primary progressive aphasia

PPA SUPPORT GROUP

www.dementia.ion.ucl.ac.uk

September 2015 NEWSLETTER

Welcome to the September 2015 PPA Support Group Newsletter. We hope that the content 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.

We were delighted to welcome Dr Charles Marshall, Clinical Research Fellow, Dementia Research Centre, UCL to speak about **Emotion Recognition in PPA** and Rachael Litherland, from Innovations in Dementia CIC who shared her experience of **The Dementia Engagement and Empowerment Project – DEEP ,** at the July meeting. Summaries of their presentations are provided overleaf.

Behind the scenes here at UCL, significant and ongoing effort is being dedicated to securing and expanding the infrastructure upon which the support group depends for its ongoing function. With funding kindly supported by the Myrtle Ellis Fund and a plethora of your own fundraising efforts, we are able to continue existing support group activities as well as begin to look to new and expanded provision. We are currently in early stage negotiation with significant funders with a view to establishing extended regional networks and improved access to information for our members. We will of course update you in due course as these exciting possibilities develop. We are pleased to announce that we are collaborating with colleagues at Buckinghamshire Healthcare NHS Trust in the provision of a regional support group meeting in Sept 2015. See the 'Forthcoming meetings' section of this newsletter for more information and do join us if you can.

On a more scientific front, the Alzheimer's Association International Conference took place in Washington USA, during July 2015, with a number of UCL Dementia Research Centre [DRC] colleagues attending and contributing to that event. Please see Chris Hardy's contribution to this newsletter for a summary of the PPA specific research findings he was able to take away from the conference.

May I take this opportunity to invite you to the forthcoming support group meetings as listed on the back page of the newsletter. I look forward to seeing you at these meetings or indeed being in contact with you in whatever capacity is most appropriate.

Jill Walton

World FTD Awareness Week—October 4-11 2015

This year, for the first time, countries across the globe will observe World FTD Awareness Week. From October 4th -October 11th, 2015, FTD support organizations in at least 10 countries will collaborate on many exciting events and outreach activities. As October fast approaches, we want to encourage support group members to embrace World FTD Awareness Week. There are many ways to participate.

The following are just some of the events being planned around the world:

* FTD Education Forums and Conferences
* Grassroots fundraising and awareness events, which offer people a chance to learn more about FTD and at the same time contribute to the momentum of work to fight FTD.

Examples of grassroots events include hosting FTD "Food for Thought" Events (such as dinners, coffee mornings ,cake sales and other food-related activities); fun runs or bike rides, jewellery/art auctions, FTD documentary film viewing events and social and mainstream media FTD awareness campaigns.

FTDSG website details can be accessed at http://www.ucl.ac.uk/drc/ftdsupport and our just-giving sites are easily accessible at https://www.justgiving.com/FTDSG/ and www.justgiving.com/Myrtle-Ellis-Fund .

Please let us know [jill.walton@ucl.ac.uk] of events you host during World FTD Awareness Week. Send us your photographs and stories...however big or small, and we look forward to taking this initiative forward on a yearly basis.

July 16 PPA Support Group Meeting: Presentation Summaries

Dr Charles Marshall : Emotion recognition in PPA

Charlie first gave an overview of PPA – explaining that proteins that misfold and form tiny clumps are what damage nerve cells in the brain. In PPA the cells are normally damaged in the left hand side of the brain, where language is processed: different areas cause the different diagnoses within PPA (SD, PNFA, LPA). However, we still don't fully understand how these misfolded proteins cause cell death and why particular areas of the brain are affected in different syndromes. Research focuses on more accurate and early diagnosis so that when medications are developed, they can be matched to the people they will work best in. Development of medications involves a long pathway of examining cells in a petri dish, to looking at effects in mice before we can then try anything in humans.

