

PCA SUPPORT GROUP

Newsletter

Welcome to the PCA Support Group Newsletter

Issue 6, October 2009

Welcome to the 6th edition of the PCA Support Group Newsletter. The PCA Support Group has now been running for 2 years, and during that time, many people have come together to learn more about PCA, to meet others facing similar challenges, and most importantly to develop friendships with people who can provide support, understanding and encouragement. At the last meeting in July 2009, we held a number of small group discussions for people with PCA and their family members and supporters.

We were delighted to be joined by a number of new members, and the group now provides support not only for people with PCA attending the National Hospital but also people travelling from as far afield as Cornwall, Cambridgeshire and Norfolk. We are currently seeking funding to support additional regional meetings, so that people affected by PCA across the whole country may have the opportunity to meet regularly with others who really understand what it is like to live with PCA.

Next PCA Meeting: Friday 13th November 2009 (RSVP to Jane or Seb)

11am with lunch from 1pm

Conway Hall, 25 Red Lion Square London WC1R 4RL

(*Please note the new venue – directions are provided on page 2)

This meeting will be mainly a social event, providing an opportunity to meet and get to know other group members both new and old. There will be a short presentation on aids and devices from the RNIB which may be of use to those coping with PCA.

Please confirm your attendance:

Jane Douglas 08451 555 000 x 723560 or email jdouglas@drc.ion.ucl.ac.uk
Sebastian Crutch 08451 555 000 x 723113 or email s.crutch@drc.ion.ucl.ac.uk



Myrtle Ellis Fund

The PCA Support Group is generously supported by the Myrtle Ellis Fund, as part of the National Hospital Development Foundation (Charity number 290173). For more information on the work of the Fund, please contact the Foundation on 020 7829 8724.

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Directions

Conway Hall, 25 Red Lion Square London WC1R 4RL

Underground

Nearest station is Holborn (Central and Piccadilly lines) approx 3 min walk. Also within reasonable walking distance are Chancery Lane and Russell Square. London Underground Infoline: 020 7222 1234.

Buses

The following buses pass through or near Holborn stopping just a few minutes walk to the Hall:

from Oxford Street: 8, 25, 55; 98 (terminates in Red Lion Square)

from Euston Station: 59, 68, 91, 188

from Waterloo Station: 1, 59, 68, 188, 521, 243

from Victoria: 38 (Theobalds Rd, rear side of Hall)

