

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



2024 PAR-CON



11 & 12 October 2024

Royal Armouries, Leeds and online

Programme

Welcome to Par-Con 2024

and thank you so much for joining us online.



I'm Beverley and I have Parkinson's. I'm part of a group of dedicated volunteers who have shaped this year's event. We've helped plan everything from the venue and the food, to the topics, activities and speakers, to make Par-Con 2024 interesting, engaging and helpful for everyone in the Parkinson's community.

On day 1, we'll have sessions exploring revolutionary research that's helping us push towards new treatments, faster. We'll also look at transformational technologies that are changing how we research, treat and live with the condition.

After lunch, you can join a special online session delving into the hidden symptoms of Parkinson's – including non-motor symptoms, mental health and thinking and memory challenges.

I'm especially looking forward to ending the day with a chance to put questions to the experts in our final session: Parkinson's Question Time. Make sure to submit your questions during the day!

Day 2 kicks off with a session on how to live well with Parkinson's, covering physical activity, diet and nutrition, creativity and more. This will be followed by the chance for Parkinson's UK members to attend the charity's AGM.

Non-members will be able to connect, network and get to grips with managing medication.

Finally, after lunch, we'll end the event with the return of the Community Awards – an opportunity to recognise and celebrate the amazing contributions of people in the Parkinson's community doing amazing things up and down the country. You won't want to miss it!

We've made sure there are plenty of breaks in the programme so you can recharge, and get to know others in the Parkinson's community.

I hope you enjoy Par-Con 2024 and go away with new connections, knowledge and ideas.

Beverley

Thank you to our Par-Con working group:

Joe Gregory
Dan Sanzen-Baker
Peter Lake
Yvette Bordley

Adrian Wrigley
Colette Wood
Jagdeep Singh Aujla
Beverley Price

Sponsors

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We're currently funding 39 research projects across England, Scotland and Wales, with £13 million of investment.

Agenda day 1

Friday 11 October

Time	Session	Speakers
10.00–10.15	Arrival and welcome	
10.15–11.30	Revolutionary Research Where we are, where we're going, and how to take part.	Chair: Dr Shafaq Hussain-Ali Speaker: Professor Camille Carroll Flash talk speakers: Professor Sagnik Bhattacharyya, Richelle Flanagan, Katie Purdy
11.30–12.00	Break	
12.00–13.00	Transformational Technology Find out about the pioneering tech transforming research, treatment and living with Parkinson's.	Chair: Professor David Dexter Speakers: Professor Stephen Jackson, Kuhan Pushparatnam
13.00–14.00	Lunch	
14.00–15.00	Hidden Symptoms Hear more about research into the non-motor symptoms of Parkinson's, and tips on how to manage them.	Chair: Dr Rowan Wathes Speakers: Claire Stevens, Dr Robin Fackrell, Emma Edwards
15.00–15.30	Break	

15.30–16.30

Parkinson's Question Time

Your opportunity to ask questions to our expert panel of neurologists, nurses, Parkinson's UK staff and people with lived experience of Parkinson's. We'll then close the day with a musical performance from Bibi Heal.

Chair:

Gary Shaughnessy

Panellists:

Carl Beech,
Emma Edwards,
Caroline Russell,
Professor David Dexter,
Professor Camille Carroll

Special guest: Bibi Heal

Since 2021, we've been prioritising making research inclusive and accessible to everyone, through our Race Equality in Research project.

Agenda day 2

Saturday 12 October

Time	Session	Speakers
9.30–9.45	Arrival and welcome	
9.45–11.00	Living Well with Parkinson's The hosts of the 2 <i>Parkies in a Pod</i> podcast speak with leading researcher Professor Bas Bloem on how to live well with Parkinson's every day.	Chairs: Kuhan Pushparatnam, Dave Clark Speaker: Professor Bas Bloem
11.00–11.30	Break	
11.30–12.15	Parkinson's UK Annual General Meeting Parkinson's UK members are invited to join our AGM to hear updates and ask questions.	
12.15–13.15	Medication Management Delivered by a Parkinson's healthcare professional, this session will help answer your questions on medication for Parkinson's.	Chair: Winston Marshall Speaker: Dr Gurjit Singh Chhokar
13.15–14.00	Lunch	
14.00–15.00	Community Awards Celebrate and shine a light on the compassionate individuals who strengthen our Parkinson's community.	Host: Paul Mayhew-Archer



The Parkinson's UK Brain Bank, the only brain bank worldwide solely dedicated to Parkinson's research, has supported over 500 research projects across the world.

