

Marathon Fundraiser: Laura Sweet is running the London marathon in April 2015 and raising awareness of FTD in doing so. Lauras dad has bvFTD and her Justgiving page link is <https://www.justgiving.com/Laura-Sweet-runs-the-marathon/>



House of Lords Event

On Dec 9th 2014 the support group co-hosted an event in the House of Lords to raise awareness about young onset dementia, and FTD. We were delighted to get coverage on Channel 4 news in a feature which focussed on FTD specifically and included an interview with a member of the FTDSG. For more information about the event go to https://www.ucl.ac.uk/drc/support-groups/house_of_lords

Forthcoming Carer Support Meetings : Visit the website for details

London: Carers meetings will take place between **11.00am-1.30pm** and will conclude with a visit to local restaurant for lunch for those who wish to stay on: Thurs Feb 26 2015, Mon April 27 2015, Mon July 13 2015 [Venue :Wilkins Front Main Quadrangle]. Contact Jill Walton 07592 540 555 or jill.walton@ftdsg.org for details closer to meeting dates.

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR : Please contact Mary Dawber on 01625 879 104 or email mary1246@hotmail.co.uk. Meetings usually take place between 1pm and 3pm

Yorkshire Yates Wine Bar, Boar Lane, Leeds LS1: Next meeting Nov 14 2014. E-mail ftld1@yahoo.co.uk for details of forthcoming meetings.

South West: :Lyme Regis : contact Penelope Roques –01297 445488 for details of forthcoming meetings

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

Cornwall: October 9 2014 12noon-2pm Contact Cindy Reeve on 01726 71562 for details

Cambridge: Contact Val freestone at valerie.freestone@addenbrookes.nhs.uk or Tel 01223 768005 for details.

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

FTDSG Regional Volunteer 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 Anne Miller milleranne89@gmail.com tel 01436 268476

Yorkshire— Rev. Ron Carter 01904 610 237 and Ann Squires 0113 2947139

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

Trent— position vacant

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

Manchester/Stockport—Helen Griffiths and Mark Perry 0161 716 4505

West Midlands— Sister Ann Johnson 01743 255 856

Central— Emeline Keown emelinekeown@youngdementiauk.org 01865 747698 Mob: 07909 060430

Northamptonshire —Rob Hasker (email by preference) Roberthasker1985@hotmail.com or 07889875422

Cambridgeshire— Valerie Freestone valerie.freestone@addenbrookes.nhs.uk or Tel 01223 768005

Hertfordshire/Bedfordshire— Richard Pleydell-Bouverie (email by preference) ropb@easykey.com or 01438 833022

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

Norfolk - Mrs Gillian Litson 01263 514624

South West— Miss Penelope Roques 01297 445 488

Cornwall— Mrs Cindy Reeve 01726 71562

North Wales—position vacant

Lynne Ramsay: Volunteer adviser regarding funding and services

Tel: 0208 467 1462 Mob. 07760 224 396



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

FTD SUPPORT GROUP
FTDSG

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9th International Conference on FTD - 2014

Thanks to a generous sponsor Jill was able to attend the 9th international conference on frontotemporal dementias, held in Vancouver in Oct 2014. The conference highlighted the development of collaborative global efforts, incorporating a range of scientific, clinical and social presentations as well as a caregiver meeting with an ever stronger network of caregiver associations considering caregiver issues and topics. Particular bullet points Jill wants to share include:

- There is a 19% misdiagnosis rate in FTD, with women being more likely than men to be labelled as having a psychiatric disorder. Bipolar illness, schizophrenia, depression, personality disorder and OCD remain the typical misdiagnoses.
- FTD disease mimicking presentations can be very difficult to distinguish from true FTD, as can phenocopy presentations. In all cases we must remember that the symptoms represent the disease, not the person. This comes with poignant reminder not to take symptoms personally; they are part of the disease.
- FTD is primarily a disorder of emotion, social reward and social cognition. Changes in appreciation of humour are noted up to 8 years prior to diagnosis, with a particular preference for farcical humour being demonstrated in bvFTD patients, compared to a humourless characteristic noted most frequently amongst people with semantic dementia.
- The GeNFi study has been a successful initiative. Better understanding of the genes that cause familial FTD help us to understand the process of the disease, and understand how we might treat and stop the formation of abnormally developing proteins. Follow up studies will direct research around global preventative and treatment objectives.
- It is possible to begin with 1 particular FTD syndrome or diagnosis and progress/overlap into another over time. Symptom onset and speed of progression is linked to the protein involved: tau – typically 5-15 years, progranulin-typically 3-10 years, chromosome 9 – variable and up to 20 years, MND/FTD – very rapid, up to 2 years [these figures are in general and approximate].
- **Caregivers of people with FTD have a significantly higher level of burden than AD, and caregivers of younger people have additional burden. FTD caregivers are more stressed than any other set of caregivers per se and there is a growing body of research incorporating the complexities of living with 'ambiguous loss' and the changes it inflicts upon a relationship. Whilst we all recognise aggression as a particularly difficult symptom to manage, it is the characteristic of APATHY that has been shown to have the most detrimental effect upon a marriage relationship. FTD is ultimately an illness of the family and more research is needed on the effects it imposes upon the way relationships integrate. Changes to the marriage relationship, the effect of a diagnosis on children, and indeed the way in which all relationships are ultimately affected by this diagnosis is under recognised.**
- Whilst support groups have been shown to reduce depression in caregivers, it must be acknowledged that they aren't for everyone and that alternatives such a therapist or counsellors may be more appropriate in some instances.

The spirit of the 2014 conference was excellent at all levels, and the event provided a valuable opportunity for networking as well as learning. Munich will host the 10th international meeting in 2016, by which time the caregiver support organisations have set some tangible and collaborative targets which we look forward to reviewing and building upon. **More information about the conference is available at:** <http://www.alzforum.org/news/conference-coverage/vancouver-frontotemporal-dementia-conference-shows-awakening-field>

Annual Seminar 2015

Our Annual Seminar will take place on **Thursday March 5 2015**, in the usual venue:

Basement Lecture Theatre, 33 Queen Sq, London WC1N 3BG. The agenda includes expert speakers across a range of FTD related issues including genetic and imaging developments in FTD, caregiver coping strategies, the role of speech and language therapy in FTD and current/future drug treatments. More information is available via the website or from jillwalton@virginmedia.com tel. 07592 540555

Continuing Health Care Funding

Inequalities in the allocation of continuing healthcare funding for people with dementia has long been a source of debate and controversy.

On 24 Nov 2014 **Baroness Greengross** asked Her Majesty's Government whether they have any plans to increase the extent of community healthcare coverage to conditions, such as frontotemporal dementia, which to date they have considered highly socially complex, rather than medically complex, and not deemed a primary health care need. (HL3094).

Earl Howe, at the Department of Health, has provided the following answer: 'Health and Wellbeing Boards in each upper-tier Local Authority are responsible for the development of Joint Strategic Needs Assessments to identify the current and future health and wellbeing needs of the local population and a Joint Health and Wellbeing Strategy that sets the strategic direction for local commissioning decisions. This may include assessment of the prevalence and impact of dementia, and appropriate actions for prevention, diagnosis and care. The healthcare provided is inclusive of all types of dementia including frontotemporal dementia.'

There remains a need to raise awareness around the specific needs of people affected by diagnoses of dementia and the FTDSG is keen to support campaigns which represent this issue.

Miranda Stephenson is a member of the FTDSG and is campaigning about the inequalities in this funding. She writes:



Our Story

I would really appreciate your help— I feel as if I am banging on the NHS doors for help and there is no one home. Our GP and consultants are great, it's the wider function of the NHS in terms of support for dementia, which is poor and unfair and in my view unfit for its purpose as well as possibly being illegal.

The reason for this is the ambiguity between the descriptions of social and medically complex conditions and the definition of a primary care need rated against the criteria for CHC.

Peter was diagnosed with frontotemporal dementia 4 years ago.

Peter is now in relatively advanced stage of the disease with significant levels of dependence. He is able to carry out very few activities of daily living by himself and needs help with dressing, mobility, eating and personal hygiene.

Swallowing difficulties mean that he is at an increased risk of choking upon food and his own saliva. He has also recently begun having epileptic seizures and is in a wheel chair. This is as a result of a medical condition, not a social illness, so surely this is a primary care need and he should receive help financially for his care needs which are 24 hours a day.

