

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

**Edinburgh Branch  
48<sup>th</sup> Annual General  
Meeting  
11 March 2020**

***Welcome!***

Members, Care-partners, Volunteers &  
Special Guests:

**Annie Macleod, Scotland Director**  
Parkinson's UK

**Dr Karen Matthews**  
Queen Margaret University

# TODAY'S PROGRAMME

**A) AGM Business**

**B) 2019 Activities & Volunteering**

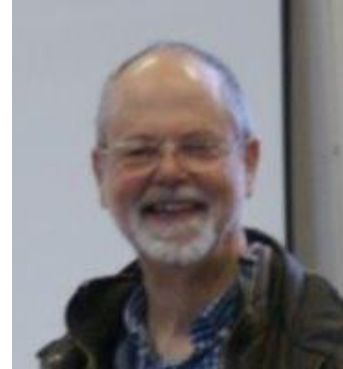
**Including ERIG, and much more ...**

**C) Annie Macleod, Scotland Director  
Parkinson's UK**

**D) Karen Matthews, QMU, about PPI  
(Public Patient Involvement)**

*Remembering with love and gratitude:*

***Ken Bowler***



***Heather Robertson***

# BUSINESS AGENDA

- 1) Apologies for absence
- 2) Minutes of the meeting held on the 13<sup>th</sup> March 2019
- 3) Treasurer's Report and Accounts for the year ending 31/12/19
- 4) Short Report of the Branch Committee by the Chair
- 5) Appointment of Hon Independent Examiner, *Susie Tastard CA*
- 6) Election of Office Bearers and members of the Committee  
Hon Treasurer – *Weir Brown*, Hon Secretary – *Olivia Bell*,  
Committee – *Eileen Blackwood, Louise Ogilvy, Bill Wright, Hagop Bessos, David Melton (Chair ERIG), Nick Shelness, Gina Allen, Anne Chalmers, David Waughman, Scott Wilson (Chair EYPSG)*,
- 7) Election of Hon Chair – *David Adams*
- 8) Election of Hon Vice-Chair – *Patrick Mark*
- 9) Any other competent business –

**Thanks for Committee Service:**

**Judith Shepherd**

**Cathie Quinn**

# Treasurer's Report

# Income & Expenditure 2019

	£		£
<b>Total Income</b>	56,652	<b>Total Expenditure</b>	62,366
<i>of which:</i>		<i>of which:</i>	
Donations	17,576	Research donations	2,000
Legacy – S.Robertson	16,592	Research group exps.	3,086
Fundraising Activities	3,587	Activities	45,456
Other (Gift Aid tax, membership, etc)	14,315 4,582	Meeting Room hires	1,911
		Website Development	3,007
		Admin, printing, mailing	6,906
		<i>Deficit</i>	<i>(5,714)</i>



# Activities 2019

<b>Income</b>	<b>£</b>	<b>Expenditure</b>	<b>£</b>
Pilates	5,779	Pilates	14,341
Singing4fun	4,964	Singing4fun	9,746
Tai Chi	1,487	Tai Chi	4,886
Neurodynamics	1,202	Neurodynamics	5,417
Yoga	423	Yoga	2,910
Thistle Foundation	460	Aquatherapy	2,665
		Nordic Walking	1,800
		Thistle Foundation	2,550
		Art/Therapies	940

# Donations/Fundraising 2019

## Donations

	£
General Donations	13,591
Gift Aid Tax Reclaimed	997
In Memoriam	3,985
Annual lecture	717
Fundraising	
Art Club sales	1,129
Craigleith Centre	2,202
Kevin Brown 2018/19	1,508
Harps of Gold Concert	356

## Group Donations

	£
Mrs M.Black Trust	1,000
Willowbrae Ladies Bowling	900
Edin.Women's Bowling Ass	300
Edin. High Constables	1,000
Roseburn House Rsdnts	1,943
Humber Lions Club	150

# Personal Donors & Fundraisers 2019

## *Special thanks*

Kevin Brown

Pat Stewart

Shirley Lush

Louise Ogilvie

James Henderson

Deirdre Grennan

Nigel Wilson

J. Reid

Lindsay & Linda  
McDermid

Ian Young

## *And Volunteers*

# Branch Committee's Report

# *Short Branch Report – We stand for*

## **Research & Better Treatment:**

The Lecture; ERIG; Public Patient Involvement (PPI); Training support; EPPSAT; QMU; UofE; ENU; HWU. +WPC5, Kyoto

## **Personal Wellbeing:**

Activities, Exercise: 20 choices for group participation.

