

Welcome to the PPA Support Group Newsletter. I hope that the content of the newsletter is of interest to all who read it; however, I am acutely aware of the difficulties in producing information which meets everyone's needs and in a style which they are comfortable to embrace. Please do let me have any suggestions regarding the format of the newsletter and indeed any contributions you wish to make.

Autumn 2014 was a busy time with events culminating in a support group led initiative to raise awareness of young onset dementia, and PPA in particular, at an event in the House of Lords on December 9th. Baroness Sally Greengross [crossbench (independent) member of the House of Lords and co-chair of the All-Party Parliamentary Group on dementia] and Professor Nick Fox [director of the Dementia Research Centre, UCL] welcomed an invited list of over 130 guests on our behalf, including support group members, MPs, Peers and a range of professionals from across the social care and charity sectors. The primary objective of the event was to have key players leave with an understanding that dementia is not only about memory loss and that it affects younger people too. Everybody who attended the event was provided with hard copy information about young onset dementia , including PPA specifically, as well as being presented with data in the form of a usb memory stick to take away and circulate within their professional domain. This event was a support group initiative and one which I hope you regard as a platform from which your views were represented. We are grateful to Alzheimer's Research UK [ARUK] for their assistance in some of the administrative tasks involved with the event. We were also grateful to support group members for their contribution to the case studies described on the day and attendance at the event. Of particular value was Channel 4 news coverage of the event , including an interview with Prof Nick Fox and a feature on frontotemporal dementia generally. Please go to https://www.ucl.ac.uk/drc/support-groups/house_of_lords for more information about the event.

Prof Fox, Baroness Greengross and Malcolm Walker, CEO Iceland Foods at the House of Lords event



We were particularly grateful to Anna Volkmer who joined us at our October meeting and shared her specialist speech and language therapist expertise with the support group. A summary of Anna's presentation is provided later in this newsletter and an audio and visual recording of this presentation, and indeed of other presentations made at support group meetings is available at <http://www.ucl.ac.uk/drc/support-groups/PPA-support-group>

May I take this opportunity to invite you to the forthcoming **carers meeting on Thursday 26 February 2015**. The venue for this meeting is Wilkins Front Quadrangle Events Venue which is located just in front of the usual Wilkins Building, UCL, Gower St, London WC1E 6BT. The meeting is scheduled from 11am -2pm, with coffee available from 10.30am and lunch provided. We are expecting 2 guest speakers at this meeting;

Angela Sherman will be talking about Continuing Health Care funding applications. You can find out more about the organisation she directs at www.caretobedifferent.co.uk

Dr Eneida Mioshi: Department of Psychiatry, University of Cambridge School of Clinical Medicine, who will be talking about coping strategies for carers.

This meeting is open to carers, family and friends of people affected by the various diagnoses that our support groups seek to reach. As such we will be welcoming members from the Posterior Cortical Atrophy support group, the Frontotemporal Dementia support group, 2 support groups that are dedicated to familial variants of dementia, as well as the family and friends of people affected by Primary Progressive Aphasia at this meeting.

This meeting is in addition to the next full **PPA support group meeting on April 30** when Anna Volkmer has kindly agreed to join us again and provide a more practically based speech and language session. Dr Susie Henley, the research and clinical psychologist affiliated to the Dementia Research centre will also be speaking at this meeting.

In addition, you may be interested in joining us at the **whole day annual seminar hosted by the Frontotemporal Dementia Support Group on March 5 2015**. This event will take place in the Basement Lecture Theatre , 33 Queen Sq, London WC1N 3BG. The agenda can be viewed at www.ftdsg.org and includes expert speakers across a range of FTD related issues including genetic and imaging developments in FTD, caregiver coping strategies, the role of speech and language therapy in FTD and current/future drug treatments. More information is available via the website or from jillwalton@virginmedia.com tel. 07592 540555. I look forward to seeing you at one of these meetings or indeed being in contact with you in whatever capacity is most appropriate.

Jill Walton

Anna Volkmer is a highly specialist speech and language therapist, working at South London and the Maudsley Hospital. She presented at the British Aphasiology conference last year, and has a long standing interest in PPA having written and published on the subject. She has provided the following summary of her presentation at the October 2014 support group meeting:

Recently I had the pleasure of being invited to speak at the PPA support group on the 9th October 2014. My presentation was entitled "Growing ideas: How can speech and language therapy help your conversation?" I am currently in the middle of a research project, funded by Guys and St Thomas' Charity and based in the neuropsychiatry memory disorders clinic in the South London and the Maudsley NHS Trust. Lots of speech and language therapists report they frequently use communication training with people with PPA and their families.

