

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

NETWORK NEWS

Issue 48
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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 March issue is **Monday 8 February**.

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

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On the cover: David and Hazel campaigning for people living with Parkinson's

WELCOME

Hello everyone,



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

I've been a committee member of the Newport Branch for 10 years. In 2013, I was involved in a joint campaign with staff from the Parkinson's UK Wales office, and other local group volunteers, to create a new Parkinson's nurse role in our area. Do take a look at page 8 to hear more about the toolkit and how it can help you use your experiences and campaign for something you're passionate about.

A few words from someone with Parkinson's can carry far more weight than a presentation from a paid employee when it comes to negotiating extensions of NHS and Social Care services. I'm happy to have provided that voice on several occasions.

If you're looking for a new challenge this year, why not check out some of the opportunities on pages 6 and 7? You'll see ways you can channel your creative energy and make a positive impact.

Don't miss the story on page 4 about a new awareness initiative. Find out how you can get involved and help customer-facing organisations to better understand the needs of people with Parkinson's.

And, finally, take a look at page 9 to hear about our brand new volunteer induction and how it can support new volunteers.

Have a great month,

Jenni McCabe

THE CUSTOMER KNOWS BEST

Everyday activities like taking public transport, shopping or meeting friends at the pub are things many people take for granted. For a lot of people with Parkinson's, this can be challenging because they often have to respond to negative attitudes of staff and customers unaware of what the condition means.

We're piloting a new awareness initiative with customer-facing organisations. This includes a short awareness session that companies can use as part of their existing training programmes. The aim of the session is to give customer-facing staff a basic knowledge and understanding of Parkinson's, including practical ways they can better support customers and colleagues with the condition.



Employees at a Fuller's pub in Guildford took part in our new pilot

Diane Kay, diagnosed three years ago, has encountered some negative experiences as a customer while shopping, including being accused of being drunk in a supermarket. When she learned of this new initiative, she was delighted: "Better awareness to me personally means I would feel that I was not being looked at, and treated, as an inconvenience. It's not a nice feeling when you're highlighted as being different. The more training and education that is given will make the lives of everyone that has Parkinson's much easier.

"I think the new initiative is fantastic and it's proving that having a better level of awareness has a positive impact on customer care. It is also showing us that there is a willingness to learn about Parkinson's, which is encouraging."

The Swindon and District branch have been busy promoting this initiative in their local area. Chair Dave Logan said: "This ensures people affected by Parkinson's can continue to get out and about in the community and lead a meaningful life. We are pleased to have been able to help and support Parkinson's UK's Marketing team."

The pilot ends on **26 February 2016** and we need your help to spread the word. If you know of any retail, hospitality or transport companies in your area who would be interested in taking part in the pilot – please signpost them to parkinsons.org.uk/yourworkplace or you can order the new pocket-size hand-out from CDL 'PK0368 Workplace awareness'.

BACK TO BASICS

For this year's Parkinson's Awareness Week (18-24 April), we're aiming to shout a little louder, telling everyone in the UK who we are as a charity and how we can help.



In 2015, we surveyed the general public and found nine out of 10 people do not know what we do which makes it difficult for them to support us. We also know there are still people with Parkinson's who don't know how we can help. We want to change that this year by raising awareness of who we are, what we do and how we make a difference to people with Parkinson's.

What you can do

[Order materials for your events](#)

We've produced some free materials you can use if you're running an event. These will be ready to order from 1 February. Stay up to date at parkinsons.org.uk/awarenessweek

[Share your story and complete our survey](#)

Over the last year, we've heard from people with Parkinson's that telling loved ones, friends and colleagues for the first time about their diagnosis can be one of the hardest moments. Whether it's been a struggle or a relief to share your diagnosis, we want to hear your experience. Please share it with us by filling out our short survey at parkinsons.org.uk/pawsurvey. Telling us about your experience will help shape how we can create awareness around the realities and challenges of life with Parkinson's.

TARGETING PARKINSON'S THROUGH DARTS

We're delighted to announce we've been chosen as the Professional Darts Corporation's charity partner for 2016.



Corporate Relationships Manager Ian Savage said: "The partnership is aiming to raise £100,000. It's a fantastic opportunity to engage a large number of people and raise funds and awareness of the charity. We want to have a strong presence at each UK tournament venue in 2016, from bucket collections and darts-based games, to talking to darts fans about the partnership."

How can you help?

We need teams of volunteers to attend UK tournaments, including venues in Milton Keynes, Newcastle upon Tyne, Leeds, Aberdeen, Exeter and Minehead. As well as raising money and awareness, our volunteers will have the opportunity to watch live action. The majority of tournaments take place in the evening, between 6.30pm and 11.30pm, with some afternoon sessions, between 12.30pm to 5pm.

