

PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.

# NETWORK NEWS

Issue 50  
March 2016



*Network News* is a monthly newsletter for all branches and support groups within the local group network. If you have news you'd like to share with the network, please send your article or ideas for consideration to the email address below. The deadline for the May issue is Monday 11 April.

If you would like to receive your own electronic copy of *Network News*, please call the Local Networks team on **020 7963 9385** or email [groupnetwork@parkinsons.org.uk](mailto:groupnetwork@parkinsons.org.uk)

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On the cover: 'Walk for Parkinson's' at Brodie Castle 2015 by Highland Dreams Photography. See page 8 for more details.

# WELCOME



Hello everyone

I'm Jim, and I'm introducing this month's Network News.

I've been the Chair of the Rugby Branch for over 20 years. I joined in 1994 after my wife Gill was diagnosed with Parkinson's. Do take a look at page 6 to hear more about our group and how we support people affected by Parkinson's and raise awareness of the condition in our area.

If your group have recently been left a legacy, why not check out page 4 to see some of the different ways local groups are using their legacy funds and get some ideas about what's possible?

Don't miss page 9 where you can read about what Parkinson's UK volunteers said in last year's volunteers' survey. Find out more about what motivates our volunteers, how they like to learn and how valued they feel.

On page 10, Chief Executive Steve Ford talks about how the charity is progressing with the new strategy launched last year.

And, finally, take a look at page 7 to hear about the Mervyn Peake awards and the final call for submissions.

Have a great month

Jim Cave

# A LASTING LEGACY

Parkinson's UK received a staggering £12.7 million of its £30 million total from around 400 individual legacies in 2014. It's a figure that often surprises people. Local groups can play a big part in investing legacy money – from funding local schemes to donating to international research projects. There are lots of ways groups are ensuring legacy funds have a positive and lasting impact for people living with Parkinson's.

## Trailblazing

The Guildford and South Surrey branch are allocating £50,000 per year - from a large legacy left to their group - to provide financial assistance to people affected by the condition in the local area.

The group are keen that funds support people to 'take and maintain' control. They will promote the fund as widely as possible so those that aren't yet involved with Parkinson's UK also know the scheme is available for them. The scheme will first be run as a pilot and lessons learned will inform how a UK-wide scheme could look like in the future.

## Minding the gap

Over the past six years, the Worthing and District branch were fortunate to receive two major legacies totalling around £135,000. News of the most recent legacy came last year when the group was learning more about Parkinson's Links and our vision - to ensure everyone affected by the condition, at every age and every stage across the UK, has access to the support they need.

Rod Herod, from the branch, said: "We spent considerable time identifying local gaps in provision and where our funds might be best placed. Using this research, the committee pulled together a priority list for current and future projects and wrote a spending plan to monitor these projects over the next three years.

"We discovered people living north of our area miss out on many local activities because of difficult travel times. We're looking into investing funds to provide activities and support that people would like to see nearby."

## Adopt a project

Many local groups have also been incredibly generous in supporting research through legacy funds. Over the last two years, 70 local groups have supported vital Parkinson's research through our 'Adopt a Project' scheme - raising more than £250,000.



The scheme gives local groups, who want to donate £2,000 or more, the opportunity to support a specific Parkinson's UK-funded research project of their choice and to follow its progress.

To find out more, contact Anna Louise Smith [alsmith@parkinsons.org.uk](mailto:alsmith@parkinsons.org.uk) or call **020 7963 9398**.

**If your group have been left a legacy, there are many different options available. If you'd like to fund something locally, your Local Development team and staff team will be happy to discuss where there is a real need for activities and services, and the kind of developments that you could help to fund through your legacy spending plan.**

# LATEST NEWS

## Promote your event with online map



Our map highlighting events taking place across the UK for Parkinson's Awareness Week 2016 is now on our website.

If you're organising an event between 18 – 24 April, or even the week before, let us know and we'll ensure it's included on the map. It's a great way of drumming up more interest.

David Salmon, Marketing Manager, said: "Local events are the perfect opportunity to raise awareness of Parkinson's and support available. Many of you have told us you engage with the wider public during your events, which is a crucial part of getting more support for the work we do."

