



# RARE DEMENTIA SUPPORT

Welcome to the May 2016 edition of the PPA support group newsletter. We are currently trialling various alternative formats for the newsletter, and welcome your feedback on an ongoing basis. May we take this opportunity to welcome you to the full PPA support group meeting on July 21 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.

## An Overview of Frontotemporal Dementia and the PiPPIN study

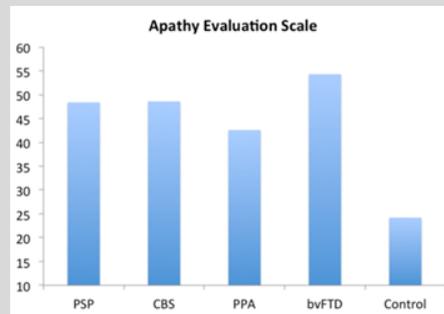
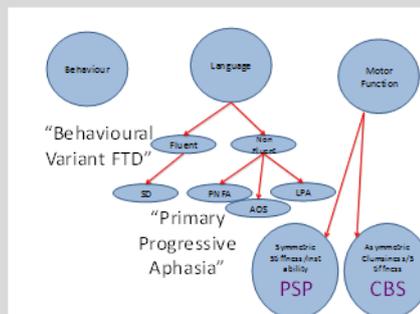
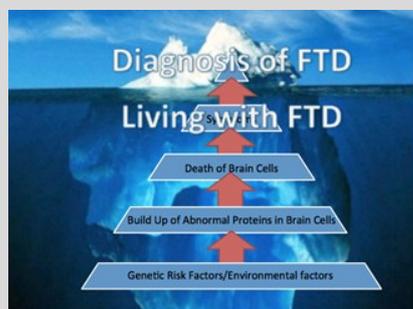
We were delighted to welcome Dr Ian Coyle-Gilchrist as the opening speaker at the FTDSG Annual Seminar, in March 2016. Dr Coyle-Gilchrist is a neurology registrar currently working at the National Hospital for Neurology and Neurosurgery whose particular research interests centre around how common FTD is and the basis of symptoms such as apathy and impulsivity in FTD.

Dr Coyle Gilchrist's research has shown for every 750 people born in the UK, one will go onto be diagnosed with FTD, or the connected illnesses CBD and PSP. Even this may be the "tip of the iceberg". He explained that FTD diagnoses in later life are often missed or misdiagnosed, and that whilst the incidence of FTD rises sharply in the mid 50 age range, the number of people with FTD continues to increase to the 74-79 year age range.

Speaking about his work assessing and evaluating the symptom of apathy in FTD, Dr Coyle-Gilchrist shared findings which demonstrated apathy as a common and significant symptom across the range of FTD diagnoses [Primary Progressive Aphasia, behavioural variant Frontotemporal dementia, Progressive Supranuclear Palsy and Corticobasal Degeneration]. It has long been considered typical of bvFTD, but its wider prevalence has significant implications, not least upon the anticipatory guidance given to people affected by diagnoses across the wider spectrum of FTD diagnoses.

The impact of apathy upon relationships is recognised as one of the most challenging symptoms for the families, friends and carers of people with FTD. Dr Coyle-Gilchrist explained how using a combination of different research techniques and brain imaging we are working to better understand how FTD causes different types of apathy, and how to measure them, which he hopes will lead on to better treatments for people living with FTD in the future.

Several of our support group members contributed to the PiPPIN study [ Pick's disease and Progressive Supranuclear Palsy, Prevalence and INcidence] Dr Coyle-Gilchrist's presentation is accessible at <http://www.ucl.ac.uk/drc/ftdsupport>



## World FTD Awareness Week Sept 24-Oct 1 2016

Please make a diary note of the forthcoming World FTD Awareness week, and start making plans to mark the event. We hope that this year's week will build on the momentum of last year's inaugural event. The theme will once again be 'Food for Thought' and so members are encouraged to host dinner parties, cake sales, lunch parties or any food-themed event to help mark the week. Raffles of cakes and sweets were also very successful last year. Jill will be able to provide promotional material nearer the time, but please do let her know if you are keen to be involved!

jill.walton@ucl.ac.uk or 07592 540 555

## 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](http://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](mailto: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](http://bit.ly/RDSfund)

Apply for a place on one of The National Brain Appeal's sports places via [nationalbrainappeal.org/challenges](http://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](mailto:brooke.parsons@uclh.nhs.uk) or phone 020 3448 4724.

