupts an intronic branchpoint in GBA1*

This discovery has identified a new variant in the GBA1 gene for our group to look for. We are currently in the process of analysing our cohort data for this variant to keep our participants informed of new discoveries relevant to them, which highlights a key benefit of continuing to engage with PD Frontline.

Understanding genetic risk factors helps researchers to identify and develop treatments that are more or less effective for people with Parkinson's that have specific variants. In the future, this could help doctors prescribe treatments that are more likely to work for certain people. This concept of tailoring treatments to the individual is called precision medicine, and it is an exciting prospect for Parkinson's Disease because it recognises that Parkinson's may develop in different ways.

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## Genetic Variants and PD Risk

The GBA1 gene makes a protein called GCase, which helps cells break down and recycle waste. Genetic variants in the GBA1 gene can reduce how well this protein works and consequently how well the cell can clear waste. Individuals with GBA1 variantshave a higher lifetime risk of developing Parkinson's disease, although the level of risk varies depending on the specific variant.

In the general population, about 3 out of 100 people will develop Parkinson's in their lifetime. For individuals with a GBA1 variant this increases anywhere from 5 out of 100 people to up to 30 out of 100 people, depending on the variant. This still means that the majority of people with a GBA1 variant do not develop Parkinson's Disease, but it does make the GBA1 gene an important risk factor to study.

## What is Genetic Counselling?

Genetic Counselling is the means by which a healthcare professional or a researcher shares information about the genetic nature of a medical condition and supports individuals and their families with understanding how this may affect them.

At PD Frontline, we provide genetic counselling for the GBA1 and LRRK2 genes. Any participant with a variant (genetic change) are called by a member of the team to discuss further, this typically involves introducing what a gene is, how they relate to Parkinson's Disease and the effect the variant has had on their risk for Parkinson's. It also includes talking to the person about how this may affect family members and sources of support and testing.

Using your data, the team developed a paper which outlines how to approach genetic counselling for people with Parkinson's that have a GBA1 variant. This is now a key resource for Genetic Counselling in Parkinson's and features in the training course provided by the Movement Disorders Society for healthcare professionals working in Parkinson's Disease.

If you would like to read more about this important work, check out the link below:

*Click here to read about genetic counselling for GBA1 related Parkinson's*



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# Clinical Trials and Studies Update

**We are pleased to share some updates for some of our trials and studies!**

## ASPro-PD

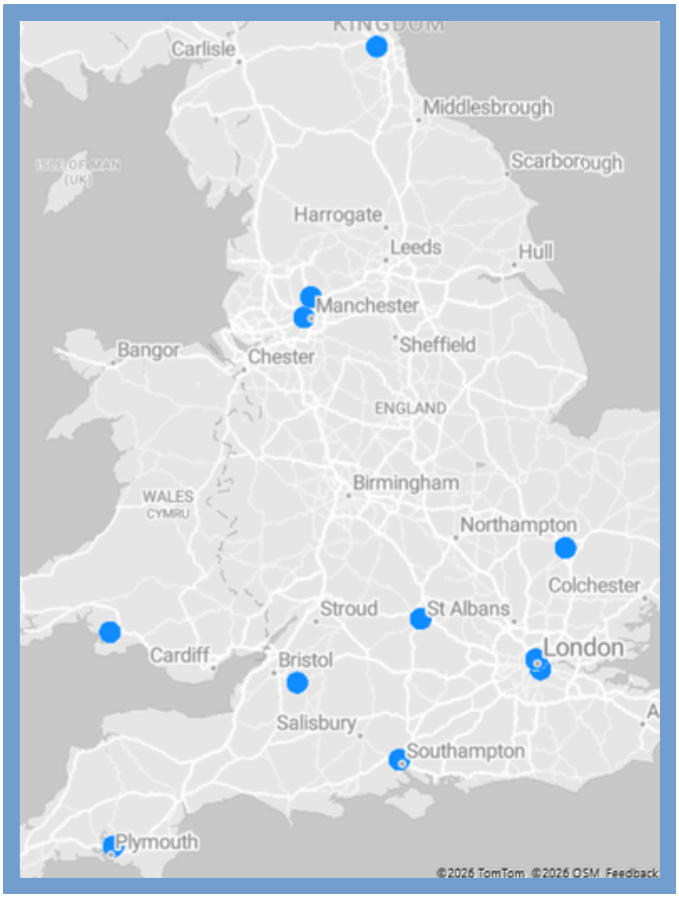
The ASProPD trial a Phase 3 study assessing whether Ambroxol can slow the progression of Parkinson's. It includes a trial arm specially selected for genetic status (GBA1), to see if Ambroxol is increasingly effective for those with a genetic change. As such, it is one of the most important studies yet done in Parkinson's, as it has potential to be effective for those with and without GBA genetic changes.

