

**PARKINSON'S<sup>UK</sup>**  
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**Edinburgh Branch  
51<sup>st</sup> Annual General  
Meeting (in person)  
15<sup>th</sup> March 2023**

**PARKINSON'S<sup>UK</sup>**  
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# ***Welcome to our AGM***

***at Inverleith St Serfs Small Hall***

Members, Care-partners, Volunteers

&

James Jopling & Alice Hall,

Parkinson's UK Scotland

# PROGRAMME

**A) AGM Business**

**B) 2022 Review**

**Including ERIG**

**C) James Jopling, Scotland Director  
Parkinson's UK**

# BUSINESS AGENDA

- 1) Introduction and Welcome
- 2) Apologies for absence
- 3) Minutes of the hybrid meeting held on the 16<sup>th</sup> March 2022
- 4) Report by the retiring Branch Chair – *David Adams*
- 5) Treasurer's Report and Accounts for the year ending 31/12/22
- 6) Election of Branch Chair – *Stephen Brannan*
- 7) Election of Officers and Committee  
Vice-Chair – *Patrick Mark*; Treasurer – *Weir Brown*; Secretary – *Olivia Bell*;  
Committee – *David Melton (Chair ERIG)*, *Gina Allen (Community Development & EYPSG)*, *Anne Chalmers (Communications)*
- 8) Reviews and Updates from Parkinson's Scotland & Ed. Branch

**2) Apologies**

**3) Minutes of 16<sup>th</sup>**

**March 2022**

# 4) Branch Chair's Report

*We do as much as we can, to the best we can, for **PwPs & Care-partners** – with Families, Friends – in Midlothian*

**2022 Highlights – bounce back after lockdown! 30+ Volunteers!:**

- **FIRST STEPS Programme June 2022**
- **Therapies 1:1 in person programme launched**
- **Community Development Group expanded**
- **Activities & Events resumed in person + Table Tennis!**
- **Thanks to Service Providers for continuing collaboration, to Members for resilience, and to Committee Officers & Volunteers for energetic support**
- **Branch membership numbers remain steady**
- **Volunteer Awards by Parkinson's UK:**

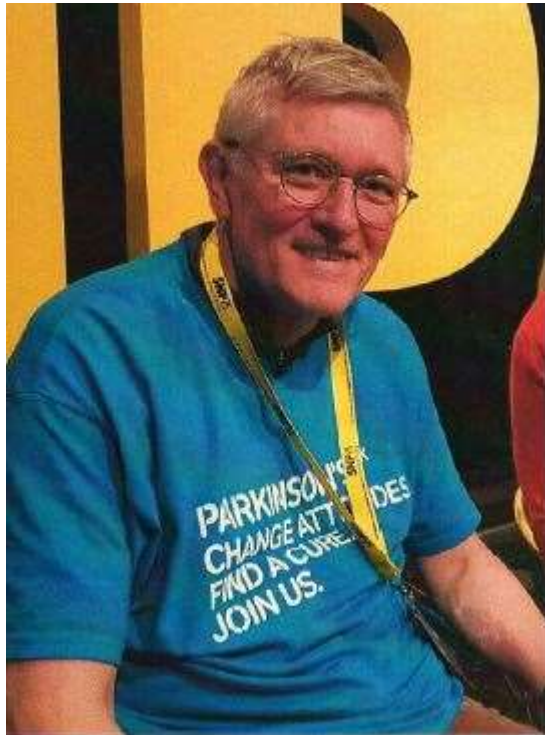
***Gina Allen***

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Parkinson's UK Edinburgh Branch AGM 2023

# Dave Wilson, 1963 - 2022



**Branch Committee  
2019 - 2022**



# Thanks for Committee Service:

**Louise Ogilvy – *Retiring from Fundraising Collections and Events since 2010***

**Maggy Douglas – Cafés & Walks (continuing)**

**Nick Shelness – First Steps (continuing)**

**Iain Steele – First Steps (continuing)**

**David Waughman – Pilates & Neurodynamics (continuing)**

**Scott Wilson – Chair EYPSG (working age)**

# Welcome to New Branch Volunteers:

**Stephen Brannan – Prospective Chair**

**Diane Kennedy – Community Development**

**Lis Kirkness – Singing4Fun**

**Precila Jose – Community Development**

**Susanna Kerr – Branch Events**

**Elaine More – Art Group**

**Noelia Pelegrina-Hidalgo – Community Development**

**Mark Scholefield – Art Group**

**Claire Stevens – Community Development**

# Regular Branch Activities

## Research & Better Treatment – action & links:

The Lecture; ERIG; Public Patient Involvement (PPI); Training support; EPPSAT; QMU; UofE; ENU; HWU.

