January 2019

Dear PCA Support Group Members,

Welcome to the January 2019 edition of the PCA Support Group newsletter which we hope you will find helpful and interesting. We are very keen that the newsletters and support group meetings meet the needs of our membership and so any feedback is really important to us. We will be continuing to look at more formalised ways of inviting this feedback, documenting it and implementing changes but for now, please continue to feel free to send any comments or suggestions to emma.harding@ucl.ac.uk. Whether you have ideas for topics you would like to see covered in future newsletters or at meetings or suggestions for potential speakers, these are all really helpful and warmly invited. Thank you as ever to those of you who have offered feedback, steering and guidance so far and for your patience as we continue to try to incorporate this, it’s hugely appreciated.

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Upcoming support group meetings –

Next PCA Support Group meeting:

Date: Friday 1st March 2019
Location: 6th Floor, Wellcome Trust, Gibbs Building, 215 Euston Road, London NW1 2BE
Directions: https://wellcome.ac.uk/About-us/Contact-us/
Time: 11:00 – 14:00 (arrival, registration and tea and coffee from 10:30)
** please note, if this is your first support group meeting, we will be running a brief introductory session from 10am if you would like to arrive a little early to be introduced to other people here for the first time and in case you have any questions or concerns about how the session will work, and mostly so that we can say hello! Please let us know when you RSVP if you would like to attend this session.

**Live-streaming:** For those of you unable to join us in person, we are hoping to live-stream this support group, meaning if you have internet access you can watch the meeting live, you should just need to visit our YouTube channel page at the time of the meeting, and the link for that is: https://www.youtube.com/channel/UCuVA3iffOcwz04qBkjZgKqg

(If you would like to submit questions to the speaker via the Comments section on the video - bearing in mind these may be visible to others - please do and we will do our best to ensure they are read out.)

**RSVP:** To register your place, we kindly ask you to RSVP by **Friday 22nd February** to Emma Harding at: emma.harding@ucl.ac.uk. This will help us with guest registration and catering provisions. Please also let us know if you have any special dietary requirements.

**Agenda:** This meeting will follow our usual format of having a talk for the whole group in the morning (with plenty of time for questions and answers), followed by lunch (and chatting) and then small discussion groups in the afternoon.

During the morning session, the **PCA team at the Dementia Research Centre (UCL)** will give an update on research going on into PCA, both nationally and internationally.

Topics for afternoon discussion groups are still to be confirmed - there will be a **clinical Q&A** group as usual about what PCA is and what we know from research about symptoms, treatment and what to expect, which may be

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**Enquiries:** contact@raredementiasupport.org | www.raredementiasupport.org
particularly beneficial for those of you who might be joining us for the first time.

If there are any other particular topics you’d like to participate in discussions about **we’d really like to hear from you** - please send any suggestions to emma.harding@ucl.ac.uk and we will do our very best to accommodate!

**Next Carers’ Support Group meeting:**

**Date:** Tuesday 7th May 2019  
**Location:** 6th Floor, Wellcome Trust, Gibbs Building, 215 Euston Road, London NW1 2BE  
**Directions:** [https://wellcome.ac.uk/About-us/Contact-us/](https://wellcome.ac.uk/About-us/Contact-us/)  
**Time:** 11:00 – 14:00 (arrival, registration and tea and coffee from 10:30)  
**RSVP:** To register your place, we kindly ask you to RSVP to emma.harding@ucl.ac.uk. This will help us with guest registration and catering provisions. Please also let us know if you have any special dietary requirements.

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**Staff updates**

Sadly, we are saying ‘goodbye’, to Laura King, who many of you will have been in touch with during her time working with Rare Dementia Support over the past year. Laura has been a huge help in her role as the central coordinator for all of the Support Groups run by Rare Dementia Support, not just the PCA Support Group. She has overseen and directed many administrative changes behind the scenes that will make things a lot smoother for us all moving forward. She will be missed by all of us here, so we would like to take this opportunity to thank Laura for all her hard work, and to wish her the very best of luck in her future.
We are very pleased to invite you to Created Out of Mind resident artist Charlie Harrison’s upcoming exhibition *Testing Situations*; a video and sound installation about dementia, narration and the landscapes of a test, at London based art space [Jupiter Woods](http://jupiterwoods.com/current/testing-situations).