Recruitment to ASPro-PD is underway and the team have opened 14 sites across the UK, an exciting milestone! The trial has recruited and randomised 154 participants and are recruiting people with Parkinson's, with or without a GBA1 gene variant, so even if you are not GBA1 positive, you could be eligible.

Candidates are identified through our PD Frontline portal. We are actively recruiting to open trial sites across the UK.

ASPro-PD

***pdfrontline@ucl.ac.uk***




### Open Sites

- University College London Hospital
- Salford Royal (Manchester)
- Fairfield General Hospital (Manchester)
- Derriford Hospital (Plymouth)
- Prince Philip Hospital (South Wales)
- John Radcliffe Hospital (Oxford)
- Addenbrookes Hospital (Cambridge)
- Southampton General Hospital
- Western General Hospital (Edinburgh)
- University Hospitals Birmingham
- Newcastle
- Northumbria
- Kings College London
- Royal University Hospital Bath



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**We are supporting EJS ACT-PD**
Thiis is a clinical trial testing new treatments for Parkinson's disease, to slow or stop Parkinson's disease progression.

PD Frontline is providing the genetic testing as a sub-study of the trial and we are assessing the genetic status of participants on this trial.

**The trial treatments currently being tested in the EJS ACT-PD trial are:**

- Arm A: Placebo (or dummy drug)
- Arm B: Telmisartan (40mg per day)
- Arm C: Terazosin (5mg per day)

Arm D is currently in development, we will keep you up-to-date with any new information.

**Sites**
There are currently 20 sites set up across the UK, with further opening this year. For more information about the sites running EJS ACT-PD, please visit the link below.

*Click here to read more and register your interest in joining the trial*

*Some of our team recently attended the annual EJS ACT-PD event, it was great to hear about the initiatives in the trial.*



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# Which trials and studies are suitable for me?

**There are some important factors when considering trials and studies.**

**If you have a GBA1 variant, we would suggest considering ASPro-PD. This trial is also open to people without a GBA1 variant.**

This is because the drug being tested (Ambroxol) is thought to be more effective for those with a GBA1 variant. ASPro-PD needs to recruit enough people with GBA1 variants to confirm this.

**If you were diagnosed over 7 years ago or struggle to travel, we would suggest considering EJS ACT-PD.**

This is because a lot of trials and studies exclude people diagnosed with Parkinson's over 7 years ago, EJS ACT-PD do not have diagnosis date as exclusion criteria. They also can facilitate online visits for a proportion of the trial.

**If you have a LRRK2 variant, we would suggest considering LITE.**

This is because the LITE focusses on the LRRK2 gene specifically. Get in touch with us for more information via pdfrontline@ucl.ac.uk

**If you do not fit these categories**

These trials are also all accepting participants with Parkinson's without genetic changes, so do not worry! Due to our large registry of people interested in research, we are also approached by research groups running trials and studies looking for people that meet their eligibility criteria, so we may contact you about in the future.



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# Catch up with our Webinar!

**We were delighted to see over 190 attendees at our latest webinar discussing the gut microbiome (bacteria within the gut) and its relationship with Parkinson's! For those that attended we thank you for your feedback and look forward to announcing our next webinar in a later issue.**

**The Gut Microbiome**
**Professor Tony Schapira**
This talk explored the relationship between the gut microbiome and Parkinson's disease, including key findings from our recently published paper and directions future research into the gut might take for Parkinson's Disease.

**The PD Biome study**
**Milly Anderson**
This talk introduced the PD Biome sub-study. Over 300 members of our cohort have participated in this sub-study and their data underlies the research presented by Professor Schapira. We are still seeking participants for this sub-study to continue this important research.

*Please get in touch via pdbiome@ucl.ac.uk if you would like to hear further information about joining this sub-study.*

**Ambassador feedback and our communications approach**
**Georgie Pittwood**
This talk shared some information about the feedback we have had from our Ambassador scheme and how this feedback is helping to shape our approach and PD Frontline's future plans for communications.

YouTube

**July 2026 Webinar**
The PD Biome study, the gut Microbiome and our future communication plan

*Click here to catch up with the webinar recording and Q&A on our YouTube channel*



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