## Personal Wellbeing – in person (some online) :

Activities & Exercise: Art Group, Cafés, Dance, Indoor Bowls, First Steps, Nordic Walking, Pilates & Neurodynamics, QL Group, Singing4Fun x2, Carers Support Group, Side by Side, Table Tennis, Tai Chi x2, Therapies, Walks in the Park, Yoga.

## Community – in person (some online):

Active Website & Social Media; Blethers & Get-Togethers; Internet Support; Newsletters; Support for Young (Working Age) Parkinson's Group; Summer & Christmas Lunches

Branch strapline: ***There is much more to life with Parkinson's!***

# Personal thanks to :

**Patrick Mark – wisest guide and mentor**

**Olivia Bell – ever present support**

**Weir Brown – care and reliability most could only dream of**

**David Melton – outstanding successor to Ken Bowler**

**Gina Allen – wise in all ways Parkinsonian...**

**Anne Chalmers – visionary attention to detail & news**

***And a Very Special Multitude of Volunteers!* (- more later)**

# 5) Finance Report

# Income & Expenditure 2022

## Income

	£
Total Income	58,373
<i>of which:</i>	
Donations	12,689
Legacy – S.Robertson	2,392
Legacy – M Macfarlane	25,612
Lunches	1,467
Fundraising	3,488
Activities	11,759
Other (Gift Aid tax, membership, etc)	966

## Expenditure

	£
Total Expenditure	62,699
<i>of which:</i>	
Research donations	3,000
Research group expenses	3,037
Activities	47,535
Lunches	2,364
Admin, printing, mailing	6,763
<i>Deficit</i>	<i>4,326</i>

# Activities 2022

<b>Income</b>	<b>£</b>	<b>Expenditure</b>	<b>£</b>
Pilates	3,954	Pilates	14,562
Singing4fun	2,223	Singing4fun	8,892
Tai Chi	1,099	Tai Chi	4,385
Neurodynamics	3,602	Neurodynamics	14,903
Yoga	544	Yoga	1,575
Nordic walking	50	Nordic Walking	1,825
Table tennis	287	Art/Therapies	1,393

# Donations/Fundraising 2022

## Donations

	£
General Donations	5,859
Gift Aid Tax Reclaimed	569
In Memoriam	2,912
Annual lecture	2,737

## Fundraising

Craighleith collections	3,487
Leith Accies collection	242

## Group Donations

	£
Caram Trust	2,000
Braid Bowling Club	528
Duddingston Art Club	125



# Personal Donors & Fundraisers 2022

## *Special thanks*

Mary Steele

Nigel Wilson

J. Reid

Martin Maxwell

Mrs Laing

David Watson

Anonymous donor  
– annual lecture

Louise Ogilvy

Deirdre Grennan

D. Hollingdale

Volunteers

# 6) Election of Branch Chair

# Election of Branch Chair

Candidate:

*Stephen Brannan*

# 7) Election of Officers & Committee

# Election of Officers & Committee

Candidates:

**Vice-Chair – *Patrick Mark***

**Treasurer – *Weir Brown***

**Secretary – *Olivia Bell***

**Committee –**

***David Melton*** (Chair ERIG)

***Gina Allen*** – Community Development, Therapies &  
EYPSG

***Anne Chalmers*** - Communications, Website & Media

**AGM concluded**

**8) - *Reviews follow...***

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# **Edinburgh Branch Research Interest Group**

**AGM review of 2022-2023**

**David Melton**

# Edinburgh Parkinson's Research Interest Group (ERIG) Aims

- To provide opportunities for members with an interest in Parkinson's research to meet, communicate and work together with local scientists and clinicians to further the cause of research.
- To encourage and develop interest in research amongst both ERIG members and the wider Edinburgh Branch.



