

PROGRESS

The research magazine of Parkinson's UK | Spring 2021

Recipe for a cure

Experts share their
recipe for success
in Parkinson's
research

P4

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**From trials
to treatments:**

Delivering the
life-changing
treatments
of tomorrow

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Research update

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David Dexter

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WELCOME

Hello and welcome to *Progress* magazine. As Director of Research at Parkinson's UK, it's great to introduce this issue and share my reflections on the current state of play in Parkinson's research.

There's no doubt that the past 12 months have been a testing time. The coronavirus (COVID-19) pandemic has had a major impact, disrupting research right across the globe and hampering fundraising efforts. But despite these challenges, Parkinson's research has delivered important advances in recent months and exciting new projects have been announced.

At Parkinson's UK we were able to protect our research budget and spend £8m on life-changing research projects in 2020, including announcing two new clinical trials towards the end of the year.

One is testing a vital new treatment for visual hallucinations in Parkinson's. The second, with US charity The Michael J. Fox Foundation, is testing a promising new drug for dyskinesia. Read more about these trials on **page 21**. And throughout 2020, the search for treatments that can slow, stop or reverse the progression of Parkinson's also continued at pace.

One major trial to report findings was the PASADENA study. This tested a new therapy called prasinezumab, an intravenous injection targeting alpha-synuclein. This offers hope of protecting brain cells and slowing the progression of Parkinson's. There were also promising signs that the therapy may improve thinking and memory. There are more details on **page 17**.

Finally, I'm hugely encouraged by the results of a survey we conducted which asked people with Parkinson's how they feel about taking part in research during the pandemic. We had an overwhelmingly positive response, with lots of great feedback and learnings. And 91% said they would feel comfortable taking part in research despite the current challenges and restrictions.

The determination of people living with Parkinson's to continue driving research forward is a constant inspiration. Thank you for everything you do to support the search for better treatments and a cure.

Arthur

We're
here for you
throughout the
coronavirus (COVID-19)
crisis. For the latest
information and support,
please visit parkinsons.org.uk/coronavirus

RECIPE FOR A CURE

We often talk about a cure for Parkinson's. But what does this word mean and what do we need to make it a reality?



A cure can mean different things to different people. Some people might see a cure as something that can prevent Parkinson's from happening, while others might see it as something that can control every one of the condition's symptoms. Whatever a cure may mean to you, at Parkinson's UK we're driving research forward to find and deliver these life-changing treatments.

We spoke to Ben Stecher, an international Parkinson's advocate, and Dr Patrik Brundin, a leading Parkinson's researcher based in the US, to get their perspectives. Seven themes began to emerge.



BEN STECHER
International
Parkinson's
advocate

Ben was diagnosed with Parkinson's seven years ago. He dedicates a lot of time to shaping research and advocating on behalf of people with Parkinson's. He's extremely knowledgeable, is in touch with many researchers, and has just written a book, *Brain Fables*.

When we asked Ben what a cure means for him, he strongly believes that a cure for Parkinson's will not be "one single thing that solves everything". His journey to discover as much as he can about Parkinson's has made him realise the complexity and variability of the condition.

It's becoming increasingly evident that multiple factors are at play. These factors are possibly why different people experience differing symptoms, but more research is needed to unpick these complexities. What this suggests to Ben, and others, is that there is a need for a range of different therapies that can be used in combination to meet the needs of the individual and their specific form of the condition.

"Parkinson's is like a bottle of water with many different holes. Plugging one hole is not going to stop the water leaking out. We need to embrace complexity if we are ever going to get to where we want to be."

BEN



DR PATRIK BRUNDIN
Leading
Parkinson's
researcher

Dr Patrik Brundin is the Deputy Chief Scientific Officer and Director of the Parkinson's Disease Center at the Van Andel Institute in Michigan, and is a hugely influential researcher in the Parkinson's field. When we asked

Patrik his perspective on finding a cure for Parkinson's, he echoed Ben's comments.

"Parkinson's is a highly individualised condition – the factors that give rise to it vary from person to person. Because of this, there likely won't be a single cure."

PATRIK

Seven essential ingredients make up our recipe for a cure, inspired by our conversations with Ben and Patrik. A recipe is a simple way of thinking about what goes into making better research and trials happen to help find better treatments for Parkinson's.



1. Subtyping Parkinson's

For Ben, the most important ingredient is to move away from the idea of Parkinson's being a singular condition. And with this, trying to understand why Parkinson's affects people differently in terms of causes, symptoms, progression, and response to different treatments. Ben describes Parkinson's as a spectrum, where people living with the condition are spread along a scale rather than existing in a singular group.

Many believe that grouping people into subtypes of the condition would help improve care and treatment options at an individual level. It could also help accelerate the hunt for new and

better treatments for Parkinson's. Patrik also thinks this is a very important area of research. There is ongoing work to group people into subtypes based on their symptoms. For instance, some people may have tremor as one of their main symptoms, while others may experience non-motor symptoms such as trouble with their memory, sleep or smell. So how can we study this? One answer is to track a group of people with Parkinson's over time.