Speakers



Professor Bas Bloem

Presenting at: Living Well with Parkinson's (speaker)

Professor Bloem works as a consultant neurologist at Radboud University Medical Centre in Nijmegen, The Netherlands. He graduated from Leiden University Medical Centre with honours in 1993 and got his PhD in 1994. He trained in neurology at the same place from 1994 to 2000 and then specialised in movement disorders with fellowships at the Parkinson's Institute in California and the Institute of Neurology in London. In September 2008, he became a professor of neurology, focusing on movement disorders.

Professor Bloem has written over 1,000 works, including more than 870 research papers, and has supervised 68 PhD students, seven of whom graduated with honours. His top rankings in Parkinson's disease research show his strong influence in the field. He has been the president of the International Society of Posture and Gait Research and the secretary of the International Parkinson and Movement Disorder Society. In 2011, he was named National Healthcare Hero, and in 2012, Citizen of the Year in Nijmegen. His recent awards include the Stevin Prize in 2022 and being knighted in the Order of the Dutch Lion in 2024.

In 2002, he started the Radboudumc Centre of Expertise for Parkinson & Movement Disorders and created ParkinsonNet with Dr Marten Munneke, which has won several awards for healthcare innovation. His research interests include brain compensatory mechanisms, healthcare innovation, and using wearable sensors and AI to prevent Parkinson's disease.



Professor Camille Carroll

Presenting at: Revolutionary Research (speaker), Parkinson's Question Time (panellist)

Professor Carroll is a professor of clinical neuroscience at Newcastle University and an honorary consultant neurologist at University Hospitals Plymouth NHS Trust. She has two main research interests: clinical trials and digital health technologies. Professor Carroll is involved in designing and running clinical trials for therapies that might slow or stop the progression of Parkinson's.

Together with Professor Tom Foltynie at UCL, she also co-leads the Edmond J Safra Accelerating Clinical Trials in Parkinson's Disease (EJS ACT-PD) initiative. This has developed a large trial to test multiple different therapies, and is due to open at the end of 2024.

Professor Carroll develops and uses digital tools to improve care for people with Parkinson's – in particular to enable them to understand and manage their Parkinson's, and to allow care to be provided more effectively. She has developed a unique care pathway which remotely monitors people with Parkinson's using a wearable sensor to help identify when a clinical review or medication adjustments might be helpful.

All of Professor Carroll's work involves and is jointly led by people with Parkinson's and their care partners. She is the joint clinical director of the Parkinson's Excellence Network, and enjoys working with several teams and committees within Parkinson's UK and Cure Parkinson's.



Carl Beech

Presenting at: Parkinson's Question Time (panellist)

Carl is a social entrepreneur, published author, keynote speaker, podcaster and commentator on matters of justice and community transformation. He has founded several charities, most recently a non-governmental organisation to help child cobalt miners in the Democratic Republic of Congo, which he visited this year.

Diagnosed with young onset Parkinson's, Carl is also now CEO of Spotlight YOPD, the charity committed to enhancing awareness and delivering specialised resources for people with young onset Parkinson's. Before his diagnosis he completed multiple endurance cycling and running events. He also has a slight obsession with bonsai trees, annual flowers and is overly excited about getting a greenhouse.



Caroline Russell

Presenting at: Parkinson's Question Time (panellist)

Caroline is proud to be CEO of Parkinson's UK and of the organisation's relentless drive to listen, work with and be guided by the Parkinson's community.

She says: "I have the privilege of being in a position where I can connect with people affected by Parkinson's and listen to and learn from their experience to ensure that the charity is delivering what they view as important. I also have the great honour of being in a position to say thank you to the many people and organisations who support the charity to ensure that we have the resources to deliver our offer.

