

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

NETWORK NEWS

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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.

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

WELCOME

Hello and welcome to the August issue of *Network News*.

August is the month when it seems like the whole world flocks to Edinburgh for the annual Fringe festival. This month in *Network News* we announce why the Parkinson's community could be visiting the capital for the Edinburgh Parkinson's lecture in October. See page six for this exciting news.

There's also a report from the 'let's get moving' exercise event, hosted by the Edinburgh branch. This received great feedback and some branches are already interested in holding similar events in their area.

Elsewhere in this issue, we reveal how the recent engagement events with our local groups went down on page eight. On page nine, we speak to Education Programme Manager Fiona Barrett about the work Parkinson's UK is doing to educate health and social care professionals about caring for people with the condition.

Local groups in the South West and London are in for a treat as the acclaimed play 'Kinetics', about a woman with early onset Parkinson's, begins a tour of venues in your part of the country. See page four for more information on the play.

Enjoy the issue, and see you in September, where you'll see a newer, refreshed *Network News* – stay tuned.

Katherine Crawford

Country Director, Scotland



Cover image: This month, two important surveys are seeking your views on health and social care services. Read more on page five.



LATEST NEWS

PARKINSON'S PLAY TOURING THIS AUTUMN

A play that explores an unlikely friendship between a woman who has early onset Parkinson's and a teenage boy who enjoys free running (Parkour) is going on tour this autumn.

'Kinetics' will be touring parts of the South West of England and London in September and October.

Critical acclaim

Written by, and starring Sue Wylie, Kinetics was first performed in June 2015. That was swiftly followed by two sellout shows at the Dorchester Corn Exchange.

Further performances at locations in Bournemouth and Taunton have received acclaim from media and audiences alike.

Sue, who was diagnosed with Parkinson's just after she turned 50, said: "After the initial shock, I knew I wanted to write about it. As a professional actress



I know how communication through a script is a powerful tool."

See it for yourself

If your local group is interested in organising a night out to see the play, performance dates, times and locations can be found at dt2productions.co.uk and by clicking on 'tour'.

2016 ANNUAL GENERAL MEETING IS FAST APPROACHING

The 2016 Annual General Meeting (AGM) will be held on Saturday 3 September at The St John's Hotel, 651 Warwick Rd, Solihull B91 1AT.

Full details about the AGM were sent out on Wednesday 3 August. If we have got any of your details wrong, please contact our Supporter Services team on [020 7932 1344](tel:02079321344) or SSThelpdesk@parkinsons.org.uk

If you are a member of the charity and haven't received any information about the AGM or would like to receive it in a different format, please contact the Electoral Reform Services on

[020 8365 8909](tel:02083658909) who will be happy to help. You can reserve your place to attend by visiting parkinsons.org.uk/agm or by calling Tyler Events on [01509 631 530](tel:01509631530) by Friday 26 August 2016.

If you have any other queries about the AGM or the wider governance of Parkinson's UK, contact Company Secretary Sarah Day on [020 7932 1327](tel:02079321327) or governance@parkinsons.org.uk

SOLIHULL BRANCH RECEIVES PRESTIGIOUS AWARD

The Solihull branch recently won the Queen's Award for Voluntary Service, in recognition of its work in the community supporting people with Parkinson's and their carers. Many congratulations to the committee, supporters and everyone involved with the branch for this great achievement.

LATEST NEWS

EVERYONE'S VIEWS COUNT

Are you getting what you need from health and social care services? Tell us your views in the **Parkinson's 2016 – Your life, your services** survey.

Let us know

Head of Involvement and Inclusion Luis Perpetuo said: "We want to know if health and social care services that people living with Parkinson's are getting are right for them. If we know where the gaps are, we can start to work on filling these.

"That's why we need as many people as possible to do our latest survey about different aspects of life with Parkinson's. The survey was sent out to all our members.

"We would really appreciate it if you could encourage your group members to complete the survey too – and highlight just how important it is."