# September 2022: Edinburgh Parkinson's Lecture

Back in front of a live audience at the Royal College of Physicians of Edinburgh. The Lecture was also watched live online by 900 people.

We heard an inspirational Lecture from Julie Jones, a physiotherapist specialising in Parkinson's and Senior Lecturer at Robert Gordon University in Aberdeen.



The Importance of Exercise for People with Parkinson's: Evidence, Empowerment and Enablement.

The event ended with a powerful personal view from Branch member Dr Alison Williams of the benefits of exercise for her Parkinson's.

# November 2022: What The Parkinson's Excellence Network can do for you & an update on local clinical trials

Combined ERIG/Branch online meeting attended by over 30 members.

Dr Gordon Duncan is Clinical Director, Medicine for the Elderly and Stroke, NHS Lothian and is also an Honorary Clinical Senior Lecturer, University of Edinburgh.

Gordon leads the Scotland East and South part of the UK-wide Parkinson's Clinical Excellence Network.

Gordon described how the Excellence Network was working to improve the standard of care for PwPs.

Gordon also reviewed the progress of current local clinical trials for Parkinson's and outlined new trials planned for 2023.

He explained that to improve therapies it was essential to get enough PwPs to participate in trials.



# December 2022: Our first in person ERIG event in nearly three years

Dr Martine Verheul, Institute for Sport, Physical Education and Health Sciences, University of Edinburgh, gave an illustrated talk about whether frame running could be an exercise option for people with advanced Parkinson's.



Then, after we had all had a good look at the frame running bike that she brought along, Prof Kia Nazarpour (School of Informatics, University of Edinburgh) gave a short presentation on plans to establish an artificial intelligence and technology-based approach to assist our NHS healthcare teams to better monitor PwPs and optimise their care plans.

# January 2023: Parkinson's and Obstructive Sleep Apnoea



## Sleep Breathing and Parkinson's Disease

*Introducing the CPAP-PD study*

Amber Roguski

Research Assistant

Department of Sleep Medicine, Royal Infirmary of Edinburgh

Obstructive Sleep Apnoea (OSA) is a common condition where the upper airway collapses during sleep, causing breathing pauses and fragmented sleep. It is more common in People with Parkinson's and it can make their Parkinson's symptoms worse.

Amber described an upcoming local research study to investigating OSA therapies in People with Parkinson's. They need PwP volunteers to participate in the study!

# Edinburgh Research Interest Group

More details and recordings of all ERIG talks:

<https://www.edinburghparkinsons.org/research-interest/local-research-events/>

and Edinburgh Parkinson's Lectures:

<https://www.edinburghparkinsons.org/edinburgh-parkinsons-lecture/>

are available on our Branch website( <https://www.edinburghparkinsons.org/> )

## Join us!



# Hope!

This video, submitted by Alison Williams, is one of 12 shortlisted for the **People's Choice Award** at the opening in July of the **2023 World Parkinson Congress** in Barcelona.

Voting opens in April:

<https://www.youtube.com/watch?v=KJ9la-C0IW0>

# 2022 Branch Activities and Volunteering Review

# Resuming Branch Get-Togethers

*well worth joining in!*

- *September* – Dalcroze Eurhythmics research project
- *October* – Community Development Group: Experiences of Diagnosis
- *November* – Branch Visit by Caroline Rassel, David Dexter & James Jopling
- *December* – Christmas Lunch
- *February* – Isobel McCoy, Speech Therapist



*New venues: Inverleith St Serf's & Liberton Kirk*



## 2022 - Community Activities & Events:

- Active Website (new host: Lunaria) & Social Media
- Branch Blethers and Get-Togethers
- Summer and Christmas Lunches
- Newsletters online and in post
- Expansion of Community Development Group
- One to One Therapies Programme launched
- Walks in the Park, Cafés & Bowling revived
- First Steps Programme held online
- Art Group revival at The Botanic Cottage
- Table Tennis with EYPSG at North Merchiston Club



