

NETWORK NEWS

THEME:
The difference
you make

FEBRUARY 2017 | ISSUE 57

SUMMER DAYS

Get your garden festival ready



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

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Send your stories to localnetworks@parkinsons.org.uk
 Any questions? Call 020 7963 3929.



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Hello



Hello and welcome to the February *Network News*.

This month's issue celebrates all our Parkinson's UK local groups and the difference you make. Thank you for your commitment and passion for supporting people affected by Parkinson's.

My grandfather Bob started showing early signs of Parkinson's in his 50s. It began with a tremor in his arm, followed by a range of symptoms that made walking and talking increasingly difficult.

After his diagnosis, he joined his Parkinson's UK local group and thoroughly enjoyed the activities and outings, as well as the support that came with it.

Inspired by my grandfather, some Ashfords LLP colleagues and I nominated Parkinson's UK as our Charity of the Year for 2016. We did everything we could – from running, swimming and cycling to baking, singing and quizzing – to raise more than £150,000 for the charity.

I am so proud to be a part of Ashfords and to have had this opportunity to raise vital funds and awareness for such an important cause. Happy reading and keep up the good work!

Best wishes

Lucy Nash
 Solicitor
 Ashfords LLP

New locations for self-management groups

New self-management groups have been announced on our website, and include locations such as Derby, Sheffield, Cardiff, Basingstoke, Sunderland and Glasgow.

Designed to help you navigate your life with Parkinson's, our self-management groups are for people with the condition, plus their partners and carers. There are many benefits to joining – boosting confidence, helping people feel less alone and creating a personal action plan for doing specific things, such as exercise and other therapeutic activities.

The groups will take place from April to the end of May 2017. They're free to attend but you need to book a place in advance.

OVER TO YOU

For the list of locations and to register your interest, please visit parkinsons.org.uk/self-management. If you want to find out more, or talk about whether our self-management groups would be right for you, email selfmanagement@parkinsons.org.uk or call 020 7963 3924.



New options for transferring funds

Our transfer form is getting an update – with two new options for where you'd like funds from your group to go. In addition to any transfers already planned for 2017, you'll soon be able to transfer money to support Parkinson's Links or to a specific local development team too.

Local development teams work in each area with local groups to develop access to Parkinson's Links UK-wide. They collect information about what support and activities people can access nearby, to find out where the gaps are and work to fill them. This includes those provided by local groups, and within the community. Many groups have been talking about local priorities while planning and budgeting for 2017. The new options on the form will enable you to transfer surplus funds or budgeted money to support Parkinson's Links.

OVER TO YOU

Find the new transfer forms at parkinsons.org.uk/treasurers

Shining stars of services

We're delighted to announce the finalists for the UK Parkinson's Excellence Network Awards – celebrating outstanding services for people with the condition.

We asked you to tell us about the services that made a big difference to you and shortlisted the seven best entries. Award-winning journalist and presenter John Stapleton will host the awards on Friday 3 March. He says: "Showcasing examples of great services is cause for celebration for all who want those with Parkinson's to receive high-quality care."

The finalists include the Heart of England Foundation Trust Parkinson's Quality Improvement team, and Cardiff and Vale University Health Board Parkinson's Clinic.

OVER TO YOU

Find out who the other finalists were and the services these organisations provide at parkinsons.org.uk/news

VICTORY OVER ATTENDANCE ALLOWANCE

The future of Attendance Allowance – a lifeline for people living with Parkinson’s – has been saved thanks to Parkinson’s UK campaigners in England.

The disability benefit for people aged 65 or older came under threat when the government announced, in December 2015, it would invite local councils to pay for it. This would have had catastrophic consequences for people with Parkinson’s in England who need it to manage extra costs in future.

The UK government’s proposals on devolving Attendance Allowance to local authorities only applied to England. Arrangements for Wales and Northern Ireland were unclear, and in Scotland they were unchanged.

A big difference

Phil Reynolds, our Policy and Campaigns Adviser, explains: “Attendance allowance isn’t a huge amount at £55 to £80 a week. It isn’t means tested but people who claim tend to have fewer savings – so it can make a big difference with energy bills or shopping.

“Devolving responsibility to local authorities would’ve been one of the worst things to happen and had huge implications, including tougher eligibility rules. We sprang into action.

Crucial campaigning

“We gathered evidence on what it would mean for people with Parkinson’s. Thanks to the

fantastic work of Parliamentary and Public Affairs Adviser Natasha Burgess, we met 25 MPs at the Houses of Parliament. We explained what this would mean, and received cross-party support.

