

# Parkinson's UK Edinburgh Branch

**Annual General Meeting 2019**

**Wednesday March 13<sup>th</sup> at 2.15pm**

***WELCOME***

**Bellevue Chapel, Edinburgh**

# ***Welcome!***

Members, Carers, Volunteers &  
Special Guests:

**David Allan**, Scotland Trustee

**Alice Hall**, Volunteer Coordinator E&S-E Scotland  
Parkinson's UK

*Apologies:*

**Annie Macleod**, Scotland Director

# TODAY'S PROGRAMME

A) AGM Business

B) Our Volunteers & Special Reports

Including ERIG, and much more ...

C) David Allan, Scotland Trustee; Alice Hall,  
Volunteer Coordinator Parkinson's UK

# BUSINESS AGENDA

- 1) Apologies for absence
- 2) Minutes of the meeting held on the 14<sup>th</sup> March 2018
- 3) Treasurer's Report and Accounts for the year ending 31/12/18
- 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 – *Liz Hume*,  
Committee members – *Cathie Quinn, Eileen Blackwood, Louise Ogilvy, Bill Wright, Judith Shepherd, Hagop Bessos, Scott Wilson, David Melton*
- 7) Election of Hon Chair – *David Adams*
- 8) Election of Hon Vice-Chair – *Patrick Mark*
- 9) Any other competent business –

# Income & Expenditure 2018

## Income

	£
Total Income	39,995
<i>of which:</i>	
Donations	22,646
Pilates	5,122
Singing For Fun	4,368
VAT Refund	2,080
Other (activities, membership, etc)	5,779

## Expenditure

	£
Total Expenditure	50,669
<i>of which:</i>	
Research donations	7,164
Research group exps.	5,253
Pilates	12,346
Singing	6,541
Other activity classes	9,041
Admin, printing, mailing	5,187
<i>Deficit</i>	<i>(10,674)</i>

# Fundraising 2018

## Donations

	£
General Donations	11,386
Gift Aid Tax Reclaimed	812
In Memoriam	4,232
Annual lecture	530
Ross Girl's Family Trust	5,000
Fundraising	
Art Sales	600
Teddy Bear raffle	122
Pat Stewart - Pram race	417

## Group Donations

	£
Mrs M.Black Trust	1,000
Goldenacre Bowling Club	110
Corstorphine Tangent	100
Dalkeith Rotary Club	1,000
Roseburn House Rsdnts	1,069
Maitland Bowling Club	700

# Personal Donors & Fundraisers 2018

## *Special thanks*

Annette Mcleod

T Bridgham

Keith Grant

Paul Mayhew-Archer

Kathleen Bessos

Deirdre Grennan

Lynne Gallacher

Jeannette Ross

Nigel Wilson

# Branch Purpose

*We stand for*

**Research &  
Better Treatment**

**Personal  
Wellbeing**

**Community in Action**

*for PwPs & Carers  
- with Families, Friends - in Lothian*

# Branch Committee 2018 Report

## Activity Highlights

### Research & Better Treatment:

- Lecture, September
- ERIG meetings
- Edinburgh/Dundee
- Neurological Voices

### Personal Wellbeing:

- 16 Continuing Activities!
- Meetings with Nurses
- New: Aquatherapy, Adaptive Yoga, Tandem Cycle, Chess, and more...