"Understanding how patients differ is critically important. It is highly likely that some degree of personalised medicine will be the way forward. One can envision a future where there are several identified subtypes, each with their own specialised treatments. Certainly, understanding the stage of a person's Parkinson's will also be important."

PATRIK

Parkinson's UK has helped to fund such studies, like the ongoing Discovery Project at the Oxford Parkinson's Disease Centre. It's following and monitoring over 1,400 people with and without Parkinson's to build a picture of the different subtypes of the condition. Another UK-wide initiative is called Tracking Parkinson's,

which has gathered data over five years from 2,600 people with Parkinson's.

"We need to study real people. There is not enough research looking at people living with Parkinson's over time or aging studies in general."

BEN

More work is needed to continue to build a more complete picture of the subgroups, and to discover how these impact on the rate of progression and how people respond to different treatments.



2. Designing better clinical trials

Understanding the subtypes of Parkinson's will help ensure new treatments are designed and tested with specific groups of people in mind, making clinical trials more efficient and likely to succeed. As well as changing the landscape of future trials, looking back at existing clinical

trial data may identify certain subgroups of people within a trial who responded better to a specific experimental treatment. Ben goes as far as saying there may be cures that already exist for individuals but we need to match them together.

“If we look at past trials, for example the GDNF trial, some people responded remarkably and others didn’t. What can we learn to understand why some people responded better than others?”

BEN

Today, there are trials already under way aiming to target a specific group of people with Parkinson’s. For instance, by identifying people who have specific genetic differences that are linked to Parkinson’s.

While genetics isn’t the main cause of Parkinson’s in the vast majority of people, we are learning more about how differences in our DNA may be linked to types of Parkinson’s.

In some people, small differences in certain areas of our DNA, such as the LRRK2 or GBA genes, can contribute to an increased risk of Parkinson’s. This group of people, if identified, could make good candidates for therapies that are designed to target the problems that these genes are causing.

Such treatments include Ambroxol, which is being investigated for its potential to boost brain cells in those with differences in the GBA gene. And a potential drug, called DNL151, has been developed by Denali Therapeutics to target the problems caused by the LRRK2 gene. It’s currently moving into phase 2 trials.

Ben believes this is a promising line of research that may even bear fruit in the next five to 10 years.

“I think we will have some better answers about subtypes of Parkinson’s. By that point some of the phase 3 trials will be complete for LRRK2/GBA targeting treatments. Hopefully we will have at least one therapy that will slow progression and this will be a real proof of concept that clinical trials designed for subtypes of Parkinson’s are the way forward.”

BEN

Research supported by Parkinson’s UK continues to uncover why cells are lost in Parkinson’s, so we can develop new potential treatments that target the specific cause of the condition. While each one of these treatments may only work for a subset of people with the condition, the hope is that developing trials that take our individual differences into account will be the path to a cure.



3. Improving the way we measure the success of potential treatments

Both Ben and Patrik believe one of the main hurdles to real progress is the lack of a reliable



way to track the course of the condition. A challenge that could be overcome by finding biomarkers for Parkinson's.

A biomarker is a measurable change in the body that could help diagnose a condition and/or measure whether it is getting worse or better. For example, an increase in body temperature can be a sign of infection and monitoring blood sugar levels can help people with diabetes manage their condition.

At the moment, the success of clinical trials in Parkinson's is measured using various motor and non-motor scores that are determined after a participant undergoes a series of questionnaires and tests. Some people believe this is too subjective to accurately measure the condition and inform whether a potential treatment is working or not. Therefore, a lot of research is focusing on understanding more about Parkinson's to hopefully find a biomarker.

"The development of a biomarker that reflects the progression of the condition in a rigorous and reliable manner would be a game-changer. This marker could take a number of forms, including possibly a brain imaging marker or, even better, a simple blood test."

PATRIK



4. Enabling earlier diagnosis and intervention

Changes in the brain that are contributing to Parkinson's can occur many years before someone experiences movement symptoms and ultimately receives a diagnosis.

Understanding the causes and early signs of the condition is something that is still being pieced together. Increasing this understanding is vital to earlier and more accurate diagnosis.

"Focusing on developing ways to slow or stop progression by targeting the underlying mechanisms of the condition is a very promising avenue. There are many promising drugs that are currently being tested against a variety of targets."

PATRIK

This could lead to earlier intervention, which could pave the way for treatments that prevent symptoms from ever appearing.

This is an area that Patrik is particularly interested in and believes is vital in getting us closer to a cure for Parkinson's.

These targets include those looking to stop the build-up of harmful proteins that cause trouble in brain cells and other damaging agents that contribute to the causes of the condition.

It is vital to understand these underlying mechanisms but it's also important to understand what makes someone more at risk of developing Parkinson's.

Understanding more about the risk factors and earliest signs of the condition could lead to a way to delay or even stop the onset of the condition.

Research, such as the Parkinson's UK-funded Predict PD study, aims to understand more about the earliest signs of the condition to potentially predict an individual's risk.