Whether you're interested in volunteering yourself - or know someone who might be - we'd love to hear from you. Simply contact our Volunteering team on 020 7963 9328 or volunteering@parkinsons.org.uk

NEW YEAR, NEW CREATIVITY

The beginning of the year brings a spirit of fresh starts and new opportunities. Are you looking for a new project to kick off 2016? Here are creative ways you can flex your artistic flair.

Showcase your creativity

The Mervyn Peake Awards are the perfect opportunity to share your artistic skills with others. Now in its 15th year, the event recognises the creative talents of people with Parkinson's in memory of the late Mervyn Peake, a much-admired artist and writer who had Parkinson's.

This year, the categories are:

- Art
- Photography
- Poetry
- Books
- 'Inspire' – themed multimedia category including film, and for the first time, music

You can even enter one piece of work in each of the five categories. Selected entries will be exhibited online and at an event in London, including an awards presentation for the winners.



Alan Osborne was highly commended in the Mervyn Peake Awards 2015 photography category for Autumn Glory – The Golden Hour (pictured above). He said: "I get a buzz from being able to create excellent art, and for me, Parkinson's actually heightened my creative skills and talent. The Mervyn Peake Awards gives me the opportunity to display these skills."

Find out more

You can download your entry form and read about last year's winners by at parkinsons.org.uk/mervynpeake. To request an entry form, please call **020 7963 3940** or email mervynpeake@parkinsons.org.uk

Please send your work to us with your entry form and fee of £6 per entry, per category between 1 and 31 March 2016. Please note that you have only a month to enter, so make sure you give yourself enough time to create your masterpiece. You can find further details on how to enter your piece on the entry form.

Needles at the ready

Looking for a new project to do in the cold winter nights? Why not join us and knit, crochet or craft some brooches to support Parkinson's UK?

As part of our partnership with one of the UK's largest all female voluntary service organisations, Inner Wheel, we will be selling brooches to raise funds for Parkinson's UK. But we need your help to create as many brooches as possible to make the most of this great opportunity.



We've put together some patterns to get you started but feel free to be as creative as you like with your brooches. Here is one of the patterns.

Knitted flower brooch

You will need:

Oddments of double knitting wool
4mm knitting needles
A bead or button
A brooch or safety pin



Method:

- Cast on 30 stitches
- Knit 4 rows in stocking stitch, ending after a purl row
- Next row: knit 1, (next stitch, knit into front then back of stitch to increase) repeat to last stitch, knit one
- Knit 3 rows stocking stitch beginning with a purl row
- Next row: knit 1, (next stitch, knit into front then back of stitch to increase) repeat to last stitch, knit one
- Cast off loosely purlwise
- The work will form itself into a spiral. Wind it fairly tightly and sew the rows together to form a rose shape
- Finish with a bead or button in the centre of the flower
- Sew the brooch or safety pin to the back of the flower and sew in all loose ends.

For more information and patterns, visit parkinsons.org.uk/innerwheelbrooches or contact us at fundraising@parkinsons.org.uk or 020 7963 3912.

Can you imagine?

'What I See When I Look At' is a project started by Graphic Designer Robert John aimed at re-engaging us with the things we see everyday.

Robert's father lived with Parkinson's for many years before he passed away. He developed Parkinson's dementia and began seeing things which were not visible, yet they were so real to him. He could see these things, smell them, even touch and feel them. This made Robert think about what our concepts of reality are and what we choose to see. This project asks us to use our imagination, and show everyone what we see in the world around us.

The show is the first of its kind and features the work of many different artists. If you would like to see the show, you are welcome to attend one of the exhibition days at the GX Gallery in London, Camberwell, between 27– 30 January. For more information, email rob.john@whatisewhenilookat.com



CAMPAIGN FOR CHANGE

Want to see changes made for people living with Parkinson's in your local area? Try your hand at campaigning – and our new toolkit will give you all the support you need.

The Campaigns Toolkit features information on how to plan your campaign, the type of action you could take — from writing letters to organising publicity stunts. It even gives suggestions on keeping motivated and celebrating successes.



Local group action sees results

Sue Randall and her husband Malcolm – who's been living with the condition for six years – campaigned for more nurses and the local area is reaping the rewards. They joined forces with other local groups and, following nine months of relentless action, they saw two new Parkinson's nurses recruited.

Sue, Chairman of Woking and Weybridge branch, said: “We only had one Parkinson's nurse, who is fantastic, but couldn't possibly handle the volume of people with the condition in the area. I surveyed branch members and it revealed worrying results. Some people hadn't seen a Parkinson's nurse for years and were self-medicating.

“We teamed up with other local groups in the area and asked everyone to write letters to the local Clinical Commissioning Group. We soon found out that service provider Virgin Care had been allocated budget to recruit four Parkinson's nurses but we only had one.

