



RARE DEMENTIA SUPPORT

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On line dementia course features dedicated bvFTD module

We are delighted to announce that a free online course has been developed by colleagues here at UCL, featuring a whole module dedicated to **behavioural variant FTD**. 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 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 10,000 people signed up to do the first run of this course in March 2016. Interest for the September course is now being registered. Visit www.futurelearn.com/courses/faces-of-dementia now to join the conversation , sign up and visit the welcome page.

Use the opportunity to raise awareness of FTD by circulating the invitation to participate in this free course.



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 years week will build on the momentum of last years 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



World
FTD Awareness Week

FTD in the media

April 2016 heralded a peak in 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. Dr Laura Phipps, Science Communications Manager at Alzheimer's Research UK contributed to a lengthy FTD specific interview on BBC Radio London. Laura has helped develop a robust and ongoing relationship between the FTDSG and Alzheimer's Research UK and comments: "As a research charity, we're currently funding over £4m of research into FTD and have contact with supporters whose lives have been affected by the disease. We're committed to continuing to drive forward research to better understand FTD and how it's diagnosed and treated. We're pleased to be providing funds to Rare Dementia Support so that they can continue to expand on the important work they do."

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 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 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. Apply for a place on one of The National Brain Appeal's sports places via 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 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 Brookfield 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.

Jennifer Mackie 1939 – 2016

It is with great sadness that we announce the sudden death of Jenny Mackie from Salisbury. Jenny's husband Bonar suffered from FTD and Jenny was a loyal member of our group and was a Regional Representative for her area for many years. Following her husband's death Jenny was immensely supportive to carers of people with any type of dementia. She had many friends and was always helpful in so many ways. Jenny was very involved with her family, a loving grandmother and will be enormously missed by her many relations, friends and colleagues.

West Sussex Regional Meeting

Jill Butcher, the volunteer regional facilitator for West Sussex is facilitating a meeting for the carers, family and friends of people affected by bvFTD. Jill invites you to join her at 11.00am Wednesday 11th May, at The Beech Hurst Harvester, Beechurst Gardens, Butlers Green Road, Haywards Heath RH16 4BB.

She suggests the people meet initially for coffee, but those who wish could stay on for lunch afterwards. The Beech Hurst Harvester is on the B2272 on the right just as you come into Haywards Heath from the Cuckfield direction. There's a big car park for anyone planning to drive.

Please could anyone interested contact Jill either by email, jillbutcher@onetel.com or tel. 01444 451837 or text on 0786 768 3280. [Jill asks you to note that she will be away from 16th-23rd April and that her husband cannot be relied upon to take messages].

An Overview 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.

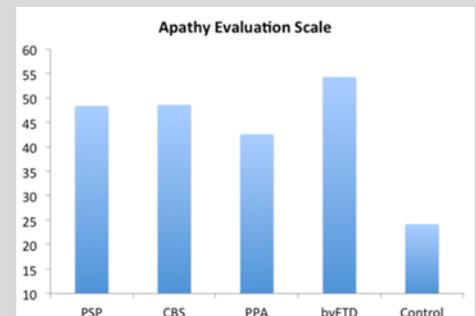
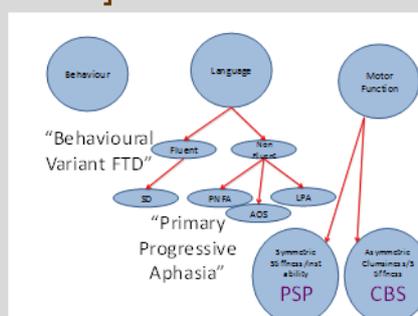
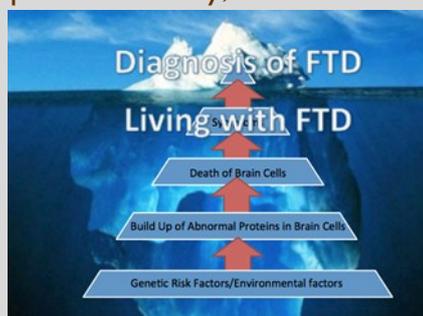
Dr Coyle Gilchrist's research has shown for every 750 people born in the UK, one will go onto be diagnosed with FTD, or the connected illnesses CBD and PSP. Even this may be the "tip of the iceberg". He explained that FTD diagnoses in later life are often missed or misdiagnosed, and that whilst the incidence 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.

Dr Coyle-Gilchrist's presentation will shortly be accessible at <http://www.ucl.ac.uk/drc/ftdsupport>

Several of our support group members contributed to the PiPPIN study [Pick's disease and Progressive Supranuclear Palsy, Prevalence and INcidence]



Disclaimer: Please note that you assume full responsibility and risk in the use of information contained on our website, in our newsletters and at support group meetings.

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

London: Carers meetings take place between **11.00am-2pm at UCL Gower St site venue.** Contact Jill Walton 07592 540 555 or jill.walton@ucl.ac.uk for details . May 23, July 7 2016

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 PL16 0AA : 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.

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

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

Northamptonshire— Hilda Hayo 07920 819523
hhayo@talk21.com

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

London –

Rob Perry robertkerry@live.co.uk Tel 07812 393968

Northern – Mrs Jillian Ramsay 0191 421 4069 m0770 885
438

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

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

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

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

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

West Midlands – Sister Ann Johnson 01743 210097

West Sussex– Jill Butcher 01444 451 837
jillbutcher@onetel.com

Birmingham— Pauline Ross 07815285876
polly.ross@bopenworld.com

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

Kirsty O'Dwyer 07887800947 kross38@hotmail.com

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

Cornwall—Mrs Cindy Reeve 01726 71562

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

Lynne Ramsay: acts as a volunteer adviser on funding and services:

Tel 0208 467 1462 email lynnerramsay1@gmail.com