“As Co-chair of the Disability Benefits Consortium, we co-ordinated a strategy with other charities. We made a list of MPs we wanted to reach and took Attendance Allowance to the party conferences. MPs were aware of the devolution proposal but not that Attendance Allowance was being sneaked in. We asked campaigners to write to local councils and talk about the benefit’s value to people with Parkinson’s.”


Councillor Charles Nightingale, Cambridge Branch Chair, says: “It was very rewarding being part of a powerful campaigning team at the conferences. Thanks to all the MPs who gave us their time and support.”

Result!

Phil says: “We sent our response to the consultation before Christmas. We met the minister in January to list our concerns. On 19 January, we found out Attendance Allowance would continue to be managed by central government.”

Campaigner Suzette Shahmoon, whose husband Ronnie has Parkinson’s, adds: “We won! We couldn’t be more grateful to Parkinson’s UK for giving us the opportunity to feel like we’ve made a real difference. It feels amazing!”

OVER TO YOU

Want to get involved in our campaigning? Email campaigns@parkinsons.org.uk 

REACHING OUT UK-WIDE

Our theme for the issue is the difference you make. And it's definitely apparent in the amazing work you do at the local groups – reaching out to people with Parkinson's in your communities.



Caithness Support Group with second year pupils from Wick High School

We spoke to local groups across the UK that have been doing particularly good work attracting people from far and wide. And what we heard was nothing short of inspiring.

Caithness Support Group

This group in the far north of Scotland, close to John O'Groats, struck on the idea of alternating their meetings between the towns of Thurso and Wick, more than 20 miles apart. This way, they'll now reach as many people in the dispersed rural community, stretching across Caithness, as they can. Sandy Mowat, Treasurer of Caithness Support Group, whose husband Jimmy had Parkinson's, says: "The group previously met

in Thurso only. Sharon, the Parkinson's nurse specialist based in Inverness, let the east side of the county know we're starting up meetings in Wick too. We held a meet-and-greet there at the end of last year and had a Christmas lunch together.

"Our hope is that people will go to both meetings and we'll do activities together. It's a case of 'safety in numbers' – talking makes things better. We have a lot of carers and they also get the chance to talk to each other."

At the time of writing, the February meeting had just taken place in Wick, with a speech therapist coming along to speak to the group.

Northampton, Daventry and Towcester Branch

This branch covers three towns in Northamptonshire, with a branch meeting in Northampton once a month. However, the branch offers a range of support and activities in the area.

There's a group for people with Parkinson's and carers jointly, an Exercise and Wellbeing Group, and a Younger Person's Group. The Tulip Centre offers different activities from exercise to singing to mutual support. So that more people in Northamptonshire can have access to and benefit from these activities and support, the branch will

work with its local development team to look at how we develop this centre and services further.

John Peachey, Chair, explains the branch ethos: "You might think you know what people want but you don't until they tell you." This was the reasoning behind the survey the branch sent out to members. "People asked for a buy-and-sell column in the branch newsletter, letters to the editor, and a music group.

"We don't want people to see us as a closed club. Kettering, Corby and Wellingborough all have branches and we keep in touch."



John Peachey receiving a £600 cheque from the Northampton East Salvation Army Band and Songsters, who held a festival concert in aid of the Northampton, Daventry & Towcester Branch in October 2016

Cardiff Branch

Over in South Wales, a brilliant new communication support project is up and running, thanks to our Cardiff Branch volunteers and members. More than 80% of people with Parkinson's experience a voice or speech disorder, meaning they're less likely to engage in conversation and often become more isolated as a result.

Parkinson's UK Wales worked closely with speech and language therapists in Cardiff and Vale Health Board and Cardiff Metropolitan University to develop the Live Loud! sessions. People with Parkinson's can practise using their voice and develop strategies to improve it in a fun and supportive environment with others experiencing similar difficulties.

Live Loud! couldn't have happened without the generous support of Cardiff Branch, who pledged to fund Live Loud! as part of their 2016 financial planning. They covered venue and refreshment costs, as well as training and 'out of pocket' expenses for project volunteers. Fortnightly communication support sessions started in November 2016.

Already, 30 people with Parkinson's have been referred to the Live Loud! project, following assessments with speech and language therapists. Thanks to Cardiff Branch's outstanding commitment, support and belief in the project!



Members of the Live Loud! team

Omagh & District Branch

In Northern Ireland, the Omagh & District Branch has developed an extensive exercise programme for members and non-members with Parkinson's.

Chair John McFarland approached the local leisure centre. He says: "Fortunately, someone there specialised in movement disorders. First, we started an aqua aerobics class – people found the buoyancy of the water helped."

