
EDINBURGH BRANCH PARKINSON'S UK

Branch History

in aid of
PARKINSON'S^{UK}
SCOTLAND
**CHANGE ATTITUDES.
FIND A CURE.
JOIN US.**

What follows are milestones and events from the establishment of the Branch in 1971 through to the time of launch of a new website summer 2020. The intention is to paint a picture of the founding and continuing Branch ethos while also acknowledging individuals who have made a significant contribution to the Branch's development and achievements – they are Members, Volunteers and Friends. The new website's pages will carry forward our story as will its Photo Gallery which already holds some of the more memorable moments from recent years. The website version of this history contains links to further information about some of the items.

1969: Mali Jenkins founded The Parkinson's Disease Society (PDS) having become frustrated by the lack of information for Parkinson's Disease patients and their families – Mali's sister had been diagnosed with Parkinson's some years before. In 2010 the Society changed its name to Parkinson's UK.



Mali Jenkins



Original PDS Logo



Professor Gillingham

1971: The Edinburgh Branch, one of the oldest in the UK was founded by Professor (Francis) John Gillingham CBE, FRCSE and others, who included the Countess of Rosebery (Lady Rosebery). Professor Gillingham was a Dorchester-born neurosurgeon who spent most of his career in Edinburgh, becoming internationally recognised for his pioneering work in surgical neurology including PD. Lady Rosebery acted as President and Professor Gillingham as Vice-President of the Branch for many years until the cessation of their office-bearing roles. Lady Rosebery continued to maintain an interest in our activities long after retiring as President

The Branch rented an office at 44 Frederick Street for two hours a week to conduct Branch administration and hold Committee Meetings, finally giving up the facility in 1981. Branch activities included monthly meetings in North Morningside Church Hall with a variety of speakers, coffee mornings, Burns' Suppers, wine and cheese parties, fashion shows, and

outings to the theatre and places of interest. On occasions, Members were entertained by a variety of local amateur choirs including the Gilbert & Sullivan Society. Members gave talks to clinicians and other health professionals as well as business societies about their experience with PD. By 1980 there were 181 Branch Members.

Over the years some of these activities have continued but many have been replaced as lifestyles and Members' needs have changed. For decades the most consistent annual event was the Branch Coffee Morning, bringing Members, their families and friends together to fundraise through stall sales, to chat over tea and scones and to raise awareness of the Branch to people local to the various locations used. These gatherings were managed by a wealth of individual Members who each year would plan, organise and lead a team of willing volunteers to ensure the smooth running of the event. Here is Scottish MP Margo MacDonald (see also 2005) opening one of the Coffee Mornings held in Davidson's Mains.



1983: The Branch organised the first holiday in Scotland for people with Parkinson's (PwPs). It was for a fortnight in May at the Trefoil Centre, Gogarbank and accommodated 12 PwPs and 3 relatives. Physiotherapists, Speech Therapists and Nurses were on hand to offer their services while a variety of outings and activities also took place during the two weeks.

1989: Branch Secretary, Winifred Stuart Hardie was awarded the British Empire Medal (BEM) for her unstinting service to the Branch over the previous 17 years

1991: Thanks to a substantial legacy, the Branch was able to fund the establishment of the multi-disciplinary *Edinburgh Parkinson's Assessment Clinic* at the Royal Victoria Hospital, on the basis that NHS Lothian would take over EPAC after two years (later extended). Priority was given to Branch Members but *anyone* could be given an appointment by GP referral or by self-referral. Administration was handed over to the Royal Victoria in 1994. Here we have Member Patrick Mark with EPAC Therapists after presenting them with a laptop and printer from the Branch.



1997: The Branch appointed and fully funded the costs of a Welfare Visitor, Sheila Smith, to cover the Lothian area, visiting members in their homes to discuss problems and offer advice. The role was later filled by Gina Allen (see also 2000) and in 2005 a second Welfare Visitor was appointed with the aim of helping to reduce the excessive workload on the Parkinson's Nurse Specialist, Alison Stewart (see 1999). Administration of the WV service was carried out

on our behalf by the Citizen's Advice Bureau with PDS taking ownership in 2009. The WV role became Community Support Worker (CSW) and eventually developed into that of (by then Parkinson's UK) Local Adviser in 2017.

1999: A Parkinson's Nurse Specialist was appointed to the Western General Hospital, the Branch funding fifty per cent of the first two years' costs. After major Branch campaigning, one became three in 2009 – they are *L to R*: Allison Darbyshire, Alison Stewart (original PDNS), Tina Daniels. It has always been a principal aim of the Branch to represent Parkinson's interests to NHS Lothian and associated bodies. But the campaign around the establishment of a strong PDNS team was the start of significantly greater effort by the Branch to push for the best possible health and care services for PwPs in the region. Patrick Mark has been a significant player in these efforts – see *2001* and the *Appendix* to this Branch History.