There is lots of evidence to support this type of communication training with people who have post-stroke aphasia but little evidence to support this type of therapy for people with PPA. I have developed a new program called "Better conversations with PPA". I have successfully trialed the program with three couples. I am planning to apply for further funding for a larger study. This will allow me to pilot the program with a larger group of people with PPA.

At the presentation I was able to speak to the group (run a focus group) to get some advice on developing the program. People at the group made lots of useful comments. The group felt the program would be useful and made suggestions including that the program needs to be flexible enough to be delivered at home or in an outpatient setting, that the program should include information to plan for the future and to direct people to where they can get support after therapy finishes e.g. groups etc. The advice was really useful in supporting the development of the program and my application for further funding for the research. Fingers crossed we are successful and I will look forward to feeding back to everyone about how it progresses. If anybody had any unanswered questions, or thought of any additional comments please feel free to contact me on anna.volkmer@slam.nhs.uk.



YoungDementia UK Steering Committee

Jill is delighted to have been asked to represent the support groups on a new steering committee created by the charitable organisation YoungDementia UK.

The committee aims to create a national highly visible identity/focus for young onset dementia (YOD), since there is currently none in place. Its' purpose will be to improve the lives of people with young onset dementia and their families by harnessing passion, energy, experience and knowledge.

With this momentum, we will create effective connections and use these connections to exert a powerful influence over key areas that present a barrier to living fully and well with dementia as a younger person.

By acting with strength and determination, the committee hopes to bring about significant changes that will have a lasting benefit for people living with young onset dementia.

Updated Resource for Healthcare Professionals and Caregivers

Prometheus Books has just released the Third Edition of 'What If It's Not Alzheimer's? A Caregiver's Guide to Dementia.'

Edited by Lisa and Gary Radin, who cared for their husband/father, Neil Radin, this book offers a wealth of information for healthcare professionals and caregivers of someone diagnosed with a non-Alzheimer's dementia, especially FTD.

This expanded edition includes chapters authored by experts from across the US and around the world in medicine, nursing, occupational and physical therapy, community services, hospice, respite, grief and legal and financial issues. In addition to providing current medical information (in lay language) the book is a practical guide to managing the team of medical experts, managing daily care and tending to a caregiver's own needs.

Dementia Engagement and Empowerment Project (DEEP)

The support group is considering joining the DEEP network. The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK and is a network that is growing and becoming more influential.

DEEP is about hearing the voices of people with dementia - and supports groups in which people with dementia have a space to express their views/perspectives.

We look forward to hearing more about the DEEP network at a future support group meeting.

In the meantime:

Watch a short film about DEEP on the [Mental Health Foundation website](#)

Read the report from the first phase of DEEP on the [Joseph Rowntree Foundation website](#)

Go to the DEEP project website: www.dementiavoices.org.uk



RHAPSODY
research and strategy for dementia in the young

RHAPSODY is a European research project aiming to improve care for people with young onset dementia.

Dementia is commonly viewed as a health and social problem of older adults, however it may strike at a younger age. Dementia occurring before the age of 65 is particularly challenging for those affected and for family, carers and healthcare professionals. Existing health and social care structures do not meet the needs of this group appropriately in any country. Specific services for people with young onset dementia (YOD) - including cognitive, physical and behavioural training - are only slowly being implemented. No pharmacological treatment is currently available for most people with YOD. Therefore, counselling and support of family and carers are of outstanding importance.

RHAPSODY will evaluate the policy and information environment that provides the framework for the treatment and care of people with YOD in six European countries. Also, the specific needs of this particular group and their carers will be assessed. Based on this information, RHAPSODY will create an educational, web-based, interactive e-learning programme which is tailored to the needs of carers. The learning course will be tested in a pilot study at three sites in France, Germany and the United Kingdom.

To achieve these ambitious aims, a multidisciplinary consortium of researchers has been assembled representing excellence in the fields of psychiatry, neurology, neuropsychology, neuroscience, health economy, multimedia design and information systems.

The project was launched in April of this year and will last for three years.

