



Inside this issue: World FTD Awareness Week, update from the International FDT Conference in Munich, regional informal support group to start in Hampshire, fundraising and research updates.

World FTD Awareness Week Sept 24-Oct 2 2016



World
FTD Awareness Week

With 'Food for Thought' as the theme of the week, members are encouraged to join us in hosting any food themed event to help mark the week. Dinner parties, lunch events, cake sales and raffles of cakes and sweets were all very successful last year. Please

click [here](#) to download a generic flyer to promote the week, and [here](#) for access to a version which you can personalise according to the event you plan to host.

At the London FTD support group carer's meeting on September 26th 2016, Dr Jon Rohrer (Consultant Neurologist, UCL) will provide an update on our current understanding of FTD and we will be showing an FTD specific film entitled 'Looks like Laurie, Sounds like Laurie'. There will be an opportunity to speak to other people affected by FTD during the interval time, when popcorn and liquid refreshments will be available! This carers meeting will be held during FTD Awareness Week in the basement lecture theatre at 33 Queen Sq., London , WC1N 3BG from 5pm –9pm.

Please confirm your attendance by emailing jill.walton@ucl.ac.uk or r.crane@ucl.ac.uk

American Frontotemporal Dementia Association Education Conference

Resources from the recent American FTD Association Education Conference may be of interest to our members and [are available here](http://www.theaftd.org/newsroom/event-archive/2016-aftd-education-conference) [www.theaftd.org/newsroom/event-archive/2016-aftd-education-conference] Of particular relevance is Darby Morhardt's presentation on the impact of FTD upon a family and the Mayo Clinic guide to Managing Stress.

Information for Children

A variety of age specific resources do exist for young people [children and teenagers] who find themselves facing a diagnosis dementia in a family member or friend.

Carers Trust: [Young Carers](#)

Information for [Young Carers from the NHS](#)

When Dementia is in the House – [for parents and teens](#)

Alzheimer's Association; [Living with Alzheimer's – just for kids and teens](#)

ARUK—'[Dementia Explained](#)'

FTD specific resources are obviously valuable additions to this general provision and can be accessed at

[What about the Kids?](#)

[TDSG page on supporting children](#)

'[FTD Through our eyes](#)' (YouTube Video)

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.

Coming up...

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>]

Simultaneous Virtual Global Quiz, 12th November 2016

Finally, if you would like to take part in this annual event raising funds for Rare Dementia Support, please go to the [JustGiving page](#) [<http://www.justgiving.com/fundraising/%20SGVQ16>] for more details of how to take part.

10th International Conference on Frontotemporal Dementias

August 31-September 2, 2016 Munich/Germany



The work of the Dementia Research Centre was recently featured at the 10th International Conference in Frontotemporal Dementias in Munich. This is the major (biennial) conference dedicated to these diseases and helps set the research agenda and clinical practice standards on a global stage.

Researchers from the DRC presented a total of 32 papers covering a breadth of topics ranging from cell and tissue pathology to dementia care delivery, and including five invited lectures and chairing of two plenary sessions; while Jill Walton was invited to address the Caregiver Symposium, a particularly highly valued component of the conference.

The findings from the GenFI cohort (led by UCL) were highlighted as a flagship resource for detecting and tracking disease at the earliest stages in people with genetic mutations and have set a model for exciting parallel consortia involving major US centres.

Among the most exciting developments reported were the identification of new spinal fluid markers for assessing disease onset and severity, new MRI signatures of genetic frontotemporal dementias and physiological markers of disease that bring us closer to measuring brain protein malfunction directly. The work of the DRC has helped establish each of these initiatives.

Another key theme of the conference was the unification of frontotemporal dementia with motor neuron disease and Parkinson's-like syndromes, setting up shared strategies for understanding disease mechanisms and designing treatments.

In the realm of molecular biology, we heard about remarkable recent progress in modifying disease gene and protein activity in model systems, with the promise of translating these to human patients in the foreseeable future.

We also heard the results of the first human drug trials in frontotemporal dementia: while these have not identified an effective treatment, they represent a tremendous commitment of organisation and collaboration between doctors and scientists and have taught us many lessons that will bear fruit in the selection of new drugs and the planning of larger and more powerful trials in future.

There is a real sense of progress at large in the field of frontotemporal dementia and well founded optimism looking forward. Our Centre is at the forefront of the international research effort in frontotemporal dementia thanks to the tremendous support of our patients, families and caregivers who make our work possible.