Therapies: 7 options on referral. Meetings with Nurses.

## **Community in Action:**

Participative Events: Get-togethers, Cafés, Lunches, Outings, Fun Support for Young (Working Age) Parkinson's Group

## **Branch Strategy:**

*Do as much as we can, to the best we can, for as long as we can afford it...for **PwPs & Care-partners** – with Families, Friends – in **Midlothian** **There is more to life with Parkinson's***

# Appointment and Elections

## BUSINESS AGENDA (contd.)

- 5) Appointment of Hon Independent Examiner, *Susie Tastard CA*
- 6) Election of Office Bearers and members of the Committee  
Hon Treasurer – *Weir Brown*, Hon Secretary – *Olivia Bell*,  
Committee – *Eileen Blackwood, Louise Ogilvy, Bill Wright, Hagop Bessos, David Melton (Chair ERIG), Nick Shelness, Gina Allen, Anne Chalmers, David Waughman, Scott Wilson (Chair EYPSG)*,
- 7) Election of Hon Chair – *David Adams*
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- 9) Any other competent business –

**AGM complete!**

***more to follow...***



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# **Edinburgh Branch Research Interest Group**

**AGM review of 2019-2020**

**David Melton**

# September 2019: announcement of the Ken Bowler Travel Bursary at the Edinburgh Parkinson's Lecture



For PhD students registered at a university in Edinburgh and carrying out research into Parkinson's to attend a conference relevant to their research project.

# April 2019: David Breen

## Six myths about Parkinson's Disease and why they are untrue



~~Six~~ myths about Parkinson's  
disease (and why they are wrong)

A very positive message about treatments for PD, explaining many common misunderstandings - and still going strong at myth17 !

# August 2019: Tilo Kunath wins prestigious Tom Isaacs Award for his engagement work with the local Parkinson's community



Fake ERIG event was arranged to get Tilo along to receive the award !