### To add an event:

1. Visit [parkinsons.org.uk/pawevents](http://parkinsons.org.uk/pawevents)
2. Enter the event details on the online form and click the 'submit' button at the bottom of the page
3. Provided you've given all the right information, your event will be viewable in two working days

If you have any questions or comments, email [web@parkinsons.org.uk](mailto:web@parkinsons.org.uk)

## Share your experiences



Help us shape our work by sharing your experiences of Parkinson's. The voice of people with Parkinson's is at the heart of everything we do and your stories could improve how we do things. There are different ways you can get involved:

- Take part in focus groups to give views on existing or potential projects
- Attend meetings on how we deliver the goals for our five-year strategy
- Become a mystery shopper to help assess our customer service standards
- Become a taking control champion, supporting other people to feel more in control of their Parkinson's

Travel is not required for all roles. For more information, contact [involvement@parkinsons.org.uk](mailto:involvement@parkinsons.org.uk) or **020 7963 9324**.

## Smartphone application



Your local group may have been approached by an organisation called Beats Medical Groups, which is offering a treatment application for smartphones and tablets to help people with Parkinson's improve their walking and mobility.

We are reviewing and assessing several applications from different suppliers at the moment and Parkinson's UK is not in a position to endorse any particular applications at this time. Local groups must not fund the purchase of this or any other application and any group member who chooses to purchase this application does so wholly at their own cost and assessment. It is worth noting that the Beats Medical application comes at a cost, while several other applications are free of charge.

# BOWLED OVER



The Rugby Branch warmly welcomed *Network News* to their weekly bowls – where we enjoyed getting to know members over some pretty spirited games.

It's a big year for the branch as they approach their 25<sup>th</sup> anniversary in May. We found out more about how the branch supports people living with Parkinson's.

David, diagnosed with Parkinson's in 2006, said: "I like playing bowls here because the game feels non-confrontational. We've adjusted the rules so everyone gets a turn to throw the jack – not just the person who wins."

The game has a very friendly set-up but that certainly doesn't quash competitive spirit. Bernie, who played cricket for 39 years before he was diagnosed, said: "I enjoy coming along every week because it's one of the few sports I can still play. It keeps me fit and I've still got an appetite for competition."

This is just one of many activities organised by the branch. The packed schedule includes conductive education, a 'communicating with confidence' course and singing sessions.

So, how has the branch found out what people affected by Parkinson's really want?

Gill, who has Parkinson's and has been part of the group for 20 years, said: "We have a good relationship with the Parkinson's local adviser and also chat to people we meet and at group meetings to find out what's important.

"Some people don't want to take part in group activities and that's okay."

## Supporting carers

The group have recently set up a support group for carers. Margaret, Group Treasurer who cares for her husband David, said: "As carers, a few of us were quite naive at first and didn't necessarily see ourselves as carers. Some people, for example, didn't know they could sign up to the carer's register at the GP. This group helped us to see we have something in common and could support one another to get more help. We recently had a visit from the care commissioner for Warwickshire who came to hear our views to help shape legislation impacting carers."



## Raising awareness

The group were clearly passionate about raising awareness of Parkinson's in the wider community. They were hard to miss - dressed head to toe in cyan - vibrantly raising the profile of the charity.

Chairman Jim Cave added: "During Parkinson's Awareness Week, we use an empty shop in the local shopping centre to set up information stands and posters. It works really well because you're at the heart of the community."



The group have also been involved in training at care homes, and more recently, they've been along to a training day for young doctors.

## Rising to the challenge

The group feel very fortunate to have Beryl Emery, who won the British Empire Medal for fundraising in 2012, as their main fundraiser.

Along with three other ladies, Beryl formed the group back in 1991 and has remained an active member of the branch ever since - even taking the Chair role for three years in 2003.

However, despite having Beryl's valuable expertise, raising funds can often be a challenge for the group. Margaret said: "The difficulties lie in the need to constantly be creative and keep people motivated.

"We're trying to come up with less labour-intensive ways of raising money. It might help to have younger volunteers to share their expertise in setting up a Just Giving page, or using mobile phone apps to raise money. It's something we'd like to look at."

If you would like to get in touch with the Rugby branch, contact Jim Cave on 01788 573 399.