2000: The VOCAL charity ran a successful course for the Branch's care-partners, repeated on several occasions. The Branch and our PDS Community Support Worker, Gina Allen, then decided to run the course in-house. CSW involvement was later withdrawn by PDS, after which Branch Member Cathie Quinn took on the running of the course in 2009, supported by Member Heather Robertson. It became our hugely appreciated bi-annual Side-by-Side Course for Parkinson's and later inspired the establishment of monthly Carer's Support Group meetings where care-partners could meet for two hours to talk and share experiences. An independent Young Parkinson's Carers Support Group was established some years later for people of working age. The Side-by-Side Course frequency reduced to once a year when the West Lothian Group introduced an annual event run along the same lines.



2000: Work began that year on a Branch website, designed by Angus Mark, son of Patrick Mark (see *below*). Angus also designed our printed Annual Branch Calendar. The website was ultimately developed and maintained by Member Professor Ken Bowler.

2001: Patrick Mark had joined the Branch as a Committee Member in 1999. In 2001 he was elected for a three-year term as PDS Trustee for Scotland and later chaired the Society's Nominations Panel for a number of years. This recommends the recruitment of appointed and co-opted Trustees so that the Board has the full range of skills and expertise it needs. Patrick went on to become Branch Chair and it was during his time in the role that the Branch led its campaign to increase the size of the Lothians' PDNS Team (see *1999*), which later became referred to as the Parkinson's Nurse Specialist Team. Patrick was awarded Parkinson's UK Honorary Life Membership in 2013 "in recognition of his long-standing, committed and substantial support for the work of Parkinson's UK".

2002: The Branch launched monthly Drop-in Centres for PwPs, their families and friends, to meet informally with staff of EPAC, the PD Nurse Specialists and the PDS Community Support Worker, as well as to share experiences, listen to speakers on a variety of relevant topics and participate in an exercise class. These monthly sessions were run initially by Val Young, former secretary to Professor Gillingham, and were held at the Royal Victoria Hospital which at the time was the base for the Edinburgh Parkinson's Services. Subsequently, Drop-in Centres were established at Drummond Grange Care Home, Lasswade and at St. Raphael in the Grange, Edinburgh South.

2002: Tom Isaacs, diagnosed with PD at the age of 27, met Branch Committee Members while on his 4,500-mile walk anti-clockwise around Britain's coastline to raise funds for Parkinson's research. Tom became a co-founder of the Cure Parkinson's Trust in 2005. In 2007 he published a detailed account of his walk titled "Shake Well Before Use" – an honest, revealing and inspiring read in which you travel with him. *Tom with Branch Members:*



Standing (L to R): Patrick Mark, Ron Partington, Bill McBain, Margaret Boyne, Cathie Quinn, Pat Stewart, George Boyne

Seated (L to R): Kate Mark, Tom Isaacs, Liz McBain

Tom's tee-shirt shows the logo for his walk which he named **Coastin'** to convey a sense of progress – around the coastline and towards a cure.

2002: An annual Indoor Bowls Challenge was established between the Edinburgh and Fife Branches. This event is a reflection of the close inter-branch ties we have with Fife. The two Branches alternate as hosts – some years we win, some years the honour goes to Fife but hanging on to the trophy seems fraught with mishap. The original trophy donated by the then Manager of PDS UK Scotland, Richard O'Grady, disappeared, then a replacement trophy went missing and in 2018 the third trophy was nowhere to be found but was finally unearthed by Edinburgh Branch on returning home after winning that year.



Photo taken at 2018 event

2003: The findings were published of a University of Paisley Study which the Branch had commissioned thanks to a significant legacy. The study objectives were to provide information and evidence about PwPs and their care-partners in Scotland and particularly the Lothians, as well as the resources available to meet identified needs locally as well as nationally. The exercise provided a major opportunity for Branch Members to consider and recommend the needs of our community, which has continued to be an ongoing process for us.

2003: The discussions prompted by the Paisley Study and other opportunities for Member exchanges led to the successful application by the Branch for a CREATE IT PDS Millenium Award for the development of a Lifestyle Management Programme to help PwPs live as active and rewarding a life as possible. It was developed for the Branch over a four-year period by inspirational Ross Grieve and his team at the Thistle Foundation charity. Ross's approach was to work with individuals living with the condition *not* the condition itself, focusing on strengths, assets, and support to live life based on what matters to the individual.

Each course ran for 10 weeks and covered topics which included lifestyle, getting active, energy and time management, relaxation, goal setting, mind-body connection, recovery from lapses, communication skills, and forward planning. The Millenium Award covered the first two courses then the Branch funded them for a number of years. Over 100 people attended. Exercising regularly proved such a benefit for many participants that the Branch began to fund a weekly exercise class at Thistle.



