



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

- \*Dementia Awareness Week    \*London Marathon    \*8th International FTD Conference  
 \* Links with Genetic Alliance and Rare Disease UK    \* What do YOU want out of research into FTD?  
 \*Research opportunities    \*'Your Contributions'



**Dementia Awareness Week 2012** This year's Dementia Awareness Week took place between 20 and 26 May 2012. The aim of the week was to increase public awareness and understanding of dementia and get people thinking and talking about it. It was therefore only right that the Frontotemporal Dementia Support Group be represented at the main UCL Hospital in Euston Road during this week. We took our place alongside the Alzheimer's Society and DENDRON [The Dementia and Neurodegenerative Diseases Research Network] and

were pleased to have the opportunity to display and distribute information.

## LONDON Marathon 2012

Whilst disappointed for Lori Westcott, who had to withdraw from entering the marathon due to injury, the FTDSG was represented amongst the cheerleaders present on the day. Several runners completed the course, raising funds for The National Brain Appeal, the charity under which we are registered. I am informed that there are usually several places allocated to the charity for runners who want to enter.....any takers?



## The 8th International Conference on Frontotemporal Dementias

5th –7th September 2012

### The 8th International Conference on Frontotemporal Dementias

5-7 September 2012  
Manchester Central  
Manchester



During this conference, a one-day meeting will be held on 6th September 2012 for family members, friends and support workers who care for a person with frontotemporal dementia or related condition (semantic dementia or progressive aphasia). The meeting will be organised by members of the Cerebral

Function Unit Carers group in liaison with the Association of Frontotemporal Degeneration (AFTD) and the Frontotemporal Dementia Support Group, International and British lay organisations dedicated to improving the lives of families coping with frontotemporal dementia and advancing research into treatment and a cure. The caregivers' meeting will run in parallel with the main FTD conference, providing the opportunity for caregivers to listen to talks from international speakers. The caregivers' programme will cover the latest research findings as well as clinical, social and practical information relevant to FTD.

There will be a strong emphasis on informality and the day will provide a forum for interactivity and discussion. The goal is to facilitate communication between caregivers, lay organisations, health professionals and scientists with the aim of increasing understanding of FTD and improving the global provision of services to support families.

For more information please contact [www.ftd2012.org](http://www.ftd2012.org) or Tel: 0207 383 8030

# FTD UK 2012

The FTDSG [formerly Pick's Disease Support Group] has been invited to speak at an international meeting for frontotemporal dementia researchers. At this meeting, researchers will come together to talk about advances in the field and the future of FTD research. The meeting will allow people to share their work and ideas and will foster collaboration between research groups interested in FTD in the UK.

I have been asked to deliver a presentation which addresses the question: **'What do what patients and carers want from FTD research?'**

In order to accurately represent your views, I would be very grateful if you could spend some time completing a specifically designed questionnaire.

Please visit [www.ftdsg.org](http://www.ftdsg.org) and click on 'Survey' in the drop down menu.

Either email your response to [jill.walton@ftdsg.org](mailto:jill.walton@ftdsg.org), or post to 22 Brushwood Dr, Chorleywood, Herts, WD3 5RT

The meeting will take place in September, on the day before the International FTD Conference which is advertised elsewhere in this newsletter. Please visit: <http://www2.kenes.com/ftd2012/Pages/Home.aspx> - for more information about this meeting as registration is now open.

Thank you in advance for any contributions you are able to make, and I look forward to making the most of the opportunity to present your views at this important meeting.

## 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](mailto:jill.walton@ftdsg.org), Tel 0845 458 3208 or post to 22 Brushwood Dr, Chorleywood, Herts, WD3 5RT. Longer articles are also welcome!