Online version also available

There is also an online version of the survey, which can be found on our website at parkinsons.org.uk/yourlifeyourservicesurvey. Printed copies are available through CDL, product code PK0338.

If you have any questions about the survey itself, please email feedback@parkinsons.org.uk

YOUR EXPERIENCES AS A PATIENT NEEDED

The Neurological Alliance has launched its 2016 patient experience survey – to develop a picture of the experiences of people living with neurological conditions.

Policy and Campaigns Adviser Morgan Vine said: "The survey will cover key issues such as diagnosis, health care, social care and access to benefits.

"As part of the Neurological Alliance, Parkinson's UK wants as many people as possible to share their views on diagnosis and treatment in this survey.

"This survey is open to anyone living with a neurological condition in England. Your responses will help us understand how much progress has been made to improve neurological services, and what still needs to get better."

Share this link www.surveymonkey.co.uk/r/IHTBMTS with people living with Parkinson's so they can get their voices heard. The survey closes on 30 September 2016.



EDINBURGH EVENTS ATTRACT THE PARKINSON'S CROWD

As the Fringe festival draws to a close, the Parkinson's community will be flocking to the Scottish capital for the 2016 Edinburgh Parkinson's lecture.

This year's Edinburgh lecture will be given by world-renowned neurologist Professor Bastiaan Bloem.

The lecture serves to inform and educate the public on the fight against Parkinson's by attracting international experts to review recent progress. This year's lecture, delivered by Professor Bloem, is entitled 'The Future of Parkinson's Care.'

Past speakers

The Edinburgh Parkinson's lecture began in 2012 when Cambridge Neuroscientist Professor Roger Barker spoke about how close we are to solving the problem of what goes wrong in Parkinson's.

Since then, others who have delivered the lecture include Professors Ray Chaudhuri and Tony Schapira of University College London. Last year, Professor Patrik Brundin talked about advances made in the treatment of Parkinson's, using cell implantation, gene therapy and drug repurposing.

About Bastiaan Bloem

Professor Bloem is a consultant neurologist at Radboud University Nijmegen Medical Centre in the Netherlands. Together with Dr Marten Munneke, he developed ParkinsonNet. The ParkinsonNet concept is widely recognised as an example of best practice for care in Parkinson's. Over the past ten years, it has demonstrated how better specialist training, team working, communications, service structures and patient involvement can result in better patient care and lower costs.

Scotland Director Katherine Crawford said: "It's a privilege to have Professor Bloem give this year's Edinburgh research lecture. He's an internationally recognised physician and his work on ParkinsonNet was rewarded in 2006 with an award for the best health care innovation in the Netherlands."

When

The lecture will take place on Tuesday 11 October in the Chancellor's Lecture Theatre at Edinburgh Royal Infirmary. Entry to the lecture is free, but by ticket only. To register, visit edinburghparkinsons.org and click on 'Edinburgh Parkinson's lecture 2016' for more information.



Above: Professor Bastiaan Bloem joins the list of esteemed experts to have delivered the Edinburgh Parkinson's lecture

EDINBURGH BRANCH GETS MOVING

Keeping mind and body healthy were the key themes at a special event organised by the Edinburgh branch.

The 'let's get moving' event attracted around 60 people, including healthcare professionals and branch members.

Volunteer Co-ordinator for East Central and South East Scotland Gina Allen said: "The aim of the day was to highlight the importance of exercise in helping people manage with their Parkinson's.

Morning talks

"We began with a talk from Professor Lynn Rochester from the Institute of Neurology at Newcastle University. She spoke about research conducted on the effects of exercise and general activities for people with Parkinson's, and fielded questions afterwards.

"Julie Jones, a Senior Lecturer in Physiotherapy from Robert Gordon University, then talked about gait and measures that could be used by physiotherapists in treating patients.

"The lectures were followed by a session on voice work by Wendy Carle Taylor. Wendy is a voice coach to the 'Singing4Fun' community singing group run by Edinburgh branch members Cathie Quinn and Heather Robertson."