There's also a global study run by The Michael J. Fox Foundation called Fox Insight. It aims to collect a range of information from people with and without Parkinson's to understand what genetic and environmental factors might increase someone's risk of the condition.

“While genetics play an important role, we know that it is only a minor part of the total risk landscape. Being exposed to certain environmental factors early on in life might contribute to a series of changes in the body that lead to Parkinson’s later down the line. Targeting these changes, especially early on, has the potential to give people more years with fewer or even no symptoms, perhaps for the remainder of their lives. This approach isn’t a ‘cure’ in the traditional sense, but the result could be much the same.”

PATRIK

condition, ways to improve managing symptoms could help move us closer to a day when people’s symptoms no longer get in the way of their day to day activities.

“There’s a lot of exciting research happening in the area of symptomatic control. DBS is an amazing miracle for a lot of people, and adaptive DBS systems could make this an even better tool than it already is.”

BEN

Ben believes these treatments will have the most impact in the coming years and specifically highlighted the potential of deep brain stimulation (DBS).

DBS is the most common type of surgery for Parkinson’s. It involves placing very fine wires into the brain to electrically stimulate particular groups of brain cells involved in controlling movement.

Research into DBS is continually evolving, with newer, more adaptable forms of treatment being developed.

Another area of research that Ben singles out is cell replacement therapies – where researchers are looking to find a way to replace the dopamine-producing brain cells that have died in Parkinson’s. If successful, this could help increase dopamine levels in the brain to in turn reduce symptoms of Parkinson’s.

Ben acknowledges this research will take some time to come to light, as ongoing clinical trials will require time to ensure the safety and possible long term benefits and side effects of this type of therapy.

“The new generation [of cell replacement therapies] is much more advanced so we should see a much higher success rate.”

BEN



5. Managing the symptoms of Parkinson’s

As well as ongoing research to find ways to slow, stop or reverse the





6. Lifestyle changes

While research into cell replacement therapies continues, one area of research that has already been shown to help with the management of symptoms, and maybe even impact on the progression of the condition, revolves around lifestyle changes.

Exercise, diets and supplements need to be better investigated to understand what role these accessible and existing factors could play in the search for a way to live better with Parkinson's.

"The preliminary evidence that one can slow progression through exercise, and possibly even diet, is accumulating. It would be great if there were large studies that clearly could demonstrate benefit in a rigorous way. It is quite possible that exercise and diet have different effects between people given the individualised nature of Parkinson's."

PATRIK



7. Working together

Finally, an ingredient that underpins research as a whole – and is vital to getting us closer to a cure – is for more researchers to work in partnership with people with Parkinson's, their carers and loved ones. This is vital to understanding research needs and priorities.

People affected by the condition have an understanding that researchers don't have, and

Ben believes this needs to be "tapped into more".

People living with Parkinson's are our driving force at Parkinson's UK and have a vital role in shaping, steering and taking part in research. It's essential that all research reflects this approach to ensure we are united in the search for a cure.

"Unlike researchers we can't go to sleep and forget about Parkinson's. In a variety of different ways we understand it better than anyone else ever could. Patients have a critical role to play for researchers to be confronted with the reality of what they are working on."

BEN

What's next for our recipe for success?

We believe the recipe for a cure has come a long way in the past few decades and we continue to drive research forward in these vital areas.

Alongside this, we are accelerating the chances of success by fast tracking the projects with the greatest potential to transform life for people with Parkinson's.

Research needs you

If you're interested in taking part in research looking for genetic differences linked to Parkinson's, read more about the PD Frontline study on **page 23**.



JOIN OUR RESEARCH NETWORK

Ready to take the next step on your research journey?
Join our growing online Research Support Network.

Join today at parkinsons.org.uk/RSN

- Join our community of over 5,000 people affected by Parkinson's helping us find a cure.
 - Attend online and local Q&A events with experts. And learn about work in the lab.
 - Get involved in shaping future research by sharing your Parkinson's experience.
 - Receive our monthly Research Roundup email. Get the latest news and opinions on the science.
 - Take part in research. From surveys to trials, whether or not you have Parkinson's.
 - Connect with our local research interest groups, or set up a group in your area.
-

“The next decade will herald a breakthrough in Parkinson's research. The RSN epitomises the true sense of working together for the good of the Parkinson's community.”

Carroll Siu, Research Volunteer



FROM TRIALS TO NEW TREATMENTS

Researchers use clinical trials to test whether a new treatment works and is safe for people to take. These trials are the most costly and lengthy part of the whole research process. They represent years, if not decades, of scientific advancement.

One of the biggest myths in Parkinson's is that no new treatments have been developed in the last 50 years. One of the biggest advances in the treatment of Parkinson's came about in the 1960s with the discovery of levodopa – a drug that remains the gold standard in Parkinson's medication. However, since then there have been lots of other advances. Today, these improve the quality of life for between seven and 14 million people with Parkinson's worldwide.

From surgical interventions like deep brain stimulation, to drugs that manage a myriad of symptoms, Parkinson's research is delivering on its promise of a brighter tomorrow.