- **My husband, recently passed away (7<sup>th</sup> May) following aspiration pneumonia. He was diagnosed with Picks Disease in November 2007. I have visited the PDSG site often and am on your email mailing list. As a member of the online FTD Support Forum I came across the attached You Tube. It is a talk given by an experienced Hospice Nurse, Barbara Karnes. It proved invaluable when my husband developed pneumonia. I was able to 'read' the signs of the end of life approaching. I had just finished reading Vivienne Hughes piece [FTDSG newsletter April 2012] and thought it may be something that you could share with those in the Support Group as to what to expect. Whilst it is not dealing with a dementia illness specifically, there were many indicators that the end was approaching. Barbara describes many of the symptoms which my husband experienced very shortly before he died. I hope this is of help and some comfort to those who have to face the inevitable.**  
<http://www.youtube.com/watch?v=PPx-qpos57g>
- **For further information on end of life care with people with dementia the following resources may be of interest: [www.dyingmatters.org](http://www.dyingmatters.org), ('Leaflet#11:Time to talk?' now available -call 0800 214466), [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk), The National Council for Palliative Care [www.ncpc.org.uk](http://www.ncpc.org.uk),**
- **Patricia Currie started to write a daily blog when her husband was diagnosed with semantic dementia in December 2010. It captures much of the ordinary comings and goings of life, but also catalogues the changes she and her family were facing every day in light of the diagnosis. It may be helpful for others people in a similar situation to read Patricia's account of what it is like living with a husband with semantic dementia.** Visit <http://trishcookingcurrie.blogspot.co.uk>

## THANK YOU

**Margaret Perkins** has written to thank everyone who contacted her regarding her request for help in the April news letter: "I received around eight contacts from various parts of the country, undertook face-face interviews with a smaller number but additionally had detailed telephone calls to others on the phone. A couple sent materials they themselves had written on the issues involved which they were kind enough to let me have. Everyone has been so helpful and willing to be involved. I am currently pulling together all the information for a report to the LSE Research Committee and then with my colleagues will see how we can progress the work. I will retain the contact details of all the contacts so that I can go back to them at a later stage of the work, assuming we can secure further funding. It is clear that there are huge needs 'out there' for this particular group of people. Again, very many thanks "

## Wanted – people with semantic dementia or FTD

Helen Beaumont will be a name that is familiar to many members of the support group. Her husband Clive was diagnosed with young onset frontotemporal dementia at the age of 45. During the following 6 years Helen had to address the legal implications of the illness, apply for benefit payments, find nursing homes and juggle her responsibilities as a wife, a mother and an employee.

Helen is a founder member of YoungDementia UK [formerly The Clive Project] and author of the book 'Losing Clive to Younger Onset Dementia'

She is currently involved in research into frontotemporal dementia at the University of Manchester and is keen to contact people with semantic dementia or FTD. Helen asks:

Do you live within reasonable travelling distance of Manchester, UK?

Do you, or someone you care for have a diagnosis of semantic dementia or frontotemporal dementia?

Are you/they prepared to have an MRI scan and take some cognitive tests?

If the answer to all of these questions is "Yes", I would love to hear from you.

I am trying to develop a system which can identify people with FTD or semantic dementia.

I am using some new MRI scans and new cognitive tests. The MRI scans take around an hour, and the cognitive tests around 3 hours.

If you are included in the study, I will visit you at your home for an initial round of cognitive tests, and then I will ask you to visit Manchester for the MRI scan and a few more tests.

If you are interested, please pms me , phone me on 0161 275 5154, email me at

[Helen.beaumont@postgrad.man.ac.uk](mailto:Helen.beaumont@postgrad.man.ac.uk) or snail-mail to Helen Beaumont, ISBE, Stopford Building, Oxford Rd, Manchester M13 9PL.

For more detailed information click [here](#)

## Active Links with Genetic Alliance and Rare Disease UK

The FTDSG has recently been involved in 2 interesting activities coordinated by Genetic Alliance and Rare Disease UK.