Branch Member Kate Mark well deserves acknowledgement for taking ownership of the original project, as does supporting Member Liz McBain. *Kate is in pink on the right of the photo from the second course, Liz having participated in the first one. Ross is in the centre.*

Parkinson's UK launched *its* self-management programme in 2017, with Branch Members, Bill Wright and Liz Hume training as volunteers to facilitate those run in Edinburgh. Regrettably, in 2019 the programme was curtailed.

2004: Mark Dumas, Chairman Parkinson's UK 2004-2009, visited the Branch and made a presentation to Ron Partington, the retiring Branch Chair at the time. Mark also visited the Parkinson's Disease Society MRU (Mobile Research Unit), which the Branch had begun to use to help raise awareness of Parkinson's. Over the years the MRU made outreach visits to areas that included Craigmillar, Gilmerton, Leith, Muirhouse, Penicuik and Sighthill.

The MRU had been fashioned from a converted horsebox chassis with seating and office accommodation inside so that visitors could come in and talk informally about PD to Branch Members and health professionals. On one occasion, permission was given to locate the MRU next to the Royal Scottish Academy building at the foot of The Mound, but that day was one of the least successful due to torrential rain (*on the right – a wet murky Edinburgh day*).



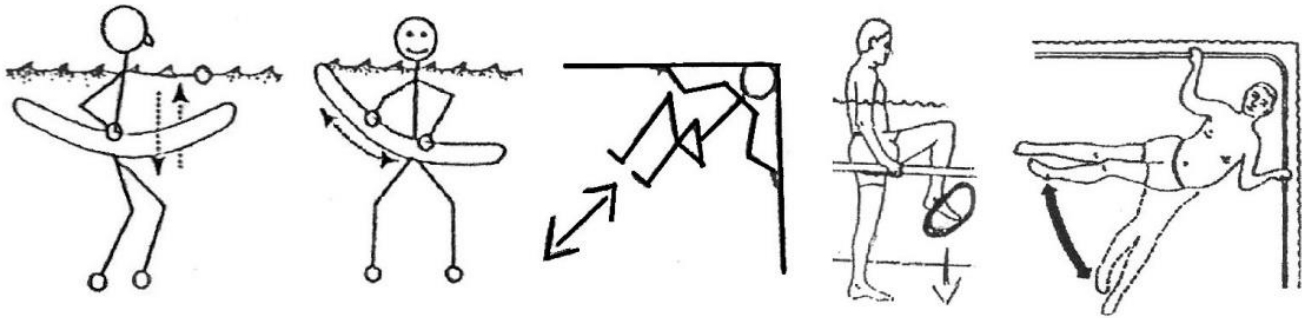
2005: Margo MacDonald, who served as a Scottish National Party and later an Independent Member of the Scottish Parliament for Lothian from 1999 until her death in 2014, spoke to the Branch. She later arranged for Branch Members to visit Parliament. Margo had been diagnosed with PD in 1996 and ultimately pursued a campaign to legislate for the right to assisted suicide. A Bill in her name, the Assisted Suicide Scotland Bill was before the Scottish Parliament at the time of her death. It was rejected in May 2015 by 82 votes to 36 following a debate at Holyrood.



2007: Pat Stewart, a founder Branch Member, long-serving Committee Member and later Branch Secretary including membership duties, was awarded Honorary Life Membership of PDS. This was for her sterling contribution to the work of the Branch, not the least of which was establishing a highly effective Branch administration. Added to this was her empathetic ear on numerous occasions when taking telephone calls from Members or their care-partners in crisis or in stressful situations. (Pat's father had PD.) Pat also made numerous outreach visits to organisations to tell them about Parkinson's and the work of the Branch. The photo shows Pat and the three Chairs with whom she served. *Left to right are Ron Partington, David Adams and Patrick Mark.*



2008: The Branch commissioned and funded a series of hydrotherapy courses run by therapists at the Astley Ainslie Hospital using the therapy pool within the Physiotherapy Department of the hospital. Participants could then carry on with pool work at Branch sessions organised at Braidburn School's Hydrotherapy Pool using exercise sheets given to them on the course.



These courses ran for several years until curtailed by staffing problems plus closure of the pool for significant maintenance work. However, they ultimately inspired the introduction in April 2018 of Aquatherapy sessions using the Astley Ainslie pool, with the sessions being funded by the Branch for PwPs and led by an independent Physiotherapist and Hydrotherapy specialist, Jackie Rochmankowska.

2008: The Branch created a set of PD information cards that could be carried in a pocket or bag to hand to friends, family, shop or office staff, people in meetings or on public transport, when someone with Parkinson's needed to seek help or explain the problems arising from PD. The cards covered general PD information, specific difficulties arising from particular symptoms, medication issues, the effects of being "on" and "off", and more. They were the brainchild of Branch Member Pat Cox who was assisted in the project by fellow Member Margaret Seager, with much discussion among the Committee to get the wording right – exclamation marks were banned. The cards were professionally produced and each set packaged in a small bag. PwPs could carry all 10 cards or a selection most pertinent to their needs. They were ideal for family and friends to use in explaining Parkinson's to others.



