

# BRANCH BULLETIN

August 2010

## Introduction

Inside this month's *Branch Bulletin* you can read about our members' experiences at our Open Day in London – and find out how you can let us know if you'd like us to run a similar event in your area. Read our *Fundraising Tips* to get some inspiration for your Christmas fundraising.

We've got updates from our Policy and Campaigns Team about NHS "Continuing Care", benefits tests, and the current consultation on carers in England.

We'd love you to take part in our web survey – we really want to continue to improve our website to make sure we're providing you with the information that you need.

Don't forget to use your recycling envelopes – there are two included in this month's *Branch Bulletin*. Inside this issue you can also read about our new Christmas card offer, and how to take part in the Great South Run for Parkinson's UK.

Don't forget to take this copy of the Branch Bulletin to your local group meeting so that everyone can keep informed about Parkinson's UK news. And remember you can always request a copy of the *Branch Bulletin* via email by emailing [internalcomms@parkinsons.org.uk](mailto:internalcomms@parkinsons.org.uk)

## Inside this issue:

- Open Day at 215
- Our six goals
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- Vetting and Barring Scheme
- Benefits test survey
- Consultation on carers in England
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- Great South Run places available
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- Twin city Parkinson's exchange

## Attachments enclosed

- *Fundraising Tips* - August 2010
- *Finance News* - claiming Gift Aid
- Gift aid declaration/submission forms
- Sponsorship form
- Christmas catalogue pack

## Reminders:

- **1 September** – deadline to send us your views on benefits tests
- **6 September** – deadline to send us your views if you are a carer in England
- **3 September** – deadline to send us examples of Goal one achievements
- **22 September** – web survey deadline
- **21 October** – deadline to attend November Open Day
- **24 October** – Bupa Great South Run
- **4 November** – Open day at 215

## 30 July - Open Day at 215

We held an Open Day at 215 in London on 30 July. The event was a great success, providing an opportunity for members to meet staff and people from other local groups and to find out and give feedback about the work we're doing. Members attended from nine local groups across the country from Stranraer to Fulham.

The day enabled members to:

- understand what Parkinson's UK does
- discuss different areas of work
- share ideas, experiences and learning
- chat and network over lunch
- tour the office building and meet teams

Members told us what was working well and what wasn't, and we'd like to thank them for their input, which we'll use to help us improve what we do.

From feedback, we know that people really enjoyed the day. Here are some of their comments:

"It was enlightening to see the inner workings of the charity. Thank you for an enjoyable day, we are glad we came."

"I had a good day on Friday...it was worth the trip. Please thank everyone involved for the day. It was good to put faces to names and to know that you are all working very hard for people like us. It was all very interesting and reassuring."

One member praised "Parkinson UK's willingness to listen, friendly staff, helpfulness, open attitudes and hospitality."

We are holding another Open Day in London on 4 November from 11am to 3pm. If you would like to come, please call Arlene Greene **by 21 October** on 020 7963 9324 or email [agreene@parkinsons.org.uk](mailto:agreene@parkinsons.org.uk)

Expenses will need to be covered by individuals or paid out of branch funds.

We are also considering holding similar events outside of London that would be more accessible for people who are distant from London. If you think this is a good idea, please let Arlene know.

## Our six goals – call for best practice examples from local groups

Forthcoming editions of the *Branch Bulletin* will feature pullout supplements on our six goals. The first supplement will look at goal one: "No one will have to face Parkinson's alone".



We're looking for examples of local groups who are working to achieve this goal.

**Please write and tell us about some of your projects and successes in this area of work by Friday 3 September.**

It would be great if you could include some photos to accompany your contributions.

Write to:  
Rachel Jasper  
Marketing Officer  
215 Vauxhall Bridge Road  
London SW1V 1EJ

Or email [rjasper@parkinsons.org.uk](mailto:rjasper@parkinsons.org.uk)

## Parkinson's UK conducts survey of "continuing care"

People with Parkinson's whose health needs are complex, severe or unpredictable may be eligible for NHS Continuing Care - a package of care that is arranged and funded by the NHS to meet health needs of people with a long term disability, injury or illnesses.

