

Ken Bowler

It is with great sadness the newsletter is accompanied by the announcement Ken Bowler died on 14th October. Ken had attended the Edinburgh Parkinson's Lecture just two weeks before, when in recognition of his exceptional service to the Branch as well as the wider Parkinson's community, *and* in the hope of perpetuating his inspiration, a presentation was made to him announcing the establishment of a Branch travel bursary to be awarded once a year to a young Parkinson's Researcher. *See photos foot of page.* Enclosed with the newsletter is a full appreciation of Ken's outstanding contribution based on a press release from Parkinson's UK Scotland.

Edinburgh Parkinson's Lecture 2019

This year's Lecture was delivered at the Royal College of Physicians of Edinburgh on 30th September by leading neurosurgeon Professor Andres Lozano from the University of Toronto. The 260 attendees from the local Parkinson's community, medical professionals and university researchers listened to an excellent and accessible talk in which Professor Lozano described the good long-term therapeutic results that can be achieved with deep brain stimulation and the prospects for a new non-surgical approach using focused ultrasound.

The Closing Remarks were given by Annie Macleod, Scotland Director of Parkinson's UK, in which she expressed appreciation of the contribution the Parkinson's community in Scotland has made to research progress through their interest, donations and participation in clinical trials. The evening ended with the presentation to Ken Bowler.

A link to the lecture video is available on the Edinburgh Branch website where you can also access photos of the event. [Material from *Previous Edinburgh Parkinson's Lectures* is available via a button at the bottom of the website Main Menu.] Thank-you to David Melton, Edinburgh Research Interest Group (ERIG) Chair, and to Tilo Kunath (see next page), the driving forces behind the 2019 Lecture organisation, to our sponsors, and to the evening's cohort of helpers.

Ken Bowler with Annie Macleod and Tilo Kunath taken at the Lecture.



Congratulations to Tilo on Winning the Tom Isaacs Award 2019

The Cure Parkinson's Trust (CPT) and the Van Andel Research Institute (VARI) unanimously voted Dr. Tilo Kunath, Group Leader at the MRC Centre for Regenerative Medicine, the 2019 award winner. Tilo is well known to Branch members through his involvement with ERIG and the Edinburgh Lecture. The Award was created in memory and recognition of former CPT co-founder and President, Tom Isaacs, who died in 2017. CPT and VARI present this award to a researcher who has had the greatest impact on the lives of people living with Parkinson's and/or has involved people with PD in a participatory way in their work.

Quoting from the CPT website "Dr Kunath is one of the world's leading stem cell researchers and it is his compassion and enthusiastic engagement with the PD community, and his willingness to share his expert research knowledge that particularly impressed those who nominated him and the panel of judges." The award was announced in August during a symposium at the Van Andel Institute in Michigan and a simultaneous video link to a meeting in Edinburgh where Joy Milne presented the award to Tilo. For the 2-minute video of the presentation, please see www.cureparkinsons.org.uk/ti-award-tk-2019 – well worth it for the surprise reaction from Tilo.

Possible Drama Group and Voice Work



We had a lively and entertaining Branch Get-together on the 9th October. Isobel McCoy from the Adult Community Speech and Language Therapy Service and Drama Teacher, BBC Radio Producer and Director, Pam Wardell demonstrated exercises that can help anyone's speech, and particularly those with Parkinson's. We are hoping the event sparked enough interest to get a drama group up and running. This wouldn't be aimed at performance but provide the opportunity to work with the voice through vocal exercises, readings, storytelling and other vocal communication. The intention would be to keep the vocal folds (cords) and facial muscles working well and improve voice projection, speech clarification and intonation. If you believe this is a group that would interest you, please let your Newsletter Editor know (*see foot of page 4*).