Earlier this year we were approached by Genetic Alliance UK to assist with a 'submission of an opinion' regarding pre implantation diagnosis of Picks Disease to the Human Fertilisation and Embryo Authority. We were delighted to be able to work with Nick Meade at Genetic Alliance and submit that proposal to the HFEA according to the deadline.

The [Human Fertilisation and Embryology Authority](#) [HFEA] is the UK's independent regulator overseeing the use of gametes and embryos in fertility treatment and research.

The HFEA licenses fertility clinics and centres carrying out in vitro fertilisation (IVF), other assisted conception procedures and human embryo research.

The second consultation was a submission, on behalf of the FTD support group, to the Department of Health Screening & Specialised Services Team. This formed our contribution towards the response to the Consultation on the United Kingdom Plan for Rare Diseases, as coordinated by Rare Disease UK. We are very grateful to Sue Rendell for her work in representing the views of our organisation and the people we seek to represent in this response. This was an important opportunity for our group to express the needs of people with FTD within a wider and hopefully influential setting.

### The Vanishing Mind *A Wife's Heartache*

This extract from an article published in the New York Times on May 5 2012 will resonate with many of our members. The full article is lengthy , but well worth a read.

Find it at <http://www.nytimes.com/2012/05/06/health/a-rare-form-of-dementia-tests-a-vow-of-for-better-for-worse.html? r=1&pagewanted=all>

'He threw away tax documents, got a ticket for trying to pass an ambulance and bought stock in companies that were obviously in trouble. Once a good cook, he burned every pot in the house. He became withdrawn and silent, and no longer spoke to his wife over dinner. That same failure to communicate got him fired from his job at a consulting firm. By 2006, Michael French — a smart, good-natured, hardworking man — had become someone his wife, Ruth, felt she hardly knew. Infuriated, she considered divorce.

Mr. French, now 71, has [frontotemporal dementia](#) – a little-known, poorly understood and frequently misdiagnosed group of brain diseases that eat away at personality and language. Although it was first recognized more than 100 years ago, there is still no cure or treatment, and patients survive an average of only eight years after the diagnosis.

He was an engineer, lectured at conventions, belonged to a book club and ran marathons. Now he can no longer speak, read, write or walk. On most days, Mrs. French spends several hours with her husband at the nursing home in Manhattan where he now lives. She had to move him there last year after she was no longer physically able to take care of him. "At times, I ache for him to be back in the apartment," she said. "But I ache for him to be back as him."

## ANNUAL SEMINAR 2013: CHANGE OF DATE

Owing to a double booking in respect of the lecture theatre at 33 Queen Square, the 2013 Annual Seminar will now take place on Wednesday March 6th 2013

## Forthcoming Carer Support Meetings

**London: The Old Boardroom of the National Hospital for Neurology and Neurosurgery, Queen Square, WC1N 3BG:** 10 Sept 2012, 10 Dec 2012. **Joint FTDSG/PPA Carers Meeting:** 4 Feb 2013 11.30-2pm, [Annual Seminar: March 6th 2013,] 10th June 2013. 9th Sept 2013. 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 :** July 19, Sept 20, Nov22 [for details contact Mary Dawber on 01625 879 104 or email mary1246@hotmail.co.uk Meetings usually take place between 1pm and 3pm .]

**York: Yates Wine bar, Boar Lane, Leeds, LS1:** August 22nd, 11am-2pm [for details contact Mary Dawber on 01625 879 104 or email mary1246@hotmail.co.uk ]

**South West:** Arundel Arms, Lifton, Devon PL16 0AA: Sept 14th[ for details contact Penelope Roques 01297 445488]:

**Lyme Regis:** Sept 22nd [for details contact Penelope Roques 01297 445488]

**Bristol :** The Priory, Portbury, BS20 7TN: July 20th [ for details contact Penelope Roques - 0845 458 3208]

## PDSG 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**– Mrs Elaine Anderson 01292 442 273

**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

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

**Oxfordshire**– Mrs Sue Smith [Young Dementia 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

**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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