This exhibition will present project work made as part of the Created Out of Mind residency (including the ‘Neva’ film, made in collaboration with members of Rare Dementia Support) alongside a new installation-based artwork. The exhibition will run from the 11th January until 3rd February, with a discussion event also being arranged (details TBC but details will be available here when confirmed: [http://jupiterwoods.com/current/testing-situations](http://jupiterwoods.com/current/testing-situations)). If you would like any further details or have any questions or concerns about accessibility please contact the exhibition space here: [info@jupiterwoods.com](mailto:info@jupiterwoods.com)

We hope to see you there!
We were really encouraged to hear PCA discussed on a recent episode of BBC Radio 4’s In Touch programme. The episode is available to listen to online if you missed it, and you can find it here:

https://www.bbc.co.uk/programmes/m0001b1m
Funding success!

Alzheimer’s Society fellowship award:

We are delighted to announce that Dr Keir Yong, Senior Research Associate at the Dementia Research Centre at the UCL Queen Square Institute of Neurology, has been awarded a prestigious fellowship award from Alzheimer’s Society.

Many of you will know Keir from his significant involvement with and contribution to the PCA support group over many years. You’ll also likely know a lot about the extensive work that Keir has done researching PCA and dementia-related visual impairment more broadly throughout his PhD and following that in his post-doctoral work on the ESRC-NIHR funded ‘Seeing What They See’ project. Keir’s work has primarily focused on investigating how Alzheimer’s disease and posterior cortical atrophy may affect visual perception and spatial awareness. His research combines approaches of neuropsychological and engineering disciplines to develop and evaluate strategies supporting independent activities, including assistive technology and environmental adaptations to support reading, object finding and navigation.

The project funded by Alzheimer’s Society that Keir will begin shortly intends to develop strategies to support activities particularly reliant on reaching and coordinating movements, for example, during dressing activities or when picking up and handling objects.

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Many congratulations to Keir and we look forward to hearing about the project as it develops!

**ESRC-NIHR Dementia Initiative 2018:**

We are delighted to announce that Prof. Seb Crutch at UCL, along with a team of national and international colleagues at Bangor University, Canterbury Christ Church University and Nipissing University, Ontario, has been awarded funding as part of a £15 million ESRC-NIHR initiative on research to improve the lives of people living with dementia. The proposed project is centred on understanding and developing support group services for those living with rarer dementias, and here are some excerpts from the press release:

“Between 5% and 15% of people living with dementia receive a diagnosis of a young onset or rare dementia, such as frontotemporal dementia or posterior cortical atrophy. Many people affected by these types of dementias are not able to meet others in a similar situation for practical and emotional support because there aren't people with the same type of dementia living locally.
Researchers at UCL will lead a project to develop and evaluate a multicomponent support group for people living with young onset and rare dementias. The project builds on face-to-face support group meetings that the research group runs around the country.

Prof Crutch, clinical and research neuropsychologist at the Dementia Research Centre, University College London, said: “We’re thrilled that the ESRC-NIHR have agreed to fund this work looking at the value of support groups by, with and for people with young onset and rare dementias. The support groups grew initially out of our local London clinic, but we have a vision that everyone living with, or at risk of living with, a rare form of dementia has access to specialist information, support and contact with others affected by similar conditions.”

Roberta McKee-Jackson joined a rare dementias support group in 2012 when her late husband Noel was diagnosed with posterior cortical atrophy. She said: “Many support group members are located in remote areas and unable to attend meetings in London, which can be very limiting. So many carers in particular feel very lost, are always searching for local support, and want to share knowledge with others in a similar situation. The opportunity for more access to online support, research, and knowledge sharing would be incredible. The possibilities from the ESRC-NIHR funding award for carers and people living with a rare form of dementia are amazing.”
The project comes as part of an Economic and Social Research Council (ESRC) announcement of £15 million of funding in collaboration with the National Institute for Health Research (NIHR) for the ESRC-NIHR Dementia Research Initiative 2018. The initiative has funded four projects that will run for five years and start in January 2019.

The ESRC-NIHR Dementia Research Initiative was launched to boost social science research in dementia, with the goal of creating a step change in social science funding of dementia from small projects to a critical mass of expertise. The 2018 funding follows an earlier 2012 joint initiative that provided £20 million for six research projects on dementia interventions and care*. The projects have involved people with lived experience of dementia as coResearchers, advisors and participants, and have developed social science methodology and capacity in dementia research.