# September 2019: Edinburgh Parkinson's Lecture Prof Andres Lozano

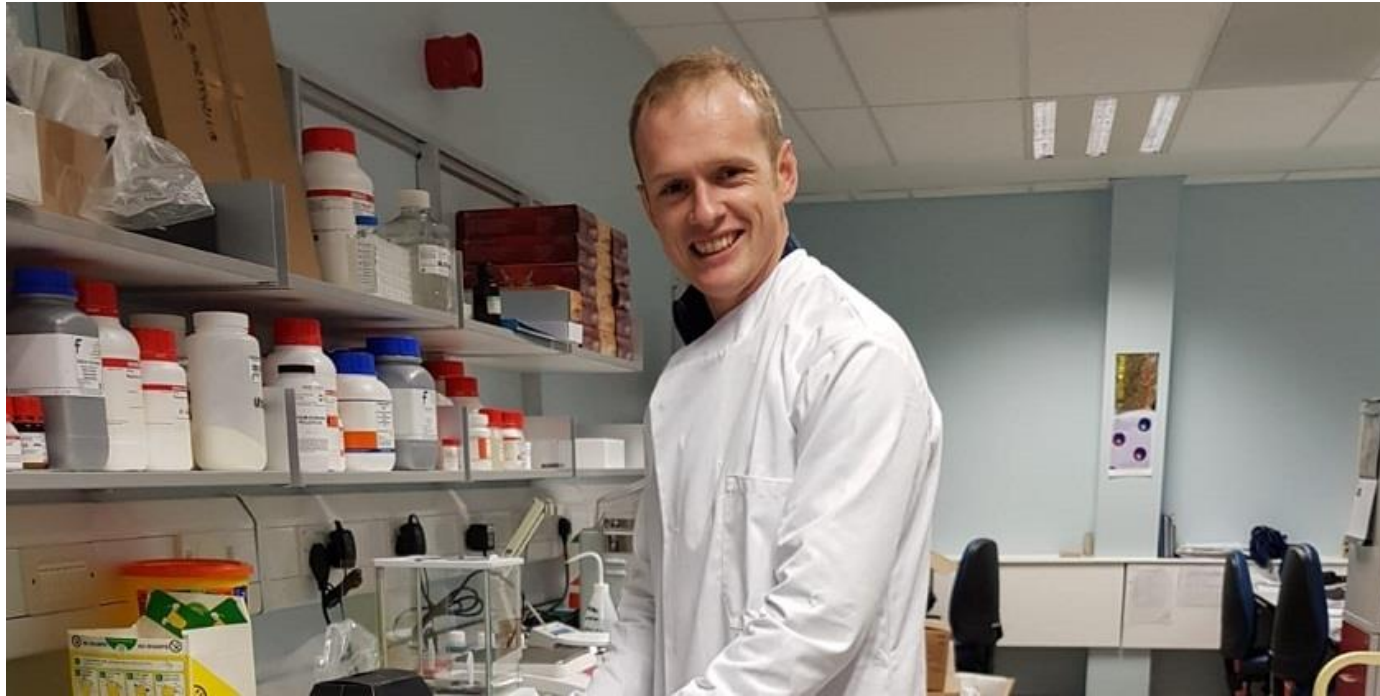


Advances in surgery for Parkinson's

Audience of 270 heard a very engaging lecture about the good long-term benefits from DBS and the prospects for a new treatment - focused ultrasound.

# January 2020 : Mathew Horrocks

## Parkinson's under the microscope – progress towards a diagnostic test



High resolution microscopy and high tech image analysis to see the early stages in the formation of neurotoxic  $\alpha$ -synuclein protein aggregates.

# February 2020 : visit to Wellcome Trust Clinical Research Facility at WGH



EDINBURGH CLINICAL RESEARCH FACILITY

15 people (mostly PwPs) on the visit. Where the Edinburgh arm of the phase 3 clinical trial for Exenatide will take place, local PI is Gordon Duncan.

# ERIG - join us!



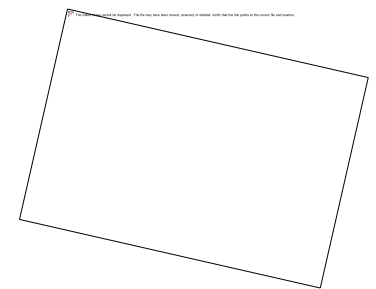


# 2019 Activities and Volunteering Review

# What we did in 2019

## In Community:

- Branch Programme
- 7 Branch Get-togethers
- Summer & Xmas Lunches
- 7 Parkinson's Cafés
- Paul Mayhew-Archer's Show
- Canal Outing
- Newsletters, Leaflets, Folders
- Membership update
- Website Project
- Burns Night



# What we did in 2019 cont.

## Wellbeing for PwPs:

- Art Group
- Adaptive Yoga\*
- Aquatherapy
- Indoor Bowling
- Tandem Cycling\*
- Dance for Parkinson's
- Drama for Fun\*
- Nordic Walking
- Pilates & Neurodynamics\*
- Physiotherapy at MCH\*
- QL Group

\*new activity



# What we did in 2019 cont.

## Wellbeing for PwPs:

- Singing4Fun
- Sunshine Yoga\*
- Tai Chi
- Tai Chi Wu Style\*
- Thistle Foundation
- One/one Therapies\*:

*Aromatherapy, Emotional Wellbeing Coaching, Indian Head Massage, Reflexology, Reiki, Massage*

## Wellbeing for Care-partners:

- Side by Side course
- Support Group

\*new activity



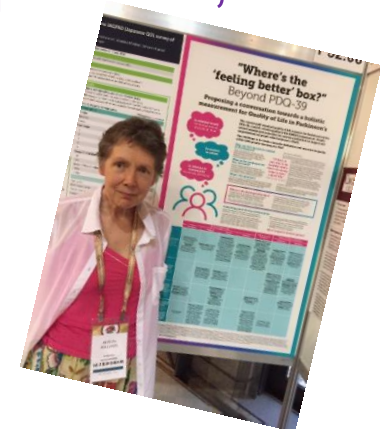
# What we did in 2019 cont.