But this is a story that is just beginning to get exciting. Inside labs around the world, scientists have bigger plans. They're building on foundations laid through decades of discovery and delivering more drugs and therapies into clinical trials than ever before.

Here, we take a look at the remarkable breadth of these studies and the promise they hold to deliver the life-changing treatments of tomorrow.

The clinical trial landscape

If you could see all the active Parkinson's clinical trials across the world right now, how many would you count? A handful, 20, more? Would it surprise you that a paper written by a team of scientists and Parkinson's advocates found 145 active trials last year?

That's a lot! But to really understand what this means we need to know a little more about the treatments being tested in these trials and what stage they're at in the pipeline. After all, clinical trials start small and focus on safety. It's not until we get to the larger, later stage trials that we really find out if a treatment is effective.

Testing drugs that improve symptoms

Some of the Parkinson's trials active today aim to improve treatments that are already available. They can improve our knowledge about when best to use different treatments, or deliver drugs in new ways.

For instance, instead of being packaged into tablets, levodopa might be delivered as an intestinal gel. Other drugs might be administered as a patch worn on the skin that delivers a slow consistent dose of medication throughout the day.

Type of trial

88 trials are focused on short-term symptomatic relief

57 trials aim to modify the course of Parkinson's progression

Stage of trial

51  are in **phase 1** (early safety)

66  are in **phase 2** (safety and early efficacy)

28  are in **phase 3** (large scale efficacy and safety)

There are also trials into drugs that might work better than the drugs currently available today, aiming to give better symptom relief, over longer periods, and with fewer side effects.

Lots of new treatments are being developed to tackle the aspects of Parkinson's that current treatments don't manage so well. These trials are focusing on tackling both motor and



non-motor symptoms. They hope to manage some of the most troublesome aspects of the condition, such as hallucinations and uncontrollable movements known as dyskinesia.

Testing drugs which may slow the progression of Parkinson's

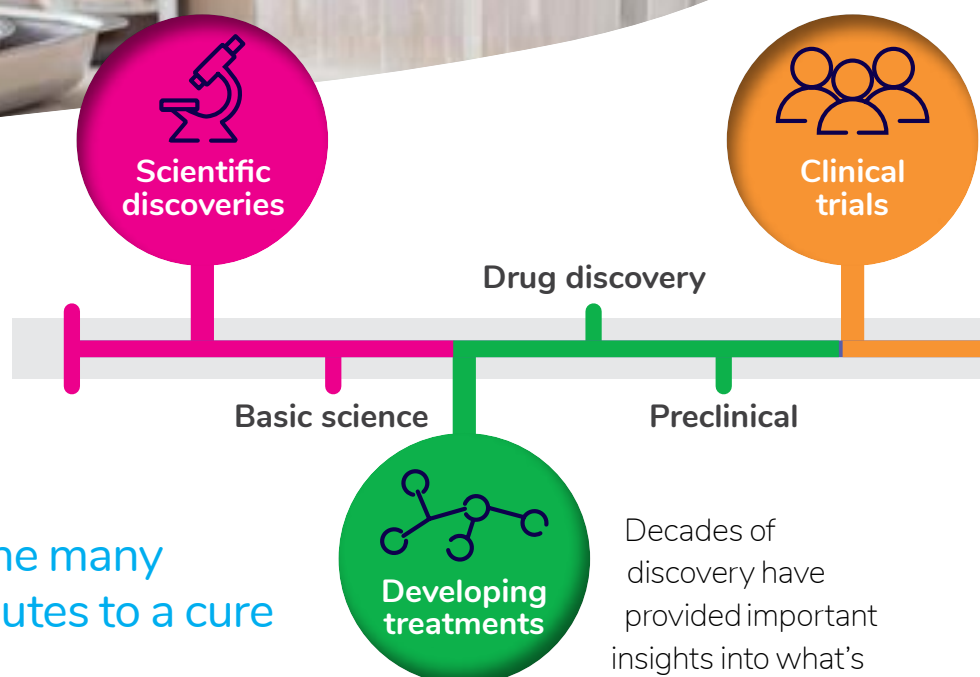
On the other side of the coin, trials are developing treatments that aim to slow, stop or even reverse Parkinson's.

We now know that a cure is probably not going to be the same for everyone. But ultimately, treatments that protect or replace precious brain cells and slow the spread of the condition will be part of this cure. So how do researchers hope to make this possible?

The many routes to a cure

Trials into treatments that slow the course of Parkinson's show how much our understanding of the condition has progressed over the last 50 years, and how far science has come in this time.

Researchers have now identified protective molecules, like antioxidants and growth factors (a family of naturally produced proteins), that may have a role to play in slowing progression. Trials are currently underway to test the effect of delivering high doses of growth factors to the areas of the brain affected by Parkinson's. This could prevent further harm and even repair damaged cells.

