

PCA SUPPORT GROUP

Newsletter

Welcome to the PCA Support Group Newsletter Issue 10, February 2011

Welcome to the latest edition of the PCA Support Group.

We enjoyed a slightly different structure to our last meeting in November, with a talk about research in PCA and a questions and answer session with Prof Martin Rossor before lunch, and a choice of musical or discussion activities after lunch. We are particularly grateful to the players from the City of London Symphonia for coming along to share their enjoyment of music making in such an accomplished yet relaxed environment. Photos of the musicians can be found on page 3, with information about the whole meeting in the minutes at the end of the newsletter. Sincere thanks to Celia Heath for her diligent work keeping a track of the topics discussed for the sake of those unable to attend the meeting in person.

The next two support group meetings will be on **Friday 18th March** and Friday 1st July 2011. The venue for these meetings will again be Conway Hall (please see directions overleaf).

Also in this newsletter: reports from a special 'dementia and sight loss' event; travel insurance dilemmas; and the appointment of a dedicated nurse adviser.

Additional Carers' Meeting – 20th May

There will be an additional carers' meeting on Friday 20th May at 1.30pm in the Dementia Research Centre. This meeting is primarily for carers of people with PCA, and provides an opportunity to discuss nursing, social care, residential and end-of-life issues. The meeting is targeted mainly but not exclusively at carers, and especially carers of people with PCA who are no longer able to attend the main support group meetings in person, or who have passed away.

Next PCA Meeting: Friday 18th March 2011 (RSVP to Jane or Seb)

11am - 1pm (half hour coffee break/snack lunch included)

Conway Hall, 25 Red Lion Square London WC1R 4RL

This meeting will include a review of the symptoms of PCA for new members and discussion about the impact of PCA upon your relationship with family, friends and colleagues.

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

PCA SUPPORT GROUP Newsletter



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 or to make your own contribution to the running costs of the PCA Support Group, please contact the Foundation on 020 7829 8724.

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)

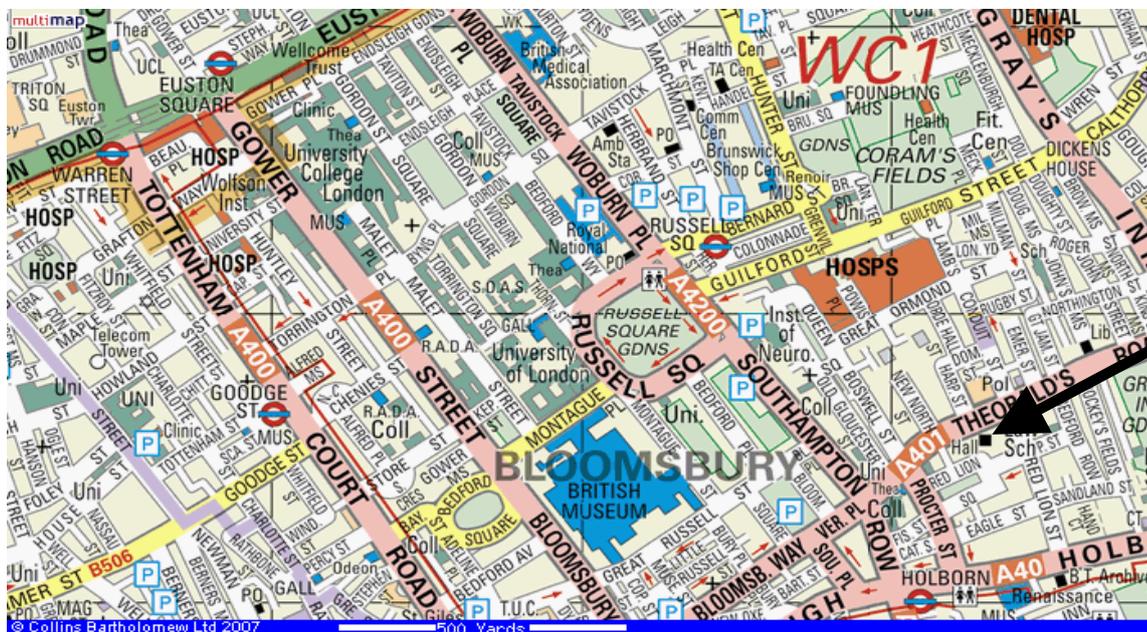
London Buses Infoline: 020 7222 1234

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.



PCA SUPPORT GROUP Newsletter

Appointment of dedicated support group Nurse Adviser



We are very pleased to announce the appointment of Jill Walton as a Nurse Adviser to the PCA Support Group and other similar groups run by the Dementia Research Centre (DRC).

Jill is a registered nurse by training and worked in the Dementia Research Group at St Mary's and the National Hospital between 1993-1996 whilst completing her MSc in Gerontology. More recently Jill has been working for the Pick's Disease Support Group (PDSG), a similar but much larger organisation to the PCA group, which works with people with progressive behavioural problems across the country. As a result Jill comes to us with a wealth of invaluable experience.

