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Cafe Culture Grants Feeding back Fighting Fit Diary dates Contact us

Welcome to Spark

Welcome to the very first Spark - our regular new newsletter keeping the Parkinson's community in Scotland up to date with the latest news. Spark aims to give you a flavour of everything going on in Scotland and link you to further information. All of our work in Scotland will be featured as will the activities of our support groups.

We need your help to make sure Spark is not just for the Parkinson's community, but by the community too. We'd like to have someone from each of our 50+ support groups and cafes take up the challenge to keep us informed about what's happening in your area. Find out how to become involved by emailing Graham Kerr.

Spark is best viewed in your web browser, just click on the link at the top of the document. We promise to keep our stories short and to make Spark even easier to read we've designed it in such a way that you choose where to go next, what to read and what to pass by. Spark is also downloadable and printable to make it easy to share with folks without internet access.

Spark is your update so please let us know what you think of it and share it with your friends and family. Eventually we'll ask you to subscribe to Spark and you'll be able to receive it hot off the press as an email but for now issues around data protection means we will host Spark on our web page.

Thanks for reading and even more thanks for being part of our fast-growing and active Parkinson's community in Scotland.

Best wishes

Annie

Annie Macleod, Scotland Director, Parkinson's UK



Grants

For groups

Wee grants for wee groups is a new grant scheme from the Robertson Trust. There's a simple application process for grants of £500-£2,000. The grants are available for groups who work to improve the quality of life for people with physical and/or mental health issues and their carers.

The Robertson family business now operates as the global company Edrington. Glasgow-based, they are one of Scotland's largest companies and owner of several well-known whisky brands such as The Macallan and Highland Park.

And for individuals and families

Parkinson's UK has grants available of up to £1,500 to help people with Parkinson's and unpaid carers fund electrical items, respite care, specialist equipment or activities.

Applications are reopening this month. To find out more please visit our website.

If you need help and advice when considering applying for any grants please email Claire McNeill, Scotland Trusts and Statutory Fundraiser.

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Fighting Fit

Great to see our fantastic Research Fellow Julie Jones writing in the Press and Journal about her work to examine how exercise can be best structured to give the greatest benefit to people with Parkinson's.

It's well worth a read. There are now more than 500 regular activities for people with Parkinson's taking place around Scotland - many of them are exercise based. Dance, circuit training, Nordic Walking, Boxercise are all increasingly popular with new classes and opportunities springing up everywhere. To find out what's available near you check out the look up tool on our website and if you want to find out more contact Cathy Orr.



Cafe culture

Parkinson's cafes have really taken off over the last year with regular gatherings now established in Edinburgh, Glenrothes, Montrose, Alloa, Cowal, Dumfries and Cumnock.

And now Glasgow is in on the act too with a new cafe launching this month at the Saramago Terrace Bar in the CCA on Sauchiehall Street. The cafe is on from 2-4.30pm on the last Tuesday of every month (except December).

Please come along and if you want more information contact Dave Wilson on 07982 232741 or drop him an email. To find out more about Parkinson's cafes contact Chloe MacMillan.

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Fundraising news

Welcome Rebecca

Rebecca Ratcliffe has joined us to support the fundraising team in Scotland and Northern Ireland. Based at our Perth office, Rebecca will be involved in co-ordinating and promoting all of our fundraising events and activities. You can email Rebecca or call her on 0344 225 3724.

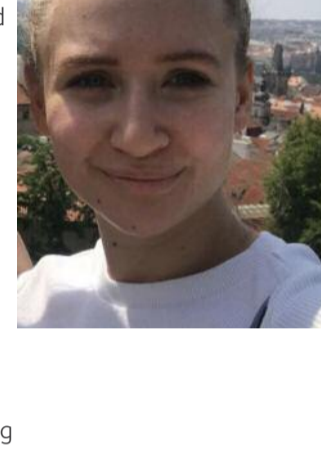
Fundraising via Facebook

Many of you will have noticed that Facebook Fundraising Pages are appearing as a new option for online fundraising. Although we of course will always look for ways of making it as easy as possible for our supporters to fundraise and donate to us; there is an important issue to note.

Tracking fundraising activity on Facebook is challenging and any funds we receive this way can't be targeted such as for research or for a local group.

We are working to sort this but for anyone wishing to donate or have their fundraising restricted should use Just Giving - good to hear too that Just Giving has removed charges from its platform this year.