Next were six spinning classes followed by six gym sessions, using treadmills, rowing machines and cycling machines.

John explains: "The programmes have a lifespan – we ask people at our monthly meeting what they'd like to try next, although aqua aerobics runs indefinitely. I leave the ball in the members' court."

Everyone involved in the classes has reported improvement in their movement. "We invited non-members with Parkinson's too – those who want to exercise but aren't necessarily comfortable with joining the branch. One class attendee now takes an active part in the branch.

"The classes have particularly helped one member who only left the house to go to monthly meetings. Now, he attends aqua and gym sessions, and also goes to the gym on his own. The exercise regime has boosted the confidence of many of our members." **NN**



OVER TO YOU

If you live in the Cardiff and Vale area and think the Live Loud! project could help you, please contact the Parkinson's UK Wales office on **0344 224 3786** or email wales@parkinsons.org.uk

PARKINSON'S LINKS

Becoming more local – faster

How amazing would it be for people with Parkinson's to have access to the right support, activities and friendship within their local community – whether they lived in Hull or the Highlands?

That's the ultimate ambition of Parkinson's Links – and to help us get there faster, we've launched a new project. In four test areas, local development teams, local groups and those with the condition will join forces to identify and prioritise needs on their patch.

Chris Holmes, Local Networks Development Manager, explains: "Local development teams were created to bring Parkinson's Links to life across the UK. For example, if there's a real need for an exercise class or support like a drop-in or Parkinson's cafe in a particular area, these teams will make this happen. We want everyone to have access to support and activities, wherever they live, and whether they're a regular at a local group or not.

"That's why this test project is so exciting, as we'll be working together to make things happen. We'll be tapping into the invaluable knowledge local groups have about their members' wants and needs, as well as all the information that local development teams have. The project will explore how we can make decision-making and accountability local. It will also help identify other responsibilities that could become local in the future."

How will it work?

The test areas will each have a project team made up of people with Parkinson's, volunteers and staff. They will develop new ways of working in their local area and have complete ownership of outcomes.

They'll communicate what's happening and why to their areas, and agree what success looks like. They'll also decide how to evaluate the changes they bring. Launching in April, we'll keep you updated on how the project unfolds.

OVER TO YOU

Let your lead volunteers know about this project and email your ideas on how your area could work more closely together to shape Parkinson's Links to localnetworks@parkinsons.org.uk



Help us find our longest-serving member

We're looking for the charity's longest-serving member to help us celebrate Parkinson's Awareness Week and the 200th anniversary since the first written record of Parkinson's.

We want to find out how opinions of Parkinson's have changed over the years, and are hoping one of our members can share their experiences.

OVER TO YOU

If you think you know who could be our longest-serving member, email pr@parkinsons.org.uk or call 020 7963 9370.

WHAT'S NEW

All the fun of the festival

This summer, you don't have to go to Glastonbury to get that festival feeling. Garden Gathering is your chance to put on your own mini-festival at home.



Whether you go for a craft beer barbecue or a picnic with Pimm's and pink lemonade, it's your unique way to help find a cure and support everyone affected by Parkinson's. And, as it's your personal festival, you pick the headliners. Adele or David Bowie, the Stones or the Beatles, Coldplay or Jimi Hendrix – the choice is yours.

We'd love to see people up and down the country holding their Garden Gathering on 1 July 2017. And if you could help spread the word, and encourage as many people as possible to hold a Parkinson's UK Garden Gathering in 2017, we'd be thrilled.

OVER TO YOU

Request your free fundraising pack, containing our Get Festival Ready booklet with fundraising tips and ideas, eye-catching donation box and wristbands to hand out to your guests. Find this and more at parkinsons.org.uk/gardengathering, email gardengathering@parkinsons.org.uk or call **0800 138 6593**.

Let your creative juices flow

Creativity is a key tool for taking control of Parkinson's, and we know many people with the condition enjoy different types of creative writing. That's why we've come up with our very own toolkit.

The original idea came out of a workshop of people with Parkinson's and was produced by a group of creative writers with the condition, in collaboration with the charity.

Contributor Nicola Wood says: "Being creative helps me deal with the emotional and mental aspects of Parkinson's, things like depression, anxiety, frustration and anger."



Aimed at writers of all levels, including those who've never written, the creative writing toolkit is available on our website. Each section gives you hints, tips and links to useful resources that will help you develop your skills, explore new styles of writing and learn about the writing industry. So why not pop over and have a look at parkinsons.org.uk/creativewritingtoolkit?