Charlie's research focuses on finding out which damaged parts of the brain cause specific symptoms in dementia. This is particularly relevant to conditions such as PPA because misfolded proteins are found all over the brain, but only certain areas shrink causing very specific symptoms to develop. Knowing more about this may help inform us about how the disease develops, and how we can distinguish between the different syndromes more accurately. Charlie's work looks at emotion processing, which we know can be affected in some forms of dementia. Some neuroscientists think that we often understand emotion by unconsciously and involuntarily mimicking what we see – for example if we see someone who is sad, our facial muscles start to form a sad expression on our own faces, which helps us to empathise and identify that person's emotion. In healthy young people, he found that frown and smile muscles react to seeing facial expressions before people have even decided what emotion they saw – good evidence that we interpret our facial muscle reactions to make sense of emotions. This will also be a useful way of measuring emotional reactions in syndromes such as PPA when people find it difficult to express their answers verbally, or to understand the questions being asked. He also found that people's awareness of their own heartbeats (again, being connected to your body) related to how well they could identify emotions. He wants to try this idea in people with PPA and another form of dementia that affects behaviour (behavioural variant FTD) – will this affect people living with PNFA, who have difficulties in the signals between the facial muscles and the brain? Or is it the interpretation of the facial muscle movements that may impair emotion judgement? Charlie will look at people's brain scans to see if there is any link between these functions and a certain area of the brain. He also wants to delve further into other emotional stimuli such as sounds and music.

Rachael Litherland The Dementia Engagement and Empowerment Project – DEEP

Rachael, who works for Innovations in Dementia, presented the work of DEEP (Dementia Engagement and Empowerment Project). The main aim of this project has been to increase the voice of people with dementia so their opinions, experiences and hopes can be heard. Her organisation teamed up with the Joseph Rowntree Foundation and Comic Relief to start a project to provide links between small community groups so they would gain power in numbers. They started off with 12 regional groups and have now expanded to around 60 – totalling around 1,200 individuals with dementia. This way these combined groups can have more influence over things that affect them, such as policy and educating professionals. People with dementia are experts by experience and are the best people to ask about what it is like living with this condition! These groups have worked on a variety of projects, such as advising the House of Lords, providing more pre-diagnostic information and educating people that dementia is not just about memory. Some of the members have been involved in making films, and using technology that allows responding in real time to give quotes about news events related to dementia; they have also been advocating for a change in the language the mainstream media use when talking about dementia. The DEEP project helped people to find something they want to change, and join up to gain a greater influence in making the change happen. Rachael noticed how these groups have gained confidence over time; DEEP has worked to connect smaller groups and fill in geographical gaps, but otherwise most of the ideas and work have come from the groups themselves.

Our rare dementia support groups are looking to get involved by perhaps making a short film and producing some information booklets detailing the personal journey to diagnosis and life with a rarer diagnosis of dementia. If you'd like to get involved please let Jill know at jill.walton@ucl.ac.uk

The Importance of Dementia Support Groups

The following letter is a summarised version of the submitted on-line rapid response article which was subsequently published as a letter in the BMJ on July 23 2015.It forms part of our ongoing commitment to promote awareness and understanding of the unique challenges faced by people embracing rarer diagnoses of dementia.

Robinson and colleagues refer to non-Alzheimer diagnoses of dementia. These less typical diagnoses pose complex problems for those with the disease and for their families, friends, and carers. When these forms of dementia affect younger people the problems can be even more challenging.

When asking the question: "What constitutes best practice in early intervention?" we must acknowledge that people living with a diagnosis of dementia generally do so in the community, supported by informal caregivers typically made up of spouses, relatives, friends, and neighbours.

Support groups have an important role to play in offering people the opportunity to acknowledge their diagnosis and its consequences alongside peers in a similar position. Apart from the social and emotional benefits of participating, disease specific support groups enable the exchange of valuable professional and personal information and advice. They are also gateways to understanding and sharing, enabling people to cope better and for longer.

Support groups can extend to provide supportive networks across telephone, internet, and social media platforms, as well as providing the opportunity for one to one peer relationships that are continued outside of formal meetings.

Directing patients and their families to such sources of advice and support forms an important part of the post diagnosis consultation. "Rare dementia support" offers information, advice, and support to people affected by frontotemporal dementia (behavioural variant and primary progressive aphasia), posterior cortical atrophy, familial Alzheimer's disease, and familial frontotemporal dementia.

Distinct from the personal and individual benefit to group members, support groups also fulfil an advocacy role on behalf of their members by raising awareness and representing the needs of people within the group by contributing to debates and discussions at a more strategic level.

