

frontotemporal dementia

**[FTDSG] SUPPORT GROUP**(formerly **Pick's Disease Support Group**)

www.ftdsg.org

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## FTDSG Annual Seminar Thursday March 10 2016.....save the date!

Provisional agenda includes:

An overview of FTD and the Pippin study - Dr Ian Coyle Gilchrist

Emotion recognition in FTD - Dr Charles Marshall

Disease stages in FTD: common deficits and management tips - Prof .Eneida Mioshi

'What's On Your Mind..?' a question and answer session Prof. Nick Fox

'No laughing matter: why do patients with FTD like (or stop liking) the things they do?' Prof. Jason Warren

**Cost including lunch:** £10 for family members      £75 for professionals [concessions available]

Contact Emilie Brotherhood [e.brotherhood@ucl.ac.uk](mailto:e.brotherhood@ucl.ac.uk) or **020 3448 3609** to book your place

## Book Review : The Dance—our journey through frontotemporal dementia by Deborah G. Thelwell

This is a moving personal account, by his wife, of a 53 year old man's decline over a period of 5 years as a person with FTD. Although much of the detail is distressing to read I would certainly recommend it as a useful reference book.

The family had emigrated to the USA from England and 8 years later Alan was diagnosed with FTD with additional subsequent Alzheimer's features. The diagnostic process seemed remarkably swift, with thorough testing procedures and a conclusion reached more speedily than perhaps most peoples experience in the UK. Drug therapies were available readily [albeit with not notable success] with accessible professional support and similar groups to ours.

The effects of Alan's illness on every member of the family are described factually and remind us that a diagnosis of such a disease reached into all aspects of family life.

When the time came, some 4 years into Alans illness, for an appropriate residential care home to be found, the family experienced the mixed successes and failures so familiar to many of us. One big difference was the availability of state funding for the residential care, once eligibility was proved. The sadness of Alan's passing away in a hospice emphasises the inevitable outcome of this cruel disease, whilst highlighting positive future hopes.

Reviewed by **EMS**

## Fundraising update: With Christmas approaching, members may be interested to know that they can now give as they spend!

National Brain Appeal has agreed to ring fence monies donated via Easyfundraising to raise money for FTD research. Instead of going straight to sites such as Amazon, John Lewis, etc...if you log into [easyfundraising.com](http://easyfundraising.com) and then choose Amazon or whatever site you wish to purchase from, a minimum of 1.5% plus gift aid if requested will go to National Brain appeal, and hence FTD research at no cost to the purchaser.

## Your contributions.....

'Following your snippet about tracking devices I bought my sister a smart phone and installed Familo on it. I've given her a new GiffGaff SIM card for the new phone so that she can carry on using her old phone for phone calls and texts and told her to charge it every night and carry it everywhere. Familo tells me and other family members if the battery drops below 2% and when she leaves home. For instance, I was notified she left home the other evening and walked to her daughters. I'm not convinced she always takes it out with her, so it's not perfect, but it does take a little of the stress away. It's a collaborative project between the University of Dresden and Dresden City Council so it's free and there are no adverts or efforts to sell you more products. It's not specifically for dementia but I think it covers most requirements.' Details available at - <https://www.familo.net/en/>



# RARE DEMENTIA SUPPORT

## All Change at the Frontotemporal Support Group An update from Penelope Roques, FTDSG — Nov 2015

### **History:**

When Jill Walton and I worked at St. Mary's Hospital Professor Martin Rossor suggested that we set up a Support Group for carers of people with Pick's Disease. Jill and I then transferred to working at the National Hospital for Neurology and Neurosurgery in the Dementia Research Group and we held our first meeting of the PDSG as it was first called. Shortly after Jill left to bring up Jasmine, Ella and Joshua. I remained at the National until some fairly serious surgery forced me to retire and it was suggested I should run the PDSG from home with support from the Dementia Research Centre. I enrolled Carol Jennings to help and the support group continued to evolve. I had first met Carol through the research into her family's history of Alzheimer's disease and it was in her family that the first gene for Alzheimer's disease was identified. We were all very sad when Carol started showing symptoms of Alzheimer's disease and she decided to leave the PDSG. I am still in touch with Carol and her husband and they come and stay with me in Lyme Regis when they can. Both Carol and Stuart are very involved both in research and promoting awareness of dementia affecting people of working age. Carol's leaving left a gap and I persuaded Jill to work for us. It was very brave of her considering the lack of infrastructure and the uncertain financial position. I am very proud that we have never had to ask let alone hassle for donations and that people's generous donations have kept us afloat. Jill's background of a degree in Psychology, MSc. in gerontology as well as her nurse training made her perfect for the job. Jill has made a tremendous difference to the group and projects such as raising awareness, support for Regional contact people and collaboration with other groups have had a great impact.