### Parkinson's Community in Action

- Monthly Branch Gatherings
- Summer & Christmas Lunches
- Parkinson's Cafés (new!)
- Young Parkinson's strengthened

# *Warm Thanks*

Leaving the Committee

Annette McLeod

Heather Robertson

Joining the Committee

David Melton, ERIG

Retiring from Branch in September

Helen Harris

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A) AGM Business - *concluded*

**B) Our Volunteers & Special  
Reports**

**C) David Allan & Alice Hall**

# **Our Volunteers & Special Reports**

# Edinburgh Branch Research Interest Group

## AGM review of 2018-2019

**Ken Bowler, Group Chair**



# Another successful year....

**June 2018** Talk by Professor Wladyslaw Gedroyc,  
St Mary's Medical Centre, London

**“MR guided focused ultrasound of the  
brain”**



**Sept 2018** Parkinson's lecture  
by Professor Giovanna Mallucci



# Interested in research?

## Join the Edinburgh Research Interest Group:

- suggest topics and speakers for RIG meetings
- keep informed about the latest developments
- let me know and I'll add you to the email list

## Join the Research Support Network (RSN)

- keep informed about the latest developments
- be part of a community of interest with > 4000 members
- contact ([lnash@parkinsons.org.uk](mailto:lnash@parkinsons.org.uk))

## Become a lay grant reviewer for PUK

## Looking ahead.....

The Parkinson's Lecture 2019 will be given by Prof Andres Lozano and is entitled

**“Advances in surgery for Parkinson's disease”**

**My role is finished: I am pleased to say that Professor David Melton has agreed to take over from me as Chair of the group with effect from today. I am immensely grateful to the many friends and colleagues who have helped to make ERIG the success which I believe it to be.**

# Acknowledgements

**Patrick Mark, Vice-Chairman, Edinburgh Branch**

**David Adams, Chairman**

**Dr Tilo Kunath, CRM**

**Sheila Edward, Hagop Bessos**

**Members of the Edinburgh Branch: Liz & Bill McBain, Liz Hume, Cathie Quinn, Heather Robertson, Helen Harris, Annette McLeod, Alison Williams, Bill Wright and many others**

**Parkinson's UK: Katherine Crawford, Anna-Louise Smith, Claire Bale, Liz Nash**

# *Volunteering is our Backbone*

Our 28 *fabulous* Volunteers have all completed the Parkinson's UK induction course, now online

10 of them live with Parkinson's

# Our Volunteers - \*New

- **Alison Williams** – QL Group, Dance, Research, Visiting Professor QMU, WPC participant
- **Anne Chalmers** – Support Group, Bellevue, Eventbrite bookings
- **Annette Mcleod** – Singing, Dance, Bellevue
- **Bill Wright** – QL group, Nordic Walking, Self Management Course
- **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
- **David Waughman** –Aquatherapy Lifeguard, Neurodynamic Exercise, Boxing
- **Eileen Blackwood** – Young Parkinson's, Ethnic Minorities, Education talks, Parkinson's Awareness Week
- **Gina Allen\*** - Young Parkinson's Group Secretary, Therapies Project, Activities
- **Hagop Bessos** – ERIG, Edinburgh-Dundee Research Initiative, Drop-in Café, Swimming, WPC participant
- **Heather Robertson** – Singing, Support Group, Side by Side, Bellevue
- **Helen Harris** – Exercise Activities Co-ordinator, Newsletters, fliers, leaflets, Printing, Promotions, Reports

# Our Volunteers - \*New

- **Judith Shepherd** – Committee
- **Julia Melton** – Publications, Member info packs, QL Treasurer, WPC participant
- **Kathy Fraser\*** - Aquatherapy support, Young Parkinson's Group
- **Ken Bowler** – ERIG, Lecture, Parkinson's UK Research, Membership, Eventbrite, Website
- **Kenneth Williamson** – Indoor Bowling, Chess
- **Lindsay Mcdermid** – Art Group
- **Louise Ogilvy** – Fundraising events
- **Liz Hume** – Secretary, Minutes, Correspondence, Branch Meetings, Payments & Donations
- **Martin Maxwell\*** – Fundraising Collections
- **Marge Barker** – Indoor Bowling
- **Patrick Mark** – Vice Chair, NHS & Neurological Voices Programme, Neurological Improvement Plan, Lecture
- **Scott Wilson** – Chair and Organiser of Edinburgh & Borders Young Parkinson's
- **Sheila Edward** – Support for ERIG, Backup for Minutes, Support for meetings & activities
- **Weir Brown** –Treasurer