OVER TO YOU

Please promote the pack to your members. Why not give some of the writing exercises a go with your group? You never know what creativity will come to light! To receive a copy of the toolkit in the post, call Kieran O'Driscoll on **020 7963 9324** or email feedback@parkinsons.org.uk

AROUND THE NETWORK

We bring you stories from folk across the network – who are just going to prove the huge difference you all make.

Fundraising fun

Bernie Brothwell has raised tens of thousands of pounds for Parkinson's research over the past eight years. A member of both Spalding and District Branch and Boston Parkinson's Cafe, he organised his first golf day in 2009 as a one-off and made £540.

Since then, the event held at Boston Golf Club for the past two years, has gone from strength to strength. Last year's day raised a whopping £7,140, taking Bernie's grand total to more than £31,000, all of which has gone towards research into Parkinson's.

Bernie, who was diagnosed with Parkinson's in 2002, says: "I didn't think I could do anything like this. The first golf day was me and a few mates. We raised about £500, so I thought I'd try it again. Seven years later and the amount we've raised every year has gone up each time.

"It's now become too big for me to organise on my own. Thankfully, Boston Golf Club has agreed to take over the reins with a little help from me."

Golf day number nine will take place this year with £1,000 already pledged.

Bernie adds: "I'm really grateful to everyone who has contributed and would like to thank Boston Golf Club very much, for all their support and for continuing with the golf day in the future."



Bernie Brothwell (second from right) presents a cheque for £7,140 to Katie Thomas, Regional Fundraiser for Parkinson's UK

Three cheers for the Chair

Chair of Newark and District Branch Trisha Butt has been awarded honorary life member to recognise the difference she makes to the lives of people with Parkinson's in the area.

Trisha has been Chair of Newark and District Branch – which has people with Parkinson's at the heart of everything it does – since 2010. With a wonderful committee of volunteers behind her, she organises all sorts of mutual support such as day trips, coffee mornings and get-togethers. She's also spearheading a new exercise class called boccia – a precision ball sport.

Recently, the branch has developed a presence in the local hospital, and members are on hand with leaflets and a friendly word for anyone with Parkinson's attending clinics. Trish has encouraged support for Parkinson's research and every couple of years hosts a research event where members can listen and talk to a top researcher. Other Parkinson's groups are welcomed to the event.

Tyna Brych, Head of Local Networks, and Lorraine Ray, Volunteer Co-ordinator, presented Trisha with a certificate and flowers.



Trisha Butt, Honorary Life Member, with Lorraine Ray, Volunteer Co-ordinator

MEET LAURA PAYTON

Senior Supporter
Services Officer
(Outbound)



How long have you been with the Supporter Services team?

Just over 18 months. Before I joined, I remember being very impressed with the charity's ambition and scope – the equal importance put on campaigning and support for people affected by the condition, as well as research. I felt Parkinson's UK sees the bigger picture.

What's your role?

I'm responsible for the outbound communications the team sends. So I look at our letters, the sorts of emails we're sending and how we can ensure that our supporters are getting the best possible experience when they're communicating with us. It's a really exciting challenge.

And of course there's still the day-to-day work the team shares – speaking to supporters and members, answering their questions, and taking and processing donations. That doesn't stop! The team has recently grown in size, which means we can do a lot more, and we have some exciting ambitions for 2017. It's all go in the Supporter Services team!

What inspiring stories do you hear?

Every day we get something that stands out – supporters who are doing crazy fundraising events, throwing themselves out of planes, walking foot-blistering distances because they believe in what Parkinson's UK is doing. And we frequently receive very moving letters from people who refuse to let Parkinson's win.

How do you know our supporters are making a difference?

When you hear about the latest bit of research or a campaign that's been successful, you know that's because of our supporters. The best example is the GDNF research trials. The fact these happened is thanks to our amazing supporters. The fact we're able to make a positive difference to the lives of people with Parkinson's is down to them.

And our supporters help shape our future too. It's great that there are so many opportunities for people to get involved and help change lives.

What's the best part of your job?

Sometimes we'll speak to someone who's been recently diagnosed and hasn't been given any support. We can help them feel a little less adrift by putting them in touch with our colleagues on the helpline if they need any advice or someone to talk about local support in their area. It's great to be able to end a conversation knowing the person on the other end is in a better place than before they called. **NN**

PARKINSONS^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.



CONQUER THE SKY

Want to try a new and unique adventure? Walking on the wings of a vintage biplane is an exciting and once-in-a-lifetime experience.

You can choose from three conveniently located airfields in:

• Essex • Dorset • Lincolnshire

We're flying in May and September 2017.

Find out more and book your place today at parkinsons.org.uk/wingwalk

Or get in touch by calling us on 020 7963 3912

or emailing fundraising@parkinsons.org.uk