# Celebrating our *backbone* of Volunteers - 1!

**Alexa** Cornish – Botanic Cottage Art Group Support

**Alison** Williams – QL Group, Research, Scotland Advisory Group, Visiting Professor QMU

**Anne** Chalmers – Website & Newsletters, Support Group, Eventbrite bookings, Community Development Group, Committee

**Bill** Wright – Quality of Life Group

**Cathie** Quinn – Carers Support Group, Side-by-Side

**Claire** Stevens – Community Development Group

**David** Adams – (*Retiring*) Chair Branch & Committee Meetings, Activities

**David** Melton - Chair ERIG, Lecture, Committee

**David** Waughman – [Aquatherapy Lifeguard], Neurodynamic Exercise, Pilates, Committee

**Diane** Kennedy – Community Development group

**Dot** Brown – Nordic Walking

**Elaine** More – Art Group

**Gina** Allen - Young Parkinson's Group Secretary, Therapies Project, Activities + Table Tennis, Community Development Group, Committee

**Helen Harris** – Volunteer Therapist

**Iain** Steele – First Steps, Committee

**Julia** Melton – Publications, Member info packs, QL Treasurer

**Katrina** McGougan – Art Group Co-ordination

# Celebrating our *backbone* of Volunteers - 2!

**Kenny Williamson** – Indoor Bowling

**Kirsty Low** – (*Retired*) First Steps

**Lindsay & Linda McDermid** – Art Group at Botanic Cottage

**Lis Kirkness** – Singing4Fun

**Louise Ogilvy** – (*Retiring*) Fundraising, Committee

**Maggy Douglas** – Community Development Group, Cafés, Committee, Walks in the Park

**Martin Maxwell** - Fundraising

**Nick Shelness** – First Steps, Dance for Parkinson's, Yoga, QL Group, Committee

**Olivia Bell** – Branch Secretary, Singing4Fun, Correspondence, Branch Blethers,

**Patrick Mark** – Vice Chair, Membership

**Scott Wilson** – Chair, Edinburgh Young Parkinson's Support Group, Table Tennis

**Sheila Edward** – Support for meetings & Cafés, Walks in the Park

**Stephen Brannan** – Community Development Group

**Sue Owen** – Volunteer Therapist

**Weir Brown** –Treasurer, Budgets, Legacy Plans, Website, Committee

## 2022 - Activities with Service Leaders:

- Dance for Parkinson's – *Jen Cunningham*
- Nordic Walking – *Trevor Jones*
- Pilates & Neurodynamics – *Sasha Baggaley*
- Quality of Living Group – *People with Parkinson's*
- Singing4Fun – *Penny Stone, Sally Jaquet*
- Sunshine Yoga – *Karen Watts*
- Tai Chi – *Kevin Brown*
- Tai Chi Wu Style – *Philippa Hope*
- Therapies, one-to-one – *misc. providers & Gina Allen*
- Yoga – *Karen Watts*

# 2022 – *Extra Support*

for Care-partners:

- Side-by-Side course – *Cathie Quinn & Marysia Williamson*
- Carers Support Group - *Cathie Quinn*

for working age people with Parkinson's:

- Young Parkinson's Group – *Scott Wilson & Gina Allen*

*That's it from me, folks....*



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# Outlook for 2023

# Activities for 2023

Develop First Steps – improving support for people coming to terms with their Parkinson's

More Branch Get-Togethers

ERIG and The Lecture

Continuing in person Activities

Community Development Group

Parkinson's Cafés & Walks

Branch social and participative events

Continuing public patient involvement – PPI

***More Volunteers???***



# 2023 – *Following First Steps?*

The First Steps Programme is

- for early stage people with Parkinson's
- given by people with Parkinson's
- led by Parkinson's UK PwPs and Staff

Edinburgh Branch first in the UK to initiate a trained Local Programme, in collaboration with the First Steps Team

*- Thanks to Nick Shelness, Iain Steele, Kirsty Low*

However,

- voluntary coordination is impractical
- we look for alternative ways to meet the need

# World Parkinson Congress, Barcelona



# Volunteering in 2023?

## Some important roles:

- **Activities & First Steps Co-Ordinator**
- **Assistant Treasurer**
- **Side-by-Side Course Leader**
- **Fundraiser/rota organiser**
- **Parkinson's Cafés - Outreach Leaders**
- **Social Events Leader/Promoter**
- **Inter-group Parkinson's contacts person**