"My background of being a CEO in the NHS and having started my career in local government allows me to bring the learning and connections from those roles into my current position. I care passionately about end of life care and as such I am trustee of my local hospice.

"Being active is also something I believe strongly in, as it's great for your physical and mental health and allows you to make new and different connections. I'm an avid and proud parkrunner and have now graduated onto collecting parkruns to spell both my name and the letters of the alphabet."



Claire Stevens

Presenting at: Hidden Symptoms (speaker)

Claire cares for and supports her husband, who was diagnosed with Lewy body dementia at the age of 65, following a Parkinson's diagnosis the year before. They have actively engaged with Parkinson's UK and our Edinburgh Branch from the start.

To mark her retirement from work earlier this year, Claire raised over £2,000 for the Parkinson's UK Edinburgh Branch, through donations from colleagues across the voluntary and public sectors. Prior to retiring, for 12 years Claire was Chief Executive of Voluntary Health Scotland, a national charity and network working to address Scotland's deeply entrenched health inequalities.

Claire has held paid and voluntary roles in Scotland's third sector for over 40 years and is currently a trustee of the Neurological Alliance of Scotland. In 2021 the Faculty of Public Health elected her as an honorary member, for services to public health. She is also a member of the Scottish working group Parkinson's UK recently established to scope how the charity might better support and advocate for people with Parkinson's who are also living with dementia.



Dave Clark

Presenting at: Living Well with Parkinson's (chair)

Most recognisable from Sky Sports' live darts coverage, Dave Clark was diagnosed with Parkinson's in 2011.

Dave has been an incredible supporter of Parkinson's UK over the years, helping to raise awareness of Parkinson's with dozens of TV and radio interviews. In 2016, he became the Parkinson's UK Champion of Walking, and has since raised tens of thousands of pounds with his own walking challenges. In September 2018 he conquered the Dales Way in his 90-mile March for a Cure.

Dave also played a key role in helping Parkinson's UK secure a valuable partnership with the Professional Darts Corporation. Since 2022, he has been co-host of the *2 Parkies in a Pod* podcast.



Professor David Dexter

Presenting at: Transformational Technology (chair), Parkinson's Question Time (panellist)

Professor Dexter joined Parkinson's UK in 2017. He brings over 30 years of experience in Parkinson's research to oversee the charity's research activities, accelerating better treatments, and ultimately a cure.

David was previously professor of neuropharmacology at Imperial College. One of his roles there was scientific director at the Parkinson's UK Brain Bank, the UK's largest supplier of brain tissue for research dedicated to Parkinson's.

As well as being an internationally recognised expert in Parkinson's biology, David is passionate about research to improve life for people living with Parkinson's today. This led to the launch of Parkinson's UK's non-drug approaches grants scheme. More recently it has also led to the development of the Parkinson's UK Tech Guide – a service which aims to support people with Parkinson's to find technologies to help them manage the condition.



Emma Edwards

Presenting at: Hidden Symptoms (speaker), Parkinson's Question Time (panellist)

Emma has been a qualified mental health nurse for 28 years. She's spent the last 14 years as a Parkinson's specialist nurse, working in the community in south-west England. She has a special interest in suicide prevention.

Emma teaches about mental health as part of the Parkinson's Masterclass with the Neurology Academy, as well as talking with staff across the UK about suicide prevention. She also works with Spotlight YOPD and does a regular podcast with people living with young onset Parkinson's. Emma sits on the Royal College of Nursing's Neuroscience Nursing Forum too.



Gary Shaughnessy CBE

Presenting at: Parkinson's Question Time (chair)

Gary is chair of Parkinson's UK, England Athletics and the Z Zurich Foundation. Over the last 35 years, he has held senior roles in financial services, culminating in being CEO of EMEA for Zurich Insurance and a member of the company's Group Executive until 2019.

Gary was diagnosed with Parkinson's in 2015. When he stepped back from full-time commercial life, he took on the role of chair at Parkinson's UK, having already been a trustee. He has also continued to be chair of the Z Zurich Foundation, a charitable trust focusing on climate resilience, mental wellbeing and social equity programmes across the globe.

