



RARE DEMENTIA SUPPORT

Welcome to the May 2016 edition of the PCA support group newsletter. We are currently trialling various different formats for the newsletter, and welcome your feedback on an ongoing basis. The newsletter is available as an audio recording, accessible via the website www.rarementiasupport.org. Minutes from the February 5 2016 meeting are available separately and upon request to jill.walton@ucl.ac.uk. May we take this opportunity to welcome you to the full PCA support group meeting on June 10 and the Joint support group meeting on July 7, details of which are listed on page 4. We look forward to welcoming you to these meetings or indeed being in contact with you in whatever capacity is most appropriate.

Online dementia course features dedicated PCA module

We are delighted to announce that a free online course has been developed by colleagues here at UCL, featuring a whole module dedicated to **Posterior Cortical Atrophy**. Throughout the course learners discover some of the key issues in dementia care and research by exploring four less common forms of dementia through the eyes of people affected by the condition, and world-leading experts at UCL. This course is presented by experts from the UCL Institute of Neurology and Division of Psychiatry who are highly regarded for their work as scientists and clinicians. Importantly, course participants hear from people who have been diagnosed with dementia, and people who care for a family member with dementia to get a better understanding of the impact that a diagnosis of dementia brings.

They will be able to understand how dementia affects people by watching video interviews, look deeper into the topics by reading articles, interact through activities and questions, and also learn from others on the course by taking part in the discussions that accompany each step.

Over 8,500 people took part in the first run of this course in March 2016, and we hope to replicate this success as we repeat the course in July and October. Visit www.futurelearn.com/courses/faces-of-dementia to watch the trailer, register for free and join the conversation.

Everybody is welcome to take part in this course, so please use the opportunity to raise awareness of PCA by sharing the invitation with anyone who might be interested.



Facilitating Reading in Posterior Cortical Atrophy

Aida Suarez-Gonzalez is a researcher based at the Dementia Research Centre, UCL. She and her colleague Ashley Peacock will be presenting a summary of their work and demonstrating the app that is currently being developed alongside it, at the June 10th support group meeting. Aida writes:

‘Reading is central to our lives. It is a tool for learning, to keep ourselves informed and a great source of pleasure for many of us. Along with my team at the DRC we are working on the development of an App to help people with Posterior Cortical Atrophy, and other degenerative conditions that impair vision, to maintain their reading skills.

Our App aims to compensate for the effect of visual disorientation, visual crowding and oculomotor apraxia. In order to do so we manipulate the text presentation in a variety of ways aimed to reduce the need for ocular movements and alleviate spatial demands. We will soon be initiating the second phase of the pilot study (many challenges arose from the first!) and hope to have this ready by the beginning of 2017. Thereafter, we will launch a home-based trial to evaluate the effect of the tool in real life.’

Frequently Asked Questions : Hints and Tips on how to cope

In response to requests from support group members, we are compiling a new resource which will combine a series of 'frequently asked questions' alongside those 'hints and tips' that people living with PCA have incorporated into their lives and found helpful. Practical examples, strategies you have found useful, frequently asked questions, frequently recurring issues—practical, behavioural or academic in nature can all be included in your responses.

We would like to invite members to shape the content of this resource, which will essentially be informed by the people who know most about living with PCA: YOU!. Please e-mail items for inclusion, specific things that you have found helpful in your PCA journey, but which wouldn't necessarily be covered or referred to in a standard 'advice' factsheet to a.carton@ucl.ac.uk

Holidays
Lighting-
Mealtimes..

Fundraising for Rare Dementia Support

On 29 February, both Leap Day and Rare Disease Day, we launched a new fund for Rare Dementia Support. This fund is held by The National Brain Appeal and brings together the previously existing FTD Support Group Fund and the Myrtle Ellis Fund. This has been done to increase fundraising efforts and both sustainably maintain the service and extend it. Our vision is that all individuals with, or at risk of, a rare form of dementia will have access to specialist information, support and contact with others affected by similar conditions.