This appointment marks something of a departure for the Myrtle Ellis Fund, which now becomes the umbrella fund for all of the support groups run from the DRC, including

the PCA group, the longstanding Primary Progressive Aphasia (PPA) support group for patients with language and communication difficulties, and the newly-formed Familial Alzheimer's Disease support group, which works with individuals with or at-risk from the rare, directly-inheritable forms of Alzheimer's.

In addition to helping with the planning, fundraising and organisation of the groups, Jill will also be working with us to try to increase the availability of specialised support group care to individuals with PCA, PPA and FAD across the UK. Currently all of our meetings are held in London, and whilst many group members travel long distances to be present, many others are unable to attend. We envisage a role for our support groups in enabling people living with these conditions to be in touch with others within their local or regional communities who share similar experiences and challenges. The PDSG has shown this is possible, co-ordinating multiple small local meetings in many regions of England, Scotland and Wales. It is a significant challenge, but one that we will try to tackle over the coming months and years.

Jill is looking forward to meeting many of you at the next meeting on 18th March. We are sure you will all make her very welcome.

PCA SUPPORT GROUP Newsletter

Vision day

In December, Tim attended an event called “Dementia and Sight Loss”, a day conference for policy makers, commissioners and practitioners run by the RNIB, Alzheimer’s society, ARUP and the Thomas Pocklington Trust. He’s written a short report below.

This event brought a range of people together to think about the relationship between dementia and sight loss, to inform each other about their experiences and to learn how we can improve care. Although the focus was on all forms of sight loss in people with all forms of dementia, the topics discussed were very relevant to people with Posterior Cortical Atrophy. One of the talks that stood out for me was from a member of the RNIB who told us about “low vision officers” who can visit people’s homes to help them make it safer, give advice about how to prevent falling and how to get around outside. Another was given by Graham and Susan Doggett about their journey to getting a diagnosis of PCA, and gave some advice to people working with those with sight loss - particularly to speak to them so that they can know who you are.

Other speakers included a lecturer in visual neuroscience emphasising the importance of regular eye tests and wearing the right

spectacles. Although unfortunately this can’t rectify the visual problems that PCA causes, it is important to give the best chance. Finally there was a talk about the environmental changes that could be made in people’s homes and care homes. The importance of good lighting, use of colour and contrast were highlighted.

This conference gave a chance to talk to opticians and ophthalmologists about the problems in diagnosing PCA, something that has come up in previous support group meetings. The people I spoke to felt that opticians would be able to help in the diagnosis, and that an article in their continuing professional development journal would raise awareness of what to look out for. Sebastian and I hope to write an article for this journal, and for ophthalmologists, outlining the signs and symptoms that should lead the practitioner to suspect PCA, and differentiate it from other possible causes of visual problems. Professor Rossor has kindly offered to help us create a video demonstrating the techniques for assessing and identifying symptoms of PCA which will hopefully then be published online, allowing opticians and ophthalmologists who may not have encountered someone with PCA before to recognise it. Hopefully these articles and videos may raise awareness of PCA

PCA SUPPORT GROUP Newsletter

amongst those who are in the best position to identify it early, potentially reducing the time taken for people to reach the correct diagnosis.

Making music

...with players from the City of London Symphonia (CLS)



Travel dilemmas

One of the issues discussed at the previous support meeting was obtaining and selecting travel insurance for foreign travel, and how this might be affected by having a diagnosis of PCA. Many policies don't cover claims arising from a pre-existing medical condition, which could mean that any claim

linked to PCA would not be covered. Policies that do not have this clause often have higher premiums.

We spoke to one member of the support group who told us that the major insurers tended to refuse cover for someone with PCA, but there are a few smaller companies that may offer cover. She said that although PCA doesn't always fit into the boxes provided for medical issues, there is always a clause requiring you to disclose any relevant information that you have, so it's best to make sure to include the diagnosis of PCA. One should also be wary about having different policies for you and your partner as non-disclosure of information about your partner could make a claim unsuccessful in some circumstances.

Overall it seems that honesty is the best policy, unfortunately the cost of insurance can be large, but there is peace of mind that you will be covered if it's needed. Our group member suggested that a few examples of companies that could be worth a try are Able 2 Travel, Arch and Free Spirit but different members have had varying success with them.

This is an ongoing issue so we would be interested to hear about your experience of obtaining travel insurance, and if you have any advice that could be shared with the group please do get in touch.

PCA SUPPORT GROUP Newsletter

Meeting minutes

Support Meeting 19 November 2010

Welcome: Seb. Crutch welcomed members and outlined the Agenda of our 1st meeting under the new format.

1. An update on current research by Manja Lehmann.
2. Coffee Break with lunch. There was a box for contributions towards the cost.
3. A choice of activities: Either,
 - a) The chance to listen to members of the City of London Symphonia playing and to join in a musical activity session.
 - or, b) The chance for carers to make contact and compare notes.

