



Inside this issue

- FTD Awareness Week 2016
- Police and Community Support Officers visit Cornwall carers meeting
- Fundraising update
- Research updates
- Save the date for 2017 Annual seminar

World FTD Awareness Week

Sept 24-Oct 2 2016

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.



World
FTD Awareness Week

At the London FTD support group carer's meeting on Sept 26 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! The Sept26 carers meeting will be held during FTD Awareness Week in the basement lecture theatre at 33 Queen Sq., London , WC1N 3BG from 6pm –8.30pm. Please confirm your attendance by emailing jill.walton@ucl.ac.uk

At the London FTD support group carer's meeting on Sept 26 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! The Sept26 carers meeting will be held during FTD Awareness Week in the basement lecture theatre at 33 Queen Sq., London , WC1N 3BG from 6pm –8.30pm. Please confirm your attendance by emailing jill.walton@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?](#)

[FTDSG 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 update

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; and 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](#).

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](#).

Simultaneous Virtual Global Quiz, 12 Nov 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](#) for more details of how to take part.

Update from the 2017 International FTD Caregiver Conference in Munich

This conference invites informal and professional caregivers from across the world for mutual exchange and discussion with the aim to convey updates on diagnosis, treatment and support initiatives.

After opening sessions which outlined the current state of knowledge and future directions for FTD research, the programme went on to feature a more practical input from Prof. Mario Mendez, whose presentation focussed on 'Dealing with altered social behaviour'. Prof. Mendez emphasised how symptoms of detachment, disinhibition, altered interpersonal connection and altered communication contribute to the impact of a diagnosis of FTD on the families of people affected by FTD in significant and typically detrimental ways. He made the following points:

- Disengagement or apathy has the most impact on a marital relationship

- Behavioural disturbances were the predominant reason for hospital admission in people with FTD

- Loss of emotional attachment leads to feelings of loss and anger in caregivers

- Worse strain, emotional distress and lower perceived control among bvFTD caregivers led to levels of depression for FTD caregivers which are twice as high as their Alzheimer's disease caregiver peers.

- FTD specific support groups form a key role in caregiver support and are critical opportunity for carers to reach out and talk about what is happening, as well as helping them set more realistic expectations.

The use of lumbar punctures for the diagnosis of, and research into, dementia and FTD

Dr Ione Woollacott is a Neurology registrar and FTD researcher based at the Dementia Research Centre, UCL. At a recent support group meeting in London, she explained how having a lumbar puncture can assist in the diagnosis of various types of dementia, including FTD, and can aid our understanding of FTD through its use in research. A recording of her presentation is available at [on the FTD Rare Dementia Support Meetings page](#) and we hope that Ione will be able to join us as a speaker at next year's Annual Seminar.

Dr Woollacott provides the following summary:

A lumbar puncture is a procedure used to collect small samples of cerebrospinal fluid (CSF), which bathes the brain and spinal cord. It is a safe procedure with few side effects; my presentation explains step-by-step how we do it and provides advice for those who need to have one. Examining the CSF gives us vital information about how the brain is working, as it is in direct contact with brain cells. Doctors therefore usually do a lumbar puncture when investigating someone with possible dementia, and particularly if they developed symptoms under 65 years old. At present, we can measure levels of two proteins, 'amyloid beta 42' and 'tau', which indicate whether or not someone has Alzheimer's disease. However, there are currently no CSF markers that we can use to diagnose FTD. At the Dementia Research Centre, we are using lumbar punctures in two of our FTD research studies (GENFI and LIFTD) to try and find CSF markers that might help us diagnose FTD better and earlier. We also hope to find markers that predict how quickly symptoms might change over time in patients with FTD, and predict disease onset more accurately in those at risk of familial FTD. Finally, we hope to find markers for use in future clinical trials that can detect responses to new treatments for patients with FTD, once they are developed.

DWO Review of Personal Independence Payments (PIP)

The Department of Work and Pensions (DWP) has put out a call for evidence for feedback on how PIP is working. Having a rare disease can put an extra hurdle in place for people trying to claim benefits such as PIP. If you have claimed PIP in the past, please tell the DWP about your experience [here](#).