Professor Jennifer Rubin, ESRC Executive Chair, said: “I am very pleased that ESRC is collaborating again with the NIHR to fund research that will make a real difference to the lives of people living with dementia and their carers. The four funded projects will be national and international focal points for social science research in the field of dementia and will deliver UK-wide benefits for people living at different stages of dementia and with both the more common and rarer types of dementias.”

*The ‘Seeing What They See’ project led by Seb that many of you will have heard of and generously participated in was one of these.
About the funders:

● The Economic and Social Research Council (ESRC) is part of UK Research and Innovation, a non-departmental public body funded by a grant-in-aid from the UK government. For more information visit [www.ukri.org](http://www.ukri.org)

● The NIHR was established in 2006 to improve the health and wealth of the nation through research, and is funded by the Department of Health and Social Care. It funds, supports and delivers high quality research that benefits the NHS, public health and social care, and engages and involves patients, carers and the public in order to improve the reach, quality and impact of research

National Brain Appeal update - fundraising concert

We are delighted to invite you to a fundraising concert in aid of Rare Dementia Support. Elia Benhamou (cello) and Maria Tarasewicz (piano) will be performing pieces from the great cello and piano repertoire including works by Rachmaninoff, Schumann, Schubert, Tchaikovsky and many more.

The night will take place in the Haldane room located at the heart of the University College London (UCL) campus, ideal for a nice chamber music evening.

Elia Benhamou is a second-year PhD student working at the Dementia Research Centre at UCL and part of the Rare Dementia Support team (with the PPA support group). Elia’s research has two major strands: she is exploring music processing in dementia and also using new imaging analysis techniques to help us understand more about the brains of people living with PPA or FTD.

Alongside brain imaging science in Lausanne and Cambridge, Elia has pursued a career as a professional cellist, including the Royal College of Music where she obtained a Master of Performance in 2016.
Maria Tarasewicz has already gained an enviable international reputation as a chamber musician, duo partner and a pedagogue. Maria has performed in all of London major concert venues including Wigmore Hall, Cadogan Hall, Royal Albert Hall and many others. She also appears regularly on BBC Radio 3. One of Maria’s current projects is the initiative of co-founding The Thinking Musician©, the platform organising summer music courses combining music as art, philosophy, intellectual provocations and speaking of the artist’s role in world.

For more details and to book tickets please visit:
https://www.eventbrite.co.uk/e/fundraising-concert-rare-dementia-support-cello-and-piano-recital-tickets-53211196120?aff=ebdssbdestsearch
Keep in touch! - social media

As well as signing up to our email/postal mailing lists we’d love you to follow us on Twitter and add us on Facebook (details below) where you can find lots of interesting articles and information being shared as well as meeting details – it would be great to hear from you and to spread the word so please like, comment and share!

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Travel costs

We are aware that some people travel long distances to attend our meetings, and that perhaps this isn’t always viable from a financial point of view. We have had a small donation from the National Brain Appeal to help with travel costs for meeting attendance for those who need it. Please let Emma know if a contribution towards travel expenses would help to make it possible for someone to attend the meeting.

We look forward to bringing you more of what we hope is useful and interesting PCA-specific information in our next newsletter and thank you again for all your input and thoughts as we continue to try to make the service as helpful and supportive as we can. We remain completely committed to supporting people with a diagnosis of PCA wherever possible, and hope to see as many of you as can make it at our meeting on 1st March. If you need or want to get in touch before then, please do so and we will be glad to help.

Yours faithfully,

The PCA Support Group Team

DISCLAIMER: Please note that you assume full responsibility and risk in the use of information contained on our website, in our newsletters, at support group meetings and in subsequent correspondence. Our support group based correspondence is generic in nature and we are limited in our ability to offer specific advice via this means. We aim to ensure that all information is as accurate as possible but we accept no responsibility for any errors, omissions or inaccuracies, or for any adverse consequences of any kind arising from the use of support group based content. Our regional group facilitators are volunteers. They may refer to regional facilitator guidelines from RDS but are not governed by RDS. They operate independently and with best intention and you assume full responsibility for your contact and engagement with them and in the regional groups they facilitate. Please see the clinician responsible for your care, a social services representative, or your GP if you have specific needs which require attention. Any medical decisions should be taken in discussion with an appropriate health care professional.