While on the subject of voice we remind you of our **Singing4Fun** sessions, another means of keeping the vocal folds and facial muscles working while lifting the spirits. They are Tuesdays, 2–4pm, Marchmont St. Giles, EH9 2DW and Wednesdays, 7–9pm, Bellevue Chapel, EH7 4EL. Song Leaders Penny Stone (Tues) and Robyn Stapleton (Wed) teach by call-and-response, i.e. by ear, so there is no need to read music. Words are displayed on a screen or printed hand-outs, with short rounds easy to learn by rote – good exercise for the brain cells, as indeed is learning a tune. Contact Cathie Quinn, cathie@edinburghparkinsons.org for more information.

We hope you've reserved the previously announced date of 8th December for the Edinburgh Branch of the Clarsach Society's **Harp of Gold** concert at Queen's Hall, 2.30pm. The Scottish Harp Orchestra and musicians from George Watson's College are performing and our S4Fun singers will be covering two songs. Proceeds of the raffle and a proportion of ticket sales are being donated to Parkinson's UK Scotland. So "Forget the Christmas shopping for an hour or two. Relax and enjoy an afternoon of festive music with a 'Host of Heavenly Harps,' voices to entrance, stories to entertain and carols for all to sing."



The Impact of Google Search Engine Algorithms

Many of us find ourselves using Google for information when we have health questions. Do you see the same results and advertisements as colleagues, family, or friends? If not, why not? Anna Couturier, a University of Edinburgh PhD student is working with EuroStemCell and the Algorithm Accountability Lab at the University of Kaiserslautern to begin building a picture of how Google personalises results for health query searches. Anna spoke to us about the study at the October Branch Get-together. The team will initially use enquiries about stem cell research.



Participation in the research involves allowing the study team to send search queries to Google through your browser as though it was you carrying out the search. They will look at what is returned for different people, measure the quality of results presented and the impact of Google's algorithm on health related searches. There will not be any interference with your personal data. The more users who participate, the better the results will be. To find out more go to www.eurostemcell.org/datadonation.

Contribution to Development of Nursing Programmes

The University of Edinburgh would like to invite health service users to contribute to the review and development of their nursing programmes so that your experiences and views are reflected in how the University educates its nursing students. It is currently redesigning its pre-registration nursing programme as well as developing a new shortened programme for people who already have a degree but want to become nurses. Health service users can help by participating in discussion forums. There have been two already but two more are scheduled for 2–4pm on 11th December (50 George Square) and 27th January (venue tbc). For more information, please contact Dr Marti Balaam via marti.balaam@ed.ac.uk.

Seated Pilates

Sasha Baggaley has introduced a Seated Pilates class for those who prefer to focus on the seated exercises. It is Fridays 12–1pm, Morningside Parish Church, 2 Cluny Gardens, EH10 6BQ. Sasha has run another successful trial of her Neurodynamic Exercise (NE). NE is an advanced programme incorporating both physical and cognitive activity for people in the earlier stages of Parkinson's (mild to moderate symptoms) and involves pre- and post-assessments. There is now also a continuation class for the participants who have been through the first two NE programmes. Sasha is looking to run another programme in the New Year. To find out more about this or the Pilates classes, please contact Sasha via sasha@edinburghparkinsons.org.

WPC Branch Feedback Session – Reserve Your Place

This is a reminder that the Branch Get-together, A Review of WPC 2019, is on Saturday, 16th November, 10am-4pm, Bellevue Chapel, Rodney Street, EH7 4EL when some of our Branch Members who attended the World Parkinson Congress in Kyoto in June will provide feedback from the event. Tilo Kunath will also be contributing. The event is open to everyone concerned in any way with Parkinson's, including care-partners, health professionals and volunteers and is free. However, as the day includes refreshments and a nutritional light lunch, we ask you to register via Eventbrite. A link to the Eventbrite page can be found in the relevant News item on the Branch website or if you are a Branch Member or Friend with an email address you will have received an email on 13th October entitled "Edinburgh Branch Parkinson's UK" which has the Eventbrite link in it.