# FINAL CALL FOR ENTRIES



Do you have a passion for creative arts? If so, now is your final chance to enter the Mervyn Peake Awards 2016.

This year marks the 15th anniversary of the awards, which recognises the creativity of people with Parkinson's. You can enter your artwork in the following categories: Art, Photography, Poetry,

Books and 'Inspire' – our themed multimedia category. In the 'Inspire' category only, you can also enter a short film or a piece of music. The winners and other selected entries will be showcased at an exciting exhibition in Central London this summer. Closing date for entries is Thursday 31 March 2016.

For full details and to download an entry form, visit: [parkinsons.org.uk/mervynpeake](http://parkinsons.org.uk/mervynpeake)

# USE YOUR HEAD

This Parkinson's Awareness Week we are asking everyone to take part in **Use Your Head** on **22 April 2016** to raise money and support people affected by Parkinson's. You don't have to be part of a school or workplace to get involved - you can do it yourself, or get your family, friends or local group together.

## Get involved

Anyone can get involved by making a small donation to wear something smart, stylish or downright silly on their head for a whole day. Ask your friends and family to sponsor you or get them to join in too.

Whether you wear a funny hat or don some bunny ears, there's something everyone can do.

## Download your pack now

Your 'Use Your Head' pack includes:

- hat templates
- fundraising ideas
- posters
- information resources
- handy hints and top tips
- press release templates



To find out more and to download your pack, go to [parkinsons.org.uk/useyourhead](http://parkinsons.org.uk/useyourhead)

# WALK FOR PARKINSON'S

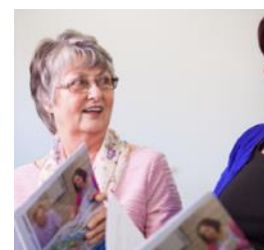
In 2015, an incredible 2,500 people signed up to our walks and raised an outstanding £265,000. Join us in 2016 on one of our many Walk for Parkinson's events taking place around the UK and help us have another successful year. Money raised from our walks will go towards our work supporting people affected by Parkinson's.

Walkers will have a choice of shorter and longer distances and with locations including some of the UK's most beautiful parks, countryside and cities - there really is something for everyone. Registration costs £10 for adults and £5 for under 16s.

We'll provide a free Walk for Parkinson's t-shirt and fundraising pack. We'll also be there on the day to cheer you on and present you with a medal. Go to [parkinsons.org.uk/walks](http://parkinsons.org.uk/walks) to find a walk near you, to register online or to download a booking form.

# SELF-MANAGEMENT DIARY DATES

Don't forget the dates and locations of the next self-management groups are now available at [parkinsons.org.uk/selfmanagement](http://parkinsons.org.uk/selfmanagement). You can also contact the Self-Management team at [selfmanagement@parkinsons.org.uk](mailto:selfmanagement@parkinsons.org.uk) or **020 7963 3924**. Some groups are filling up, so take a look soon.





# VOLUNTEER SURVEY SNAPSHOT

Thank you to all those who completed our volunteer survey in 2015. Together they've helped us to find out more about who our volunteers are, what motivates them, how they like to learn and areas where we can improve. Take a look at this snapshot from the survey.

## What motivates our volunteers?

- Unsurprisingly, most volunteers told us they help out because they want to improve services for people with Parkinson's.

"I initially got involved to support my husband who has Parkinson's. Following poor hospital care, I am now on a mission to try to ensure others do not go through what we have in the past 12 months."

## How do our volunteers want us to communicate with them?

- 88% of respondents told us that they prefer to be contacted via email and 84% said they use the internet every day.



We are reviewing the way we communicate with our volunteers. In recent years, we've developed more varied ways that people can get involved, so the communication needs of volunteers are more diverse than they used to be.

## How do our volunteers like to learn?

- Most respondents said they prefer to learn through workshops with other volunteers.

This year, we are creating a new Volunteer Learning and Development programme, which means you'll be able to find out about optional training and learning opportunities more easily and access new training that you have asked for. Wherever possible, we will also aim to make this sociable so you can meet and learn from other volunteers.

"Bringing people together gives the opportunity for people to learn from each other."