In 2007 England introduced national guidelines (revised in 2009) to make eligibility for NHS Continuing Care clearer and to ensure that applying for the care package would not be a postcode lottery. However, although more people now receive Continuing Care, people's experiences still vary on where they live. From anecdotal evidence, we know that it hasn't always been easy to qualify.

Some of the problems are:

- people find their experience of assessment varies from other people's experiences
- some assessors don't give enough time and understanding when assessing people with Parkinson's
- the NHS is reluctant to fund the care
- people being assessed are not aware of their rights (including their rights to appeal)

Our Policy and Campaigns Team, with the help from our Policy Panel is developing a policy position on NHS Continuing Care.

We need to hear from people with Parkinson's about their experiences of the NHS Continuing Care system - good or bad. Anyone who has succeeded, failed, or is in the midst of applying for continuing care should get in touch with us.

It would be particularly useful to hear about people's experiences since 2007 when the

new guidance was introduced. This will help us see whether this guidance has helped or hindered the situation.

Send your views to:

Donna O'Brien  
Social Policy and Campaigns Officer  
215 Vauxhall Bridge Road  
London  
SW1V 1EJ  
Telephone 020 7963 9307

Or email [dobrien@parkinsons.org.uk](mailto:dobrien@parkinsons.org.uk)

## Vetting and Barring Scheme

The government has decided to remodel the new Vetting and Barring Scheme that would have been introduced over the next five years. This means it isn't clear how or when the scheme will now progress. We wanted to let you know we've started to prepare to make sure we're doing the right thing and supporting our local groups and volunteers through the current scheme.

This means we're continuing to check all new volunteers involved wholly and exclusively in one-to-one work with vulnerable adults. Please continue to let us know if you are taking on a new volunteer to do this kind of work so that we can make sure the charity meets current regulations.

We'll send you an update as soon as we get more information about the Vetting and Barring Scheme.

If you have any questions call Jo Jones, Branch and Volunteer Support Co-ordinator on 020 7932 1338 or email [jjones@parkinsons.org.uk](mailto:jjones@parkinsons.org.uk)

## Benefits tests - have your say

We are calling on people with Parkinson's who've had an Employment and Support Allowance (ESA) assessment to share their experiences as part of a new investigation.

The government has asked an expert in occupational therapy, Professor Malcolm Harrington, to cast an independent eye over the system for accessing this allowance, which is replacing Incapacity Benefit. He is due to report by the end of the year.

Professor Harrington's review team has issued a call for evidence over the summer from people who have experienced the "work capability assessment" which includes a medical test on fitness to work.

People with Parkinson's who've been through the assessment say they've been rushed through the process, and that staff have shown a lack of knowledge about Parkinson's, the way the condition fluctuates and the impact of medication. This results in people being wrongly assessed as fit to work.

The Policy and Campaigns Team are contributing to the review. Unfortunately, the consultation deadline is very short. If you'd like share your views and experiences **please let us know by Tuesday 1 September**. Your views will help us to compile Parkinson's UK's response email. You can telephone us on 020 7963 9307 or 020 7932 1323 or email [campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)

To read the consultation visit the Department of Work and Pensions website at [www.dwp.gov.uk/consultations](http://www.dwp.gov.uk/consultations), then click on "The Work Capability Assessment - A Call for Evidence". You can also make an individual submission via this website by Thursday 10 September 2010.

## Consultation on carers in England

If you care for someone with Parkinson's, then you may wish to submit your views to a government consultation on priorities for carers in England.

The ten year national strategy for carers in England was produced in 2008. That strategy is now under review and the coalition government wants to hear views on what form of carer support should be a priority over the next few years. Please note benefits for carers are going to be part of a separate consultation on welfare reform.

Once all evidence is collected, the government will publish an action plan setting out how they will deliver that support. It is vital that services and support are provided through information and advice, access to breaks and emergency back-up.

If you would like your views to be included in our Parkinson's UK response, **our deadline is Monday 6 September 2010**. You can contact the Policy and Campaigns Team directly 020 7963 9307 or 020 7932 1323 or email [campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)

You can also make an individual submission by 20 September 2010 which is the actual deadline for the consultation. To read the consultation go to the Department of Health website at [www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH\\_117249](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_117249)

## Complete our web survey

Do you use the Parkinson's UK website? Do you browse the discussion forum? Or maybe you follow us on Facebook or Twitter? If so, we want to know what you think.