Branch Art Group Exhibition – Still Time to Go Along

News of the Exhibition arrived too late for the August Newsletter. It is being held at the usual venue of Bon Papillon Café/Gallery, 15 Howe Street, EH3 6TE, 9am–5pm, Wednesday to Sunday, closed Mondays and Tuesdays. We had a buzzing official opening night on 4th October which included refreshments and canapes supplied by the café and sweet treats by Member, Liz McBain. At time of going to print the exhibition had made 15 sales, proceeds being donated to the Branch. There is still time to go along and admire the Group's work and enjoy the fayre.

Yoga for Parkinson's

You may have come across a plethora of yoga tags – Ashtanga, Iyengar, Kundalini, Vinyasa to name a few but yoga in *all* its physical forms aims to improve strength, flexibility, and balance through repeated practice. We already have Jean Itier's Adaptive Yoga sessions at The Steading on Monday evenings which also has a strong psychological well-being perspective. To complement this we are trialling "Yoga for Parkinson's" sessions at Church of the Good Shepherd, Murrayfield Avenue, EH12 6AU, Tuesdays, 3–4.40 pm. This is a very gentle form of yoga exercise which can be done seated and which can also help calm the mind and reduce stress. We encourage Members and their care-partners to try it out. For more information or to book, please contact Bill Wright, bill@edinburghparkinsons.org.

SPARK Newsletter

Parkinson's UK Scotland has launched a regular Newsletter, SPARK. The first issue can be downloaded from the web page www.parkinsons.org.uk/about-us/our-work-scotland. There's mention of a new Scotland Advisory Group to advise on the direction the charity should take in Scotland, a new Get it on Time campaign, timescales for the transfer of disability benefits from the UK to the Scottish Government, and the growing establishment of Parkinson's Cafés – Edinburgh, Glenrothes, Montrose, Alloa, Cowal, Dumfries and Cumnock, with Glasgow having just launched one in Sauchiehall Street. We're pleased with the success of ours in the Festival Theatre Café, 13/29 Nicolson Street, EH8 9FT. Next date is Tuesday 29th October, 1-3pm.

Fundraising and Donations



Well done and thank-you to our Fundraiser **Lou Ogilvie** and her band of helpers for collecting **£2200** during two can (subtle) shoogling weekends in September and October at Craighleith Shopping Centre.

Thank you to **Willowbrae Ladies Bowling Club** who raised £900 for the Branch – photo of our Treasurer, Weir Brown, collecting the cheque.

Huge congratulations to **Caroline Connor** (daughter of Member Raymond Currie and mother Alison). She is the first woman to swim the three longest lochs in Scotland. After her aborted Channel swim in June due to extreme sea-sickness by her one-man back-up crew, to justify the £5,700 she had raised for Diabetes UK & Parkinson's UK, she first swam Lake Windermere and back *then* decided on Loch Ness, having swum Loch Lomond in 2017 and Loch Awe in 2018.

And as always we express our gratitude to all Members, their family and friends and event attendees who have donated money to P-UK and to the Edinburgh Branch in recent weeks.

Newsletter Editor Helen Harris, helen@edinburghparkinsons.org.

EDINBURGH BRANCH PARKINSON'S UK

Ken Bowler – An Appreciation

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

Based on a Press Release from Parkinson's UK Scotland, issued 18th October, 2019.



With the death of Professor Ken Bowler on Monday 14th October the Parkinson's community in Scotland and beyond has lost one of its giants. Ken revolutionised the relationship between researchers and people living with Parkinson's. He had not long celebrated his 76th birthday then experienced a short illness.

Originally from Luton, Ken achieved a first class honours degree from Imperial College London where he specialised in Theoretical Physics then received his doctorate in Theoretical and Mathematical Physics from the University of Sussex. He was an eminent particle physicist and retired as Professor of Physics from the University of Edinburgh in 2005. Shortly after, Ken was diagnosed with Parkinson's and became heavily involved in the vibrant Edinburgh Branch of Parkinson's UK. Using his wealth of professional experience he took specific interest in Parkinson's research.