## Research & Better Treatment

- ERIG
- Lecture
- World Parkinson Congress - & Presentation Day
- Meetings with Parkinson's Nurses
- NHS Neurological Standards
- Public Patient Involvement & participation in training with Queen Margaret Uni, Edinburgh Napier Uni, Edinburgh Uni

and

- Support for Young Parkinson's Group and new YP Carers Support Group



## *Volunteering is our Backbone*

Our *27 fabulous* Volunteers  
have completed the  
Parkinson's UK online  
induction course

8 of them live with Parkinson's

# Our Volunteers A-H

**Alison** Williams – QL Group, Dance, Research, Visiting Professor QMU, WPC participant

**Anne** Chalmers – Support Group, Bellevue, Eventbrite bookings, Committee, Website

**Annette** Mcleod – Singing, Dance, Bellevue

**Bill** Wright – QL group, Nordic Walking, Self Management Course, Committee

**Brian** Moore – Tandem Cycling

**Cathie** Quinn – Singing, Support Group, Side by Side, Bellevue

**David** Adams – Chair Branch & Committee Meetings, Activities, WPC participant

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

**David** Waughman – Aquatherapy Lifeguard, Neurodynamic Exercise, Committee

**Eileen** Blackwood – Young Parkinson's, Ethnic Minorities, Committee

**Gina** Allen - Young Parkinson's Group Secretary, Therapies Project, Activities, Website

**Hagop** Bessos – ERIG, Edinburgh-Dundee Research Initiative, Drop-in Café, Swimming,  
WPC participant

**Helen** Harris – Newsletters, Fliers, Leaflets, Printing, Promotions, Reports, Website

# Our Volunteers J-W

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

**Kathleen** Bessos – Aquatherapy, Café at Festival Theatre

**Kathy** Fraser - Aquatherapy support, Young Parkinson's Group

**Kenny** Williamson – Indoor Bowling,

**Lindsay** Mcdermid – Art Group, Tea Party, Burns Supper

**Louise** Ogilvy – Fundraising events, Committee

**Mike** Coates – New Café at Dobies, Eskbank

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

**Olivia** Bell – Branch Secretary, Committee Minutes, Correspondence, Branch Meetings,

**Martin** Maxwell – Fundraising Collections

**Patrick** Mark – Vice Chair, NHS & Neurological Voices Programme, Neurological Improvement Plan, Lecture

**Scott** Wilson – Chair and Organiser of Edinburgh Young Parkinson's Group

**Sheila** Edward – Support for ERIG, Backup for Minutes, Support for meetings & Café

**Weir Brown** –Treasurer, Website, Committee



# Special Appreciation

## Parkinson's Nurses

- we have **regular meetings with** Alison Stewart, Tina Daniels and Alison Darbyshire, **(and Tracey Fergie, support)**

## Our Service Providers:

- Sasha Baggaley, **Pilates & Neurodynamic Exercise**
- Kevin Brown, **Tai Chi**
- Jen Cunningham, **Dance**
- Chris Davies, **Thistle Foundation**
- Philippa Hope, **Tai Chi Wu Style**
- Jean Itier, **Adaptive Yoga**
- Trevor Jones, **Nordic Walking**
- Brian Moore, **Tandem Cycling**
- Jackie Rochmankowska, **Aquatherapy**
- Penny Stone, Sally Jacquet, **Singing4Fun**
- Pam Wardell, **Drama for Fun**
- Karen Watts, **Sunshine Yoga**

