



Welcome to this PPA Support Group Newsletter. We hope that the content of the newsletter is of interest to all who read it; however we are 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 us have any suggestions regarding the format of the newsletter and indeed any contributions you wish to make.

In the January newsletter, we described the 'raising awareness' event which took place in the House of Lords at the end of 2014. This event was a support group led initiative to raise awareness of young onset dementia, including PPA in particular, with 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] welcoming 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.

We are delighted to share news of new and strengthened relationships with key partners as ongoing outcomes of this event. Examples include a new relationship with the Royal College of Speech and Language Therapists that has resulted in our Primary Progressive Aphasia [PPA] support group members featuring in their recently launched educational/training video [ more details in this newsletter].

May I take this opportunity to invite you to the forthcoming full support group meeting on Thursday July 16, 2015.

The venue for this meeting is Wilkins Haldane Room which is located in the 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 delighted to welcome **Rachel Litherland**, from 'Innovations in Dementia' as a guest speaker at this meeting. Innovations in Dementia is a community interest company that works nationally with people with dementia, partner organisations and professionals with the aim of developing and testing projects that will enhance the lives of people with dementia. Visit <http://www.innovationsindementia.org.uk/> for more information

Further confirmed agenda details will be circulated nearer the time.

I look forward to seeing you at this meeting or indeed being in contact with you in whatever capacity is most appropriate.

Jill Walton

## Better Conversations with Aphasia

'Better Conversations with Aphasia' is a free e-learning resource to improve access to conversation therapy for speech and language therapists/pathologists (SLTs), and for people with aphasia (PWA) and their families.

If you are a person with aphasia, or if your family member has aphasia, you can use it to find out:

- what conversation therapy is
- what other people with aphasia think about it
- whether it is right for you
- other places to go for support and advice about aphasia and conversation.



Access the programme at <https://extendstore.ucl.ac.uk/product?catalog=UCLXBCA>

## Speech therapists giving voice to people with dementia

The Royal College of Speech and Language Therapists (RCSLT) is running the Giving Voice for People with Dementia campaign to ensure that all people with dementia and their families have access to high quality speech and language therapy support when they need it.

As part of our dementia campaign, the Royal College of Speech and Language Therapists (RCSLT) is releasing a series of videos to raise awareness of the communication and swallowing needs of people with dementia.

The series of videos are aimed at those who come into contact with a person with dementia – such as family members, carers, health staff and care home workers.

The videos examine how to recognise the signs of the condition, what life is like for people with dementia, and for their carers and families, while highlighting the role speech and language therapists play in helping those living with the condition and those who support them.

Kamini Gadhok, chief executive of the RCSLT says: “Too few people understand how speech and language therapists help individuals with dementia. This includes supporting those with communication difficulties. It also includes helping people to eat, drink and swallow safely. This prevents malnutrition, dehydration, chest infections, pneumonia and possible hospital admissions. We hope these videos will raise awareness of our role in the dementia pathway and demonstrate that we have a vital place in supporting the care of people with dementia.”



For more information, and to watch the videos, visit

[www.rcslt.org/members/clinical\\_areas/dementia\\_video\\_series](http://www.rcslt.org/members/clinical_areas/dementia_video_series)

## Volunteer for research studies

At the Dementia Research Centre, we have just launched a new programme of research that will help us to understand what happens in the brains of people with PPA – and importantly, how these changes affect cognitive functions like speech and memory. At the support group meeting on April 30th, Professor Jason Warren made the point that we are now in the 'discovery phase' of research into PPA. Over the last few years, significant advances have been made in our understanding but we still have several unanswered questions that need resolving.

We are currently asking people with PPA to spend two days with us in Queen Square, London. The visit would likely include several different components, including psychology testing and brain scanning. All reasonable transport, hotel, and other costs associated with the visit can be paid for from a grant we have to undertake this research programme. We are hopeful that this research will help us to understand about the development of PPA in the brain. Findings could play an important role in helping accurate diagnosis of the subtypes of primary progressive aphasia. It is also our hope that we will be able to use the findings to evaluate the efficacy of new drug treatments as and when they become available. Many of these studies will require comparisons with healthy older control subjects so if you are reading this as a spouse or partner of somebody living with dementia and would like to participate, we would be very grateful to hear from you too.

If you would like to express an interest in being involved, please contact Chris Hardy, a PhD student at the Dementia Research Centre by email at [c.hardy.12@ucl.ac.uk](mailto:c.hardy.12@ucl.ac.uk) or phone on **020 344 83653**.

Our research simply wouldn't be possible without the kind assistance of everyone who participates, and we remain indebted to anyone who is able to give up their time for this purpose.

**Chris Hardy**

Dementia Research Centre, UCL Institute of Neurology



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](http://www.justgiving.com/Myrtle-Ellis-Fund)

## Support Organisations



APHASIA ALLIANCE

Whilst we recognise that the Primary Progressive Aphasia diagnoses often carry a particularly unique range of symptoms, there are support organisations for people with aphasia, which offer information, advice and resources which our members may find helpful:

**Aphasia Alliance** <http://www.aphasiaalliance.org/>

The Aphasia Alliance is not an organisation, but an informal union between different organisations that share a common purpose – to improve the lives of, and support, people with aphasia and their families. The purpose of the Aphasia Alliance is to maintain communication, good relationships and collaboration between organisations focused on Aphasia.



**Speakability** <http://www.speakability.org.uk> Helpline 080 8808 9572

Supports people with aphasia and their carers through its Information Service, national network of Self-Help Groups and programme of activities.

## Message in a Bottle

The Lions' 'Message in a Bottle' scheme is a simple idea designed to encourage people to keep their personal and medical details on a standard form and in a common location – the fridge!

The scheme is free to the user. It can serve to inform the emergency services about you and your emergency contacts. By providing information about your diagnosis, indicating whether you have special medication or allergies or not, it is a potential life saver and provide peace of mind to users and their families and friends.

Bottles which are free of charge can usually be found in your local Chemist or Doctors Surgeries. Thanks to a number of other organisations, you may also find that you can obtain one through your nearest Neighbourhood Watch Group, Age UK, Council Offices, Housing Associations and many other places including police stations. If you are unable to find a Bottle, please contact your local Lions Club.

If you have any difficulties in finding your nearest Club, or would like to know more about this scheme, please E –mail: [mdhq@lions.org.uk](mailto:mdhq@lions.org.uk) or [miab@lions.org.uk](mailto:miab@lions.org.uk) or telephone: 01768 863546



## DISCLAIMER

Please note that you assume full responsibility and risk when attending support group meetings, and also in the use of the information contained on our website, in our newsletters and at support group meetings.