



FTD SUPPORT GROUP  
FTDSG

# Frontotemporal Dementia Support Group Newsletter

*(formerly Pick's Disease Support Group)*

*For carers of frontotemporal dementia: Pick's Disease, Frontal Lobe Degeneration, Dementia with Lewy Bodies, Corticobasal Degeneration and Alcohol Related Dementia*

## FUND RAISING VENTURES

Whilst we don't have the space to list all the donors and fundraisers who generously donate to the support group, we do extend our sincere thanks to all who have contributed and have a couple of fundraising ventures to share with you here...

### Eloise Hawes water bottle cover sales

Eloise's mother suffers from Pick's disease. Eloise is raising money for the FTDSG by turning her mother's old jumpers into hot water bottle covers. She will donate half of the money raised to the FTDSG. Her first sale will be at the end of November at which she will also be raising awareness of FTD via our Raising Awareness documents and flyers.

### BUPA Great South Run in Portsmouth

On 28th October 2012, Claire Goldup and her sister Kathryn ran to raise funds for the FTDSG. Claire explains: 'My uncle has Primary Progressive Aphasia. The support provided for him and his family by the Frontotemporal Dementia Support Group (registered under The National Brain Appeal) continues to be invaluable. Primary Progressive Aphasia (PPA) is uncommon and many professionals have never heard of it so the FTDSG website is crucial, not only for diagnosis but also in providing clinical information about the illness and practical ideas for coping with it.'

With regards to the run she added: 'It was a freezing cold, wet day but the Powerade, Jelly babies and crowds got us through!'

Thank you for the generous donations totaling £375 at the time of print.

**Any donations to FTDSG should be made out to 'National Brain Appeal: Frontotemporal Dementia Support Group'. See below for further information on how to donate.**



## FTDSG Research Fund News

Lynne Ramsay and Duncan Hutchinson would like to thank all those who have helped in any way to fund raise for the research fund. The research fund was established to ring-fence donations that people wanted to specifically donate towards funding research into FTD, as opposed to supporting the day to day running costs of the support group.

**Dr Jonathon Schott MD MRCP of the Dementia Research Centre, UCL** has provided the following update:

'I am pleased to report that through the generous support of the Frontotemporal Dementia Support Group (FTDSG) we have started a new study at UCL aiming to improve our understanding of the causes of speech and other problems encountered in people with different forms of dementia. This study, joint funded by an industrial partner - AVID Radiopharmaceuticals, involves scanning patients with a range of different dementia syndrome using a number of different brain scanning techniques. These include magnetic resonance imaging (MRI) and positron emission tomography (PET) scanning to determine how alterations in brain structure and connectivity are associated with symptoms. Additionally, this study uses a newly developed PET technology which allows for the protein accumulations that characterise Alzheimer's disease to be visualised. This very powerful technique has the potential to confirm or refute Alzheimer's disease as being the cause of symptoms in patients with dementia, a distinction that will become increasingly important as and when specific treatments for different diseases become available. I would like to take this opportunity to thank those who have made donations to help fund this work, and I look forward to sharing the results with you in due course.'

**Any donations to the research fund should be made out to 'National Brain Appeal: Frontotemporal Dementia Support Group: Research'. For general FTDSG donations and research fund donations please contact Leigh Stanger at The National Brain Appeal either on tel. 0203 448 4724 or at The National Brain Appeal, Box 123, National Hospital for Neurology and Neurosurgery, Queen Sq., London, WD3 5RT, or at [leigh.stanger@uclh.nhs.uk](mailto:leigh.stanger@uclh.nhs.uk)**

Please enquire about gift aid contributions if they are applicable.

**SNIPPETS.....**Penelope Roques, Secretary of the FTDSG shares some comments after attending 2 important meetings earlier in September this year:

Jill and I attended the FTDUK second Annual Meeting and Jill gave a great presentation on "What Carers want from Research". Well done to all of you who answered the questionnaire. Two professors came up and asked for copies of her slides and she was warmly congratulated. This will really help raising awareness.

We then attended the 8<sup>th</sup> International FTD Meeting. There were many very complicated presentations and 354 posters most of which I didn't even understand the titles but the overall levels of enthusiasm and huge range of professionals was impressive. The Carer's Meeting was held on Thursday and about 90 people attended.

Some snippets that I managed to glean:

There are about 3,500 people with FTD of which about 700 have the inherited form. There are various disease groups which include Behavioural variant, Primary Progressive Aphasia, Semantic Dementia, Non Fluent Aphasia and Logopenia.

There are ten different genes causing the disease but three main ones. Chr 17 causing a false metabolism of the protein tau (FTDP 17), Chr 17 (again) causing a problem with the progranulin gene and a new gene recently found on Chromosome 9. This new fault is odd in as much that the other mutations are an alteration in the genetic code for example a substitution of one letter for another but this gene is an expansion of genetic material similar to the problem in Huntington's disease. The illness either presents as Frontotemporal dementia or Motor Neurone Disease. The age at onset varies and some people who have the gene do not appear to get the illness even if they live four score and 10. A great deal of work is going into understanding the role that all these various proteins play.