*Remember 2017?*

## Inspiring Volunteer Achievement Awards



By the Lord Provost to  
**Edinburgh Branch**  
and personal awards to  
**Cathie Quinn &**  
**Heather Robertson**

# Special Appreciation

- **Parkinson's Nurses**
    - we have **regular meetings with** Alison Stewart, Tina Daniels and Alison Darbyshire, **(and Tracey Fergie, support)**
  - **Our Service Providers: [\*new]**
    - Sasha Baggaley, **Pilates & Neurodynamic\* Exercise Trial**
    - 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, **Singing4Fun - and farewell to** Ellie Logan
- Parkinson's UK:**
- Alice Hall, **Volunteer Co-ordinator**
  - Abenet Tsegai, **Local Adviser**

# Branch Committee 2018 Report

## Personal Wellbeing

Adaptive Yoga\*

Art Group

Aquatherapy\*

Bowling

Chess\*

Dance

Lifestyle at Thistle

Nordic Walking

Pilates x 4 classes

QL Group

Singing4Fun

Support Group

Swimming

Side by Side course

Tai Chi *plus*

Wu-Style Tai Chi\*

Tandem Cycling\*

2019 Trial:

Neurodynamic Exercise



# Art Group

Lindsay McDermid

*At the Botanic cottage*



# Aquathery

## at the Astley Ainslie Hydrotherapy Pool

Jackie Rochmankowska, David Waughman, Kathleen Bessos, Sheila Edward  
and...



# Dance for Parkinson's Scotland

## at *DanceBase with Scottish Ballet, Glasgow*



Participants up to 30 – waiting list (ratio to helpers)  
Dancers can contribute to class design  
Donations for classes  
Teachers: Jen, Sophie, Christina  
Musicians: Robert & Gordie

New classes across  
Scotland: Aberdeen,  
Greenock, Kilmarnock,  
Inverness, Dundee



# Indoor Bowling

## Marge Barker & Kenny Williamson

Continues to flourish at Meadowmill Indoor Bowling Club  
with 16 full members of and 4 non-members.

Every Monday 12-2pm with a break for lunch.

Played and won our annual fixture with Fife Parkinson's.

Everyone enjoys playing – and the great company!



# Nordic Walking

**Bill Wright & Julia Melton**

With Trevor Jones, at The Meadows and Links

Going for 2 years  
Up to 11 walkers  
Fresh air, good chat  
and exercise!



# Pilates

Mobility – stability – strength – balance

Sasha Baggaley

- Four weekly classes!





# QL Group

**Alison Williams & Bill Wright**

*1<sup>st</sup> Thursday of every month 2pm – 3.30pm*

**The Quality of Life Group:** thriving with 10 to 15 per meeting, welcoming new people with Parkinson's as well as regulars.

*QL Group in Fife began in 2018.*



# Singing4Fun

**Cathie Quinn & Heather Robertson**

**A singing group for People with Parkinson's and anyone else  
who wants to participate**

**Winner of the International Song Competition for WPC2019,**

to be sung at the opening in Kyoto!

**Tuesday Group at Marchmont St.Giles with Penny Stone**

**The Wednesday Group is back in Bellevue Chapel**  
(now looking for a new Song Leader)



*If you can talk you can sing - and it's fun!*



# Support Group & Side by Side

## Cathie Quinn & Heather Robertson

### Support Group

Last Wednesday of every month (except December). At BB Pollock Pavilion, 227 Ferry Road, 10.30-12.30. A time of sharing for care-partners over tea or coffee, scones and biscuits.

### Side by Side

A course for care-partners of people with Parkinson's. Run in the autumn.

An opportunity to learn from the professionals about the help and support that is there for you.