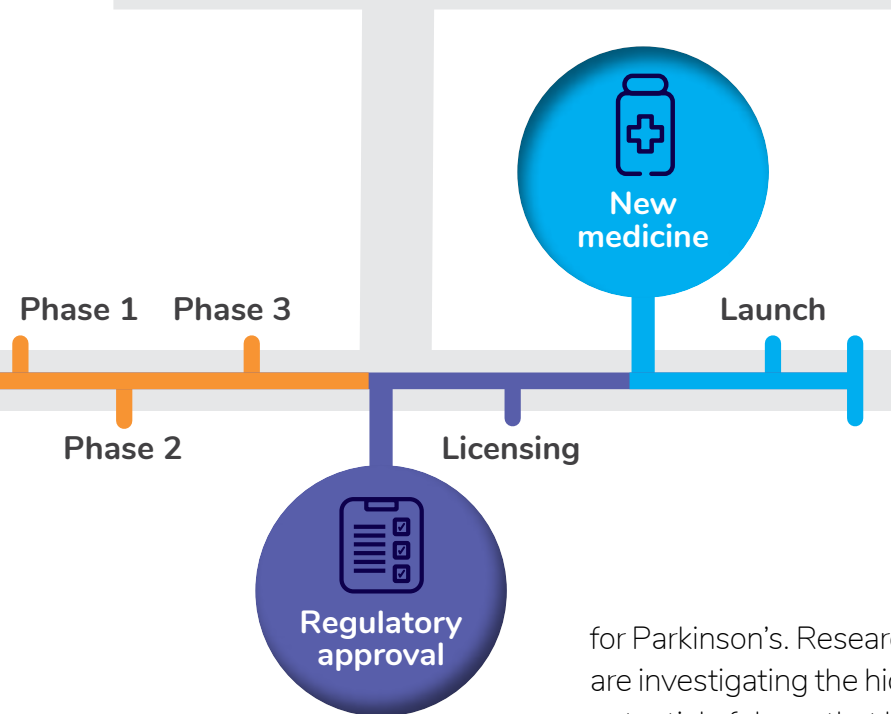


Decades of discovery have provided important insights into what's going wrong inside the brain, as well as the genetic and environmental causes that increase risk. From treatments that stop the build up of toxic proteins, to those that rescue the miniature power stations that keep our cells running, lots of areas of research funded by Parkinson's UK are now beginning to bear fruit.

Tackling the underlying problems that cause the loss of brain cells could stop the condition in its tracks. But there are even treatments in the clinical trials pipeline that could prevent Parkinson's from even reaching the brain, such as targeting early changes in the gut.

The research pipeline

From understanding what's going wrong inside our brain cells, to developing and testing new treatments to fix those problems. The research trial pipeline involves hundreds of experts, scientists, healthcare and clinical professionals, and people with Parkinson's.



What's next?

Improvements in our understanding of the condition mean that we can now manage its complexity better than ever before. But we know this isn't good enough. We know that people with Parkinson's deserve better.

Clinical trials are tricky, and trials in Parkinson's can be even more so. To deliver the next generation of treatments as quickly as possible, we need the whole Parkinson's community to come together and help drive research forward.

Not all trials will be successful. And it's impossible to know how long it will take for any one treatment to complete the clinical trial process and be made available to people. But we're incredibly optimistic about the vast array of possible avenues leading to a cure.

But it's not just our understanding of Parkinson's that has progressed. Achievements in stem cell research have allowed researchers to start the first cell transplantation trials in people with Parkinson's. And developments in our understanding of how our bodies fight infections is leading to new ways to use vaccines to activate our own immune system and help protect precious brain cells.

Finally there is a library of tens of thousands of drugs that have been developed for other conditions, some of which could be life-changing treatments

for Parkinson's. Researchers are investigating the hidden potential of drugs that have been developed for other conditions like diabetes and Alzheimer's. Drugs with potential could be fast tracked through the clinical trial pipeline. And should be cheaper than developing a new treatment from scratch.



Three examples of cure based clinical trials

1 Transplanting new cells into the brain

Today, there are several early-stage trials in progress that are investigating stem cells for Parkinson's. These include the trial in Kyoto, Japan that made the news back in 2018.

In this trial, the team aims to transplant new brain cells, which have been made from stem cells. And other trials are investigating how stem cells can be used in different ways to benefit people with Parkinson's.

While these trials are at an early stage, and mainly focus on investigating the safety of these approaches in a small number of people, positive results could mark a significant milestone in efforts to reverse Parkinson's.

2 Delivering naturally protective proteins

Growth factors are a family of remarkable molecules. Research has shown that a number of these factors seem to be crucial for the growth, development and survival of the brain cells that are affected by Parkinson's.

One of the major challenges is delivering these molecules deep into the brain where they're needed. A recent pioneering study, supported by Parkinson's UK, tested a novel delivery system to achieve this. It involved surgically implanting tubes in the brain to deliver GDNF (glial cell line-derived neurotrophic factor) directly to the affected brain areas with pinpoint accuracy, and this approach showed some promise.

Today, there are a range of further studies under way around the world that are exploring growth factors, including trials using new and less invasive approaches to deliver these important molecules to the brain.

3 Vaccines that combat Parkinson's

Research has shown that there is a build-up of a toxic protein called alpha-synuclein in the brain cells that are lost in Parkinson's.

