

Scotland Development Team Spark bites Fundraising Campaigns
Landmark Research Excellence Network Diary dates Contact us

Achieving even more in 2020

Welcome to the second issue of Spark. 2020 is off to a great start with the Scottish Government publishing its Framework for Action for neurological care and support and announcing a £4.5m investment to deliver change. It follows a year jam-packed with challenges, changes and new developments.

2019 was a year of 'firsts' – first jointly funded clinical fellow in Scotland with Julie Jones, first bespoke Golf day, first satellite AGM, first Facebook online husting, first SPARK, first challenge event in the Great Glen, first Advisory Group for Scotland, the list could go on.

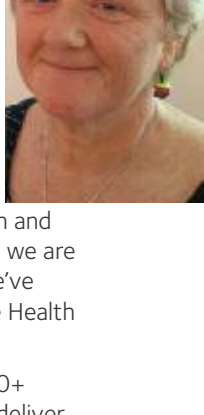
We've also been able to shape the way Government and Health Boards look at Parkinson's. Our reports on Scottish Services and Get It On Time changed the conversation and the Excellence Network is gaining traction too – the community is now seen as expert and we are being regularly consulted on a wide range of service development and provision issues. We've already seen Parkinson's nurse numbers increase and we're pressing for a meeting with the Health Minister in the new year.

All of our work is dependent on volunteers and I'm constantly amazed at how hard our 400+ volunteers work to grow the Parkinson's community in Scotland. This year they've helped deliver 5 information events, 6 Parkinson's Cafes, countless fundraising events, 1 new support group, 1 new singing group, 1 new research interest group, and much more. There are now more than 500 activities taking place across Scotland each year and we're ready for even more in 2020. See our new infographic for a round-up of 2019's achievements.

A huge heartfelt thank you from me to everyone in our incredible Parkinson's community. It really is a privilege to work with such a focused and committed group of people. I'm looking forward to what we can achieve together in 2020.

Warm wishes

Annie
Annie Macleod, Director, Parkinson's UK Scotland



Landmark day

Wednesday 20 November was a special day for the charity. Our new Parkinson's UK Scotland Advisory Group met together for the first time and we held a reception in the Scottish Parliament to promote our Get It On Time campaign.

Scotland Trustee David Allan chairs the new group – which is made up of our supporters, people affected by Parkinson's and professionals.

Our Parkinson's community was out in force at the Scottish Parliament when they took our Get it on Time campaign to Holyrood so MSPs could hear first hand about why people with Parkinson's need to get their essential medication on time, every time, when they are in hospital.



Huge thanks to everyone who braved the awful weather, to David Allan for speaking so powerfully about his experiences in hospital, and especially to our host Jackie Baillie MSP, and her Parliamentary colleagues Tom Mason MSP and Colin Smyth MSP for listening to what people affected by Parkinson's and professionals had to say. The politicians were

shocked at the scale of the problem and there's a real sense that they want to get involved to bring about change. Further meetings and discussions with them are planned. We'll keep you posted on progress here.

Email us if you'd like to know more about the group or the campaign.

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Fundraising news

£700,000 up!

With your generous support our regional fundraising team raised more than £700,000 in Scotland in 2019. The team supported nearly 400 individual fundraisers, held 4 walks supported by our volunteers. organised a host of other events and organised our first bespoke Golf Day at Royal Troon. Thank you for this amazing support and hope you'll help us make 2020 even better!

Janet's amazing year

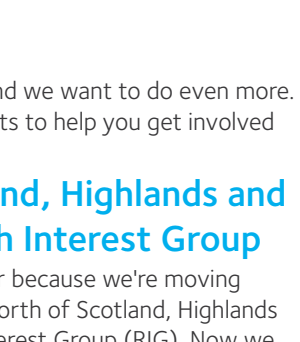
Our fab volunteer, supporter and exercise evangelist Janet Kerr has been completing 50 miles by bike, scooter, rollerskate or swimming for 50 weeks this year to raise funds for the charity. She has done so much this year to raise an incredible £5,000 but also awareness for the charity.