*"I wish I had done this sooner"- new participant*



# Swimming

**Hagop Bessos, Liz Hume**

With Edinburgh Leisure Access Programme

Get Active Card to swim (or use any other facilities) for £1 - at  
10 pools

– *care partners go free*

11 swimmers currently



# Tai Chi

## Kevin Brown

Tuesday mornings at Barclay  
Viewforth Church. 14 regulars



# Wu Style Tai Chi

## Philippa Hope

*NEW* - SCRM Building, Wednesday evenings

# Tandem Cycling

**Brian Moore**

Tandem rides for people with Parkinson's,  
based at Cockenzie House, Prestonpans

*Research supports big benefits for PwPs*

*Thanks to **Walker Group** and  
**Edinburgh Bicycle Cooperative**  
for donating the tandem and  
equipment*



# Our Community in Action 2018

## *What we did*

- **GDPR and Lists\***
- **Committee meetings**
- **Branch Website**
- **Branch programme, Meetings & Admin**
- **Car Stickers\***
- **Drop-in Cafés\***
- **Napier Marketing Study\* and Branch Workshop**
- **Parkinson's UK Working Together**
- **Newsletter & Member Communications**
- **Events: Summer & Christmas Lunches, PM-A Reception\***
- **PPI with QMU and Napier\***
- **Young Parkinson's Connection\***

# Our Community in Action 2019

## *Intended for 2019*

- **Update Committee Structure**
- **New programme**
- **Napier Marketing Study for Membership Communications**
- **Lecture, 30<sup>th</sup> September**
- **World Parkinson Congress, Kyoto; Branch presentation in November**
- **World Parkinson's Day, 11<sup>th</sup> April 2019**
- **Young Parkinson's Events**
- **More Volunteers?**
- **Inter-branch liaison?**
- **Continuing PPI**

# Parkinson's Cafés

Hagop & Kathleen Bessos, Liz Hume, Sheila Edwards, &.....

