



Welcome to the September 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.raredementiasupport.org, and recordings of presentations given at support group events are regularly uploaded onto our website too. The summer has seen us say goodbye to Tim and Amelia, both of whom sent their regards and best wishes to all of you before they left. We are however delighted to be welcoming Rachel Crane to the support group team as a Support Group Facilitator and Psychology Research Assistant - Rare Dementia Support, and we look forward to having Rachel alongside us in our ongoing ventures. May we take this opportunity to welcome you to the full PCA support group meeting on November 11th 2016 and ask you to note the new venue details as listed later in this newsletter. Dates for 2017 are also provisionally set and we look forward to welcoming you to these meetings or indeed being in contact with you in whatever capacity is most appropriate.

Alzheimer's Association International Conference Update



"I attended the Alzheimer's Association International conference in Toronto this year, where I presented some results from the 'Seeing What They See' study (<https://www.ucl.ac.uk/dementia-vision>) focusing on object localisation difficulties experienced by people with PCA. The presentation outlined findings gathered from an accessibility lab called PAMELA (Pedestrian Accessibility and Movement Environment Laboratory), where participants with PCA were asked to locate objects while tracking their movement (directness of walking paths when locating objects, hand paths when reaching for objects) and gaze position (where they were looking). Results suggested one environmental factor, visual clutter, played a particular role in influencing the ability to locate objects efficiently. I also attended the atypical Alzheimer's Disease professional interest area meeting where I learnt about international work being done on PCA, including investigations of 3D shape perception in PCA as well as the prevalence of PCA in a community-based sample." - **Dr Keir Young, Postdoctoral Research Associate**

"Going to the AAIC in Toronto was a great opportunity to meet other scientists interested in PCA. I first went to AAIC 5 years ago and it seems to me that awareness of PCA is much better now. Back in 2011, I remember a few occasions when I mentioned PCA and was met with a blank expression and I'd have to explain it, but this year it seemed like most people I spoke to had heard of PCA and were interested to know more about our research. I presented some of our preliminary work on changes in the retina (the back of the eye). We were investigating whether the changes in the brain that people with PCA have might spread to also affect the eyes, but we found fewer changes in the eye than we were expecting so it was interesting to discuss results with other researchers who are also doing similar tests." - **Dr Timothy Shakespeare, Alzheimer's Research UK Fellow**

Current PCA Research Update - Dr Silvia Primativo, Psychologist Research Associate

A recent study looking at the spelling difficulties on individuals with PCA is currently under review by experts in the field before being published in an international journal. In terms of ongoing projects, we are at the stage of analysing the PCA longitudinal cognitive data in order to better understand the progression of the disease over time. In the next few months a new study looking at the visual attention component and its interaction with basic visual functions in PCA will begin.

Alzheimer's Research UK Update

The past few months have been busy for the team at Alzheimer's Research UK. Many of our researchers discussed the latest research at the world's largest dementia research conference in Toronto this month. Many stories from the conference made the headlines, and you can read [our round-up of the research](#).

We're also pleased to be supporting a new drug discovery project, funding a team in Italy to search for new drugs to target the TDP-43 protein in FTD and motor neurone disease. We'll keep you updated on progress. Find out more about our research and how you can help on the [ARUK website](#).

We are incredibly grateful to M&G Investments for helping us support the work of Rare Dementia Support.

Fundraising Updates

Thanks...

Big thanks to all the supporters who have taken on fundraising challenges or organised events in the last few months for Rare Dementia Support. This includes:

- Sean Hession and Robert Lawson who ran the London Marathon in April raising over £6,000 between them
- Elizabeth Pooley organised a concert in May
- Ellen O'Neill and friends at Aquinas Grammar School ran the Belfast City Marathon in May raising £800
- Peter Stilwell dyed his hair pink raising £750
- Cate Coop who walked an epic 52 miles in June raising £1,200.

Also we would like to mention Elizabeth O'Donnell who at 88 years of age jumped out of a plane at 10,000 feet raising over £1,500 from her skydive for FTD Research.

In September, Chris Hardy, Research Assistant and PhD student at the Dementia Research Centre is taking on a very extreme challenge indeed – Ironman Wales, running a full marathon as well as cycling 112 miles and swimming. If you would like to sponsor Chris, please go to his [JustGiving page](#). [<http://www.justgiving.com/chrisironman>]

Sponsor...

Jill Walton is taking on the Royal Parks Foundation Half Marathon on Sunday 9 October to raise funds for Rare Dementia Support. This is a lovely, though physically testing run of 13.1 miles through the Royal Parks and central London, starting and finishing in Hyde Park. If you'd like to support Jill, you can sponsor her on her [JustGiving page](#). [<http://www.justgiving.com/fundraising/JillWalton2016>]

Coming up...Simultaneous Virtual Global Quiz,12th November 2016

If you would like to take part in this annual event raising funds for Rare Dementia Support, please go to the [JustGiving page](#) [<https://www.justgiving.com/fundraising/SGVQ16>] for more details of how to take part.