You can help us improve our website and online services by giving us just a few minutes of your time.

We want to hear from people with Parkinson's, carers, families and friends, professionals - anyone who goes online to access information about Parkinson's. We're asking people to **complete our short web survey before 22 September**.

The results of the survey will be used to determine our online priorities for the next three years.

You can fill in the survey at [parkinsons.org.uk/webusersurvey](http://parkinsons.org.uk/webusersurvey)

If you have any questions please email [webmanager@parkinsons.org.uk](mailto:webmanager@parkinsons.org.uk)

## Christmas card offer

This year, we've changed the way you can bulk order Parkinson's UK Christmas cards for resale. This year we are selling our Christmas cards to local groups at cost price. This means that when you are selling them at any events leading up to Christmas all of the profit will be going back to you.

This is a great way for you to reap the rewards of your hard work. Enclosed with this mailing is all you will need to order your Parkinson's UK cards for Christmas 2010. If you have any problems or questions please do not hesitate to contact us on 0844 415 7863 or email [shop@parkinsons.org.uk](mailto:shop@parkinsons.org.uk)

## Bupa Great South Run, 24 October - join our team

The Bupa Great South Run takes place on Sunday 24 October and is Europe's biggest 10 mile road race. We currently have guaranteed charity entry places available in the race. Each place has a minimum sponsorship target of £250, and a non-refundable registration fee of £25.

We realise that this event may not be suitable for many of your members. However, if your local group is able to recruit a runner, any money raised can go to your group, (through the Finance Team so that gift aid can be claimed).

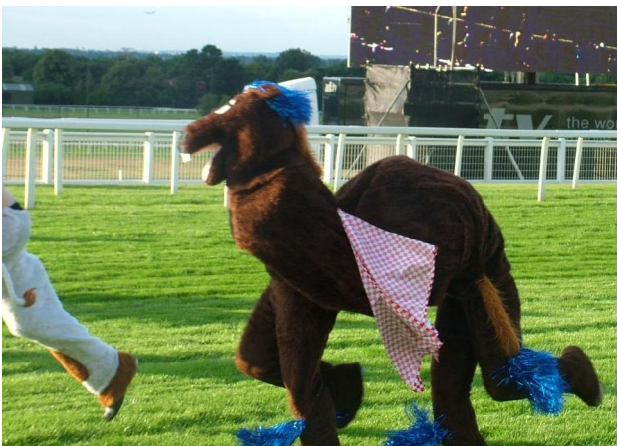
With this in mind, we've enclosed a poster that we hope you will be able to display locally, perhaps on a community notice board or in a shop window. Please get in touch if you would like more. Runners can apply at [parkinsons.org.uk/greatsouthrun](http://parkinsons.org.uk/greatsouthrun) or request a form using the details below.

We hope you will be able to help us promote the Great South Run, so we can continue our vital work. If you do have any questions, or would like more posters, please contact me on the details below.

To apply, visit [parkinsons.org.uk/greatsouthrun](http://parkinsons.org.uk/greatsouthrun) call 020 7932 1342 or email [events@parkinsons.org.uk](mailto:events@parkinsons.org.uk)

## Parkinson's UK on *Big Brother*

On 11 August, Claire Bale, Research Communications Officer and Gerda Drutyte, Data Analyst, took part in the Mayor of Elmbridge's annual pantomime horse race. Our stylish horse "Parkinson's UKick" sported blue tinsel around its ankles, tail, and a sprig on top of its head. The girls dashed alongside the 100 metres alongside the *Surrey Advertiser's* cow "Trot off the Press" and a celebrity horse made up of housemates JJ and John James from Channel 4's reality TV show *Big Brother*.