Two Parkinson's nurses recruited

“They said it was difficult to attract nurses to the role due to lack of London weighting. Our campaigning led to Virgin Care putting in much more effort into the recruitment — and two nurses have since come on board. We met up with Virgin Care several times and Paul Maxwell, who manages their nurses, even came along to a local group gathering.

“If you don't live with Parkinson's, it's difficult to understand the suffering and help people need. Parkinson's is different for everyone. There's only one person with similar symptoms to my husband in our group.”

If you want to see results in your area, rally your local group into some campaigning. You can find the toolkit on our [website](#).

A WARM WELCOME

One of the best ways we can help volunteers love their role and feel proud to represent Parkinson's UK is to ensure they get a consistent, warm welcome when they join us.

Laura Elson, Volunteer Learning and Development Manager, introduces the new Volunteer Induction and how it will give all our volunteers what they need to start their journey with us.



Laura said: "Volunteers are vital to Parkinson's UK. The launch of this new induction provides a really comprehensive orientation to Parkinson's UK, which will equip our volunteers with vital skills and knowledge they need to help improve life for everyone affected by Parkinson's."

The induction is made up of four modules, which can be accessed online. The modules cover the following topics:

- [What is Parkinson's?](#)
- [How does Parkinson's UK support people?](#)
- [Volunteering practicalities](#)
- [Managing your volunteering](#)



Teamwork

Laura said: "Volunteers have played a huge part in writing this induction. They have helped to generate ideas for engaging activities and tested the material all the way through its development."

David Little, Volunteer Learning and Development Adviser, helped to shape the induction. He shared his thoughts on the final product: "As a volunteer for Parkinson's UK, I found it refreshing to have such a thorough professional induction. It gives people a good grounding in what the charity is and what it stands for."



Time for a refresh?

If you have been volunteering for a number of years, you too are very welcome to work through the modules online. Whether you'd like to use this new year as an opportunity to refresh your knowledge, or view the hard work fellow volunteers have put in, please do check out the induction online at parkinsons.org.uk/volunteerinduction

If you have new volunteers in your group, please encourage them to talk to their staff contact on modules that will help them settle into their role.

The Volunteering team would love to hear your thoughts, so get in touch with them on volunteering@parkinsons.org.uk or 0207 963 9328.

DRUG DISCOVERY

Getting treatments to people with Parkinson's quicker and moving closer to a cure is one of the key aims of the new strategy. In a new role to Parkinson's UK, Jan Kulagowski is leading a drug discovery programme – and is keen to explain what the aims of the work are.

He said: "It's all about changing the research process so we can get nearer to bringing something relevant to patients quicker. We've been funding scientific research for many years – but sometimes it's been in areas that are very important but the research is at an early stage. Valuable work, but essentially, you're a long way from a drug that might work for people.

"Although having an in-house drug discovery programme would mark a significant change, it's complementary to this existing research funding. We will be working much more closely with research organisations to ensure that scientific discoveries translate into treatments."

Jan and the Research team are currently trying to find the first project to work on, as well as putting together an advisory panel of people with the right industry experience – particularly in developing academic ideas into drugs.

He said: "We're taking time to get the right project. We want to make sure we're spending the funding we get wisely."

A detailed proposal is in preparation and should be approved in the spring, so the first of our drug discovery projects may be starting soon.

Fundraising across the UK will initially support the work – though the hope is to produce assets that can generate a return on investment through licensing or sale. Of course, any income will go straight back into our work supporting people with Parkinson's.

Jan is well aware of the potential implications of headway that is made through this new way of working.

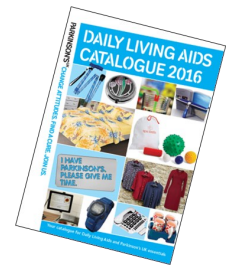
He said: "From meeting people with Parkinson's, it's clear they're frustrated by their condition and lack of progress so far in improving treatments. But they are also very interested in research and what can be done. Now it's up to us to give them more confidence that we're moving in the right direction, quicker."



If you would like to find out more, get in touch with the Research team at Research@parkinsons.org.uk

MAKING LIFE EASIER

This January, look out for our new Daily Living Aids catalogue. It's packed full of your favourite Parkinson's UK essentials and some brand new ideas too.



'I have Parkinson's' badge
PAUK569 **£2.50**

Adaptive clothing from
£37.50

Mobile device holder
PAUK1076 **£40**

Vibrating watch PAUK913
£45

Voice amplifying phone
PAUK1078 **£40**

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If you're selling unwanted items on eBay, you can choose to donate a percentage of your profits to Parkinson's UK. Simply select the 'advanced sell' option when uploading your products, and choose Parkinson's UK as the charity to receive between 10 to 100 per cent of your proceeds.

You can also support us by purchasing items that are being sold in aid of Parkinson's UK. Our [eBay for Charity](#) page lists all of these items in one convenient place. For more information, please contact trading@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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London SW1V 1EJ

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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