## Thanks to our recent fundraisers

### Marathon man

Al Denness ran the inaugural Bristol and Bath Marathon on 25 October 2015, inspired by his friend Darren Pacey who has FTD and benefits from the support service run by the Dementia Research Centre. Darren is only 47 and has himself run many marathons, so Al thought it was fitting to take on this challenge and raise money for those who are helping him. Al finished in 4 hours 17 minutes and raised £1,075 for Rare Dementia Support.

### Seeing red

A team of ten runners took part in The Santa Run in December 2015 including Shelley Barnett who ran 10k and raised over £2,000 for the Rare Dementia Support Fund. Shelley's run was particularly remarkable because she ran with a fused spine, having broken her back just one year earlier.

### Playing to the skies

The first fundraising event for the new Rare Dementia Support fund was initiated by Katrina Yates whose mother Brigid was diagnosed with FTD in 2013. Katrina is a member of the London Medical Orchestra and on 13 March 2016, they played their concert at St Mary Boswell Church in north London with Rare Dementia Support as their nominated charity. Almost 200 guests came to hear Holst's Planets Suite and other musical delights, with the event raising over £1000 in total.

### 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'!

## Improving generalisation of learning in Semantic Dementia

Aida Suarez-Gonzalez is a researcher based at the Dementia Research Centre, UCL. She is involved in multiple research initiatives and describes here a new language therapy approach to assist naming ability in people with Semantic Dementia:

‘During recent years we have seen the rise of new language therapies to help combat the progressive loss of words in the semantic variant of Primary Progressive Aphasia.

Language training has proved to be successful and, in particular, people with Semantic Dementia can rapidly and successfully re-learn word labels during cognitive intervention. However, this new learning usually remains rigid, not particularly generalizable and sometimes difficult to apply in daily life.

In order to tackle this lack of generalization and non-applicability we have designed a new therapy approach, based on the conceptual enrichment (COEN) of the semantic network. This approach aims to produce more flexible and generalizable learning in people with Semantic Dementia.

We conducted a study comparing generalization and maintenance of learning after COEN measuring performance levels achieved using a classical naming therapy. Post-intervention naming ability improved significantly following both therapies, however, words trained using the conceptual enrichment method showed a significantly greater degree of generalization than those trained under naming therapy.

Improvements in naming continued to show significant improvements compared with baseline when assessed 6 weeks after practice ceased. This work is a collaboration with Dr. Sharon Savage (Exeter University) and Dr. Diana Caine (Neuropsychology Department, NHNN) It has been submitted for publication and we hope it will soon become available as a resource for people with Semantic Dementia.’

## Online dementia course features dedicated FTD module

We are delighted to announce that a free online course has been developed by colleagues here at UCL, featuring a module dedicated to Frontotemporal dementia and featuring PPA within that. 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](http://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 PPA by sharing the invitation with anyone who might be interested.



**FTD in the media** April/May 2016 have seen much FTD media related activity. Following the launch of Rare Dementia Support, and the Alzheimer’s Research [UK](#) conference in Manchester, Dr Jon Rohrer, neurologist and researcher at the Dementia Research Centre, UCL spoke to the Times newspaper about FTD and its symptoms. His comments inspired a flurry of media interest in rarer dementias with Dr Charlie Marshall, also from the Dementia Research Centre, adding to the debate in a well-balanced interview on Radio 5 live.

## 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](http://www.alzheimersresearchuk.org)



### Support Group Meetings London

**PPA 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.

**PPA support group meeting Thursday July 21 2016:** Wilkins Haldane Room, UCL, Gower St, WC1E 6BT. 11am –2pm (coffee available from 10.30am and lunch provided)

Speakers **Prof Jason Warren**, of the Dementia Research centre at UCL who will host a PPA specific question and answer session. Please submit any questions in advance if possible to [jill.walton@ucl.ac.uk](mailto:jill.walton@ucl.ac.uk)

### Regional meetings

We are gradually extending the support group network to include regional venues across the UK. These regional meetings are co-arranged by regional facilitators [ supported by Jill walton] and provide an informal opportunity to meet other people affected by PPA. Please let Jill know if you are interested in becoming a regional facilitator and please contact regional coordinators directly for information about meetings.

**Buckinghamshire:** Jennie Grassly: [jennie.grassly@buckshealthcare.nhs.uk](mailto:jennie.grassly@buckshealthcare.nhs.uk) 01494 734415

Next meeting June 17 2016

**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](http://bit.ly/RDSfund)



**RARE DEMENTIA  
SUPPORT**