They were ideal for family and friends to use in explaining Parkinson's to others.

2008: The Edinburgh Young Parkinson's Support Group (EYPSG) was launched. Prior to this, the only provision for working age PwPs and their care-partners had been a Scotland Young Parkinson's Network which held quarterly meetings in Stirling. Yet there was a real need for frequent local meetings in the evenings as many YPs work during the day. A group was established to be run independent of the Branch with the Branch supplying initial funding and moral support. The Group's aim: to provide peer support for people of working age in an informal sociable setting. Such was the need that people came from Fife, Glasgow, Ayrshire, the Borders, even Carlisle. Some of these areas went on to introduce their own YP groups.

Initially run by Joel Houck, Scott Wilson took over when Joel moved to Fife. The Group became firmly established, with monthly evening meetings held at the Steading in Biggar Road with free, exclusive use of a conservatory to chat as well as hold talks and demonstrations. Occasional outings and events have also become a feature, as have Burns' Suppers organised by EYPSG Member, Lindsay McDermid (see 2014 Jan). The Group established a closed Facebook Group in 2018 with its own logo designed by Lindsay.



2008: In conjunction with SPRING (Special Parkinson's Research Interest Group) the Branch organised and ran a one day research conference at Pollock Halls which was attended by 60 participants. The significant success of the event contributed in part to the Branch ultimately establishing *its* Research Interest Group – see 2010.

2009: David Leventhal of the Mark Morris Dance Group ran an inspirational dance workshop at Dance Base in the Grassmarket, based on Dance for Parkinson's® principles, when the Group were presenting in Edinburgh. The workshop led to Branch Member, dancer and performer, Mo Morgan establishing the Branch's Dance for People with Parkinson's sessions. Mo's mother had PD. The sessions were funded by the Branch, with Dance Base contributing the use of their premises except in the summer when we were accommodated by the Festival Theatre. *The photo shows* Mo and class participants during one of the summer sessions. The Branch activity ultimately came under the Dance for Parkinson's Scotland umbrella.



2010: The World Parkinson Congress in Glasgow had a number of Branch Members attending, some of whom were motivated to organise a 2010 Branch Symposium to discuss the lessons learned from the event. From this, the vision and further impetus to establish a Research Interest Group emerged, so fulfilling a need of Branch Members who had a specific interest in research. The Edinburgh Research Interest Group has since inspired the establishment of similar groups throughout the UK, with the original ERIG Chair, Professor Ken Bowler a primary motivator. The Branch felt a great loss when Ken, age 76, died in October 2019, after a short illness. Ken had spent many years furthering interest in PD research.



2012 (Feb): The Branch organised a half-day participative workshop on medication at the Eric Liddell Centre supported by Alison Stewart, Senior Parkinson's Nurse Specialist, and Alison Thomson, senior Clinical Pharmacist, Neurosciences, Western General Hospital. The event was a "sell-out" with in the order of 100 attendees, reflecting the need among Branch Members to know and understand more on the subject.

2012 (May): The Scottish Centre for Regenerative Medicine was opened by HRH the Princess Royal, Chancellor of the University of Edinburgh. It later became known as the MRC Centre for Regenerative Medicine. We have developed strong links with CRM through our relationship with ERIG Member, Dr Tilo Kunath, Parkinson's UK Senior Research Fellow and Group Leader for Mechanisms of Neurodegeneration. *See also 2013 and 2019 Aug.*



2012 (May): The first Annual Parkinson's Lecture was organised by Edinburgh Branch in conjunction with the Lothian Parkinson's Service Advisory Group and the MRC Centre for Regenerative Medicine. It was held at the Royal College of Physicians and given by the eminent Cambridge neuroscientist Professor Roger Barker on the topic "How close are we to solving the problem of what goes wrong in Parkinson's?" Branch Members, Professor Ken Bowler and Patrick Mark played significant roles in organising this and later lectures, which have become a major feature in the Parkinson's calendar in the UK, with full archives for this and later Lectures available on the Branch website.



2012 (Sept): The Branch organised and funded a Therapies Residential Week-end at Peebles Hydro for Branch Members and their care-partners, taking over much of the hotel for the 56 participants. Activities included hydrotherapy, singing, line dancing, card making, painting, Ronnie Gardner Rhythm Movement (RGRM) and yoga. Presentations were given on lifestyle management, speech therapy and exercise, while various one-to-one therapies were on offer and a group experience of sound therapy.

The feedback was extremely positive with participants appreciating the range of activities, the therapies, the location and the opportunity to socialise. Credit is due to all the Members involved in the planning and organisation of this unique event, but in particular to Committee Members, Cathie Quinn and Heather Robertson.