This fine example of equine beauty appeared on *Big Brother* the following evening, and Claire and Gerda were also interviewed by Surrey and Berkshire television as representatives of Parkinson's UK – the Mayor's chosen charity. You can watch the coverage on YouTube at [www.youtube.com/watch?v=osXA-ZS4a88&feature=player\\_embedded](http://www.youtube.com/watch?v=osXA-ZS4a88&feature=player_embedded)

## Twin city Parkinson's exchange

From 14-17 June, members of the Canterbury and District Branch hosted a group of members of Reims Parkinson, a Parkinson's group in Reims, France. The city of Canterbury has been twinned with Reims in France since 1962, and since 2005 the Canterbury and District Branch of Parkinson's UK has arranged exchange visits with Reims Parkinson.

In the evening they gathered together for a singing session at Canterbury Christchurch University. They had learnt some French songs, including 'Frere Jacques' and 'Aupres de ma blonde'. The next day the Lord Mayor gave a tour of the civic buildings, and the visitors also enjoyed tours of Fordwich and Canterbury Cathedral. Before the guests made their way home to Reims they enjoyed a taster session of reflexology and were treated to a fish-and-chip lunch in the city.

For more information about how the Canterbury Branch set up their partnership with Reims Parkinson, email Beatrice Shire, Welfare Officer, at [b.j.shire@kent.ac.uk](mailto:b.j.shire@kent.ac.uk)

## Diary dates 2010

### 13 September

*Branch Bulletin* arrives this week

### 18-26 September

Trek China

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

### 28 September – 1 October

World Parkinson Congress in Glasgow

Call 0800 652 8978

[www.worldpdcongress.org](http://www.worldpdcongress.org)

### 11 October

*Branch Bulletin* arrives this week

### 4 November

Open day in London

Call 020 7963 9324

### 15 November

*Branch Bulletin* arrives this week

### 25 November-5 December

Trek Nepal

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

### 8 December

Christmas Carol Concert, London

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

### 13 December

*Branch Bulletin* arrives this week

**For more information about any of the events:**

Call 020 7963 9319

Email [events@parkinsons.org.uk](mailto:events@parkinsons.org.uk)

Visit [parkinsons.org.uk/events](http://parkinsons.org.uk/events)

## Useful contacts

### Branch and volunteer freephone

Call 0800 389 7839

Monday-Friday: 9am-5pm  
except bank holidays.

### Brand hotline

Call 0800 652 8978

Monday-Friday: 9am-5pm  
except bank holidays

Email [brand@parkinsons.org.uk](mailto:brand@parkinsons.org.uk)

### Free confidential helpline

Call 0808 800 0303

Monday-Friday: 9am-8pm  
Saturdays 10am-2pm

Email [enquiries@parkinsons.org.uk](mailto:enquiries@parkinsons.org.uk)

### Parkinson's UK

215 Vauxhall Bridge Road

London SW1V 1EJ

T 020 7931 8080

Email [enquiries@parkinsons.org.uk](mailto:enquiries@parkinsons.org.uk)

### Parkinson's UK Northern Ireland Office

Wellington Park Business Centre

3 Wellington Park, Malone Road,

Belfast BT9 6DJ

T 028 9092 3370

Email

[northernireland@parkinsons.org.uk](mailto:northernireland@parkinsons.org.uk)

### Parkinson's UK Scotland Office

Forsyth House, Lomond Court,

Castle Business Park, Stirling FK9 4TU

T 01786 433811

Email [scotland@parkinsons.org.uk](mailto:scotland@parkinsons.org.uk)

### Parkinson's UK Wales Office

Maritime Offices, Woodland Terrace,

Maesycoed, Pontypridd CF37 1DZ

T 0844 225 3784

Email [wales@parkinsons.org.uk](mailto:wales@parkinsons.org.uk)

## *Branch Bulletin highlights*

We thought it would be helpful to list the key information included in the last *Branch Bulletin*.

### **July *Branch Bulletin***

- Our plans 2010-2014
- Find out more about our research
- Coming soon - World Parkinson Congress
- Annual Parkinson's Audit
- How would you improve local group's manuals and guidance reviews?
- Update on directory information
- Petition for our Fair Care campaign
- Mervyn Peake Awards presentation
- Parkinson's UK Christmas Catalogue 2010
- Recycle your mobiles and much more
- Get the party started
- *Fundraising Tips* July 2010
- Diary dates 2010

### **Attachments in July *Branch Bulletin***

- *Fundraising Tips* – July 2010
- Two recycling envelopes
- Ten petition forms for Fair Care