Learning from others

Gina continued: "There was a panel discussion featuring members of the Edinburgh branch who talked about activities they found helped them to manage their condition. This was very well received, with one person saying they felt the panel discussion with people living with Parkinson's was possibly the best part of the day.

"They also said how inspirational it was to hear about how many different activities can help with Parkinson's symptoms."



Above: Julie Jones in relaxed mood with organisers Bill Wright (left) and Ken Bowler after her talk

Pilates to physio

The afternoon saw a series of activity taster sessions for people to get involved in, including movement and dance, Tai Chi, pilates and physiotherapy. They were specifically chosen to help with movement, muscle strengthening, general fitness, voice health and feelings of wellbeing.

Positive feedback

Feedback was positive and one attendee commented: "I learnt so much – like how to stay committed to prescribing and promoting exercise. I now feel more able to back that up with evidence and stories."

Gina added: "The day went brilliantly and we were delighted with the feedback. It was so successful, our Parkinson's nurses in Fife want to run a similar event in their area."

To read more about the event, and to download copies of the speaker presentations, visit edinburghparkinsons.org/lets-get-moving

HAVING YOUR SAY

The local engagement events held recently were a huge hit – with 441 attendees from 179 local groups coming along to around 24 events.

Everyone engaged

Head of Local Group Networks Tyna Brych said: “As we move forward to bring Parkinson’s Links to life across the country, we learned a lot about how you think Local Groups and Local Development teams can work together. Everyone was really engaged and brought plenty of views and ideas to the table.”

Communication

Tyna continued: “It was clear you wanted to be kept informed and that two-way communication was important. At every event, groups said they wanted face-to-face visits from Local Development team members and having local group representatives at their meetings was significant.

Mutual awareness

“You want to be kept informed and two-way communication was important”

“To work more effectively together, we need to be aware of what each other does. With that in mind, you

told us you wanted Local Development teams to be aware of what local groups do, the services you provide, where and who accesses them.

“You wanted to be kept up to date more regularly with progress and achievements, how much things will cost, where the money is coming from and

what fundraising activities are taking place.

“However, we need to manage this communication correctly. Groups don’t want to be inundated with information too often and it was felt there should be a structured plan in place about how we communicate this with you.”



Shared vision

It was suggested that by promoting each other’s activities, it showed the groups and Local Development teams are working towards the same vision and objectives, which you thought was important.

However, it was clear volunteers don’t want to be expected to do more than they can manage and that it will be important for the Local Development teams and groups to discuss what needs to happen and who will do this.

Tyna added: “It was very satisfying to hear that so many of our local groups are keen to work with Local Development teams to bring Parkinson’s Links to as many people as possible.”

If you have any questions or would like further information on the engagement events, please email groupnetwork@parkinsons.org.uk

HAVING A BALL IN BLACKPOOL

An annual trip beside the seaside has been a big hit with the Parkinson's UK support group in the North West for the last 16 years – and this year was no different.

What is it all about?

The week-long trip to Blackpool offers people living with Parkinson's a unique way to meet and chat to like-minded people. The Blackpool Holiday Project is run exclusively by volunteers.

David Gray, who has Parkinson's and volunteers with his wife Alma, said: "I do this because I can really see the benefit to people affected by the condition.

"When you think of Blackpool, you think of dancing in the Tower Ballroom, the famous golden mile, shows and entertainment. It's a fantastic experience and Blackpool is a great town."

Putting guests at ease

David continued: "Our guests stay at the Savoy Hotel, whose staff have had Parkinson's awareness training. This is important as it puts guests at ease and they can enjoy their holiday straight away.

"We also make sure wheelchairs and mobility scooters are available for hire, so people don't have to worry about bringing their own, if they need that support."

What's on offer?

Through an arrangement with local colleges, students come in daily to offer various pampering beauty treatments, hairdressing and massages. Each morning, 15 minutes of soft music is on offer, followed by gentle exercise with the physio team, where guests do as much or as little as they want.