2012 (Oct): Branch Members took part in the nationwide Hardest Hit campaign, organised jointly by the Disability Benefits Consortium (DBC) and the UK Disabled People's Council, bringing together individuals and organisations to send a clear message to George Osborne, the Conservative Chancellor, to "stop these cuts now".

2012 (Nov): Although not setting out to be a performance choir, our Singing4Fun Group took part in the Parkinson's UK Scotland Office Festive Concert. They went on to perform at similar concerts in 2013, 2014 and 2015. The Group also performed at a local concert with the Royal Scottish National Orchestra in 2013, at the Glasgow Commonwealth Games Baton relay in 2014 outside the Scottish Parliament, and at the Edinburgh Branch of the Clarsach Society's Harps of Gold Christmas concert in 2019 but see 2018 for S4F's greatest achievement to date. *The photo shows* song leader, Wendy Carle Taylor, leading a warm-up before the 2012 Festive Concert held in St. Mary's Cathedral, Palmerston Place.



2013: Branch Members participated in a study by Queen Margaret University Physiotherapy students on Attitudes to Exercise. The study team identified barriers to exercise as well as aspects that facilitate people with Parkinson's to take regular exercise. The Branch has since gone on to further encourage involvement of Members in the training of health care professionals.

2013: That year, Branch Members also took part in a simple experiment organised by Tilo Kunath (*see also 2012 May*) to test whether people with Parkinson's generate a unique subtle odour that Perth Branch Member Joy Milne believed she could detect. Joy's husband had had Parkinson's and she had noticed the odour from six years before he began to show symptoms. The results of that experiment led to (as at 2020) an *ongoing* study funded by Parkinson's UK into the possibilities of early detection of Parkinson's through biomarkers on the skin that can be measured to diagnose or monitor the condition.

2013 (Mar): The Branch ran a participant-led Pain and Parkinson's Workshop (*photo on the left*) conceived and managed by a team of Branch Members: Sheila Edward, Marian McIntyre, Pat Cox and Margaret Seager, supported by Werner Remmele from Fife. It provided an opportunity for people to discuss their experience of pain while health professionals gave presentations on pain and its management. It proved a very worthwhile day.

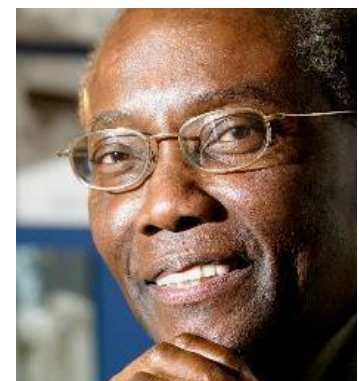


2013 (Aug): Long-standing Branch Member Liz McBain was awarded Honorary Life Membership of Parkinson's UK in recognition of her great work for the Parkinson's community in Edinburgh over many years. Liz and husband Bill had earlier attended the Queen's Garden Party at Holyrood Palace in recognition of her contribution, which was always well supported by Bill's efforts. *Above right* – Liz with Chair, Ron Partington, and Bill and her Award.

Liz's contribution included establishing Gentle Exercise classes in Portobello and Drylaw, Indoor Bowling in Portobello, Swim Sessions at the Hydrotherapy Pool in Graysmill and then Braidburn Schools, and an Art Group which originally met in Liz's home (Liz received a Highly Commended Art Category Mervyn Peake Award in 2017). She also organised quiz nights and annual fundraising ceilidhs over many years, some of the most memorable being at the Royal Scots Club. Bill and Liz's daughter, Kirsty, was a consistent helper for these events. (Ceilidh organisation was later taken over by Branch Fundraiser, Lou Ogilvie.) Liz was also the inspiration behind a Branch rap performed at the Branch Feedback from WPC Glasgow.

2013 (Oct): Three Branch members attended the 2013 World Parkinson Congress, Montreal and later reported back to the Branch. One of the three, Mo Morgan, our original Dance for Parkinson's facilitator (see 2009), together with Beata Michalska, a neuropsychology Master's researcher, had a poster displayed at the Congress. It summarised a study regarding whether or not weekly participation in a dance class could improve cognitive functioning in people with Parkinson's. The summary had also been presented in poster format at the International Congress on Alzheimer's and Parkinson's Disease in Florence earlier in March.

2014 (Jan): A few Burns' Suppers were organised in the Branch's very early days then re-established in 2014 by Lindsay McDermid of the Edinburgh Young Parkinson's Support Group when Sir Geoff Palmer gave a much lauded Immortal Memory. Sir Geoff returned for the 2016 event. He also made a strong impact when he gave a talk about slavery at a Branch Meeting, being author of a book on the subject and having spoken out extensively against the slave trade. He returned at a later date to give a lighter-hearted talk about the barley and the malt, having been a much honoured brewing science pioneer, initially based at Heriot-Watt.



