

Edinburgh Parkinson's Lecture 2019

Enclosed with this Newsletter is the flyer for the lecture being given by neurosurgeon Professor Andres Lozano from Toronto University on the evening of Monday 30th September at the Royal College of Physicians of Edinburgh, 9 Queen Street, EH2 1JQ. The title is "Recent Progress in Surgery for Parkinson's." We are looking forward to returning to the venue for this year's lecture now that improved disability access is in place. Attendance at the lecture is free but ticketed – early booking is recommended.

Secretary Role

After her significant contribution to the running of the Branch in acting as our Hon Secretary since early 2017 and for which we express our sincere appreciation, Liz Hume has had to retire due to personal circumstances. We are still looking for someone to take on the role and to this end have enclosed with this newsletter a description of the responsibilities and tasks involved. If this is a position you feel you could fill as a volunteer, please get in touch with Hon Chair, David Adams via 0131 557 5979 or chair@edinburghparkinsons.org, or it may be that you know of someone who might be a suitable candidate – do please let us know.

Complementary Therapies Project



Parkinson's UK reports that although there is little scientific evidence to show that complementary therapies can slow, stop or reverse development of Parkinson's, many people with the condition have reported positive experiences from therapy sessions. The Branch Committee recognises that care-partners may also benefit from treatments. We are now in a position to launch a Branch funded complementary therapy project open to people with Parkinson's and/or their care-partners living in Edinburgh and Midlothian. The intention is eventually to include East and West Lothian.

The Branch will pay for people to access up to 4 therapy sessions from qualified therapists we have identified. Access to the therapies will be based on referral by the Parkinson's Nurse Specialist Team or our Parkinson's UK Local Adviser. Therapies we hope to make available initially include Indian Head Massage, Reiki, Reflexology, Massage, and Aromatherapy. Treatments will be given at the therapist's premises, or where possible in a recipient's home. If you would like to find out more or be referred, please contact P-UK Local Adviser, Abenet Tsegai via 0344 225 3771 or adviser5.scotland@parkinsons.org.uk.



Cycling and Saughton Park Restoration

Now that the £8m, seven-year renovation project in Saughton Park is almost complete the Edinburgh **All-Ability Bike Centre** has sessions up and running at the park. Whether you've been a cyclist or not you might like to make use of the wide selection of bikes, trikes, tandems and adaptive cycles ABC has available. You can use these to cover the paths within the park. While you're there you can check out the results of the recent work, including the new walled gardens, the conservatories and the 110 year old bandstand. There will be a public event at the park on 31st August to celebrate the restoration of the park, HRH The Princess Royal having officially re-opened the venue on 6th June. Saughton Park was the site of the Scottish National Exhibition in 1908.

Alternatively, there are sessions at the original ABC centre in **Craighall Gardens**, EH6 4RJ. All abilities are welcome at both centres after pre-registering with ABC. For more information and days and times, contact David Glover via 07500 069357 or david.glover@cyclinguk.org.

Brian Moore continues to report positive feedback from his **tandem cycling** activity which is free. Anyone interested in sampling tandem riding on country roads can do so at Cockenzie House in East Lothian. Brian would be happy to hear from you if you would like to know more – contact him via brian@edinburghparkinsons.org. Brian also has a link with ABC in Saughton Park and would be happy to take anyone on one of their adapted bikes or tandems from there.

World Parkinson Congress 2019, Kyoto

Our Branch representatives have returned from the Congress, heads buzzing with information. Now they will be working together to prepare a presentation of the most salient points for a Branch Meeting on **16th November in Bellevue Chapel** so please put the date in your diaries. Our WPC Liaison for the Branch's winning song "Side by Side" reported that the Opening Ceremony Choir did an "amazing job" with which we would be "very pleased."

Edinburgh Research Interest Group



We welcome Professor David Melton as new Chair of ERIG. David takes over from Ken Bowler who announced his retirement from the position at our AGM in March, having been Chair since the Group's inception, inspired in part by the Glasgow World Parkinson Congress in 2010. In an email to ERIG Members, David wrote *"I am sure that you would all like to join with me in thanking Ken for his vision and hard work in establishing ERIG and making it such a good example for other Parkinson's UK Branches to follow. I hope to be able to continue his good work."*

David's wife Julia was diagnosed with Parkinson's in 2014. David has spent his research career studying the genetic, cell and molecular biological basis of a variety of human diseases and has been Professor of Somatic Cell Genetics at the University of Edinburgh since 1997.

ERIG's objectives are to provide opportunities for members with an interest in Parkinson's research to meet, communicate, work together and generally further the cause of research, while encouraging and developing *all* members' interest in research. If you have not yet joined, please give it some consideration – you don't have to have a science or medical background, just an interest in what is going on in the field of Parkinson's research including clinical trials. If you have any ideas regarding topics for meetings, please let our new ERIG Chair know via davidm@edinburghparkinsons.org.

Singing4Fun

We have a new Song Leader, **Robyn Stapleton**, taking our Wednesday evening sessions at Bellevue Chapel. Robyn is a graduate of the Royal Conservatoire of Scotland and a highly respected folk singer. Regular Wednesday evening attendees have already been singing her praises. Our Tuesday afternoon sessions with Penny Stone at Marchmont St.Giles and the Wednesday evening sessions have stopped for the summer, returning 3rd and 4th September respectively. In the meantime please put the 8th December in your diaries as S4Fun has been asked to perform at the Harps of Gold Christmas Concert, Queen's Hall on that date. This is an annual event organised by the Edinburgh Branch of The Clarsach Society and this year they will be collecting for Parkinson's UK Scotland.