Check out the diary dates for some great fundraising events and opportunities coming up in Scotland. And you can always email the team if you're looking for advice or help.



Feeding back

Everything we do is steered by you. That's just one of the reasons why we regularly issue surveys asking what you think.

Our annual 'Your life your services' survey is vitally important in tracking how people with Parkinson's feel about life and the care and support on offer. The 2019 survey has recently opened and we'd really appreciate you taking the time to tell us about you.

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Scotland Development Team

Many of the things you are reading about here have been sparked by or involve Scotland Development Team (SDT) volunteers. They also have a few specific projects that they are keen to drive forward.

Communications

The SDT is determined to improve how we communicate. They want to see more interaction between the community and the charity and much more opportunities for groups and volunteers to come together to share ideas and experience.

Spark is one of their initiatives and we want to include a **GroupXchange** section that gives space for every group in Scotland - including cafes and research interest groups - to highlight their activities and ask for advice or information from others. To make that happen we need all groups to nominate a 'Spark stringer' who can be the conduit through which information about Spark can be shared. To discuss more or nominate your contact please get in touch with Graham Kerr.

Families, friends and carers project

SDT members Linda Brown and Linda Corbett are working on a project to highlight the importance of information and support for families, friends and carers. The project follows a survey carried out by two Parkinson's groups in Devon which found:

- 1 in 3 carers feel their physical and/or mental health have been affected by their caring role
- 1 in 3 carers feel they have no one to talk to
- 1 in 3 carers feel their partners do not fully understand their feelings and the stress they are under
- 1 in 3 carers feel changes in their personal relationship with their partner
- 1 in 4 carers want more time to themselves

Feelings expressed by some include: anger, love, guilt, fear, helplessness, loneliness, stress, overlooked, sadness, disappointment, tiredness, worry, frustration and/or anxiety.

The number of information and support activities for families, friends and carers is growing within our Scotland group network, but they are not available everywhere. If you would like help developing support for families, friends and carers please email Chloe MacMillan or call her on 0300 123 3679.

Please remember our Parkinson's Local Advisers (PLA) and Helpline are here for families, friends and carers too. Don't hesitate to get in touch with the Helpline at 0808 800 0303 or find your PLA on our Scotland web pages.

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Campaigns

New Get it on Time campaign

We're taking action to make sure that everyone with Parkinson's gets their medication on time, every time when they are in hospital. We'll be publishing a new report in October, and asking everyone we know to collect signatures for our petition calling on the Scottish government to act. We also need people to come forward and lobby their local hospital and decision makers - we'll provide the information and support you need. Find out more about Get it on Time here. Please contact Tanith Muller for more details about how you can help.

Neurological conditions plan

Scottish government is expected to publish its action plan for neurological conditions (including Parkinson's) towards the end of the year. We want it to help us build on the good work that is already going on in NHS Parkinson's services, and improve the Parkinson's support available locally. For more information, please contact Tanith.

Patient transport

We've heard some disturbing experiences about public transport for people who can't drive or use public transport to get to hospital appointments, and we want to know how common poor experiences are. If you use - or have been refused - patient transport from the Scottish Ambulance Service, or a voluntary provider like the Red Cross, please could you let us know how it was for you? Please contact Tanith.

Advanced treatments

Most people with Parkinson's will be able to maintain a reasonable quality of life using standard treatments, including tablets and skin patches. But a small minority of people with advanced Parkinson's need more advanced and invasive treatments to manage severe symptoms.

You can find out more about apomorphine injections, deep brain stimulation surgery (DBS) and Duodopa on our website. We're trying to understand more about how doctors, nurses and people with Parkinson's decide whether an advanced treatment would be suitable for them, and issues like how long people have to wait for treatment. If you have experience of trying to access apomorphine, DBS or Duodopa, please contact Tanith.

New disability benefits

Disability benefits Attendance Allowance (for people of pension age) and Personal Independence Payment (PIP, for those of working age) are a lifeline for people with Parkinson's, along with Carers' Allowance. These three benefits will be transferred from the UK government to the Scottish government and Social Security Scotland from April next year. This means that there will be some changes over the next few years as everyone is transferred to the new Scottish system. The Scottish government's final plans are expected this Autumn, but the timetable for changes is as follows:

- 1 April 2020 - Scottish government takes over administration of benefits
- 2020 - 2024 transfer of Work and Pensions to Scottish Social Security Agency
- End 2020 - Scottish Attendance Allowance equivalent introduced for new claimants
- Early 2021 - Scottish PIP equivalent introduced for new claimants
- End 2021 - Scottish Carers Allowance introduced for new claimants

For more information, contact Tanith.