2014 (Jan): The Branch carried out a postal survey to all on our mailing list asking for views on activities, the website and our newsletter. The survey was designed to be anonymous, to encourage frank opinions about Branch provision and to be as inclusive as possible, reaching those who attended events regularly and those who did not, as well as those who had internet access and those without access. Branch Member, Sheila Edward, applied her skills to the questionnaire design and results analysis which highlighted areas for the Branch Committee to consider in providing greater benefits for our Members.

2014: We were introduced to Parkinson's Jam – Branch Member and PwP, Marian McIntyre, had come across a jar of plum jam labelled "Parkinson's Jam" in her cousin's kitchen. The source of the recipe was the book accompanying a brand new Parkinson's Gas Cooker in the 1950's where it was described as "New Jam". It had become a firm favourite in her aunt's repertoire with the recipe including the unusual ingredients of oranges, walnuts and raisins. You can find the recipe on our website Fundraising pages.

2014: During the years since the Branch was established there has been a long line of Branch Members, their relatives and friends who have dedicated their time and considerable effort to raising funds for the Branch and Parkinson's UK, for which we express our sincere gratitude. Many are mentioned under Fundraising on our new website launched summer 2020 but in 2014 a unique fundraising event occurred. Davey Johnstone, brother of Branch Member Liz McBain (see 2013 Aug), a renowned guitarist, song-writer, musical director, and well known for his long-standing work with Elton John, donated for auction an acoustic guitar signed by Davey, Elton, and two other members of Elton's band, Nigel Olsson and Ray Cooper. The guitar eventually found a home on the back of a £16,000 gift. At the time, Davey also donated a ukele signed by his friend, Billy Connolly.



2016 (May): The Branch organised a "Parkinson's: Let's get Moving" day's event to promote the benefits of group exercise for PwPs. Professor Lynn Rochester, Newcastle University, described research evidence about the effects of exercise on PwPs. Julie Jones, Robert Gordon University, focused on gait and the practical measures that could be used by physiotherapists in treating patients. Wendy Carle Taylor, our Singing4Fun Song Leader gave a voice work presentation (about exercising the vocal folds/cords) and there were discussion panels and professionally-led taster exercise sessions. Many came away from the day fired up with enthusiasm – participants, presenters and health professionals. Organisation of the event was a full Branch Committee effort. Our focus on the benefits of exercise has grown from strength to strength ever since. *Photo is of Julie Jones with Members Bill Wright and Ken Bowler enjoying a lighter moment.*



2016 (Sept): Two Branch Members attended the September 2016 World Parkinson Congress, Portland, Oregon, one of whom, Alison Williams, together with member, Bill Wright, had a Poster accepted and displayed at the Congress. It described the background to our Quality of Life (QL) Group, its philosophy, the benefits and how it works. The attendees reported back to Branch Members in a day symposium. *Image is the QL logo.*



Another significant reflection of our strong inter-branch relationship with Fife was the launch in February 2018 of the Fife Quality of Life Group, following discussions with our by then, well-established QL Group Members.

2017 (Mar): Warren Gatland, Head Coach of the British & Irish Lions, Gavin Hastings, former Scotland Captain & Lion, and Tom Isaacs, co-founder of the Cure Parkinson's Trust (*mentioned 2002 and 2019 Aug*) visited the laboratory of Tilo Kunath (*see 2012 May*), at the MRC Centre for Regenerative Medicine ahead of a charity fund-raiser for CPT.

2017 (Mar): Alison Thomson, wife of PwP Branch Member Ken, conceived and organised with the help of other Branch Members, a workshop "Learning About Falls" (*next photo on the left*). Topics covered the Falls Services in Edinburgh and the Lothians, physiotherapist as well as occupational therapist advice, and attendance by the Edinburgh Leisure's Ageing Well and Steady Steps activities



Participants ready for a session with Steady Steps



2017 (June): On behalf of the Branch, Ken Bowler and Cathie Quinn, accepted the Inspiring Volunteering Achievement Award at the Lord Provost of Edinburgh's Award Ceremony at the City Chambers. In addition, Branch volunteers, Cathie Quinn and Heather Robertson, were each awarded personal certificates for their outstanding volunteer work for the Branch over many years. *Above right*, Chair David Adams is with Heather and Cathie showing off their awards at the 2017 Branch Summer Lunch.

Branch Member and Art Group Leader, Lindsay McDermid, later organised a tea party at the Botanic Cottage to celebrate the awards. The cottage has been the home of the Art Group

since 2016 thanks to the generosity of Royal Botanic Garden Edinburgh. The photo album of the event is in our website archives.

2017 (Sept): The Branch launched a Drop-in Parkinson's Café to be held for two hours once a month in a dedicated space of the Festival Theatre Café so that people can find out about the Branch and meet existing Members. The Café has proved a great success in spreading the word about the Branch's activities and drawing in new Members.