2016 Christmas Card Sales

We are selling Christmas cards again this year. If you would like to purchase them, please follow this [link](#) to place your order. [<https://www.surveymonkey.com/r/6XJRG7N>]

To access all links, please click the "control" button on your keyboard and then click on the link.

Christmas Tea Party

The Hertfordshire PCA Support group is holding a Christmas afternoon tea:

Date: Wednesday 7th December 2016

Time: 3pm until 5pm

Place: [Mabel's Tearooms](#) in Reveley Lodge, 88 Elstree Road, Bushey Herts WD23 4GL

Menu: An assortment of finger sandwiches; stollen; mince pies; tea & coffee

Price: £12.50 including service, in aid of the Herts PCA Support group



To reserve your place, please email Diane & Roberta: herts.pca@gmail.com. Additionally, they are holding a raffle to raise money for the main Rare Dementia Support fund, so please bring along any unwanted gifts, a bottle of something etc., on the day.

PCA publicity during National Carers Week!

National Carers Week ran from June 6th—12th this year. This campaign salutes unsung heroes who selflessly devote their time to friends or family who are older, ill or have a disability. In this [article](#), Alison Bulmer, who has been a carer to her husband Paul, 57, since 2012 when, at the age of 53, he was diagnosed with Posterior Cortical Atrophy (PCA) tells their story.

The article touches on the dramatic changes Paul and Alison have experienced since receiving this diagnosis, as well as for their two daughters. Both Paul and Alison have had to give up work. The article refers to the changes in Paul's visual spatial awareness and coordination, and how it is now significantly compromised. As a result, Paul is no longer able to drive, cycle or go out alone. One major adjustment that Paul has sadly had to make is his running - a life-long runner, he has now sadly had to give it up.

The article makes reference to the different stages of PCA and how Paul is entering a particularly cruel phase which is affecting his short term memory and speech.

The article also touches on the lack of signposting or services which are available to those affected by PCA, however Alison acknowledges her "relief" after finding the PCA support group in which she has been able to talk to people who understood PCA.

A recent positive development is that a North West PCA support group has recently been set up, which has so far held two meetings and may be opened up to families affected by young onset dementia. For details about North West support group meetings, please contact Andy Tysoe, Dementia Specialist Nurse: Andy.Tysoe@cheshirewestandchester.gov.uk or Sandie Williams, Dementia Inclusive Communities Team, Cheshire West and Chester Council:

sandie.williams@cheshirewestandchester.gov.uk

At this point, we would like to take this opportunity to thank Andy Tysoe and Sandie Williams for their ongoing support and input for the work they are doing as North West Facilitators.

We are also very excited to include the link for a recent [YouTube video](#), recorded for NHS England, which touches on the work Andy has been doing with those affected by PCA.



[Article website: <http://www.chesterchronicle.co.uk/news/chester-cheshire-news/loving-helsby-woman-highlights-selfless-11459455>; YouTube clip: <https://youtu.be/MH3VgnzCd8E>]

Aware and sensitive to the fact that there are many of you whose grief we have not embraced, we do want to publically offer our sincere and heartfelt condolences to both the Ellis and Hotten families as they mourn the recent loss of loved wives and mothers.

Myrtle Ellis

The family of Myrtle Ellis are well known personally to many PCA support group members, and the legacy which she leaves is one which is accessible to all by virtue of the existence and provision of Rare Dementia Support services. Myrtle was born on 15 May 1937, the daughter of Louis & Esther Collins and younger sister to Rosalind. The family moved to Hendon in 1937 and she went to school at La Sagesse before doing her O levels at Henrietta Barnett. She enjoyed playing tennis and used to go to the local Jewish social club where one fateful evening, she asked a handsome chap for one of his Polo mints! From there, their love flourished and 18 months later Myrtle and Stanley were married at Dunstan Road shul. Myrtle loved learning; initially attending the Hampstead Garden Suburb Institute, she took a course in antique silver - a topic that became her life's passion. She went on to deliver her own courses as a panel lecturer at the Victoria & Albert Museum and other eminent academic organisations both in the UK and America. Researching silver collections of historic houses and her subsequent lectures on the subject, piqued her students' interest to visit them and, with the help of Stanley, she built a business of "special interest tours". Myrtle's reputation grew and, in 1985, the Central Office of Information approached her to write about the jewellery the Queen would be taking to the Caribbean, leading to her being the only person in the UK authorised by Buckingham Palace to lecture on the Queen's Jewellery. Around the same time, Myrtle set up the Silver Study Group, arranging monthly lectures and visits for collectors. After diagnosis in 2005 with a rare form of dementia, posterior cortical atrophy (known as PCA), Myrtle was referred to the National Hospital's Dementia Research Centre for a drug trial. As a way of saying thank you to the team, Susie completed a 5km fun run and together she and Diane held an event that between them raised £11,500. From this, the original Myrtle Ellis Fund was created to provide support, information and advice to individuals with PCA. Through continued fundraising, the recently rebranded Rare Dementia Support fund now supports a global community people with rare forms of dementia and their carers.