Jill Walton registered general nurse, Natalie Ryan clinical research fellow, Sebastian Crutch professorial research associate, Jonathan D Rohrer honorary consultant neurologist, Nick Fox professor of clinical neurology, Dementia Research Centre, Institute of Neurology, London WC1N 3AR, UK

[Full response at: www.bmj.com/content/350/bmj.h3029/rr-0. 1 Robinson L, Tang E, Taylor J-P. Dementia: timely diagnosis and early intervention. BMJ 2015;350:h3029. (16 June.)]Cite this as: BMJ 2015;351:h3875 ©

Forthcoming Support group meetings:

Full Support group meetings are scheduled for : **Dec 3 2015, 21 April 2016 and 21 July 2016.**

In addition to the full support group meetings listed above, and by request of support group members, we also facilitate 'carers' meetings for carers, family and friends of people affected by a rare dementia diagnosis.

Carer meetings are currently scheduled for **November 18 2015 and July 7 2016. On Nov 18 2015** Dr Liz Samson, a Senior Clinical Lecturer at the Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London and will join us to share her expert knowledge and facilitate a discussion on palliative and end of life care in dementia.

These meetings take place in rooms within UCL , Gower St, London WC1E 6BT, All the above listed meetings are scheduled from 11am -2pm, with coffee available from 10.30am and lunch provided. Exact room details, agenda details and reminders are circulated nearer the time.

Regional meetings: Tuesday 29 September, Totteridge Community Centre, Totteridge Drive, Totteridge, High Wycombe, **Buckinghamshire, HP13 6UG** 10.30am -12.30pm.

Frontotemporal Dementia Support Group Annual Seminar: an all day series of presentations by experts across the FTD field will be held on **March 10 2016** at 33 Queen sq, London, WC1N 3BG.

Contact jill.walton@ucl.ac.uk for information about these events

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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

Update from the Alzheimer's Association International Conference

In July of this year, over twenty researchers from UCL's Dementia Research Centre attended the Alzheimer's Association International Conference in Washington, DC. Chris Hardy, a researcher at the Dementia Research Centre was at the conference and provides the following update.

Three consistent strands emerged from research into primary progressive aphasia (PPA). Firstly, there were some new and exciting findings from research using brain imaging. These innovative techniques can help clinicians to tell apart the different subtypes of PPA in the clinic (i.e. semantic dementia, progressive nonfluent aphasia, and logopenic aphasia), and researchers to understand their differences at a key biological level.
The second theme was around using cognitive, psychological and behavioural testing to identify the similarities and differences within the PPA subtypes. Relating the everyday symptoms that patients with PPA experience back to the biological changes identified by brain imaging is really important, as it can help researchers to understand the way the disease works.
Thirdly, other research focussed on how language problems and other behavioural symptoms, like eating too much, can best be understood and helped in PPA.

PPA falls under the spectrum of a type of dementia called frontotemporal dementia (FTD). Professor Bruce Miller, of the University of California at San Francisco, delivered a keynote session on the second day of the conference. This highlights the importance now ascribed to FTD and PPA research by the wider scientific dementia community. His session was entitled, "Frontotemporal dementia: a quarter of a century of progress". Professor Miller is renowned for his pioneering work within the field of FTD research and spoke about advances in the field. He concluded his session with an exciting perspective on the future of FTD research, including a word on therapies that we hope will soon enter trials.

Research conducted by several researchers at the Dementia Research Centre also gained a spotlight at the conference. Camilla Clark, Chris Hardy, Katrina Dick, Liz Gordon, Cat Slattery and Jen Agustus all presented work that focusses on how we can increase accurate and early diagnoses in PPA and FTD. Amongst other things, the program of work points to altered perception of complex auditory signals like music and certain types of speech in PPA.
Other colleagues, including Lorna Harper, Martina Bocchetta and Dave Cash spoke about brain imaging – research that looks at what changes take place over time in the brains of people with FTD.

The findings that Dr Cash presented were some of the first to come out of the multi-centre European study into genetic FTD (GENFI) led by Dr Jonathan Rohrer, also of the DRC. Dr Cash spoke about subtle differences between the brains of people who are genetically at risk for developing FTD and those without this risk factor. This is a really important finding that will be extremely useful not only in terms of diagnosis, but also in helping researchers to understand the effects of new therapies when they become available for use in FTD.

On the subject of therapies, readers may have seen reports from the conference of a drug called Solanezumab that has shown some promising signs in Alzheimer's disease. It is beyond the scope of my piece here to comment on this in detail, and Alzheimer's Research UK have written a good commentary accessible at http://www.alzheimersresearchuk.org/solanezumab-trials/