2017 (Nov): Branch Members, Alison Williams, Ken Bowler, and Bill Wright had accepted for publication an article "Adventures with Parkinson's: empowering Parkinson's patients to become active partners in research and treatment" in the online Future Medicine publication, reflecting the Branch's eagerness to encourage participation in clinical trials as well as in the training of health professionals.

2018 (Aug): The year saw the beginnings of a continuing relationship with Paul Mayhew-Archer (co-writer for the Vicar of Dibley) when he came to the Edinburgh Fringe with his one-man show "The Incurable Optimist". The Branch hosted a tea-party at the Botanic Cottage for Paul and his wife, Julie. Paul returned with his show in March 2019 when we collaborated with Fife Branch to host a pre-show gathering for the couple, again reflecting our strong inter-branch relationship. *Photo on the left* is Paul's show flyer with his personal messages to the Branch and *on the right* we have Paul with some Members of EYPSG – Edinburgh Young Parkinson's Support Group.



2018 (Oct): The Branch Singing4Fun Group were announced as winners of the Kyoto 2019 World Parkinson Congress song competition in the category original lyrics AND original music. The song was created by a truly collaborative effort from a number of our singers under the inspiration and guidance of Tuesday session Song Leader, Penny Stone. For more about the song see *the Singing4Fun page on our website*.

2019 (June): Five Branch Members attended the 2019 Kyoto World Parkinson Congress. Three posters that involved Branch Member collaboration were presented at: “Where’s the ‘feeling better’ box?” Beyond PDQ39 (*Alison Williams*); Creating a Virtuous Cycle of PwP Support (*Bill Wright, Judith Shepherd, Alison Williams*); Parkinson’s Smell Levels, Symptom Management and Empowerment: When Joy Met Alison (*Joy Milne, Alison Williams*). Attendees later reported back to Branch Members in a day symposium.

2019 (June): Our Pilates Instructor, Sasha Baggaley, featured on That’s TV Scotland Headline News talking about the benefits of, and her approach to, Pilates for people with PD. *You can watch it on YouTube entry 08088 000303.* In January Sasha had introduced her Neurodynamic Exercise programme based on her training and experience in Neurophysiology, Pilates and PD Warrior. This is an advanced course incorporating challenging physical and cognitive activity for people in the earlier stages of Parkinson’s.



2019 (Aug): The Cure Parkinson’s Trust and the Van Andel Research Institute unanimously voted Dr. Tilo Kunath, Group Leader at the MRC Centre for Regenerative Medicine, the 2019 recipient of the ‘Tom Isaacs Award’, created in memory and recognition of former CPT co-founder and President, Tom Isaacs, who died in 2017. CPT and VARI present this award annually 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. You can see a video of the surprise presentation to Tilo on *YouTube – Dr Tilo Kunath – Recipient of Tom Isaac Award 2019.* *Below left: Tom Isaacs with Tilo.*



2019 (Sept): In recognition of Professor Ken Bowler’s achievements in establishing the annual Edinburgh Parkinson’s Lecture and the Edinburgh Research Interest Group (ERIG), the Branch introduced The Ken Bowler Travel Bursary, to be awarded annually to a young Edinburgh-based Parkinson’s Researcher. Ken received the award at the end of the 2019 Lecture a few weeks before his death. *Above right, Ken with Parkinson’s UK in Scotland Director, Annie Macleod.*

2020 (Apr+): In response to the coronavirus lockdown situation the Branch introduced online and video sessions, we learned how to use the Zoom platform to hold meetings and bring people together for a chat, we introduced a weekly emailed miscellany of Members' stories, anecdotes, trivia, pictures and mementoes titled "Lines, Laughs and Lockdowns" AND found time to compile this Branch History.

Appendix

A principal aim of the Edinburgh Branch has always been to try and achieve the best possible health and care services for people with Parkinson's in Lothian. How we tried to achieve this over the past 20 years is described below.

The introduction of Parkinson's Disease Nurse Specialists (PDNS) to the National Health Service in Britain transformed the level of care that could be provided for PwPs. The appointment of Alison Stewart as Lothian PDNS in 1999 was a vital development for us. Her excellent work rapidly demonstrated the huge benefit of a PDNS Service but her workload of over 1500 clients was impossibly large.

The Branch soon recognised the need to introduce additional resources and staff, including secretarial support but it seemed to us that NHS Lothian did not share this view. To shore up the PDNS Service the Branch agreed to fund the provision of a part-time secretary for Alison allowing her to focus her skills on helping people.