Talking about her year, Janet said: "What an epic year this has been. Cycling, skating, scooting and swimming, has literally brought me out of the darkness, and into the light, providing me with some of my greatest achievements. But without the diagnosis of Parkinson's I doubt I would have ever discovered what I was truly capable of. I have found an inner strength, determination and resilience that I didn't know I had."

We are so thankful for everything Janet has done and there's still time to support her at www.justgiving.com/fundraising/janetsfiftychallenge

Packed calendar

Check out the diary dates below for a list of events we'd love to see you at. There's some old favourites as well as some new opportunities such as the Inverness Ceilidh and a golf day on the hallowed links at Muirfield.



Research news

We're now funding six research projects in Scotland's universities and hospitals and we want to do even more. We'll profile some of the work in future issues but there's some new developments to help you get involved that we want to share.

Research Uncovered event

Join us to hear about our Parkinson's research strategy for 2020 and beyond. Our Deputy Director of Research, Professor David Dexter, will explain our plans and priorities for accelerating Parkinson's research forward to achieve new and better treatments.

The event is on Thursday 30 January 2020, from 2.30 – 4pm at St Mungo Museum, 2 Castle Street, Glasgow G4 0RH. (Registration and refreshments will be available from 2pm).

Book at free place here or contact Chloe on 0300 123 3679 or by email.

Calling all researchers

There's also an academics-only event where Professor David Dexter will hold research funding workshops for academics on 29 and 30 January – for further information, please contact Chloe.

Research Interest Groups

Scotland's three Research Interest Groups also have events planned for 2020 in Edinburgh, Dundee and Glasgow. Keep an eye out for details at the following websites:

<https://www.edinburghparkinsons.org/research-interest-group>; www.drug.org.uk; and

<https://www.parkinsons.org.uk/research/research-events>.

North of Scotland, Highlands and Islands Research Interest Group

Three could soon be four because we're moving closer to developing a North of Scotland, Highlands and Islands Research Interest Group (RIG). Now we need your help to shape the group by completing this short survey.

Our Research Interest Groups (RIGs) are made up of people affected by Parkinson's and researchers. The groups are vital in increasing awareness and understanding of research at a local level. They're often led by volunteers who work with the charity's local groups and staff to co-ordinate, initiate and participate in research activities including:

- ➡ creating and reinforcing links between researchers and people affected by Parkinson's
- ➡ visits to laboratories undertaking Parkinson's research
- ➡ participation in clinical trials and studies
- ➡ keeping up to date with research progress and new developments
- ➡ working with researchers to shape their research

If you have questions about Research Interest Groups, or if you'd be interested in hearing more about them, please email Liz Nash.

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Scotland Development Team

Welcome to Andrew

Welcome to Andrew Grant from Inverness who has joined the Scotland Development Team (SDT). Andrew worked at Highland Council for 37 years. He's been married for 46 years to Marsaili and they have two grown up children and two young granddaughters.

Andrew was diagnosed with Parkinson's last year at the age of 68. He's very committed to the use of exercise and diet in managing his symptoms. When asked why he was joining the team Andrew said: "I've noticed that, despite there being a tremendous amount of material and help available, there are problems with getting the most appropriate information to individuals. There's also a lack of communication between the various groups in the local area and not everyone has access to the Internet nor are comfortable using it. I've helped form a Communications Group locally to try and disseminate relevant information. I'm hoping I can contribute nationally to improving communication and awareness while representing the Highlands and Islands.



Contact the Team

The SDT are vital to ensuring your priorities are the focus of the charity's work.

To get in touch with the team contact Chloe or Cathy.