The Dementia Research Group hosts several other support groups including one for Familial Frontotemporal Dementia and these too are organised by Jill with Seb Crutch Professorial Research Associate, ARUK Senior Research Fellow and funded by the Myrtle Ellis Trust. It was decided that it would be a good way forward to organise all the groups through the Dementia research group and I am absolutely delighted as it will ensure a future for the group. Jill has now been appointed as Advisor and co-ordinator at the Dementia Research Centre which is wonderful news.

### **Structure:**

The groups are now organised through a main advisory committee and 4 sub-groups. The main advisory committee is chaired by Professor Nick Fox and includes Dr. Seb Crutch, Dr. Jonathan Rohrer who has a special interest in FTD, Mrs. Theresa Dauncey, Director of the National Brain Appeal (NBA) and Mrs. Caroline Church, Trustee of the NBA. Diana Garfield represents the Myrtle Ellis Trust and I represent the FTD and Jill Walton who does MOST of the work. The four sub groups in which we are well represented address Fundraising, External Communications, Governance and Communications. Our Chairman John Rendell sits on the Fundraising subgroup as does Lynne Ramsay.

This has amazing advantages for our group. The benefits include financial assistance for the Groups being written in to grant applications, research assistants having involvement with the groups written into their job descriptions and the expertise of over fifty members of the DRC ready to help and offer expertise and support. You can understand why I am so thrilled. There is also a plan to employ a nurse assistant for Jill.

### **Future:**

Of course we now have to agree to the terms and conditions of UCL and the constraints imposed by an infrastructure and governance. This is entirely outweighed by all the benefits which being housed in the Dementia Research Centre brings. Rest assured that Jill will be just as accessible as ever but that your interests and the interests of the FTD are going to be incredibly well represented.

We have been helped enormously over the last 20 years by some very special people. Firstly by Roberto Salina, a friend of mine, who from Italy has helped with all (mostly my) computer problems, organizing our first database and web support and posting the newsletters. Roberto has done this all for nothing for over twenty years and his only involvement with frontotemporal dementia was through me. Peter Davis has been another stalwart of our organisation and has printed our newsletters absolutely free of charge as well as printing our booklets and other publications at cost price. He has even fundraised for us by donating to us rather than sending Christmas cards. The National Brain Appeal has also been extremely helpful in handling our finances and enabling us to have charity status through them. This has saved us an immense amount of time, money, energy and stress. It is only with support such as this that we have been able to function all these years.

We will continue as a charity but now under much better organisation and with superb support.

## Research round-up

### Individual experiences of changes in empathy : Bethany Coad

**Bethany will be speaking at the Jan 24 London FTDSG carers meeting, and summarises her research interest below:**

Changes in empathy and difficulties in recognising and responding to the thoughts and feelings of other people can be an early symptom of frontotemporal dementia (FTD). These changes in how a person with FTD may respond to family and friends can be very distressing and can negatively influence a caregiver's quality of life. Because of this, researchers are making an effort to understand the changes in empathy that occur in FTD and the impact that these changes have on individuals who care for people with FTD.

Beth Coad is a PhD researcher at Cardiff University and is talking to family members about their experiences of empathy changes in FTD and the impact these have had on them and their caregiving experience. Interviews can be conducted in-person or over the phone/skype at a time and location convenient to the participant. Beth is willing to travel, ideally conducting interviews within the midlands, Wales and the south of England.

**If you would like more information on this project please contact Beth on 02920 870478 or via email at: [Coadbm@cardiff.ac.uk](mailto:Coadbm@cardiff.ac.uk)**

### Hyper sexuality Study: Natalie Tayim

**Natalie is a PhD student working with Prof Jason Warren, an eminent UCL clinical and research neurologist**

Neurological disorders can sometimes be associated with changes in the desire for sex. In some disorders, the desire for sex can increase, but in others, desire for sex can decrease. This can cause significant problems for some patients and their partners/carers. However, because this is such a sensitive topic, such problems are often underreported.