Whilst it was clear that obtaining additional Parkinson's Nurses for Lothian must be the number one priority for the Branch, how to achieve this was not obvious. The Parkinson's Disease Society (PDS) claimed to be lobbying the NHS, but as time went by the Branch concluded that we needed to take ownership of the problem. Dr Conor Maguire the senior Parkinson's physician in Lothian was entirely supportive of our view and over several years submitted business cases to NHS management arguing for additional staff. However, it was impossible to identify who in NHS Lothian was really responsible and able to act.

To make the NHS more aware of our concern, the then Branch Chair, Patrick Mark, took every opportunity to attend meetings about nurses or provision for the elderly and always ask the same question: "What is NHS Lothian's plan for developing Specialist Parkinson's Nurses, and why does Lothian only have one PDNS yet Glasgow has six?"

Eventually in 2009, Dr Maguire had an unexpected positive response to his submissions, and two additional nurses were appointed, together with secretarial support. This was a huge welcome surprise for everyone and a major step forward for Parkinson's Services in Lothian. We surmised that someone in the hierarchy was both sympathetic to the issue and knew how to find the funding.

After many years focussing on getting more Nurses, the Branch needed to review its policy and objectives. At a special Branch meeting in 2009 we discussed what the important issues might be and settled on the following:

Edinburgh Branch Priorities for Parkinson's Services in Lothian

1. Access to Parkinson's Services should be clear, structured and easily available to all.
2. The Parkinson's Nurse Specialist Team (a change of title from PDNS Team) should be supported and developed to achieve universal access.
3. Services should be provided by multi-disciplinary teams structured to focus on patient needs. Team members including Physiotherapy, Speech and Language, and Occupational Therapy professionals should all have specialist Parkinson's training and experience.

These priorities remain Branch policy but trying to achieve them in the last decade has been a challenge.

We asked ourselves: What does a good Parkinson's service look like? What is world best practice?

We did not know, but fortuitously the World Parkinson Congress 2010 in Glasgow provided an opportunity for us to hear acknowledged world experts on the subject. The most inspiring was Professor Bastian Bloem who developed ParkinsonNet, a comprehensive Parkinson's patient centred structure based on specialised and focused therapy teams.

At a special Branch Meeting in Edinburgh in February 2014, Branch Members learned more about ParkinsonNet principles from a recorded video conference involving Professor Bloem and other leading Parkinson's experts. We discussed what we had learned and there was universal enthusiasm for the ideas and a vision that it might be possible to apply them in Scotland but particularly in Lothian. You can read a review of the Branch Meeting and descriptions of the various neurological groups mentioned below in the Branch Newsletter March 2014.

As part of Branch strategy to achieve this, we invited Professor Bloem to deliver the Edinburgh Parkinson's Lecture in 2016. We had hoped that this would inject some much needed interest and enthusiasm into the Scottish Government and NHS Lothian but there is little evidence that it did. Meanwhile, ParkinsonNet is increasingly recognised as world best practice for Parkinson's.

Attention to neurological issues in general in NHS Scotland was increased by the publication of "Quality Improvement Scotland Neurological Standards 2009". These set out rules for Health Boards to follow in dealing with neurological issues and with specific conditions such as Parkinson's. One requirement was that each Health Board should produce a service improvement plan for neurology.

In 2013 Patrick Mark became a member of a group formed as Lothian Neurological Voices. This was part of a project funded by the Scottish Neurological Alliance and the Scottish Government to improve patient involvement. Neurological Voices included people involved with various conditions such as MS, Huntington's Disease and Parkinson's. The purpose was to provide a focus group to advise Lothian Health Board regarding neurological service policy. The group met with senior NHS Lothian management for this purpose. Patrick became Chair of Lothian Neurological Voices and the group developed a set of priorities.

This led to Patrick joining, as patient representative, another group tasked with developing the Lothian Neurological Improvement Plan. It was led by NHS Lothian General Manager Jane Hopton. Other group members were clinicians and managers from the NHS so Patrick was effectively the only non-professional, enabling him to offer opinions freely without being constrained by hierarchical considerations.

In practice, attendance at the group was variable, but Patrick made sure of consistently being there and as a result, we suggest, achieved a considerable influence on some of the policies proposed. The Plan was subsequently published as NHS Lothian Neurological Improvement Plan 2014 and adopted by the NHS Lothian Board.

An Improvement Group to supervise the application of the Plan's proposals was set up with Patrick again becoming a member. The chairmanship of the group changed several times, discussion was unfocussed and attendance at the meetings was poor with little being achieved. Meetings stopped and in an attempt to stimulate action, Patrick corresponded with the Chair of NHS Lothian, but to no avail. The Plan seemed to have died.

On behalf of the Branch, Patrick also became involved with the Neurological Alliance of Scotland which represents all neurological conditions. The Alliance was involved with the development of the Scottish Government Neurological Services Improvement Plan which has been published but there is as yet no structure for local implementation of it.

And so, on it goes the Branch will keep striving within the limits of our capabilities for better care and health services for PwPs in Lothian.