Update provided by Professor Jason Warren , Dementia Research Centre, UCL



PPA Regional Support Group, Hampshire

Noreen Quarrell has very kindly agreed to run the first informal regional support group meeting in Odiham, Hampshire on **Friday 14th October 2016** between **2.00pm – 4.00pm** at Odiham Cottage Hospital, Buryfields, Hampshire. RG29 1NE. Noreen is delighted to welcome Rosie Axon from Chiltern Music Therapy. Rosie provides music therapy services to people of all ages and many different needs, including people with diagnoses of dementia. The focus is not only on the benefits of music therapy, but also on specific techniques to help a person maintain their independence for as long as possible.

If you are interested in attending this event, please RSVP to either Noreen or Rachel (Rare Dementia Support Facilitator).

Contact details:

Noreen: noreenquarrell@gmail.com or 07786 767 613

Rachel, Rare Dementia Support : r.crane@ucl.ac.uk or 07341 776 317

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!

I am very much looking forward to meeting you all at future support group meetings and/or liaising over the telephone or via email.

FTDSG Annual Seminar 2017—Save the Date

The date for the 2017 Annual seminar has been booked for **Thursday 2nd March 2017**. The venue is, as in previous years, the Basement Lecture Theatre at 33 Queen Sq., London, WC1N 3BG. We will circulate more details and booking requirements nearer the time.

Living well with Progressive Non-Fluent Aphasia

In this article, Jane Twigg (picture to the right), a PPA support group member, was diagnosed with progressive non-fluent aphasia (PNFA) in December 2014. Jane describes the difficulties she encountered with getting a diagnosis, and offers some advice for professionals on how to support those with a diagnosis of PNFA more effectively. The article was supported by Jenny La Fontaine who is an established FTD researcher and practitioner.



Summary

An overview is provided of what PNFA is, and gives clear examples of the symptoms and difficulties encountered by an individual who has this diagnosis. The article goes on to describe the impact that PNFA has had on Jane's everyday life. At the end of the article, Jane has put together some suggestions on how professionals could support an individual who has a diagnosis of PNFA. Jane acknowledges that due to PNFA being unique to each individual, some of the strategies she describes may not work for everyone. However, she has put together an extensive list of what may be useful:

- Slow down your speech
- Give the individual time to talk
- Ask one question at a time
- Please do not answer for the individual
- Be honest if you have not understood the individual
- Try not to quickly change topics
- Communicating via email may be easier for the individual
- Be aware of the impact background noise may have on the individual
- Meet the individual at their home, so that they can control background noise and the environment
- Ensure you include and involve the individual and that you do not make them feel isolated

You can find the full article at: www.careinfo.org

16 The Journal of Dementia Care September/October 2016, Vol 24, No 5. In December 2014 I was diagnosed with a form of progressive non-fluent aphasia (PNFA).

You can download the article in PDF format at: <http://www.careinfo.org/wp-content/uploads/2012/05/TwiggLaFont.pdf>

All our warmest congratulations to Chris Hardy who completed the Iron Man Wales triathlon in just over 13 hours with the very creditable overall rank of **865 / 1915** competitors.

...while raising £2,983 for Rare Dementia Support!!

Quite apart from his athletic ability, those of us who have the pleasure of knowing Chris will give testimony to his humble, generous, kind yet incredibly dedicated approach to everyone he meets and all that he does. He truly is an amazing person!



Support Group Meetings, London

PPA Support Group Meeting:

Friday 1st December 2016: 11am –2pm

Coffee available from 10.30am and lunch provided.

The Hub, 5th Floor, Wellcome Collection, 183 Euston Road, NW1.

FTD Carers Meeting:

Monday 26th September 2016: 5-9pm

At this meeting, Dr Jon Rohrer (Consultant Neurologist, UCL) will provide an update on our current understanding of FTD and we will be showing an FTD specific film entitled 'Looks like Laury, Sounds like Laury'. The film depicts one woman's journey through the diagnosis.

33 Queen Square, London. WC1N 3BG.

Regional Meetings

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

Buckinghamshire:

Jennie Grassly:

Email: jennie.grassly@buckshealthcare.nhs.uk or telephone: 01494 734415

Next meeting: TBC-October 2016, Totteridge.

Hampshire:

Noreen Quarrell

Email: noreenquarrell@gmail.com or telephone: 07786 767 613

Next meeting: 14th October 2016, Odiham.

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 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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