

Welcome to the PPA Support Group Newsletter. We extend a warm invitation to as many people as are able to join us at the next support group meeting on June 5th. Please see overleaf for details of the agenda, and kindly confirm your attendance to Laila Ahsan at r.ahsan@ucl.ac.uk or on 020 3448 3652.

We have had a full support group meeting and a carers' meeting since the February newsletter was circulated, and I hope that you found both of interest and benefit.

Several support group members also attended the all-day Annual Seminar hosted by the Frontotemporal Dementia Support group on March 4th. The input from the guest speakers was of course an important part of this event, and of particular interest to PPA support group members was the presentation by Jackie Kindell, Speech and Language Therapist/Clinical Research Fellow at Pennine Care NHS Foundation Trust/University of Manchester. In some ways this was a follow up to the one she gave to our group in December last year. Jackie's talk and those of the other presenters will shortly be available for audio download via the Frontotemporal Dementia Support Groups website www.ftdsg.org and by clicking the Annual Seminar button on the menu on the left hand side of the page.

Additionally, we can make Jackie's recently published case study 'Living with Semantic Dementia: A Case Study of One Family's Experience' available to anyone who would like to receive it, by email or hard copy.

Please do let me have any thoughts regarding agendas for future meetings, or indeed feedback regarding how we can make our meetings as beneficial as possible.

I look forward to seeing familiar faces and welcoming new people alike to the meeting on June 5th!

Jill Walton 07592 540 555 or jill.walton@ftdsg.org

New Websites

Three new websites have been launched recently, and may be of interest to our members:

- The key goal of a new website, set up by Jon Rohrer and colleagues, is to provide jargon-free research updates on FTD for all people in the FTD community.

www.ftdtalk.org

- YoungDementia UK has launched a new website to offer information aimed specifically at young people who have been diagnosed with young onset dementia and their family members, friends and professionals. It is full of advice and information on living well with the condition as well as inspiring stories, many written personally by people who are living with young onset dementia. It also includes a young onset dementia specific support service listing, and a resource section full of useful blogs, books and websites relating to young onset dementia. UK Director, Tessa Gutteridge said, "Having spent our first 15 years developing a range of young onset dementia supports in Oxfordshire, it's high time, we thought, to move up a gear. We want to make more use of what we know and contribute to a better quality of life for people with young onset dementia. We hope our new website will be our first step to providing support for people on a national basis." We hope to develop the website further in the coming months and would love to know what you would like to see added. To share any thoughts you have about our website, please email web@youngdementiauk.org

www.youngdementiauk.org

- There are also several websites and publications which focus specifically on the needs of children and teenagers when coming to terms with a diagnosis of dementia in a family member or friend. Most recently launched is 'AFTD Kids and Teens' (www.aftdkidsandteens.org). Launched by the Association of Frontotemporal Degeneration this resource is designed to meet the unique needs of children and teenagers who have a parent or friend with a diagnosis of FTD.

www.aftdkidsandteens.org

- A fourth website which may also be of interest is the longer standing IMPACT, which is a site offering resources, support and updates on collaborative PPA research. Visit the site at:

<http://www.ppaconnection.org/>

How would I know? What can I do?

A new guide for carers which provides advice on how to help with pain and distress in people with dementia, has been published by NCPC as part of the Prime Minister's Dementia Challenge.

'How would I know' offers a range of advice to help carers and health and care professionals identify whether someone with dementia may be in pain or distress, advice on what may be causing this and a range of possible solutions. It follows on from NCPC's 2011 publication, *Difficult Conversations for dementia*, which provides advice on how to talk to people with dementia about their end of life wishes.

Simon Chapman, Director of Policy and Parliamentary Affairs at the National Council for Palliative Care said:

"When people with advanced dementia experience pain or distress they may behave in ways that people caring for them find difficult to cope with, and also find it hard to say what is troubling them. This is why it is so important to know how to spot signs of pain or distress and what can be done to help them. With almost half of us having a close friend or family member with dementia we really hope that this new guide provides valuable assistance."

Alistair Burns, the National Clinical Director for Dementia said:

"Too often pain or distress in people with dementia may be overlooked or viewed as an unavoidable part of their illness rather than something that can be alleviated. This excellent new guide from the National Council for Palliative Care will be incredibly helpful in helping people to better understand the realities of living with and caring for somebody with dementia".

You can download the leaflet from the website http://www.ncpc.org.uk/sites/default/files/How_Would_I_know.pdf
Alternatively it is available to buy from shop.ncpc.org.uk

BMJ Patient Partnership Strategy Recruiting Peer Reviewers

The BMJ is currently inviting people to join its panel of patient reviewers, providing a perspective on the patient focussed aspect of particular manuscripts, drawing on your experience of a particular topic, condition or intervention.

A key part of this process will involve peer reviewers being sent selected research papers, analysis and educational papers to review. The editorial team at the BMJ believe (and are setting up a research project to assess this) that your opinions on papers will add useful insights/perspectives which will complement the much valued expert opinions we get from medical, scientific and methodological reviewers.

Please contact Jill for details of who to get in touch with at the BMJ if you are interested in becoming a reviewer.

UCL feature in the Governments dementia agenda

In addition to the recent visit to UCL by Health Secretary Jeremy Hunt, UCL has received more than £8.5 million as part of the £20 million made available by the government for research into dementia. 'We desperately need to find better treatment for these devastating diseases – and at the same time we must improve

the care and support for the growing number of families that will be affected' says Nick Fox, Professor of Clinical Neurology. Prof Fox's work focuses on diagnosis and treatment for dementia while other projects at The National Hospital for Neurology and Neurosurgery and the Institute of Neurology are tackling dementia in a range of ways. 'Research at The National, the Institute and elsewhere at UCL covers the whole spectrum from basic science to health service research – and research into dementia requires investment across this spectrum', explains Prof Martin Rossor, director of the National Institute for Health Research's dementia and neurodegenerative research network.



Professor Nick Fox (left) and Dr Selina Wray with health secretary Jeremy Hunt at the UCL Institute

Forthcoming meetings

Full PPA Support Group Meeting: Thursday 5 June 2014: Wilkins Haldane Room, UCL, Gower St, London, WC1E 6BT. 11am-2pm. Coffee will be available from 10.30am. Speech and Language Therapists Luke de Visser and Rosemary Townsend will explore communication strategies to use with people with PPA which may increase success and enjoyment of conversation.

Hertfordshire regional support group meeting: Friday July 11 2014: 11am-12.30pm at The Junction, Christchurch C of E, The Common, Chorleywood, WD3 5SG. An informal event providing opportunity to meet others with PPA.

Dates for future meeting will be circulated as soon as they are confirmed. Please contact Jill Walton for further information on any of the above. Jill.walton@ftdsg.org **Tel 07592 540 555**