(Copied from an article written by Katrina Milecka, RN, BSN [RHAPSODY])

RHAPSODY is a project of the EU Joint Programme. Neurodegenerative Disease Research (JPND). JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. It aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases - www.jpnd.eu

Issues such as those cited above are now receiving a higher profile nationally and internationally through initiatives like the RHAPSODY project.

9th International Conference on FTD - 2014 Thanks to a generous personal sponsor Jill was able to attend the 9th International Conference on frontotemporal dementias, held in Vancouver in Oct 2014. The conference highlighted the development of collaborative global efforts, incorporating a range of scientific, clinical and social presentations as well as a caregiver meeting with a strong network of caregiver associations considering caregiver issues and topics. One of the most striking observations Jill made was the apparent lack of caregiver support groups across Canada. Links with professionals in the field have continued since the event, and Jill is currently working alongside a team in British Columbia, Canada, in respect of a support group initiative for people with PPA. More information about the conference is available at: <http://www.alzforum.org/news/conference-coverage/vancouver-frontotemporal-dementia-conference-shows-awakening-field>

New Service for people with Primary Progressive Aphasia in Surrey - Spring 2015

Dyscover (www.dyscover.org.uk) is an established third sector provider of specialist Speech and Language

Therapist - led, long term support for people with aphasia. Based at Walton on the Hill, near Tadworth, Dyscover's core service is focussed mainly on people with aphasia after stroke. This new course is aimed at people with aphasia as part of a progressive condition, and is designed for couples – the person with the condition together with a carer or family member.

Course details

Six group sessions, spread over 12 weeks - Friday mornings, April to June '15

Led by two specialist Speech and Language Therapists

Small group numbers – maximum of 6 couples

Based at Dyscover's purpose built centre in Walton on the Hill (KT20 7ST)

Combination of information, practical help and peer support

Ongoing group support if required

Cost - Dyscover is a charity which receives no statutory funding. We therefore ask for a total contribution of £40 per couple. If this is problematic, please let us know in confidence.

How do I find out more, or join the course?

Contact Rosemary Townsend at Dyscover by emailing rtownsend@dyscover.org.uk or phone 01737 819419.

You will be invited to meet us at Dyscover for an informal chat between January and March.

**Rosemary Townsend BSc MRCSLT HCPC registered
Manager of Professional Services**



PPA specific updates from the FTD International Conference in Vancouver Dr Jason Warren, Dementia Research Centre, UCL

Two major themes at the recent FTD conference in Vancouver were the links between PPA and other dementia diseases, and the wider repertoire of problems that people with PPA experience. We heard about recent work defining the behavioural problems developing later in the course of PPA, in many ways similar to behavioural variant frontotemporal dementia, and abnormal psychological and physiological responses to emotional signals (including humour and art) in PPA syndromes. Evidence was presented that patients with PPA have problems perceiving and interpreting nonverbal environmental sounds and music as well as speech. There has also been much recent progress in measuring brain white matter pathway changes in PPA syndromes, in aligning the clinical and brain network changes in logopenic aphasia with Alzheimer's disease and in measuring very early changes in genetic diseases that sometimes produce PPA. The conference concluded with an exciting perspective on new leads toward promising therapies that we hope will soon enter trials.

The work of UCL and the Dementia Research Centre was a spotlight of the conference and received much interest on AlzForum, the major North American lay information network in dementia. The projects led in the DRC by Jen Augustus, Camilla Clark, Miriam Cohen, Laura Downey, Phillip Fletcher, Chris Hardy and Colin Mahoney were all presented at the conference and together are suggesting new biomarkers for PPA diagnosis. The work led at UCL by Jonathan Rohrer and the groundbreaking Genetic FTD Initiative (GenFI), involving some 30 centres internationally, was headline news at the meeting and we all hope will provide a platform for taking these biomarkers into future treatment trials.



MEF

MYRTLE ELLIS FUND

supporting rare dementia

The PPA Support Group is generously supported by the Myrtle Ellis Fund, as part of The National Brain Appeal (Charity number 290173). For more information on the work of the Fund or to make your own contribution to the running costs of the PPA Support Group, please contact the Foundation on 020 3448 4724. Alternatively visit <http://www.ucl.ac.uk/drc/support-groups/PPA-support-group> or www.justgiving.com/Myrtle-Ellis-Fund