Last Tuesday of the month at  
the Festival Theatre



# Paul Mayhew-Archer – ‘Incurable Optimist’

**and Pre-show Gathering 27<sup>th</sup> March**

*6pm at Assembly Roxy, 2 Roxburgh Place*

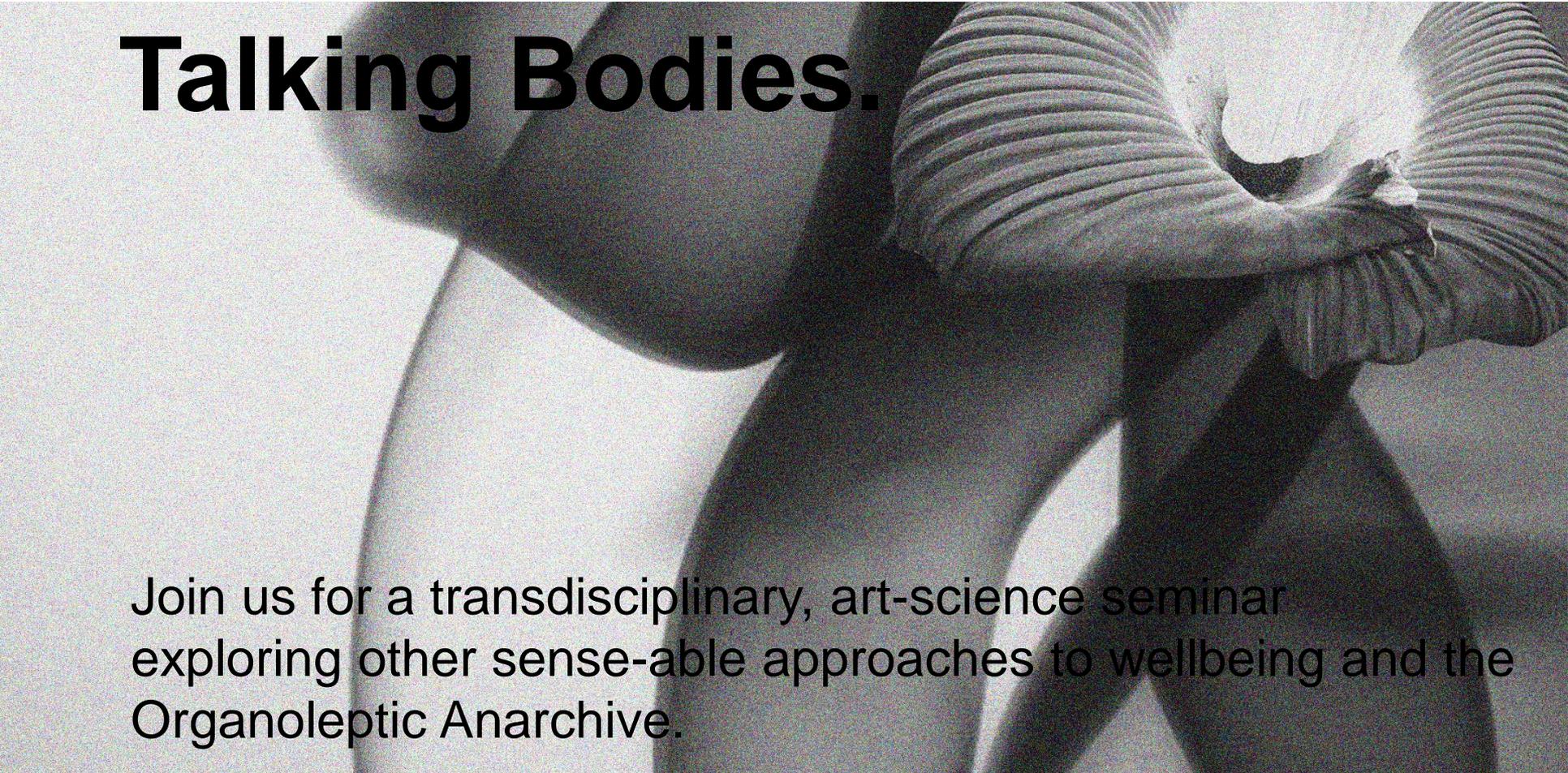
Book tickets on Theatre Website  
and for the pre-show gathering which is  
free but must be booked via Eventbrite



PAUL MAYHEW-ARCHER:  
INCURABLE OPTIMIST

19.45, 27 MAR

# Talking Bodies.



Join us for a transdisciplinary, art-science seminar exploring other sense-able approaches to wellbeing and the Organoleptic Anarchive.

Mixing people, plants, neuroscience, healthcare and Parkinson's

With: artist Susana Cámara Leret (Fellow of NHS Lothian's Art & Therapeutic Design programme at the Department of Clinical Neuroscience in Edinburgh), Joy Milne and Alison Williams.

Booking via: Talking Bodies EventBrite (free)

**3<sup>rd</sup> April 10am – 4pm**

Royal Botanic Gardens Conference Room

# 5<sup>th</sup> World Parkinson Congress



Branch attendees: Alison Williams, David Adams, David & Julia Melton, Hagop & Kathleen Bessos, Norman & Carol Yarrow

Others: David Breen, Tilo Kunath, Martin Taylor

# Volunteering Opportunities!

*Especially for:*

- **Newsletters and Communications**
- **Social Events**
- **More Cafés - outreach for membership**
- **Public Patient Involvement (PPI) – in Education & Research**
- **Inter-group Parkinson's contacts?**
- **Liaison with other neurological/caring charities?**

# *Special thanks to*

**Committee Members**  
**Hon Vice Chair**  
**Hon Treasurer, Independent Examiner**  
**Hon Secretary**  
**Activities Co-ordinator & Organisers**  
**Young Parkinson's Hon Secretary**  
**Parkinson's UK**  
*All Volunteers & Helpers*

*Who are showing that*



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