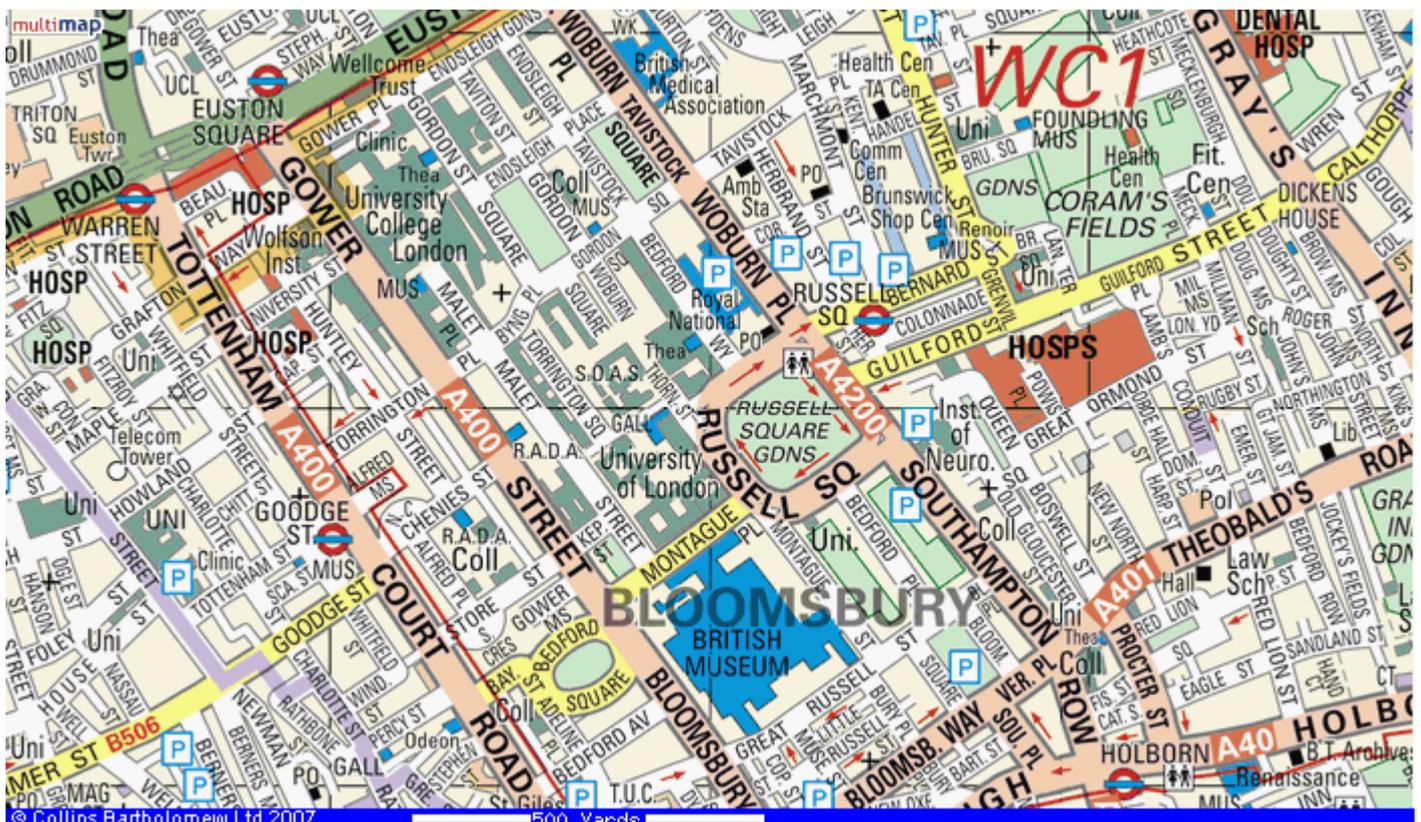
London Buses Infoline: 020 7222 1234

British Rail

Excellent connections via numerous bus routes from most central London main line stations. British Rail Infoline: 0845 748 4950.

Parking

There is metered parking available in Red Lion Square and adjacent streets, unrestricted weekdays after 6.30 p.m., Saturdays after 1.30 p.m. and Sundays all day. Please note some parking areas are for "Residents Only" and other local restrictions. For info ring LB Camden 020 7278 4444.



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Interview with Manja Lehmann



Many of you will recognise Manja Lehmann from our PCA Support Group meetings. Manja is currently undertaking an Alzheimer's Society-funded PhD, conducting research into the brain changes associated with PCA. Here we ask her a questions about herself and the research which many of you are helping with...

1. What is your scientific background?

I received a Bachelor's degree in Neuroscience in 2006, and a Master's degree in Cognitive Neuropsychology in 2007, both from University College London, UK. I have been employed at the Dementia Research Centre (DRC) since October 2007 where I have been involved mainly in trials and imaging work. I am currently working as a PhD student at the DRC. My PhD project aims to characterise the clinical, neuropsychological and imaging features of Posterior Cortical Atrophy (PCA).

2. Why are you interested in dementia research?

Besides the rising social and economic impact dementia has on our society, it is

in particular my work at the DRC which has motivated me to focus my research on studying dementia. Working at the DRC has provided me with the opportunity to meet patients with different types of dementia, including rare inherited forms, not only as part of my research but also at a number of support group meetings which are organized regularly by members of the DRC. In meeting these patients and their carers I have developed full appreciation for the impact dementia has on them and their families.

3. What are your current research interests?

The main focus of my research is the investigation of the behavioural, imaging and clinical characteristics of Posterior Cortical Atrophy (PCA). PCA is a less common variant of Alzheimer's disease in which the primary problem is not memory but visual perception. Individuals with this condition are very disabled by problems perceiving the shape, texture, colour, identity and location of objects and faces around them. We are particularly interested in how PCA affects the behaviour and brain structure of individuals with this condition, in order to improve its recognition and diagnosis. Detailed measurements of visual skills will be used to analyse the impact this condition has upon important activities of daily living and pastimes such as reading. I am further involved in projects which use data obtained from post-mortem examinations in order to shed light on the pathological processes underlying different types of dementia. Finally, I am conducting neuropsychological assessment for a study which uses a novel brain imaging technique called Diffusion Tensor Imaging (DTI) in patients with inherited Alzheimer's disease.