Dance Base Website Updated with Stunning Photos

This collaborative joint initiative managed by Dance Base and Scottish Ballet and delivered in partnership with Parkinson's UK now has seven hubs up and running throughout Scotland with two more planned for September (Peebles and Perth). The Edinburgh sessions, which were established before the joint initiative, are Wednesdays 11.30 – 13.30 at Dance Base in the Grassmarket. The Dance Base website has been updated and has some stunning photos of the Edinburgh sessions, news, articles, videos and interviews all of which expound the highly beneficial effects of these sessions for participants. Go to www.dancebase.co.uk/participation.

Aquatherapy – Spaces Available

Physiotherapist and Hydrotherapy specialist, Jackie Rochmankowska writes “Are you tired? Stiff? Sore? Come to aquatherapy on Friday afternoons at Astley Ainslie where a warm pool (and welcome) await you to exercise away your aches and pains. With more evidence emerging about the benefits of exercise for Parkinson's there has never been a better time to come along. Whether you want to work on balance, strength or flexibility there is something for all abilities at our fun friendly sessions.” See the Branch website page under *Regular Activities – Aquatherapy* for more information and contact details.

Neurodynamic Exercise

Based on her training as a neurophysiotherapist and as a Pilates instructor plus her experience with the PD Warrior programme, Sasha Baggaley has been trialling her own programme of intensive exercise for PwPs. Potential participants are required to go through an assessment to determine their ability to cope with the programme and are also assessed at the end of the 10 weeks of once-weekly sessions and exercises done at home. The programme works on cognitive as well as physical abilities. Sasha has run two programmes so far with promising results and has established continuation classes for those who want to carry on in a similar vein. If interested and to find out more, contact Sasha via sasha@edinburghparkinsons.org.

Branch Website Redesign

Our website has served us extremely well for many years thanks to the dedicated efforts of Ken Bowler. We recognise that advances in technology and access needs have changed in recent years, while our activities have expanded significantly, therefore, we have initiated discussions with our original website designers about revamping the website to satisfy changing user needs. This will involve formal consultations with a representative sample of Branch Members but in the meantime if you have any comments you would like to make regarding use of the website, please let Hon Chair, David Adams, know via chair@edinburghparkinsons.org.

Some Noteworthy Donations



Hon Chair, David Adams and Alison Williams attended a meeting of the **Society of High Constables** of Edinburgh to be presented with a £1000 cheque for the Branch, from the Society's Charitable Trust. The Society traces its history back to 1611 when Edinburgh magistrates were commanded by James VI to appoint persons to guard the streets. After enactment of the Police Act, 1805 the duties of these constables gradually changed, with attendance on the City of Edinburgh Council for ceremonial occasions becoming more pronounced

Branch Tai Chi facilitator, **Kevin Brown** well exceeded his target of £500 running the Edinburgh half-marathon in May which has raised £705 with Gift Aid bringing the total to £805.

Branch Fundraiser, Lou Ogilvy presented the Branch with a cheque for £210 from a **Line Dancing** evening with which she had been involved.

The Branch expresses its appreciation for these and all **donations throughout the year** and which were tabled at the AGM in March. With regard to forthcoming fundraising

Martin Maxwell, whom some of you will know from our monthly Branch get-togethers is organising a P-UK **can collection** at Craighleith Shopping Complex, 10am to 4pm on 10th & 11th August and 19th & 20th October. We need volunteers to hold the cans (no shoogling allowed) in two-hour slots 10-12, 12-2 and 2-4. If you can help out, please contact Lou Ogilvy via 07912 678475 (please leave a message if no answer) or via lou@edinburghparkinsons.org.

News in Brief

The **2019-2020 Branch Calendar** will be issued with an August mailing. We already have some interesting speakers booked with just a few more spaces to fill for our second Wednesday of the month get-togethers at Bellevue Chapel, the first of which is **11th September, 2-4pm** when we plan to have a forum on Self Care (physical, emotional, mental and spiritual).

Our monthly **Parkinson's Café** is having a break over the summer holiday period and will start again on 24th September at the Festival Theatre Café, 1-3pm. These have proved so successful in bringing in potential new Branch Members to learn about all the Branch has to offer while cementing relationships between existing Members, we are considering additional venues.

A pan-European team of clinicians including Professor Andrew Lees and Professor Tom Foltynie from University College London is conducting a survey about **how Parkinson's affects the day-today life** of PwPs and care-partners. The survey closes 30th June so there is just time for you to take part at www.smartsurvey.co.uk/s/PRISMSurvey_en.

Our recently introduced **Adaptive Yoga** sessions are now **weekly** and will have completed the pilot/trial stage by the end of June so we will be asking for a contribution of £3 per session from July onwards. Classes are held at the Steading, 118-120 Biggar Road, EH10 7DU, Mondays, 6-7pm and are led by Jean Itier, an experienced Yoga teacher with additional training in Yoga Therapy. To find out more, contact him via jean@yogatherapyedinburgh.com or 07985 528839.

Apologies for any difficulties experienced with our website recently, with updates also delayed. This is because of problems we have been having with a new release of WORDPRESS.

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