In September 2021, Gary was appointed as chair of England Athletics. This reflects his lifelong engagement in community sport as well as his strong belief in the power of sport to support social mobility and inclusion, and physical and mental wellbeing. Gary also combines sport with community engagement to raise funds and awareness for Parkinson's UK and other charities.

In 2023, Gary was awarded a CBE for his services to business and charity in the King's first Birthday Honours List.



Jagdeep Singh Aujla

Presenting at: Boxing for Parkinson's (instructor - in person only session)

Jagdeep was diagnosed with Parkinson's in 2021, but is still in full-time employment. He has taught martial arts for over 35 years, and has worked with many charities to raise funds by running marathons, completing long bike rides, and trekking around the world.

Having Parkinson's has given Jagdeep the drive to help others with the condition to keep active. With the help of his local Parkinson's UK group, he opened a non-combative boxing club called 'Dopamine Warriors BC', where he teaches as a volunteer. Jagdeep is an accredited Parkinson's Wellness Recovery instructor. He is also involved with Parkinson's UK as an advocate, campaigner, fundraiser and a member of the Race Equality in Research group.



Dr Gurjit Singh Chhokar

Presenting at: Medication Management (speaker)

Dr Chhokar is a consultant geriatrician with specialist interest in movement disorders. He has been dedicated to the Parkinson's community for the past eight years. Throughout this period, Dr Chhokar has collaborated closely with Parkinson's UK and colleagues to enhance the timeliness of medication at Leeds hospitals, an initiative that has since been adopted by other hospitals across the country. He has also been instrumental in improving access to Parkinson's reviews for patients admitted to hospitals and has enhanced care for those who find it challenging to attend clinics.

Dr Chhokar is interested in empowering people living with Parkinson's to engage with information, listening to their needs and preferences regarding their services and aiming to provide better support for them.



Kuhan Pushparatnam

Presenting at: Transformational Technology (speaker), Living Well with Parkinson's (chair)

Kuhan was diagnosed with Parkinson's in 2013 at the age of 38 and remains determined to live his best possible life. Having struggled with acceptance for many years, he now actively shares his experience through advocacy, participation in research and as a co-host of the Parkinson's podcast *2 Parkies in a Pod*.

Whilst Parkinson's forced him to retire early from his career in the mobile industry, Kuhan has put his experience to good use by developing the free app 'Parkinson's ON' – a self funded social enterprise, empowering people with Parkinson's to better understand and manage their condition.

His Parkinson's has also triggered a creative streak for photography, videography and writing.



Paul Mayhew-Archer

Presenting at: Community Awards (host)

Paul Mayhew-Archer has spent the last 40 years trying to make us laugh. He is a multi-award-winning writer whose credits include *The Vicar of Dibley*, *Mrs Brown's Boys* and the screen version of *Roald Dahl's Esio Trot* starring Judi Dench and Dustin Hoffman.

He also produced the much-loved Radio 4 shows *I'm Sorry I Haven't A Clue* and *Old Harry's Game*. As a script editor he has worked on everything from *Spitting Image* to *Miranda*.

He was diagnosed with Parkinson's in 2011. It's an incurable illness that gets progressively worse and has over 50 symptoms. It is also – as Paul quickly found out – funny.

involving the creation of Safer Clinical Systems for People With Parkinson's and The King's Fund which focuses on end of life decision making. He is involved with an increasing research portfolio, recruiting to many research studies. He is also a member of the British Geriatric Society Specialist Interest Group in Movement Disorders.



Phil Jerky

Presenting at: Networking event (comedian - in person only session)

Phil was diagnosed with young onset Parkinson's in 2017. He is a parent, a charity worker (trusts fundraiser) and a stand-up comedian. He lives in Birmingham, and supports Aston Villa. His hobbies include embarrassing his son, drinking coffee, and listening to rock music.



Dr Shafaq Hussain-Ali

Presenting at: Revolutionary Research (chair)

Dr Hussain-Ali started off as an NHS dentist and sedationist. She was diagnosed with Parkinson's aged 40. At this point, Parkinson's advocacy became her new passion, especially promoting volunteering in research.

She joined Parkinson's UK's Race Equality in Research group. Since then, she's been a lay reviewer for grants, taken part in research, been a catwalk model, and taken up public speaking, amongst other things.