JustGiving: JustGiving is the world's number one online platform for giving and we have set up a campaign page here for Rare Dementia Support. If you would like to make a donation to the fund or set up a fundraising page, go to bit.ly/RDSfund and please share the link with anyone you know who also wants to support the fund.

You can also text RDSF84 followed by the amount you would like to donate to 70070.

If you are interested in setting up a Direct Debit or making a payment to the fund by cheque or bank transfer, please email louise.knight@uclh.nhs.uk or phone 020 3448 4724.

Fundraising through challenges and events: Enter a running, walking, cycling or swimming event of your own and connect your fundraising on Justgiving to bit.ly/RDSfund.

Apply for a place on one of The National Brain Appeal's sports places via nationalbrainappeal.org/challenges.

Coming up this year:

- Vitality London 10,000, 30 May 2016
- Trekfest Brecon Beacons 25k, 50k, 75k or 100k, 4-5 June 2016
- Prudential Ride London, 31 July 2016
- Trekfest Peak District 25k, 50k, 75k or 100k, 3-4 September 2016
- Royal Parks Half Marathon, 9 October 2016

For more information about participating in a challenge or organising an event of your own to fundraise for Rare Dementia Support, please email brooke.parsons@uclh.nhs.uk or phone 020 3448 4724.

Thanks to our recent fundraisers

Simultaneous Global Virtual Quiz 2015

Susie Shaw organised a second annual Simultaneous Global Virtual Quiz in November 2015 – 20 plus teams from around the world logged in at 8pm GMT to take part, raising a grand total of £2680 for Rare Dementia Support. This followed on from the success of the same event in 2014 for the Myrtle Ellis Fund and it will now be an annual fixture with the next date set for 12 November 2016. Anyone can sign up to be a host so mark the date in your diary and get set to 'fun-raise'!

Christmas Cards

Over £3000 was raised for the new fund, Rare Dementia Support from Christmas card sales. Big thanks to Di Garfield for organising this and to The Good Care Company who covered all card production costs.

Mindfulness-based therapy for people with dementia and their carers

Dr Becky Gould is an academic clinical psychologist at the Institute of Psychiatry, Psychology and Neuroscience, King's College London, and has an interest in talking therapies for people with and without dementia. In her presentation, "Mindfulness-based therapy for people with dementia and their carers", she will be talking about a new form of talking therapy called mindfulness-based therapy. This approach aims to help people cope with distressing experiences such as feeling stressed or low in mood. She will discuss the research underlying this approach and how this therapy is being applied to people with dementia and their carers. She will also guide attendees through some short meditation exercises, and provide hints and tips as to how people can bring mindful awareness into their everyday lives.

We look forward to welcoming Becky to our support group meeting on June 10 2016

Dementia and Sight Loss Conference

In a recent Commons debate, Jim Shannon MP made the point that 'good vision can greatly increase a person with dementia's sense of independence, allowing them to continue to participate in daily tasks and activities and maintaining a good quality of life'.

He is keen to promote the role eye health providers can play: "There is a need to raise awareness amongst people with dementia and their carers of the disruptions to vision and eye health that may be concurrent with or arise from dementia. This means emphasising the importance of regular sight tests."

The full article is available at : <http://www.opticalconfederation.org.uk/news/latest-news/post/131-sight-lossadementia-link-ignored-mp-warns>

Useful leaflets from VISION 2020 UK on Dementia and eye tests and wearing glasses and dementia are here: <http://www.vision2020uk.org.uk/interest-groups/dementia-and-sight-loss-interest-group/blog/vision-2020-uk-dementia-and-sight-loss-group-wearing-glasses-with-dementia-factsheet/>

And here:

<http://www.vision2020uk.org.uk/interest-groups/dementia-and-sight-loss-interest-group/blog/vision-2020-uk-dementia-and-sight-loss-group-eye-examinations-for-people-with-dementia-factsheet/>

Dementia Research Centre involvement:

Researchers from the Dementia Research Centre, UCL are engaged in ongoing communication with eye health providers, facilitating better understanding of visuospatial loss associated with dementia generally and PCA in particular. Dr Keir Yong will be speaking specifically about PCA at the forthcoming 'Dementia and Sight Loss' day on 19 June 2016 in Birmingham. Details of the programme for the day are available here: <http://bit.ly/dementia-and-sight-loss-day>.