Campaigns

New nurses for Orkney and Shetland

We're delighted to announce that we are making funding available for a locally based Parkinson's nurse in Orkney. We will be working with NHS Orkney to recruit and support a nurse. This will be a huge support to local people in helping them to manage their condition. Following the recent appointment of a nurse specialist in Shetland it will also mean that at long last every health board in Scotland has at least one Parkinson's nurse post.

General Election Question Time

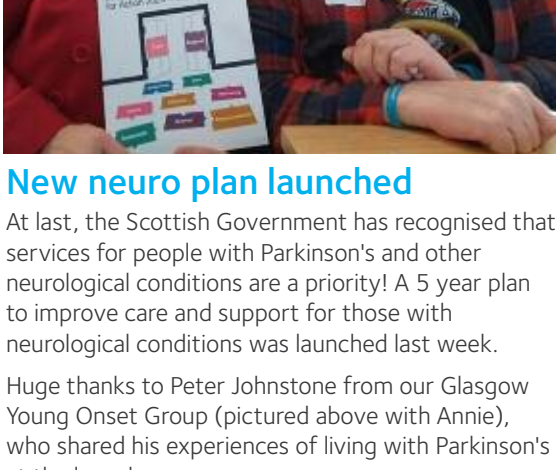
Miles Briggs MSP and Colin Smyth MSP were joined by Cllr Adam McVey, Leader of City of Edinburgh Council, in a lively evening of discussion for our first Facebook Live General Election Question Time last month.

Care charging, specialist nurse provision, support for carers were among the subjects prompted for debate by you before and during the event. Thanks to everyone involved and also to The University of Edinburgh's Datalab for hosting us and our volunteer Karen McConnell for her brilliant support.

Have you signed our GIOT petition?

We're delighted that more than 13,000 of you have. And it's not too late to add your support – sign here. And get your friends, family and Facebook followers to sign it too!

You can find out about preparing for a hospital stay – and access our free resources – on our website.



Last neuro plan launched

At last, the Scottish Government has recognised that services for people with Parkinson's and other neurological conditions are a priority! A 5 year plan to improve care and support for those with neurological conditions was launched last week.

Huge thanks to Peter Johnstone from our Glasgow Young Onset Group (pictured above with Annie), who shared his experiences of living with Parkinson's at the launch.

It's been a long time coming, but we think that the plan is a positive first step, and look forward to the plan being put into place. We hope that the £4.5m announced by Public Health Minister Joe FitzPatrick MSP is 'new' money and will make a real difference for people with neurological conditions.

You can read the Framework for Action here.

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Excellence Network

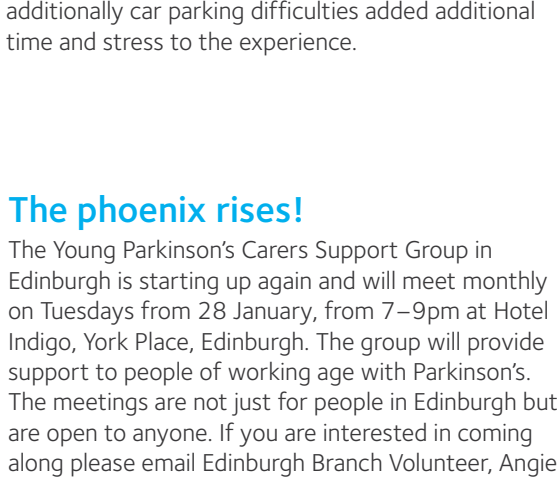
Conference

We've been talking about holding a Scotland-wide Parkinson's Excellence Network event for ages. Last month it actually happened, and what a day it was!

More than 140 health professionals enjoyed the packed agenda featured expert professionals alongside those with the condition talking about a range of topics including mental health, sleep, Get it on Time, exercise, peer support, genetics and using wearable tech to make better treatment decisions.

Hats off to Mary Elmers, our Service Improvement Manager, for organising such a great event. Mary's pictured here receiving well-deserved flowers from our three Excellence Network leads – Dr Conor Maguire, Dr Anne Louise Cunningham and Dr Carl Counsell.