She firmly believes that the 'puzzle' of Parkinson's will only be solved when people – researchers, charitable organisations, people with Parkinson's and scientists – all come together to share their knowledge. Much of her work is centred around increasing awareness of Parkinson's amongst ethnic minorities, and trying to facilitate connections between different bodies working in the field of Parkinson's.



Winston Marshall

Presenting at: Medication Management (chair)

Winston is originally from Barbados, but has called London home for many years. With a deep commitment to service, Winston dedicated over 20 years to St John Ambulance as a commercial trainer. In this role, he was responsible for educating countless people in life-saving techniques and first aid, a vocation that has touched the lives of many and left a lasting impact on the community. He can be seen demonstrating his skills in YouTube videos. For his service and dedication, Winston was made a Member of The Most Venerable Order of the Hospital of St John of Jerusalem. This is an honour only bestowed upon deserving members who have demonstrated loyalty and service to the organisation.

Winston started to experience symptoms of Parkinson's in 2019 and was diagnosed in 2022. It has been a challenge that has redefined his journey but not his resolve. He remains an inspiration to those around him, embodying resilience and courage in the face of adversity. His experience with Parkinson's has deepened his empathy and understanding, further enriching the compassion he extends to others.



Professor Stephen Jackson

Presenting at: Transformational Technology (speaker)

Stephen is Professor of Cognitive Neuroscience at the University of Nottingham. He completed his PhD in experimental psychology at the University of Cambridge, and held posts at the University of Oregon, USA, and the University of Wales, Bangor, before taking up his current position at the University of Nottingham in 1999.

His research uses brain imaging and brain stimulation techniques to investigate human sensorimotor function. His current research is aimed at developing new therapeutic approaches for brain health conditions using wearable technology incorporating non-invasive brain stimulation.

Professor Jackson serves as Chair of the Scientific Advisory Board of the Federation of European Societies for Neuropsychology (FESN) and has previously served as President of the British Association for Cognitive Neuroscience, and Editor-in-Chief of the Journal of Neuropsychology.

Want to stay up to date with Parkinson's research?

The Parkinson's UK Research Support Network connects people who want to stay up to date with Parkinson's research. This includes opportunities to take part in studies and get involved in shaping research.

Launched in 2010, the Network was designed and created in partnership with a group of passionate people affected by Parkinson's, to drive forward Parkinson's research. Now a community of over 10,000 members, the Network can help you:

- **Get connected to Parkinson's research**
Members get all the latest Parkinson's news and event invites delivered straight to their email inbox.
- **Take part in research**
Receive information about opportunities to take part in research studies, what's involved and how to get in touch with the researchers carrying out the study.
- **Have your say on what matters**
From decisions on what we fund to shaping research studies, the Research Support Network helps make sure your voice is heard in research both at Parkinson's UK and beyond.

Join the Research Support Network today by visiting parkinsons.org.uk/rsn, or speak to one of our Research Support Network ambassadors to find out more.



The more you can find out about research, the more confident it'll make you feel about taking part. I knew nothing about research before. I probably wouldn't have taken part in research if I hadn't found the Research Support Network, but it's made me feel a lot more comfortable."

Nicky – Research Support Network member



Parkinson's UK Membership

Become a Parkinson's UK member and join a community of over 40,000 people who are committed to improving life for everyone affected by the condition. Parkinson's UK members use their voices to raise awareness and take actions to influence positive change for the community.

As a Parkinson's UK member, we'll contact you with opportunities to get involved with, and influence the future of, our work. This could include completing surveys, taking part in focus groups, getting involved in national activities, voting at the Annual General Meeting, attending member events and more! You'll also be provided with opportunities to ask questions about our charitable work and feed back to us about how you think we're doing.

Parkinson's UK membership is free and you can choose what you want to take part in (there's no obligation to do anything!). We invite you to shape your membership journey to meet your needs.

Parkinson's UK members also receive regular email updates from us as well as three copies per year of our health magazine *The Parkinson* and one copy per year of our research magazine *Progress*.



If you'd like to know more about Parkinson's UK membership then please visit parkinsons.org.uk/membership. If you'd like to contact the membership team please email membersevents@parkinsons.org.uk.

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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