Get involved with social security

Scottish government is looking for people with experience of claiming benefits to join its social security experience panels. This is a volunteer role, to advise government about how the new system can work better through sharing your experiences. We'd really encourage people with Parkinson's and unpaid carers to consider joining, because your experiences matter - and it gives the Parkinson's community a voice in the process. You can find out more and apply here.

Accessing communication aids

Did you know that if you need help to be understood by others, you can access equipment and support to learn how to use it? Speech issues are very common for people with Parkinson's, and while speech therapy exercises can help more people, your needs in other supports too. Find out more about your rights in this Scottish Government article.

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Spark bites

Edinburgh lecture

Don't miss out on hearing from one of the pioneers of Deep Brain Stimulation (among many other achievements) at the 2019 Parkinson's Edinburgh lecture. Professor Andres M. Lozano from the University of Toronto will be discussing 'Advances in surgery for Parkinson's' at 7.15pm on 30 September at the Royal College of Physicians of Edinburgh on Queen Street. The event is being organised by our Edinburgh Branch. For more information about the lecture please visit their website. Admission to the lecture is free but by ticket only, on a first-come, first served basis. Book your place here.

Scotland Advisory Group

We're creating a new group to give us the direction the charity should take in Scotland. We've been blown away by the enthusiasm of people from all sorts of backgrounds who are keen to get involved with us. Watch this space and on Facebook for announcements about the group's members. We're aiming to have the group up and running before the end of the year and we'll keep you informed of progress. Email us if you have any queries about the new group.

Contact us

You'll find all the Scotland Team's contact details here. We've also produced a useful chart you can access here. If you don't have time to look it up or are unsure of who to contact then please email us.

More and more people are using Facebook to get in touch with us - keep up to date with us here.

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Yellow card!

The Healthcare and Healthcare Products Regulatory Agency (MHRA) want to hear from anyone who reports side effects of medicines or has problems with a medical device. They've tweaked their Yellow Card scheme to make it even easier to report your experiences to them. It is important that MHRA knows about any issues people have with their treatment. They've provided a couple of short videos - How to report a side effect from a medicine, and How to report a problem with a medical device. Find out more on the Yellow Card website.

First steps

Getting everyone's diagnosis is tough for almost everyone. As well as the shock of the news it can be difficult to cope with the amount of information and mis-information that's out there. That's why we've put together First Steps - a new course drawn from and delivered by people with Parkinson's.

First Steps has been tried and tested in Aberdeen and will also shortly be available in Glasgow. We aim to make it available across the country. The courses run on demand - we hold a waiting list and when there are enough people a course is set up. You can ask to be added to the list but most people are likely to be referred by their Parkinson's nurse or consultant around the time of diagnosis.

If you want to go on the course or are interested in becoming a First Steps volunteer facilitator in either Aberdeen or Glasgow please contact the First Steps team on 020 7963 9381 or by email.

Diary dates

28 September - Get your dancing trousers on for a brand new event in Perth - the Reel Fling Ceilidh.

29 September - Join thousands on the streets of Glasgow for the Great Scottish Run.

30 September - The annual Edinburgh Parkinson's lecture hears about the latest Advances in surgery for Parkinson's.

6 October - Raise funds and Nessie spot at the Loch Ness Marathon.

10 October - a unique chance to play a very special championship course and some great entertainment too at our Royal Troon Golf Day.

12 October - Join us at the Parkinson's UK AGM via the satellite link up we're hosting at the Stirling Court Hotel at the University of Stirling. Email us for more details.

20 October - another new event, enjoy our fun and friendly Afternoon Tea in St Andrews.

25 October - bringing our groups and volunteers together at the Working Together Gathering in Polmont. Everyone is welcome, please email us to find out more.

3 November - we're back in the granite city for another splendid Ladies Afternoon Tea in Aberdeen

17 November - Our Ladies Lunch in Glasgow is back for the fourth time - don't miss it!

20 November - We'll be at the Scottish Parliament to discuss our Get it on Time campaign with MSPs. If you're interested in coming along contact Tanith.

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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).

[Read our privacy policy](#)