Keen to offer as much variety as possible, there are also optional talks and classes organised throughout the week.

The real highlight of the week for many, however, is the gala dinner in the hotel ballroom, where they are joined by the Mayor of Blackpool.



Above: The iconic Blackpool Tower

David said: "While we are a support group, I like to think we offer a different kind of support – it's a great chance to get to know people from all over the country in a welcoming, friendly and relaxed environment."

More information

This year's holiday takes place from 9-15 October. For a chat about the holiday in general, call Tony Bowyer on **0151 334 4564**. For an information pack and application form, contact David Gray on **0169 7321 715**.

SPREADING PARKINSON'S KNOWLEDGE

Junior doctors, nurses, pharmacists and care home staff are just some professionals Parkinson's UK works with to ensure they know all they need to about caring for people with the condition.

We know those caring for people with Parkinson's need to have knowledge of the condition.

That's why we run a number of training courses to make sure these people are equipped with everything they need to know.

Education Programme Manager Fiona Barrett said: "The Train the Trainer and Understanding Parkinson's programmes receive fantastic feedback."

Understanding Parkinson's

"These are delivered by Parkinson's UK trained facilitators in their own workplace. They are aimed at health and social care professionals working in residential, respite, day care, home care or health settings. Participants learn about the common signs, symptoms, progression of Parkinson's and the impact it has on the person with the condition and those around them. They also learn about the communication and cognitive challenges associated with Parkinson's, impact and ways to deal with them."

Parkinson's explored/Parkinson's explained

The objective of this course is to give trainers working in the health and social care sector the chance to develop their own knowledge of the condition and be able to deliver training on Parkinson's at their own workplace.

Fiona continued: "We have developed strong relationships with health and social care professionals who have made changes to their practice – and continuously deliver learning about

Parkinson's across their organisations. One facilitator is about to reach 100 staff trained in her organisation in months."

Online breakthrough

The development of the online version of the Understanding Parkinson's programme with the Open University is a ground-breaking achievement for Parkinson's UK.

Fiona explained: "This is the first time the Open University has worked with an organisation to design a course around understanding Parkinson's. It's a breakthrough in learning design and a fantastic collaboration."

Volunteers delivering courses

Around 40 volunteers are now delivering a short introductory course. Fiona said: "The Volunteer Education programme sees people selflessly give up their time to deliver key messages about Parkinson's –

mainly to staff working in care settings. We're looking to grow this to cover the whole of the UK by 2020."

If you have any questions about these programmes, email fbarrett@parkinsons.org.uk



AIDING YOUR ADVENTURE

Whether you're getting your hands dirty in the garden or taking a road trip - our Daily Living Aids offers a selection of tools that can help. Don't forget that when you shop with Parkinson's UK, 100% of the profits go directly towards our vital work. Explore the full range at parkinsons.org.uk/shop

Garden stool on wheels PAUK739
£37



Blue Badge wallet PAUK 794
£15.50



Chaffinch birdsong mug PAUK 1000
£9.99



Radar key PAUK572
£7.25



Rollator PAUK1037
£150



VISIT A SPECTACULAR GARDEN THIS SUMMER

Get inspiration for your own green space by visiting one of 400 beautiful National Garden Scheme gardens.

Our top pick this season is the colourful Yewbarrow House in Cumbria. With spectacular views overlooking Morecombe Bay, an infinity pool and a brand new woodland walk, there's so much to explore. Open Sunday 4 September from 11am to 4pm.

Visit parkinsons.org.uk/NGS to find out more about our partnership and a garden near you.



PARTNER WITH PARKINSON'S UK

Do you work somewhere that has a charity of the year scheme - or know someone who does?

We're constantly on the look out for new opportunities to raise money and awareness with businesses - from banks and building societies to tile merchants and supermarkets. Last year, our business partnerships raised more than half a million pounds. With your help, we can make the number even bigger.

So if you know somewhere that might like to partner with Parkinson's UK, simply drop us an email at 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

215 Vauxhall Bridge Road

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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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