We have to pay personally for care, (£825.00 for 5 days) as I still need to work to keep us housed, fed and clothed. We have always been sensible; we have savings which means we are not eligible for any support which is means tested. So I work and then come home and take over from the carers. My husband needs 24 hour care and it is critical that he remains within an environment within which he feels safe and secure. Changes to his routine and or care professionals cause anxiety and leads to epileptic fits as well as other side effects.

We have now been refused continuing Health Care (CHC) twice as in their view my husband's condition is highly socially complex and not medically complex and social funding is means tested.

The reasons for Peter needing 24 hour care is as a result of his disease which is a medical condition which is degenerative.

I know this topic of social and medical care is being discussed at the moment and we are the perfect example of why CHC is not fit for purpose. It does not accommodate dementia—especially frontotemporal dementia.

Individual's needs are socially complex and the importance of looking after these needs helps in reducing the risk and need for medical intervention. Surely this has to be a more effective approach which reduces overall costs. The more anxiety the more need for medical intervention and costs to the NHS, it's a cycle which can be broken if CHC is made fit for people with dementia.

We have also made the choice to look after Peter at home to reduce the risk of anxiety; he lives in a safe cocoon at home protected from the outside world. If he engages in the world he becomes aggressive and can be a danger to himself and others. However because we keep him safe we are penalised, we have reduced the risk at our own costs and CHC argues that means it is not a primary care need!

I would like your help to raise the profile of this topic and to support us in our bid to have CHC cover socially and medically complex un-curable diseases. If you have an example or have or are going through the same battle as we are, I would love to hear from you, so that I can include your story in my evidence to members of the House of Commons and anyone else I think might be able to help.

The NHS Web Site States that: "With the exception of charges for some prescriptions and optical and dental services, the NHS remains free at the point of use for anyone who is resident in the UK. That is currently more than 63.2m people. It covers everything from antenatal screening and routine treatments for long-term conditions to transplants, emergency treatment, and end-of-life care."

Contact Miranda on Miranda@motivationinmotion.net



RHAPSODY

research and strategy for dementia in the young

RHAPSODY is a European research project aiming to improve care for people with young onset dementia.

Dementia is commonly viewed as a health and social problem of older adults, however it may strike at a younger age. Dementia occurring before the age of 65 is particularly challenging for those affected and for family, carers and healthcare professionals. Existing health and social care structures do not meet the needs of this group appropriately in any country. Specific services for people with young onset

dementia (YOD) - including cognitive, physical and behavioural training - are only slowly being implemented. No pharmacological treatment is currently available for most people with YOD.

Therefore, counselling and support of family and carers are of outstanding importance.

RHAPSODY will evaluate the policy and information environment that provides the framework for the treatment and care of people with YOD in six European countries. Also, the specific needs of this particular group and their carers will be assessed. Based on this information, RHAPSODY will create an educational, web-based, interactive e-learning programme which is tailored to the needs of carers. The learning course will be tested in a pilot study at three sites in France, Germany and the United Kingdom.

To achieve these ambitious aims, a multidisciplinary consortium of researchers has been assembled representing excellence in the fields of psychiatry, neurology, neuropsychology, neuroscience, health economy, multimedia design and information systems.

The project was launched in April of this year and will last for three years.

(Copied from an article written by Katrina Milecka, RN, BSN [RHAPSODY])

RHAPSODY is a project of the EU Joint Programme. Neurodegenerative Disease Research (JPND). JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. It aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases - www.jpnd.eu

FTDSG is delighted that the issues such as those cited above are now receiving a higher profile nationally and internationally through initiatives like the RHAPSODY project.

Updated Resource for Healthcare Professionals and Caregivers

Prometheus Books has just released the Third Edition of 'What If It's Not Alzheimer's? A Caregiver's Guide to Dementia.' Edited by Lisa and Gary Radin, who cared for their husband/father, Neil Radin, throughout his battle with corticobasal degeneration, this book offers a wealth of information for healthcare professionals and caregivers of someone diagnosed with a non-Alzheimer's dementia, especially FTLD.

This expanded edition includes chapters authored by experts from across the US and around the world in medicine, nursing, occupational and physical therapy, community services, hospice, respite, grief and legal and financial issues. In addition to providing current medical information (in lay language) the book is a practical guide to managing the team of medical experts, managing daily care and tending to a caregiver's own needs.