Jennifer Hotten

The service or remembrance and thanksgiving for the life of Jennifer Hotten focussed on the happy memories of a well loved and caring lady. A caring, but strong willed and independent young mother, Jenny never seemed to stop to sit down, and took on various roles whilst bringing up her children. She would teach swimming, play piano for a local dance school, do household cleaning and ironing, often working until 2 in the morning with no concern about having to get up early the following day. Jenny loved a challenge and it seemed she would sometimes take projects on if someone else had said that it was too difficult or impossible. That was the sort of challenge Jenny enjoyed!

Musically, Jennifer's tastes were described as quite eclectic as she not only enjoyed songs from the musicals, but also liked Rock by bands like Deep Purple and Dire Straits, and also loved to play the piano, particularly enjoying playing duets with her children. The service reflected her musical favourites and a Jenny's daughter, Karen, read a poem by Dick Underwood titled, "We think of you as yesterday".



"The poem concentrates on the long period of life prior to the onset of the disease, rather than the relatively short period of time following the onset of Alzheimer's"

Dick Underwood 2010

Welcome to the Team...

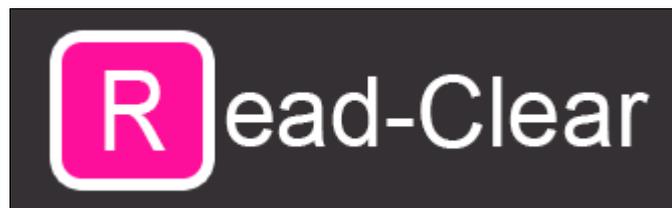
My name is Rachel Crane and I have recently joined the Rare Dementia Support Service as a “Group Facilitator and Psychology Research Assistant”, based at the Dementia Research Centre.

Having completed a psychology degree from the University of Leicester in 2009, I have subsequently worked in both physical and mental health services, as either an Assistant Psychologist or Research Assistant, within the NHS. These services include Memory Clinic, Specialist Brain Injury Rehabilitation, Improving Access to Psychological Therapies (IAPT), National Institute of Health Research projects, as well as secondary care psychological therapies services.

I have a strong research interest in dementia, specifically rare dementias. As a health professional working in this field, I have witnessed the psychological impact a diagnosis can have on the individual, alongside their family and friends. My experience has highlighted how difficult it can be to get a diagnosis of a rare dementia, and how limited people are with being able to access specialist support services.

Outside of work, I am into my fitness and enjoy walking my black Labrador called Lola. I am also a proud auntie to my niece and nephew who keep me on my toes!

ReadClear : An Update on the Progress of the Reading App



Aida Suarez-Gonzalez and her colleague Ashley Peacock have been working to develop an App to help people living with Posterior Cortical Atrophy, and other degenerative conditions that impair vision, to maintain their reading skills (www.readclear.co.uk)

As explained in a previous newsletter, this App aims to compensate for the effect of visual disorientation, visual crowding and oculomotor apraxia present in people with PCA.

By way of an update, Aida and Ashley are now well into the second phase of the study which will launch a home based trial in November 2016, with several blocks running until late Spring 2017. They are still keen to hear from people who would potentially like to be involved in the testing and trial process.

At present they are also testing the stability of the of the App amongst colleagues here at the DRC who are reportedly able to use it to read the BBC, The Guardian, The Telegraph and a small selection of books happily and over their morning coffee!!

If you are interested in knowing more about the project please email Aida Suaerz-Gonzalez to aida.gonzalez@ucl.ac.uk or telephone (+44) 020-344-83655

Support Group Meetings London

PCA Support Group Meeting:

Date: Friday 11th November 2016

Time: The meeting will run from 11am - 2pm, with coffee available from 10.30 and lunch provided.

Location: The Wellcome Collection, 183 Euston Rd, London NW1 2BE

Directions: <https://wellcomecollection.org/visit-us/getting-here>

- Go up the entrance stairs and you will find the lifts are on the left hand side. Take the lift to the 5th floor. On arrival at the 5th floor, take a left out of the lift to The Hub and press the door bell (on the day we will be around to assist!)

The provisional date for the first 2017 meeting will be **Friday 24th March 2017.**

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.

Central: Martina Wise, Oxfordshire: Please email mrsmartinawise@gmail.com, mobile: 07958 668 035 or Skype contact, username: "fivewises".

Peterborough: Please email David Holmes on david.holmes155@btinternet.com.

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)



POSTERIOR
CORTICAL
ATROPHY

raredementiasupport.org