

# Network NEWS BITE

This month's bitesized news and views

NOVEMBER 2016 ISSUE 1



## Making the world Parkinson's friendly

**Everyday things that some of us take for granted – shopping, getting the bus or ordering a drink – can be challenging for those of us with Parkinson's. Often that's down to public attitude, which is why we piloted an awareness-raising session to give staff a better understanding of Parkinson's and the ways they can support customers.**

Thirty-six organisations, including Fuller's Inn, Lancashire Police and Transport for London, signed up for the pilot. Molly, who works at Fulham's Blue Boat pub, says: "It's definitely informative. You know what to look for." The pilot's results are now in, with organisations feeding back that they'd continue using the session and would recommend it to others.

## World Parkinson Congress update

**We had a strong presence at this year's World Parkinson Congress in Portland, Oregon – with Chief Executive Steve Ford and others attending.**

The World Parkinson Congress brings the Parkinson's community together to share experiences and discuss the latest thinking in research, care, information and support. And our Parkinson's UK representatives gave us the lowdown via video blogs.

### Taking control and sharing our research

Katherine Crawford, Scotland Director at Parkinson's UK, spoke of "a real emphasis on telehealth which is positive to hear, particularly living up in Scotland".

Claire Nolan, Research Involvement Manager, spoke of her pride in sharing our achievements with a colleague from the international Parkinson's community: "I talked about the training and volunteer programme we've established, our toolkits, and providing support

We also held a focus group to find out people's experiences of call centres, airports and offices.

Senior Marketing Officer Emma Jones says: "We'll use these insights and the pilot feedback to make tweaks to sessions before we formally launch the initiative this winter. We'll have sessions available for organisations in retail, hospitality, public transport, air travel, banking and anyone who may employ someone with Parkinson's."

### OVER TO YOU

Use our pocket-size handout to tell local organisations about our awareness session and encourage them to sign up. Order a pack of 10 from CDL with the code: **PK0368**.

to researchers working with people affected by Parkinson's."

### Technological advancements

Julie Dodd, Director of Digital Transformation and Communication, discussed the growing range of connected technologies for Parkinson's, including a wearable device that helps clinicians and patients track and reduce 'off' time.

Julie also told us about a hearing aid which gives live feedback on how loud a person with Parkinson's is speaking, as some don't realise when their speech is getting quieter which can lead to social isolation.

"It's currently only available in the US but they're in discussion with some UK hospitals," Julie explains.

### OVER TO YOU

Find out more about this year's World Parkinson Congress [here](#).

## Campaigns news

We've plenty to report on the campaigns side. First off, news from the three main party conferences, which members of our team and some people affected by Parkinson's went along to.

### Meeting MPs

We talked to MPs about our campaigns to abolish prescription charges for those under 60 in England, Attendance Allowance and to ensure research funding is protected during Brexit negotiations.

Our tally comprised 11 Labour MPs, including Shadow Secretary of State for Work and Pensions, Debbie Abrahams MP, and five of the six Liberal Democrat MPs. We met 18 Conservative MPs and gained support from most on one or more of our campaigns. We also secured agreement for a meeting with the prime minister – watch this space.

### Attendance Allowance update

We're continuing our work to ensure Attendance Allowance isn't devolved to local authorities in England. We're concerned that, if this happens, eligibility criteria and awareness-raising about its availability will vary across England, and in some areas the benefit could stop altogether.

#### OVER TO YOU

Any proposals to change Attendance Allowance won't affect those currently receiving it. But if any group members already get it, and would like to share how helpful it is, please call us on **020 7963 9349**.



Left to right: Phil Reynolds, Parkinson's UK Policy and Campaigns Adviser, Ronnie Shahmoon, who has Parkinson's, his wife Suzette Shahmoon, and Lillian Greenwood MP.

## Grantham Branch in the spotlight

Each *Newsbite*, we'll hear about a different local group's recent



activities. **Grantham Branch recently allocated funds to research through our 'adopt a project' scheme and organised a special event to say thank you to supporters, as well as raise awareness of Parkinson's.**

The 70-strong audience heard from guest speakers Steve Ford, Parkinson's UK Chief Executive, and Professor Oliver Bandmann of the Sheffield Institute for Translational Neuroscience. Movements disorder neurologist Dr Lorraine Kalia, whose research Grantham Branch is partly funding, spoke live via video link from Toronto Western Hospital in Canada.

On a different note, members visited the Battle of Britain Memorial Flight at RAF Coningsby in Lincolnshire and were allowed into areas where the general public don't usually go. Looking inside the Douglas Dakota was the tour's highlight for many. They also saw a Spitfire, Hurricane and Lancaster Bomber take off.

#### OVER TO YOU

If you'd like your group to feature in a future *Newsbite*, email [localnetworks@parkinsons.org.uk](mailto:localnetworks@parkinsons.org.uk) or call **020 7963 3929**.

## Parkinson's Awareness Week 2017

The next Parkinson's Awareness Week will be Monday 10 to Sunday 16 April 2017. The week will include the 200-year anniversary of James Parkinson identifying the symptoms of the condition – World Parkinson's Day on 11 April. So make a note of the date, let your group know and include the week in any plans.

## When I Dance

Enter the When I Dance competition and spread the word to friends and family.

9–30 November 2016  
[www.whenidance.uk](http://www.whenidance.uk)