There are multiple vaccines that have been developed to target alpha-synuclein at various stages of clinical trials.

Examples of these trials include two phase 2 studies that, combined, will test these potential therapies in over 600 people with Parkinson's.



PASADENA TRIAL SHOWS PROMISE



By Arthur, Director of Research

"The search for treatments that can slow, stop or reverse the progression of Parkinson's also continued at pace in 2020. One major trial to report findings was the PASADENA study."

This major clinical trial tested a new therapy called prasinezumab, which is given via intravenous injection. This therapy is one of many in development that aim to target alpha-synuclein – a protein that forms sticky tangles and clumps inside the brain cells affected in Parkinson's.

Prasinezumab has been designed to recognise alpha-synuclein and help the brain's immune system to eliminate this damaging protein. The hope is that removing excess alpha-synuclein could help to protect brain cells and slow or stop Parkinson's.

The results were not clearcut but encouragingly, people who received prasinezumab did significantly better on assessments of movement symptoms than people who received a placebo (dummy treatment) after one year. This offers hope that the therapy was protecting brain cells and slowing the progression of Parkinson's. There were also promising signs that the therapy may improve thinking and memory.

Based on these encouraging findings, pharmaceutical company Roche is now exploring next steps for prasinezumab which will hopefully be further, larger trials. We'll be keeping a close eye on this and other disease-modifying approaches being tested around the world and will report on any important advances.

TELL US WHAT YOU THINK OF PROGRESS MAGAZINE?

1. On a scale of 1 to 5, how interesting is *Progress* magazine?

PLEASE CIRCLE

1

2

3

4

5

2. How does reading *Progress* magazine make you feel? (please circle all that apply)

☐

Inspired

☐

Hopeful

☐

Informed

☐

Confused

☐

Frustrated

☐

Disheartened

Other (please specify):

3. How could we improve *Progress* magazine and what would you like to read about in the future?

4. After reading our magazine how likely are you to want to get involved in research?

PLEASE CIRCLE

1

2

3

4

5

5. Are you already a member of the Research Support Network (RSN)? If you are, you'll receive regular Research Roundup emails from the Parkinson's UK Research team.

☐

Yes

☐

No

☐

I don't know

Send us your answers

BY POST: Tear out this page and send it to:
Research team, Parkinson's UK, 215 Vauxhall Bridge Road, London, SW1V 1EJ

ONLINE: Fill out our quick questionnaire online at parkinsons.org.uk/progress-2021

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

OUR RESEARCH PROGRAMME: AN UPDATE

Professor David Dexter, Associate Research Director at Parkinson's UK, shares updates from the last few months.

Since joining Parkinson's UK four years ago, I've had the pleasure of shaping a research strategy that puts people with Parkinson's at the centre of everything we do.

With a growing number of people getting involved, there's a real sense of collaboration. The Parkinson's community is taking a leading role spearheading the initiatives that will change the future of living with this condition.

This, alongside an ever increasing understanding of the causes of Parkinson's, means a real momentum is building in the research community and beyond.

International investment to accelerate research

At any time, day or night, somewhere in the world, researchers are working on the next big discovery in Parkinson's. One of the ways we can accelerate research is by working together. And technological advances mean that it has never been easier to collaborate on ideas, share data and results, and bring together world leading experts.

This mindset is at the heart of the Aligning Science Across Parkinson's (ASAP) initiative. In 2020, ASAP injected a massive \$161m investment in

global Parkinson's research. By investing in basic research and fostering global collaboration and multidisciplinary working, they aim to uncover the roots of Parkinson's and clear a more direct pathway to a cure.

Of the 21 new ASAP projects, four teams are being led by researchers who have benefited from Parkinson's UK funding. We're proud that their new projects build upon early work supported by the charity.

Today we continue to support research that lays the foundations for future developments in Parkinson's. In fact we support over 30 different projects investigating every aspect of the condition.



These projects will unlock the treatments of tomorrow. From the launch of more clinical trials, to the delivery of new treatments, we're excited to continue to see the impact of research supported by Parkinson's UK.

Driving drug development forward

If you've been following our research for a while, you'll know that, in addition to investing in world leading research projects, our aim is to take the bold risks needed to accelerate research.

That's why we launched the Parkinson's Virtual Biotech

in 2017. It's an international initiative that aims to fill a critical gap in drug development and turn our understanding about Parkinson's into new treatments.

Through the Virtual Biotech, we've developed a powerful global movement of scientists and supporters, investors and innovators. All driven by people with Parkinson's every step of the way. We're on track to invest at least a further £20m in our Virtual Biotech and are



**THE PARKINSON'S
COMMUNITY IS
SPEARHEADING
INITIATIVES TO
CHANGE THE
FUTURE OF
LIVING WITH
THE CONDITION.**



pushing to deliver a life-changing new treatment to people with Parkinson's by the end of 2024. Today, despite the global pandemic, the Virtual Biotech continues to go from strength to strength. You can see three of the latest developments on the next page.