4. What do you think people with

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dementia should expect from research in the next 10 years?

In general, large clinical trials will show advances in the development of new treatments. We will also see improvements in the accuracy of recognition and diagnosis, and in the ability to identify people at risk of developing dementia.

Regarding our research in PCA, our findings will lead to improvements in recognition, diagnosis and management of patients with visual problems secondary to neurodegeneration. We will improve information that is available to patients and their families both in terms of explaining an individual's problems and the prognostic information provided. We will gain a better understanding of which aspects of visual dysfunction contribute to impairments experienced in everyday tasks which will facilitate the subsequent design and implementation of clinical and behavioural interventions which improve quality of life (e.g. reading aids). Finally, our findings will also help to understand

the un-recognised visual problems experienced by people with other forms of dementia.

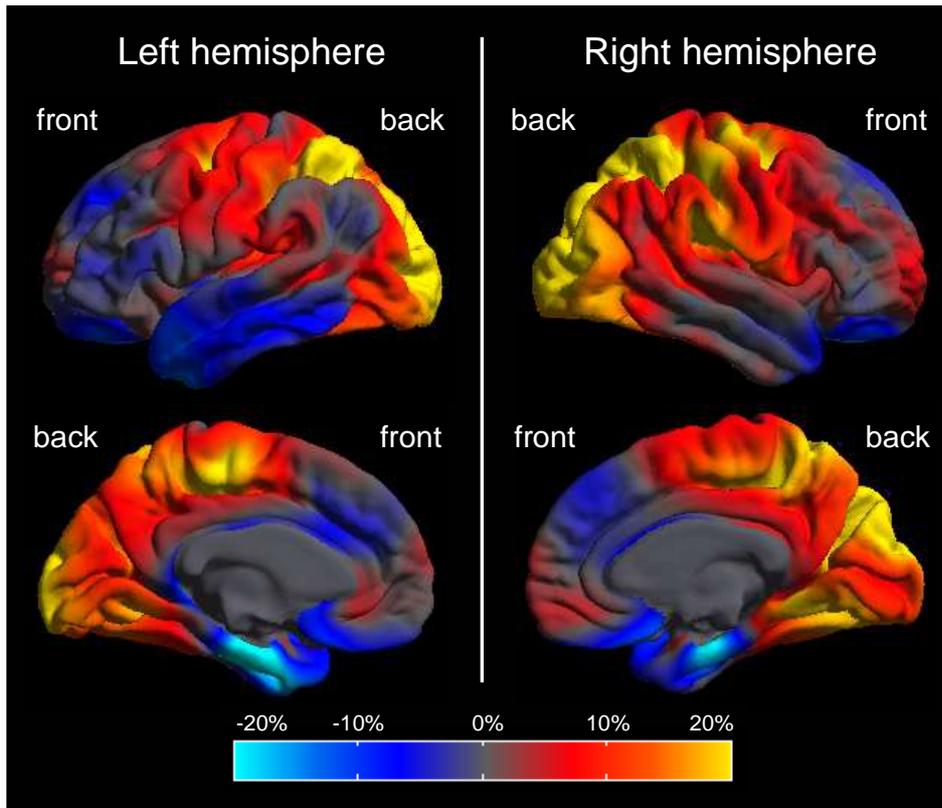
5. What needs to be in place for this to happen?

The future of dementia research relies on the availability of trained scientists and funding. It is further of great importance to make research findings available to the public and to incorporate these into everyday practice. The continuous commitment and support from patients and carers and their involvement in research studies are further vital for research projects to take place.

6. What interests do you have outside of your research?

I enjoy reading both English and German literature, and I am particularly enjoying the wide range of exhibitions and facilities available in London. I am also a keen traveller and in quiet moments I enjoy playing the guitar.

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This picture shows a comparison between the brains of people with PCA and typical Alzheimer's disease. The warm colours (yellow-red) show where people with PCA have lost more brain cells than people with typical AD (i.e. in the visual areas at the back of the brain). The cold colours (light-dark blue) show where people with PCA have lost less cells than people with typical AD (e.g. the front of the brain). The top row shows the outer surfaces of the brain, and the bottom row the middle surfaces.