A study that has been set up at Queen Square in collaboration between the DRC and Department of Uroneurology seeks to further our understanding of this important issue, and hopefully lead to improved treatment. This will be done by investigating:

- (1) the prevalence of any changes in sexual desire in neurological disorders;
- (2) the physical, psychological and cognitive factors associated with such changes;
- (3) the impact of these on the patient and their carer.

After this, it is hoped to develop a suitable psychologically-based treatment for people affected by changes in sexual desire.

This study aims to understand the changes in sexual behaviour that may occur in dementia and the impact this has on carers. This will be done using a semi-structured interview and questionnaires.

Participants will be asked some general questions about the health of the person with dementia ( and their sexual behaviour). Participants will then be asked about how changes in the sexual behaviour of the person with dementia has impacted them.

It is hoped that the information gained from this study will help improve our care for people with neurological disorders and their carers. It is hoped that this research will inform :

- (1) our understanding of the predisposing, precipitating, and prolonging factors involved in the development of hyper sexuality, to reveal predictors of the disorder; and
- (2) the development of a psychological intervention for people affected by hypersexuality, to reduce distress and promote wellbeing.

**If you would like more information about this study, please contact the researcher, Miss Natalie Tayim, at 07490090010 or email at [natalie.tayim.12@ucl.ac.uk](mailto:natalie.tayim.12@ucl.ac.uk)**

**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 see the website [www.ftdsg.org](http://www.ftdsg.org) or 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](mailto:jill.walton@ucl.ac.uk) for details . Jan 24, [Annual Seminar March 10] May 23, July 7 2016

**Liverpool:** Contact Mary Dawber on 01625 879 104 or email [mary1246@hotmail.co.uk](mailto:mary1246@hotmail.co.uk) for details.

**Yorkshire Yates Wine Bar , Boar Lane, Leeds LS1.** Contact [ftld1@yahoo.co.uk](mailto:ftld1@yahoo.co.uk) for details .

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

**South West: Arundel Arms, Lifton, Devon PL16 0AA :** contact Penelope Roques –01297 445488 for details.

**Hertfordshire/Bedfordshire:** Contact Richard Pleydell-Bouverie on [richard@lawrenceend.com](mailto: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](mailto: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](mailto:milleranne89@googlemail.com) or Tel 01436 268476 for details.

**Surrey:** Contact Karen on 07525597503 or email [Karen.Tapson@alzheimers.org.uk](mailto:Karen.Tapson@alzheimers.org.uk) for details.

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

## **FTDSG Volunteer Regional Contacts** For carers, there is often a sense of isolation when

**Scotland**—Anne Miller 01877382654  
[milleranne89@googlemail.com](mailto:milleranne89@googlemail.com)

**Northamptonshire**— Hilda Hayo 07920 819523  
[hhayo@talk21.com](mailto:hhayo@talk21.com)

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

**London** – Mrs Carole Ivey 0207 603 0550  
Rob Perry [robertkerry@live.co.uk](mailto: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](mailto:valerie.freestone@addenbrookes.nhs.uk)

**Manchester/ Stockport**—Helen Griffiths  
[helen.griffiths@nhs.net](mailto:helen.griffiths@nhs.net) 0161 716 4505

**Herts/Beds**—Richard Pleydell-Bouverie 01438 833022  
[richard@lawrenceend.com](mailto:richard@lawrenceend.com)

**Mersey and North West** – Mrs Mary Dawber 01625 879 104  
Email [mary1246@hotmail.co.uk](mailto:mary1246@hotmail.co.uk)

**Kent/Sussex**– Jane Smissen Bell 01323 504156  
[6bells.jane@gmail.com](mailto:6bells.jane@gmail.com)

**West Midlands** – Sister Ann Johnson 01743 210097

**West Sussex**– Jill Butcher 01444 451 837  
[jillbutcher@onetel.com](mailto:jillbutcher@onetel.com)

**Birmingham**— Pauline Ross 07815285876  
[polly.ross@btopenworld.com](mailto:polly.ross@btopenworld.com)

**Norfolk**—Gillian Litson 01263 514624

Kirsty O'Dwyer 07887800947 [kross38@hotmail.com](mailto:kross38@hotmail.com)  
Kirsty is happy to take calls from anyone whose parent is affected by FTD

**South West** – Miss Penelope Roques 01297 445 488  
[frontotemp@aol.com](mailto:frontotemp@aol.com)

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

**Cornwall**—Mrs Cindy Reeve 01726 71562

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

Tel 0208 467 1462 email [lynneramsay1@gmail.com](mailto:lynneramsay1@gmail.com)