## How supported and valued do our volunteers feel?

- 85% of respondents said they know who to go to if they need support
- 75% said that they felt their contribution was recognised
- Local group volunteers told us that they feel the workload is too much

We are introducing a new programme focused on valuing volunteers during 2016 to ensure that they have the tools and support they need to fulfill their roles, understand the impact their contribution is making to people with Parkinson's and are recognised in ways that are meaningful to them as individuals.

If you would like to find out more, please get in touch with the Volunteering team on **020 7963 9328** or email [volunteering@parkinsons.org.uk](mailto:volunteering@parkinsons.org.uk)

# WE'VE MADE A GREAT START



Chief Executive Steve Ford receives charity leader of the year award.

Bringing forward the day when no one fears Parkinson's underpins our five-year plan - focusing on three themes: better treatments and a cure - faster, empowerment to take control, and quality services as standard.

One year in, we chat to Chief Executive Steve Ford about how we're getting on with turning this bold and ambitious strategy into reality.

Steve said: "We've already made a great start. Last year, we continued to grow our income and increase our profile. We restructured our teams on the ground so they are better geared to provide high-quality support and services to people with Parkinson's across the UK."

This is one step closer to putting an end to the postcode lottery we know so well. Steve continued: "We launched the UK Parkinson's Excellence Network—bringing together health and social care professionals to transform the care of people with the condition by equipping them to influence changes at both national and local level.

"The introduction of the Critical Path for Parkinson's Consortium could mark a definitive change in the way clinical trials for potential new Parkinson's treatments are carried out. We'll be working with international researchers, regulators and drug companies to get treatments that work to people sooner."

Parkinson's Links – a list of support that people living with Parkinson's want to see in their local area from mutual support to therapeutic activity – has been well received. Steve said: "I'm really pleased how this has captured the imagination of local groups and look forward to working with you on how this will begin to meet the needs of more people locally."

## What's in store for 2016?

Steve said: "We'll soon have the results of the Parkinson's Audit and Your life, Your Services survey so many of you kindly took part in. This will give us the biggest ever dataset about the quality of Parkinson's services in the UK. This crucial information will enable us to target priorities and gaps you identified.

"We'll press on with our drug discovery programme – where we'll be working closely with research organisations to ensure scientific discovery translates into treatments. We'll continue to further embed our newly structured local teams so we provide the best possible service and support locally. And of course we have to pay for all this and our Fundraising teams have some important, ambitious plans to achieve this."

## A big thank you

Steve added: "Local groups play a vital role and I want to thank you for selflessly giving up your time to dedicate to the cause and helping people at local level."

# GROWING STRONGER TOGETHER



We're thrilled to announce that Parkinson's UK has been chosen as a full-time beneficiary partner of the National Gardens Scheme. In three successful years, as its guest charity, the partnership has raised an incredible £522,000 for Parkinson's nurses, including matched funding.

You can support our partnership by simply getting out and exploring one of the stunning gardens near you. The 30 acres of gardens at Spetchley Park in Worcester is known as one of Britain's best kept secrets. With wheelchair access, tea and cake and plants for sale, it's the perfect place to visit with your local group.

To find out more about the partnership, and to find an open garden near you, visit

[parkinsons.org.uk/ngs](http://parkinsons.org.uk/ngs)



## EASTER TRAVEL

If you're planning a last minute Easter break, travel insurance is essential – but it can be hard to find. We've teamed up with Unique Insurance to arrange cover for people with pre-existing medical conditions such as Parkinson's, plus their carers and family or close friends. Find out more at [parkinsons.org.uk/insurance](http://parkinsons.org.uk/insurance)

## RECYCLE YOUR OLD STAMPS



Been collecting stamps for Parkinson's UK? Now you can turn them into money.

Whether your stamps are old or new, every donation helps. So, spread the word and start recycling today. Simply clip your stamps, leaving a small border, and send them to: **Parkinson's UK, PO Box 6107, Stromness KW16 9AB**. For more information about recycling stamps, visit [parkinsons.org.uk/recycling](http://parkinsons.org.uk/recycling) or email [corporate@parkinsons.org.uk](mailto:corporate@parkinsons.org.uk)

Every hour, someone in the UK is told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control- from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day  
when no one fears Parkinson's**

Parkinson's UK

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Free confidential helpline **0808 800 0303**

(Monday to Friday 9am–7pm,  
Saturday 10am–2pm). Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

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