# *Special thanks to*

**Committee Members**

**Branch Vice Chair, Secretary, Treasurer**

**ERIG Chair, Independent Examiner**

**Activity Leaders & Organisers**

**Parkinson's UK**

***All Volunteers & Helpers***

*Window sticker:*

**There's more to life with Parkinson's**

**Find out at [www.edinburghparkinsons.org](http://www.edinburghparkinsons.org)**

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# THANK YOU

**End of Branch Volunteering  
Review**

**Questions?**

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# **Edinburgh Branch AGM 2023**

**James Jopling**

**March 2023**

**Thank you...**

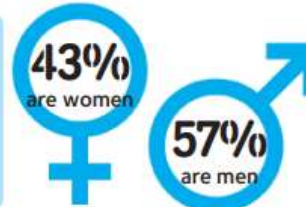
# Parkinson's in Scotland

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# 12,184

people live with Parkinson's in Scotland.

85% - that's around  
**10,400** - are  
aged over **65**



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**1** in every **375** adults in Scotland has Parkinson's.

About **30** people are diagnosed with Parkinson's in Scotland every week.

**1** in **3** people living with Parkinson's in Scotland are aged over **80**

**4,295** people with Parkinson's were admitted to hospital during 2015/16 and their average length of stay was almost **18** days. This accounts for more than **75,000** bed days.

**6,000** people live with more advanced Parkinson's.

**6,000** people with Parkinson's in Scotland - almost half of the total - could benefit from social care support.

**1** in **3** people with Parkinson's in Scotland have Parkinson's dementia.

People with Parkinson's are **x6** more likely to have dementia.

**1,200 to 1,800** care home residents have Parkinson's



**75,000** BED DAYS



More than **6** in **10** admissions for people with Parkinson's in Scotland are unplanned.

**60%** of people with Parkinson's experience falls, and **40%** fall repeatedly. These people fall an average of **21** times per year.

People with Parkinson's **x3** more likely to fracture a bone.



On average, households affected by Parkinson's in Scotland lose £13,375 per year because of Parkinson's.

**£683** is the average cost of welfare reforms to each household affected by Parkinson's.

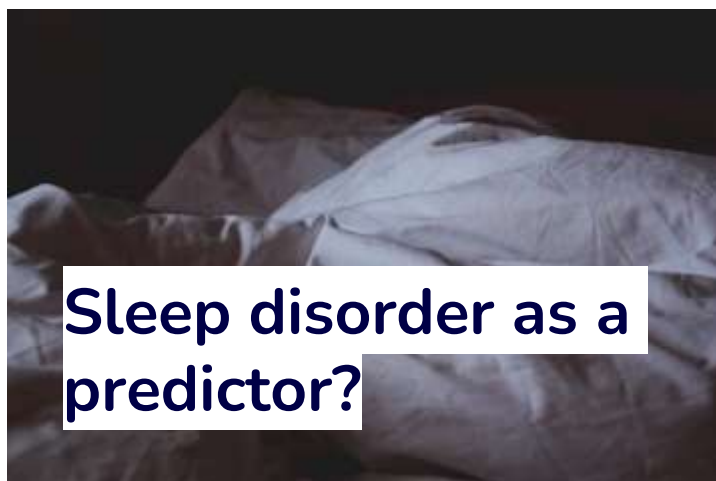
More than **1,500** people with Parkinson's will have to go through needless disability benefit assessments.



# Scotland Team Plans for 2023

- Better access to treatments for advanced Parkinson's
- People with dementia and Parkinson's, struggling with their mental health and Parkinson's
- Developing groups and better presence in deprived communities, YP, Friends family and carers, newly diagnosed, remote and rural communities
- 10 new local authority support areas for Parkinson's Active
- Supporting grant applications for physical activity, Parkinson's nurses and clinicians -both people and projects

# Trials testing new treatments through the Parkinson's Virtual Biotech



**Co-funding £1.1m in a phase 3 stage clinical trial, investigating the potential of ambroxol for slowing down the progression of Parkinson's**

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**Charitable Foundation**

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# THANK YOU

**Contact:**

**[jjopling@parkinsons.org.uk](mailto:jjopling@parkinsons.org.uk)**

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