**Parkinson's UK:** Alice Hall, **Volunteer Coordinator**

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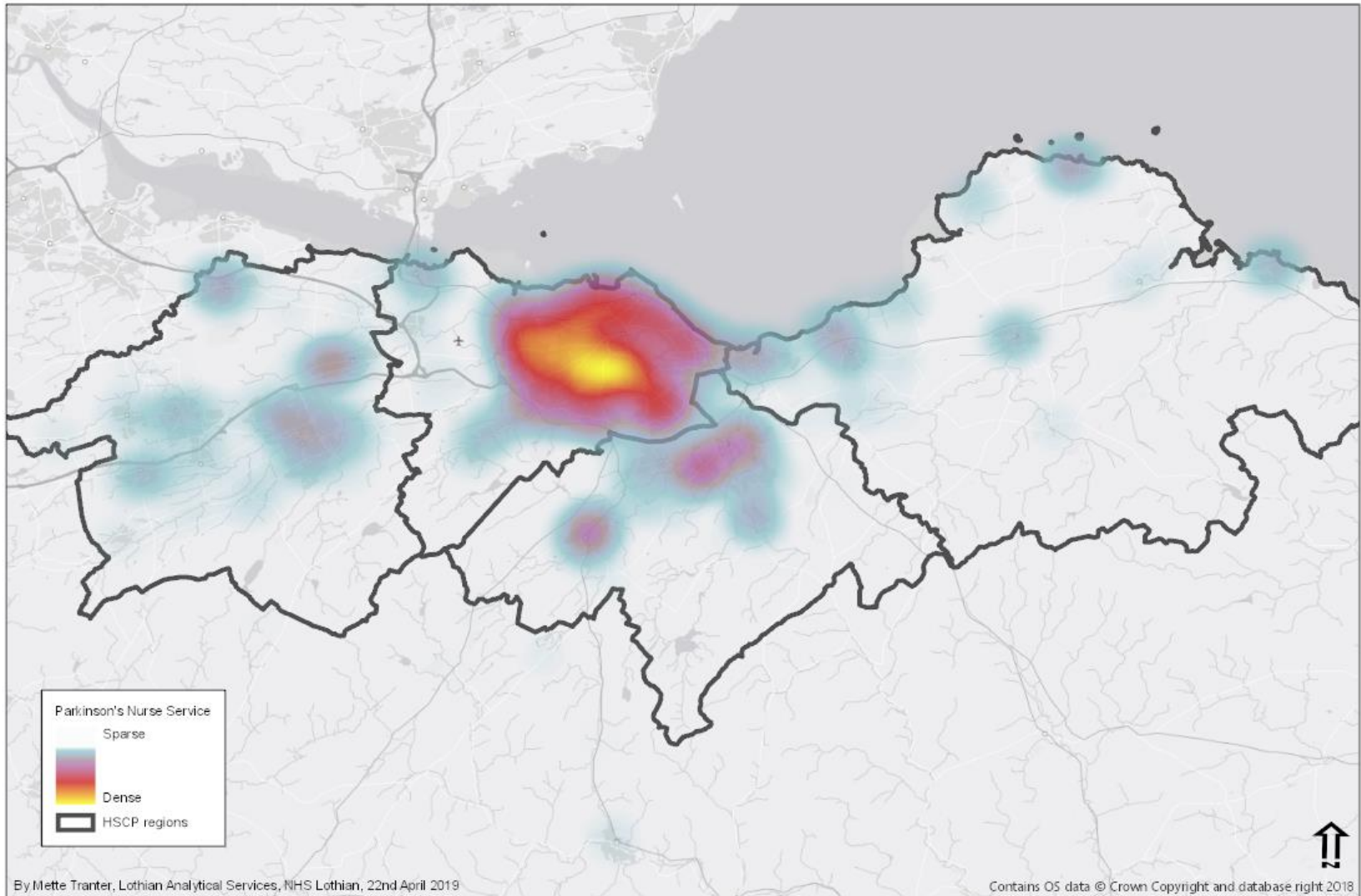
# Plans for 2020

# Agenda for 2020

*How can we reach more  
People with Parkinson's,  
and their Care-partners?*

# This is where they are

## Heat Map of Parkinson's Nurse Service



# Agenda for 2020

New Website – *coming in April* - [people to test it?]

New Venue for Branch Get-togethers

New programme and format....

*More Parkinson's Cafés ..*

More public patient involvement – PPI

**More Volunteers???**

*Coronavirus ???*

Continuing Activities!

# September 2020

Branch Get-togethers at the **Small Hall** (it's big!),  
**Inverleith St Serf's Church,**  
Ferry Road/Clark Rd – Buses 14, 21, 23, (27, 8)



**PARKINSON'S<sup>UK</sup>**



# Volunteering in 2020?

Some very special roles:

- **Activities Co-Ordinator -**
- **Parkinson's Cafés - Outreach Leaders**
- **Social Events Leader/Promoter**
- **Inter-group Parkinson's contacts person**

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

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

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# *Special thanks to*

**Committee Members**

**Hon Vice Chair**

**Hon Treasurer, Independent Examiner**

**Hon Secretary**

**Activity Leaders & Organisers**

**Young Parkinson's Hon Secretary**

**Parkinson's UK**

***All Volunteers & Helpers***



# THANK YOU

## End of Branch Committee's Review

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Parkinson's UK Edinburgh Branch AGM 2020

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**Next:**

**Annie Macleod**

**Dr Karen Matthews**