Supporting life-changing research

In 2020, Parkinson's UK was able to invest £8m in life-changing research, our largest yearly investment in research yet. But perhaps more importantly, we have continued to work in partnership with people affected by Parkinson's to identify where our investment and support can make the most difference.

Our Research team has worked hard to help clinical researchers adapt their studies so they can continue in the face of all the challenges caused by the coronavirus (COVID-19) pandemic. This has ensured that vital research isn't put at risk.

We've also been busy adapting our research programmes. Last year we launched a brand new grant scheme to support and accelerate research to

develop non-drug approaches for Parkinson's. The idea behind this scheme is simple: we know that developing drugs that may slow Parkinson's takes time, but research into other ways of managing Parkinson's might deliver treatments quicker.

These other approaches may include living aids, exercise, and physio, speech and occupational therapy, which already play a vital part in helping people manage daily life and take control of Parkinson's.

We're getting ready to announce the first successful projects from this new grant round in the near future. We'll continue to take the bold steps needed to improve life in the short term as well as looking for a cure in the longer term.



**DESPITE COVID,
WE'VE BEEN ABLE
TO ENSURE VITAL
RESEARCH ISN'T
PUT AT RISK.**

Our Virtual Biotech: three highlights from 2020

AUGUST

In August, we announced a further £1m investment in our partnership with NRG Therapeutics.

This research aims to develop drugs that can protect and boost mitochondria. Mitochondria are the tiny, energy-producing batteries that power our cells, but in Parkinson's they don't work properly. This may be central to why brain cells die.

Our partnership with NRG Therapeutics has already made important progress in identifying new molecules which look very promising. This new investment will enable us to develop them further. The ultimate ambition is to create a new drug, with the potential to slow or stop the progression of Parkinson's, that we can take forward into clinical trials.

OCTOBER

In October, we launched our second clinical trial to investigate if a drug used to treat sickness in chemotherapy patients could alleviate hallucinations for people with Parkinson's.

Ondansetron influences visual processing in the brain and its potential for treating visual hallucinations in Parkinson's was first identified in the early 1990s.

This major new study will test the promising treatment in over 200 people who experience hallucinations. If successful, the positive results from the trial could open doors and see this repurposed drug – which is already widely used in the NHS – quickly progress to become an available treatment for Parkinson's.

NOVEMBER

In November, we announced that we're joining forces with The Michael J. Fox Foundation to fund a third, groundbreaking trial.

The trial will investigate the effects of a new drug for dyskinesia – a common side effect of current Parkinson's medications. The drug, called NLX-112, was originally developed for pain relief but biopharmaceutical company Neurolix spotted its potential for treating dyskinesia for people with Parkinson's.

We previously invested to support Neurolix to conduct the final lab-stage testing of NLX-112. We were then able to help them secure approval to take it forward into clinical trials. It's fantastic for Parkinson's UK to be able to support this crucial next step. The trial will take place in Sweden and we hope to have results within two years.



TAKE PART IN RESEARCH

Did you know you can contribute to important research studies? From sending off saliva samples to using an app on your phone, there are lots of research opportunities you can do from the comfort of your own home.



GENETIC RESEARCH

OBJECTIVE: To identify Parkinson's associated genetic changes in people with Parkinson's – PD Frontline

The design of research trials is changing. We've found that people's genetic sequencing has the potential to help personalise and improve research.

Professor Anthony Schapira and his research team at Queen Square Institute of Neurology, UCL, are hoping to test potential therapies that target genetic changes associated with Parkinson's.

The team will identify people with Parkinson's who have small alterations in their genes, such as LRRK2 or GBA, who can be invited to take part in future research trials.

"There is a lot of research at present focused on people with GBA and LRRK2 gene alterations, with new treatments being designed specifically for them, such as in our recent Ambroxol phase 2 trial.

"Knowing whether or not someone with Parkinson's has one of these gene alterations may enable them and their family to participate in clinical trials of new treatments for Parkinson's."



Professor Anthony Schapira, Head of Department of Clinical and Movement Neurosciences, UCL Queen Square Institute of Neurology.

Who do the researchers need?

1,000 people **diagnosed with Parkinson's** who live in the UK. Research is conducted **at home**.

What does the research involve?

You'll need to register on the PD Frontline website. There, you'll be asked to complete an online consent form and a short 10-minute survey. Once you've completed these steps, you'll be sent a saliva sample collection kit, which will be posted to you with return pre-paid packaging.

Interested?

Visit the study website at www.pdf frontline.com or find out more at parkinsons.org.uk/PD-Frontline

CORONAVIRUS ATTITUDES RESEARCH

OBJECTIVE: To understand attitudes about coronavirus (COVID-19) and health – ATTACH

Dr Anna Hood is a research fellow at University College London. She's investigating what people's attitudes and behaviours are towards the coronavirus pandemic, and the public health strategies that have been put in place to tackle it.

The research aims to see if it is possible to monitor people's feelings using smartphone technology. The researchers also want to see how this potentially impacts mental health outcomes, particularly for older adults and those with medical conditions such as Parkinson's.

"The ATTACH study seeks to understand attitudes about COVID-19.