Everybody was excited when a mouse model of AD and FTD was made, mice do not get these illnesses so it had to be introduced. Now it is possible to take a skin biopsy (about the size of the rubber at the top of a pencil and under local anaesthetic) from a person with FTD and grow numerous stem cells. These fundamental cells can then be programmed into being brain cells and there in a dish it is possible to study the changes in the brain. We saw a video of some cells programmed to be heart cells and they were beating!

There is also another fascinating line of research trying to work out how the disease spreads through the brain. If the illness starts in the left temporal lobe causing speech problems why does all the brain end up becoming affected?

A presentation on eye reactions was ingenious. It is possible to monitor reactions to happy and depressing events. It proved that people with FTD have decreased emotions – something carers have known for a long time but wouldn't it be great if an eye test could be inserted into the battery of tests needed to get a diagnosis of FTD; non-invasive and reasonably quick to do.

There was an extremely interesting presentation on retraining people with Semantic Dementia. You make a computer programme of about 30 different useful household objects, such as fridge with the name written underneath and a voice naming the article which the patient then repeats. The patient watches this programme for 5 days a week for 3 – 4 weeks and it seems that the words become re-lodged. The programme can then be restarted with another batch of words.

There were 17 posters outlining the problems experienced by the family as well as the patient. Hopefully there will be even more at the next Conference in Vancouver in two years' time.

It was nice to meet up with many doctors and scientists from the Dementia Research Centre at The National Hosp. who give us so much support.

In nearly all of the presentations the role of the person with dementia and the carer was acknowledged.

## Your contributions

This section of the newsletter is for members to have the opportunity to contribute any helpful hints, experiences, or points you want to raise...email [jill.walton@ftdsg.org.uk](mailto:jill.walton@ftdsg.org.uk), Tel 0845 458 3208 or post to 22 Brushwood Dr, Chorleywood, Herts, WD3 5RT. Longer articles are also welcome!

### *Does anyone have any advice to offer in respect of how to stop a person from grinding their teeth?*

My husband was diagnosed with FTD in April 2009, aged 58, and since December 2009 has been resident in a specialist nursing home where he is cared for very well. His dementia has progressed quickly and he is now largely unresponsive; he has had no language for about 3 years. He is calm and likes watching TV. Recently he has started grinding his teeth loudly - I think he does this for most of the day. I wonder if other carers have experience of this, and if there are any tips on how it may be stopped.

# The Annual Seminar 6<sup>th</sup> March 2013 9:30am –4pm

National Hospital for Neurology & Neurosurgery, Lecture Theatre: 33 Queen Square, London WC1N 3BG

- **Welcome and Update** - John Rendell, Chairman and Jill Walton, Nurse Advisor/ Support Group Coordinator, FTDSG
- **Speaking my language – understanding FLD and its effects”-** Baroness Greengross, Chair of the All- Party Parliamentary Group on Dementia
- **FTD: An Overview** -Dr Phillip Fletcher, Clinical Research Fellow, Dementia Research Centre, UCL
- **Research Initiatives in FTD** - Laura Phipps, Alzheimer’s Research UK
- **Swallowing Problems in FTD** -Luke deVisser, Speech and Language Therapist, NHNN
- **Treatment Trials in FTD and Other Dementias** - Dr Richard Perry, Consultant Neurologist and Honorary Senior Lecturer, Imperial College NHS Trust
- **‘What’s On Your Mind..?’ a question and answer session for carers.** - Dr Jason Warren, Reader in Neurology, Dementia Research Centre, UCL
- **The Unmarked Road to Diagnosis** - Jan Welsh , whose husband was diagnosed with FTD in 2009
- **Refreshments and lunch will be provided .**
- **To book, contact [jill.walton@ftdsg.org](mailto:jill.walton@ftdsg.org) or tel: 0845 458 3208. Cost: £75 for Professionals £10 for Caregivers. Cheques payable to ‘National Brain Appeal: FTDSG’ and c/o Jill Walton, 22 Brushwood Drive, Chorleywood, Herts, WD3 5RT**

## DRUG TRIAL ANNOUNCED FOR PEOPLE WITH bvFTD

You may have heard that a drug trial for people with behavioural variant FTD was announced in September 2012 by the pharmaceutical company TauRx therapeutics.

Approximately 25-30 study sites will be participating in this international study , which aims to recruit 180 people worldwide, 60 of those being from within the UK.

The drug being tested is a new molecule based on one that was tested previously called *remember*<sup>®</sup>. In previous clinical trials, *remember*<sup>®</sup> was given to more than 300 people with Alzheimer’s disease throughout Britain and Singapore.

The trial will be a randomized, placebo-controlled 12-month study in people with behavioural-variant FTD (bvFTD). The study will be clearly explained to people who are interested in taking part and participants will need to be screened in order to ascertain their eligibility for involvement. As well as falling within various testing parameters, participants will need to be aged 70 or under and be living at home with a caregiver who is also willing to participate. The study will typically involve 10 visits to the clinic, as well as various ‘telephone visits’.