As a volunteer with the charity, Ken brought his enthusiasm for research and his experiences as a person with Parkinson's to the task of assessing applications for research funding. He then played a vital role in establishing the charity's national Research Support Network, which inspires people affected by Parkinson's to get involved in research. The Network is now approaching 6,000 strong and thriving. **Claire Bale, Head of Research at Parkinson's UK**, said: "Ken was a very special person, hugely knowledgeable, generous and kind. He was a collaborator, a listener and do-er, he never wanted to be centre stage. Everyone who worked with Ken – staff, scientists and volunteers – valued him as a colleague and a friend. He has left an incredible legacy to the Parkinson's community that will continue to bring people together in the quest for a cure."

In 2010 Ken and **Patrick Mark, then Edinburgh Branch Hon Chair, met with researcher Dr Tilo Kunath** and discussed the novel idea of creating a world class annual lecture in Edinburgh, and a regular Edinburgh Research Interest Group (ERIG). Ken's remarkable partnership with Dr Kunath, Reader in Regenerative Neurobiology at Edinburgh University, has been the key to the outstanding success of both these initiatives. Combining a wealth of professional experience, quiet determination and considerable ability to persuade others, they have drawn on the prestige of the University's Centre for Regenerative Medicine and the support of the Edinburgh Branch of Parkinson's UK, to give new inspiration to researchers, people with Parkinson's and their families.

Dr Kunath recalls how Ken's persistence, professionalism and leadership ensured ERIG would be, firstly, a success then subsequently a model that could be followed elsewhere: "Ken worked tirelessly, most often behind the scenes, to engage the Parkinson's community with research and researchers. He travelled the country to help other cities set up 'RIGs'. We, the Parkinson's community, have a lot to thank Ken for. He did a tremendous job at erasing the line between scientist and patient, and I am very grateful for that." There are now eight Parkinson's UK Research Interest Groups across the UK based on Ken's Edinburgh model and there are plans for more.

Ken's roles with the Edinburgh Branch of the charity included taking on the Branch website created by Patrick Mark, which Ken went on to develop and maintain. A natural collaborator and organiser, Ken attracted the most pre-eminent scientists from around the world to come to Edinburgh to deliver annual Parkinson's lectures. The eighth lecture took place two weeks before Ken died and it was fitting that his work for the Branch was honoured that evening with the announcement of a new bursary bearing Ken's name and established for young researchers in Edinburgh.

In an open letter from **Edinburgh Branch Hon Chair David Adams**, Ken and the audience were told: "The value of all your activities and skills cannot be overstated. You give a powerful and continuing stimulus to the world-class specialists at work in Edinburgh and further afield, connecting researchers more strongly than ever with the people whose lives they are working to improve. Your passion, conscientiousness and the reach of your unassuming capability, are an inspiration to people with Parkinson's, their carers and health professionals alike. You challenge and extend the horizons of our thinking, our scope for ambition, and our courage for commitment."

Katherine Crawford, Services Director at Parkinson's UK, was the charity's leader in Scotland during the time Ken flourished. She said: "Ken's intelligent approach and broadminded perspective meant that he could always see the bigger picture, and that has really helped the charity develop in all aspects of its work in Scotland. Ken used his skills to best advantage, from delivering meticulously organised events to influencing the charity's work in health and research. Ken's warmth and kindness shone through in all that he did. He always had time to remember people, to share a joke and perhaps an update on the latest rugby scores. We will all miss him very much."

Annie Macleod, Scotland Director of Parkinson's UK concluded: "The Parkinson's community in Scotland was enriched by Ken's presence. Though his place can never be filled we work hard to ensure his legacy thrives. Scotland is at the leading edge of Parkinson's research and when the discovery of a cure comes, and it will come, it will be thanks to the efforts of people like Ken Bowler."

Ken is survived by two daughters. A private funeral will be followed by a celebration of Ken's life to which family, friends and people in Ken's network are invited at Prestonfield House, Priestfield Rd, Edinburgh EH16 5UT on **Monday 28 October at 3:00pm**.

Original Press Release was composed by Graham Kerr, 07827 982626, 07961 460248 (out of hours), gkerr@parkinsons.org.uk.