"By participating in this study, people will significantly increase our understanding during this unprecedented time and help us see how to target future mental health interventions."



**Dr Anna Hood, Research Fellow,
University College London**

Who do the researchers need?

2,000 people **with and without** a diagnosis of Parkinson's over the age of 16. Research is conducted **at home**. Participants need to have a smartphone and live in the UK.

What's involved?

You'll be asked to download the Air My Opinion app onto your smartphone. Twice a day, you'll receive a notification to answer a 1-minute question about how coronavirus is affecting you. Once a month, you'll be asked to complete a short 10-minute survey. If you have a monthly plan or pay-as-you-go bundle there is no additional cost to you. If your phone plan is traditional pay-as-you-go, you'll pay per SMS message.

Interested?

Download the Air My Opinion app or find out more at parkinsons.org.uk/covid-attitudes



VISUAL PERCEPTION RESEARCH

OBJECTIVE: To investigate the influence of Parkinson's on visual perception

Megan Readman, a PhD scholar at Lancaster University, is investigating how Parkinson's may alter visual perception. This is the way someone processes information about their surrounding environment based on what they see.

The aim of the research is to understand how visual perception may alter the physical abilities of people with Parkinson's and affect their daily life.

"Parkinson's is an incredibly diverse experience to the extent that no two people's journey with Parkinson's is the same. We as researchers know a great deal about the motor effects of Parkinson's, however, the influence of Parkinson's on non-motor cognitive processes is not as well documented.

"This is what my research focuses on, the influence of Parkinson's on a host of cognitively based processes including visual perception."



**Megan Readman, PhD Student,
University of Lancaster**

Who do the researchers need?

30 people diagnosed with Parkinson's who can walk independently.

What does the research involve?

A one-off 30-minute virtual session via Zoom, Microsoft Teams or Skype. In this session you'll be asked about your Parkinson's history and you'll complete a questionnaire about your physical ability. You'll also be asked to estimate the sizes of a number of different household items.

Interested?

Please contact Megan via email on **m.readman1@lancaster.ac.uk** or phone **01524 592 947** before 7 July 2021 if you'd like to take part. Find out more at **parkinsons.org.uk/perception**

Find an approved research study you can join

Enter your postcode on our Take Part Hub. Studies can be done from home, or safely on-site in line with coronavirus

guidance. Our Take Part Hub is regularly updated so please keep checking for new opportunities.

**parkinsons.org.uk/
takepartresearch
020 7963 3964**

ASK THE EXPERTS

Got a question about Parkinson's research? Want to know about the latest treatments, trials or tips? Our Research team has the answers!



Could the coronavirus (COVID-19) pandemic lead to a rise in Parkinson's?



COVID-19 is a new disease and we're still in the very earliest stages of understanding its full impact. However, there is no evidence that the virus causes Parkinson's directly.

To date, there have only been a handful of reports of people being diagnosed with Parkinson's following COVID-19, and this could simply be a coincidence.

Previous research has suggested that some viral infections may increase the risk of developing Parkinson's in the longer term. In the years following the last major global pandemic, the Spanish Flu in 1918, there was a significant increase in Parkinson's-like disorders.

It's too soon to know whether COVID-19 could lead to an increase in Parkinson's in years to come. But as the pandemic continues, it's vital that the long term effects of the virus on the brain are a priority for research.



Got a question about research?

Email research@parkinsons.org.uk with the word "Progress" in the subject line.

Q I know exercise is meant to be good if you have Parkinson's. What suggestions do you have for what types of exercise to do?

A Exercise is good for you. And it's especially good for you if you have Parkinson's.

Whether you have Parkinson's or live with someone who does, there's no one-size-fits-all approach.

With Parkinson's, the best exercise to do depends on how the condition affects you. But the message is the same for everyone – go for it!

At the moment we're all spending more time indoors, which means our daily routines have had to change. This makes staying active and exercising all the more important for our physical and mental wellbeing.

Visit our website to find out more about different types of exercise for people with Parkinson's, including how to stay active at home:

parkinsons.org.uk/exercise

Q I came across a non-invasive light therapy treatment online. Is it worth it?

A There are different types of light therapy that have been proposed for people with Parkinson's. Although light therapy is thought to be safe with minimal side effects, we don't advise people seek out this therapy as a treatment. Overall the evidence so far shows that the effects can be variable and more large scale trials are needed to assess the long term benefits.

Q Have the recent small scale trials, carried out by Parkinson's UK, come to any final conclusions on the benefits of Symprove for people like myself with Parkinson's?

A The clinical trial of a drinkable probiotic called Symprove is still underway and so we don't yet know if it is scientifically beneficial to people with Parkinson's. There is some early evidence that Symprove may improve gut health in people with the condition, and we eagerly await the results from the full clinical trial to understand if this may impact on motor and non-motor symptoms.

We don't have an exact date for when the full results will be available, but we'll continue to keep you up to date with news stories on our website and in *Progress*, and through the Research Support Network.



We are Parkinson's UK.
Powered by people.
Funded by you.
Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

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