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Taking the pulse on services

More than 30 people affected by Parkinson's and who get their services in Glasgow from the Queen Elizabeth, New Victoria and Gartnavel hospitals attended an event to give their views on services. People were generally very happy with the service that they receive – many people felt the staff were brilliant. But transport was a problem issue with long journeys, often requiring multiple buses and additionally car parking difficulties added additional time and stress to the experience.

The phoenix rises!

The Young Parkinson's Carers Support Group in Edinburgh is starting up again and will meet monthly on Tuesdays from 28 January, from 7–9pm at Hotel Indigo, York Place, Edinburgh. The group will provide support to people of working age with Parkinson's. The meetings are not just for people in Edinburgh but are open to anyone. If you are interested in coming along please email Edinburgh Branch Volunteer, Angie Lockhart or our Volunteer Co-ordinator Alice Hall or call Alice on 0344 225 3725.

Look North

We've held discussions with Connecting Carers – a voluntary organisation that supports carers across the Highlands – to explore the possibility of them running a carers course in the spring – along the lines of the incredibly popular Side by Side courses held in Edinburgh and West Lothian. We'll keep you posted on progress. (We hear there's some appetite for a similar course in the West of Scotland – if you think you can help us to run it please email Linda Brown from our Scotland Development Team.)

Calling all Blue Badge holders and those who support them

Transport Scotland is exploring technical solutions to help Blue Badge holders and their carers, particularly those in or near Aberdeen, Dundee, Edinburgh and Glasgow. The work is taking place because these cities are thinking about creating Low Emission Zones. This means that older and more polluting vehicles would be charged to enter city centres.

Transport Scotland is investigating affordable technology for giving Blue Badge holder exemptions from these charges (even if the holder is travelling in someone else's car).

Read more about the project here.

As part of the project Transport Scotland are now starting to consult those who would be affected. £20 is being offered to people for 30 minute interviews or to attend focus groups with Blue Badge holders, people who drive Blue Badge holders as passengers, and Organisational Blue Badge holders (such as charities/care homes).

Consultation events will be held in Glasgow, Edinburgh and Aberdeen/Dundee in January. Right now they are looking for you to complete a survey. Make sure you click on the right one.

Blue badge holders

People who drive with Blue Badge holders as passengers

2020 fundraising events calendar

7 March – The Reel Fling Ceilidh, Inverness

12 April – Walk for Parkinson's – Kelpies, Falkirk

26 April – Kiltwalk Glasgow

9 May – Great Glen Challenge, Inverness

10 May – Forth Rail Bridge Abseil, South Queensferry

23 May – Parkinson's UK Highland Swing, Killiecrankie

23-24 May – Edinburgh Marathon Festival

31 May – Walk for Parkinson's – Chatelherault, Hamilton

7 June – Kiltwalk Aberdeen

16 August – Kiltwalk Dundee

23 August – Pedal for Parkinson's Stirling

6 September – Walk for Parkinson's – Brodie Castle

13 September – Walk for Parkinson's – Loch Leven

14 September – Kiltwalk Edinburgh

4 October – Great Scottish Run

22 October – Parkinson's UK Scotland Golf Day – Muirfield

1 November – Ladies Afternoon Tea, Aberdeen

29 November – Glasgow Marriott Hotel

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About us

We're the Parkinson's charity that drives better care, treatments and quality of life. Together we can bring forward the day when no one fears Parkinson's.

Contact Parkinson's UK Scotland at Suite 1–14, King James VI Business Centre, Riverview Business Park, Friarton Road, Perth PH2 8DY Parkinson's UK is registered at 215 Vauxhall Bridge Road, London, SW1V 1EJ and is the operating name of the Parkinson's Disease Society of the United Kingdom. A registered charity in England and Wales (258197), and in Scotland (SC037554).

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