Update from Alzheimer's Research UK: Alzheimer's Research UK is proud to be a founding partner of the new UK Dementia Research Institute (DRI), committing a further £50m to expand its ability to support cutting-edge biomedical science. The pledge, alongside Alzheimer's Society, will see the Institute become the UK's largest collective endeavour in dementia research. We'll also work hard to integrate the work of our new Drug Discovery Institutes into the research taking place at the DRI, to make sure we're capitalising on every opportunity to translate scientific breakthroughs towards new treatments. Find out more at www.alzheimersresearchuk.org

Journal of Dementia Care feature on PCA and the PCA Support Group

The Journal of Dementia Care featured articles on PCA in the Nov/Dec 2015 and Jan/Feb 2016 editions, highlighting the diagnosis and commending the support group resources.

Read the articles at <http://bit.ly/1NBkxS0> and <http://www.careinfo.org/posterior-cortical-atrophy-resources-and-information/>

Support Group Meetings

London

PCA support group meeting Friday June 10 2016: Wilkins Haldane Room, UCL, Gower St, WC1E 6BT. 11am –2pm (coffee available from 10.30am and lunch provided)

Speakers include **Dr Becky Gould & Aida Suarez-Gonzalez**, both of whom feature in this newsletter.

PCA and Joint Carers meeting July 7 2016: Medical –Legal Issues: Front Quadrangle Events Venue, UCL, Gower St, WC1E 6BT. 11am –2pm (coffee available from 10.30am and lunch provided).

James Malby is a solicitor specialising in Private Client law and is experienced in the preparation of Lasting Powers of Attorney and Advance Statements. He advises on all aspects of their use, benefits, registration and other issues that often arise. James will give a presentation to help dispel some myths and outline the benefits of making these documents and the processes involved.

Regional meetings

In some areas support group meetings are arranged by regional facilitators and provide an informal opportunity to meet other people affected by PCA. Please contact regional coordinators directly.

Berkshire. Please email Helen Shepherd on Helen@shepherdcharles.com for more information. These meetings are held at Barkham COAMHS, Wokingham Hospital and in are organised in conjunction with the 'Young People With Dementia' Berkshire West group.

Hertfordshire Please email Di Garfield on herts.pca@gmail.com for more information.

Chichester Please email Fiona Chabaane on fchaabane@hotmail.co.uk for more information.

Scotland Please email Julia Mackenzie on jmackenzie@alzscot.org for more information.

North-West Please email Andy Tysoe on andytysoe@nhs.net for more information.

Gloucester Please email Richard Southerden on rsoutherden@aol.com for more information.

Disclaimer: The information contained on our website, in our newsletters and at support group meetings is for information purpose only. You assume full responsibility and risk for the appropriate use of the information contained herein and attendance at any support group meetings.

Rare Dementia Support runs specialist support group services for individuals living with, or affected by, one of five rare dementia diagnoses: frontotemporal dementia (FTD), posterior cortical atrophy (PCA), primary progressive aphasia (PPA), familial Alzheimer's disease (FAD) & familial frontotemporal dementia (ffTD).

Our vision is for all individuals with or at risk of one of these rarer forms of dementia to have access to specialist information, support and contact with others affected by similar conditions.

Rare Dementia Support is a Fund held by the National Brain Appeal (registered charity number: 290173)

Rare Dementia Support activities are charitably funded—for information on how to make a donation please go to go to bit.ly/RDSfund.



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SUPPORT**