For more information go to:

[www.picksdementiastudy.com](http://www.picksdementiastudy.com) (Please note that this information is managed by a third-party, MediciGlobal, a market research and marketing agency hired by TauRx to support its clinical trials activities.)

<http://clinicaltrials.gov/ct2/show/NCT01626378>: for a more detailed description of the design of the study, inclusion/exclusion criteria, endpoints, etc.

The FTDSG has spoken to [Ginnette Kitchen RMN.RGN.MSc, Trial Co-ordinator/Dementia Research Nurse at the Dept. of Neurosciences, Charing Cross Hospital](#). She is excited at the prospect of this study and will be able to provide more specific information about the trial, and explain where your nearest trial centre may be.

Tel: 00 44 (0) 203 3135515 or Mob: 00 44 (0) 7903241429

Your GP will be informed about your potential inclusion in this study.

## CareAware

Many of you are aware that the FTDSG has subscribed as a member of CareAware for many years. Of particular benefit, we hope, has been the access to independent help and information about funding care costs, legal issues, and advice about how to act on another persons behalf. The FTDSG were therefore delighted to learn that Suffolk County Council has set a precedent in being the first local authority to make provision to refer residents and families to the Care Aware helpline for advice on a wide range of funding, benefit and associated care issues, We feel that the initiative affirms our longstanding arrangement and subscription to CareAware on behalf of our members.

## LEEDS FTD SUPPORT GROUP

We are delighted to announce the second Leeds regional meeting for people affected by FTD.

Are you caring for someone who has Frontotemporal lobar degeneration (FTLD)? The term 'fronto-temporal dementia' covers a range of conditions, including Pick's disease, frontal lobe degeneration and dementia associated with motor neurone disease.

On Friday 7<sup>th</sup> December, between 11.00 am and 2.00 pm, a small group of carers from across Yorkshire will be meeting for an informal chat and optional refreshments at Yates's on Boar Lane, Leeds. They will make any new

## Forthcoming Carer Support Meetings

**London: The Old Boardroom of the National Hospital for Neurology and Neurosurgery, Queen Square, WC1N 3BG:** 10 Dec 2012. **Joint FTDSG/PPA Carers Meeting:** 4 Feb 2013 11.30-2pm, [Annual Seminar: March 6th 2013,] 10th June 2013. 9th Sept, 4th Nov, 2013. The regular carer meetings take place between 11.00-am-2.30pm and conclude with a visit to local Italian restaurant for lunch. Contact Jill Walton 0845 458 3208/jill.walton@ftdsg.org for details

**Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR :** 22 Nov 2012, 17 Jan 2013, 14 March 2013, 23 May 2013, 8 July 2013, 19 Sept 2013, 21st Nov 2013 [for details contact Mary Dawber on 01625 879 104 or email mary1246@hotmail.co.uk Meetings usually take place between 1pm and 3pm .]

**Yorkshire Meetings:: Yates Wine Bar , Boar Lane, Leeds LS1:** Friday 7th Dec 2012, 15 March 2013 at 11am –2pm. It's fine to just turn up on the day, or you can e-mail [ftld1@yahoo.co.uk](mailto:ftld1@yahoo.co.uk)

**South West: :Lyme Regis : 9 Feb 2013** ( for details contact Penelope Roques –0845 458 3208)

**South West: Arundel Arms, Lifton, Devon PL16 0AA 14 Feb 2013**( contact Penelope Roques –0845 458 3208)

**FTDSG 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:

**Yorkshire**– Rev. Ron Carter 01904 610 237

**Northern**– Mrs Jillian Ramsay 0191 421 4069-mob. 07708 857438

**Trent**– Mrs Janet Carpenter 0116 239 2913 [Also the contact person for Carers of Alcohol Related Dementia]

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

**West Midlands**– Sister Ann Johnson 01743 492 175

**Central**– Mrs Sue Smith [YoungDementia UK Mon-Thurs] -01235 522 382

**Northamptonshire** –Rob Hasker (email by preference) -Robert.hasker1985@hotmail.com or 07889875422

**Suffolk**– Mrs Gillian Gubb 01502 569077

**London** - Mrs Carole Ivey 0207 603 0550

**Southern [Hants, Wilts]** - Mrs Jenny Mackie 01722 336 352

**Southern [Surrey, Sussex]** - Mrs Val Bywater 01420 362 123-Mob. 07792 721853

**South West**– Miss Penelope Roques 01297 445 488

**Kent**– Tina Stirling 01892 723130 email tinastirl@tiscali.co.uk

**North Wales**-Mr Roy Jones 01248 351 537

**South Wales**-Mrs Pat Coulson 01792 883 684

**Northern Ireland**- Mr Martin McCrory 02887 753 812

**Lynne Ramsay:** Adviser re. the medical profession and obtaining funding and services

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