FTDSG Annual Seminar 2017—Save the date

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

Police and Community Support officers at the Cornwall regional meeting

Cindy Reeve, the regional facilitator for FTD support group carer meetings in Cornwall would like to invite people to join her at the forthcoming meeting on Sept 14th 2016, when the local Police and Community Support Officer will join them to talk about community policing and how it might impact and support someone with FTD.

Please contact Cindy directly for venue and other details on tel 01726 71562.

We do hear various examples of ways in which local police services have supported people affected by FTD in the community, and regional facilitators may want to consider making a similar invitation to their local PCSO with regard to coming to speak at their own regional meetings.



Meetings & Contact

Carer Support Meetings - In some areas support group meetings are arranged by regional coordinators. Please contact regional coordinators directly:

London: Contact Jill Walton 07592 540 555 or jill.walton@ucl.ac.uk for details . Next meeting is Mon Sept 26 2016, 6-8.30pm , 33 Queen Sq., London WC1N 3BG

Liverpool: Contact Mary Dawber on 01625 879 104 or email mary1246@hotmail.co.uk for details.

Yorkshire: Contact ftld1@yahoo.co.uk for details .

South West: Lyme Regis : contact Penelope Roques on 01297 445488 for details .

South West: Arundel Arms, Lifton, Devon contact Penelope Roques on 01297 445488 for details.

Hertfordshire/Bedfordshire: Contact Richard Pleydell-Bouverie on richard@lawrenceend.com or 01438 833022 for details.

Cornwall: Contact Cindy Reeve on 01726 71562 for details. Next meeting is Sept 14 2016.

Cambridge: Contact Val Freestone at valerie.freestone@addenbrookes.nhs.uk or tel 01223 768005

Scotland: Carer support group meeting takes place on the second Thursday of the month .Contact Anne Miller at milleranne89@googlemail.com or Tel 01436 268476 for details.

Surrey: Contact Karen Tapson on 07525597503 or email Karen.Tapson@alzheimers.org.uk for details.

Stockport: Contact Helen Griffiths on 0161 716 4505 for details.

Kent/Sussex: contact Jane Smissen-Bell on 01323 504156 for details or email 6bells.jane@gmail.com

West Sussex: contact Jill Butcher on 01444 451 837 or email jillbutcher@onetel.com . Next meeting is XXX

FTDSG Volunteer Regional Contacts For carers, there is often a sense of isolation when faced with the distress and burden that frontotemporal dementias cause. The FTDSG puts you in touch with people who understand.

Scotland—Anne Miller: 01877382654
milleranne89@googlemail.com

Yorkshire – Rev. Ronald Carter: 01904 610 237
Anne Squires 0113 2947139

Northern – Mrs Jillian Ramsay: 0191 421 4069 /
0770 885 438

Manchester/ Stockport—Helen Griffiths:
0161 716 4505 / helen.griffiths@nhs.net

Mersey and North West – Mrs Mary Dawber: 01625
879 104 / mary1246@hotmail.co.uk

West Midlands – Sister Ann Johnson: 01743 210097

Birmingham— Pauline Ross: 07815285876

/ polly.ross@btopenworld.com

Kirsty O'Dwyer: 07887800947 /

kross38@hotmail.com

Kirsty is happy to take calls from anyone whose parent is affected by FTD

London – Rob Perry: robertkperry@live.co.uk /
07812 393968

Central - Emeline Keown [**YoungDementia UK**]:
07909 060430 /
emelinekeown@youngdementiauk.org

Northamptonshire— Hilda Hayo: 07920 819523
hhayo@talk21.com

Cambs— Val Freestone: 01223 768005 /
valerie.freestone@addenbrookes.nhs.uk

Herts/Beds—Richard Pleydell-Bouverie: 01438
833022 / richard@lawrenceend.com

Kent/Sussex— Jane Smissen Bell: 01323 504156 /
6bells.jane@gmail.com

West Sussex— Jill Butcher: 01444 451 837 /
jillbutcher@onetel.com

South West – Miss Penelope Roques: 01297 445
488 / frontotemp@aol.com

Cornwall—Mrs Cindy Reeve: 01726 71562

Lynne Ramsay acts as a volunteer adviser on funding and services: 0208 467 1462/m 07760224396 or email lynneramsay1@gmail.com

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

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.



**FRONTOTEMPORAL
DEMENTIA**

raredementiasupport.org