Matters arising:

1. Re the difficulty other health professionals have in explaining treatment and giving instructions to PCA sufferers in hospital. Jane Douglas has written Notes for Hospital Staff on the Admission to Hospital of PCA Patients.
2. Celia Heath has volunteered to take minutes. We still need a Social Secretary to arrange lunches and possibly other events after meetings.
3. Many members live far from London. Your experiences of travel to meetings (also generally when travelling) would be valuable and could be posted on the Web Site.
4. We are sorry to hear of the recent deaths of Gerald Heath and Greta O'Brien and extend our sympathy to their families
5. Riitta Kukkastenvehmas outlined a new initiative to set up a support meeting for Carers of PCA Sufferers whose condition is too far advanced for them to attend meetings, along with Carers recently bereaved. Celia Heath spoke briefly about her experiences of bereavement and about what such a group would mean for her.
6. There was a call for suggested topics for the Spring Meeting.
7. The Myrtle Ellis Fund is supporting research into early diagnosis of PCA. There has been a big grant from the Alzheimer's Association. Tim Shakespeare and Keir Yong are involved in this research and were happy to answer questions over lunch and during the second session of the meeting.

Update on Current research by Manja Lehmann.

8. Manja thanked those who have been part of current research. Her talk included explanations of the following areas of research. We are most grateful to her for her clear exposé of the slides relating to the following areas.
9. How paper and pencil tests highlight and measure areas of loss in memory, language and perception. Please be patient with these, they are a valuable tool in plotting the progress of the disease! These tests show the implications of the patient's current condition for social interaction and are not "needling the things found difficult" by PCA patients: we all have to cope with this feeling sometimes!
10. There have been considerable advances in the use of computers to monitor and interpret brain scans. She explained how the differences in PCA and classical Alzheimer scans are now clearer, since physical changes in the affected areas of the brain show up more effectively. The ongoing drive to diagnose more accurately and hence to preserve the quality of life, language and behaviour for longer is not yet perfect but there is significant progress.
11. Participation in research opens up new directions. For example, how letters are perceived: Newspaper headlines cannot be read by some patients, who can read the smaller text of the article successfully. Hence enlargements do not necessarily help, since patients cannot perceive the complete letter in one "snapshot". The use of computerised cameras to record and track eye movements is fuelling this research. It is hoped that it will soon be available to support ophthalmologists in the diagnosis and testing PCA patients.

PCA SUPPORT GROUP Newsletter

12. Sue and Graham Doggett will be having talks with Ophthalmologists shortly and would appreciate hearing from members about their experiences.

13. It was clear from comments from the floor that PCA sufferers use a variety of visual prompts to recognise faces and to understand the spoken word which often needs to be reinforced by visual gestures.

Questions to Martin Rossor

- *Can a trauma trigger PCA?*

We don't know. Head injuries are "bad news" and may trigger or facilitate Alzheimer's and similar diseases (e.g. in Mohammed Ali).

- *Why do professionals use both PCA and Alzheimer's in their terminology?*

Professionals do tend to slip between the two terms. "Alzheimer's" tells us about proteins in the body and how cells die. "PCA" describes loss of cells at the back of the brain and can be triggered by other forms of disease.

- *When does PCA start? What predisposes people to get it earlier or later?*

Recent evidence suggests changes in the brain may precede the first symptoms of Alzheimer's disease by 10 years or more. We don't yet know what predisposes people to develop PCA. Some studies suggest that one of the genetic factors (so called Apolipoprotein E4) for Alzheimer's disease is in fact present less often in PCA than in people with typical Alzheimer's.

- *When is it beneficial to stop drug treatment?*

There is a longstanding and ongoing discussion parallel with Parkinson's disease practice. Any negative side effects which lead to cessation of treatment are usually clear within 2 to 3 weeks. Those who are being helped by drugs should continue with them.

- *There is a difficulty of diagnosis of PCA by GPs and other professionals. Is a diagnosis template possible to point non-specialists in the right direction?*

People freeze when there is a suspicion of neurological decline. There is a need to alert more opticians to the possibility that disease may be in the cortex rather than the lens. PCA sufferers may be able to read small print but unable find the way back to the door. Seb Crutch suggested that guidelines of this kind could go on the website. A brief video might help. Organisations such as YouTube might also be vehicles for such knowledge.

- *What of the diagnosis of PCA in dyslexics?*

The use of multiple tests (e.g. shapes) is helpful; however professional practice is to go by the overall picture.

- *Can PCA be caused by classical Alzheimer's or Lewy Body Dementia?*

Yes. It can also occasionally be caused by a condition called corticobasal degeneration.

Napkins

PCA sufferers have problems of keeping themselves clean when going out socially to eat. Jo Barbary and Tina Stevens have developed a special napkin which elegantly covers the chest and the lap. A kind of double napkin which tucks under the chin and is secured at the waist.

Musicians from the City of London Symphonia

The majority of attendees chose this option which was encouraging and entertaining – as we had hoped it would be. Katie (viola), Rachel (cello) and Alison (flute) first played a short piece followed by very entertaining short talks on the playing and orchestral practice of their instruments. This was followed by short demonstrations of individual playing.

With the help of Gillian and Marika we found ourselves building up to a surprise rendering of Daisy Daisy! This was followed by a further piece in which everyone used real percussion instruments.

Discussion Option

A smaller group preferred the quiet of this option and the chance to talk to Tim and Keir.