FAD SUPPORT GROUP Newsletter

Welcome to the FAD Support Group Newsletter *Issue 1, March 2011*

Welcome to the first edition of the Familial Alzheimer's Disease (FAD) support group newsletter.

The Familial Alzheimer's disease support group had its inaugural meeting on July 30th 2010. This was quite a historical day as it was, to our knowledge, the first time that people from families affected by the disease had the opportunity to get together and discuss shared experiences and concerns. The day included interesting discussions amongst the group on a range of topics including issues surrounding genetic counselling, diagnosis and support and talks from experts in the field including Professors John Hardy and Nick Fox. After Nick's opening talk, two family members in the group spoke eloquently about how FAD has affected their lives. John Hardy, whose team worked with families from the UK to identify the very first genetic mutation for the disease back in 1991, then spoke about the genetics of familial Alzheimer's disease. *(continued on p.2)*

Next FAD support group meeting: Wednesday 6th July 2011, 11am - 4pm

Wilkins JBR, University College London, Gower Street, London WC1E 6BT

An opportunity to meet others affected by Familial Alzheimer's Disease and to discuss diagnosis, support and research

Timetable

Coffee will be available from 10:30am

11am	**Professor Martin Rossor** - *Perspectives on FAD: past, present and future*
12pm	**Dr Selina Wray** - *Cell models in FAD*
1-2pm	Lunch - *Lunch will be provided in the Wilkins Old Refectory*
2pm	**Dr Natalie Ryan, Dr Seb Crutch and Jill Walton** - *Support group planning and the ADAD (Autosomal Dominant Alzheimer's Disease) Forum*
3pm	**Professor Nick Fox** - *Question and answer session*
4pm	Close of Meeting

Please confirm your attendance:

Natalie Ryan: 02076912303 x 723856 or email ryan@drc.ion.ucl.ac.uk

Myrtle Ellis Fund

The FAD Support Group is generously supported by the Myrtle Ellis Fund, as part of the National Hospital Development Foundation (Charity number 290173). For more information on the work of the Fund or to make your own contribution to the running costs of the FAD Support Group, please contact the Foundation on 020 7829 8724.

John Hardy and Selina Wray

Dr Natalie Ryan then provided an update on international research studies that people from families affected by FAD can take part in. These included the DIAN (Dominantly Inherited Alzheimer Network) study and a new project examining stem cells in individuals with genetic mutations known to cause FAD. These cells can be generated from a tiny skin biopsy taken from the arm under local anaesthetic. This exciting new research aims to better understand the changes that these genetic mutations bring about at a cellular level. It is a collaborative study with Professor John Hardy and his postdoctoral research fellow Dr Selina Wray (pictured above). Selina will be coming to talk about this kind of research further at this year's FAD support group meeting.

The morning session ended with a question and answer session with Nick Fox. After lunch, Dr Sebastian Crutch and Penelope Roques spoke about support groups and the experience they have had of developing similar groups to support people affected by other types of young onset dementia. The afternoon continued with open discussions amongst the group. We felt that the day went really well and people were keen for the group to meet again so we will be holding a similar event this year on 6th July.

FAD support group: New faces

We are very pleased to announce the appointment of Jill Walton as a Nurse Adviser to the FAD Support Group and other similar groups run by the Dementia Research Centre (DRC).

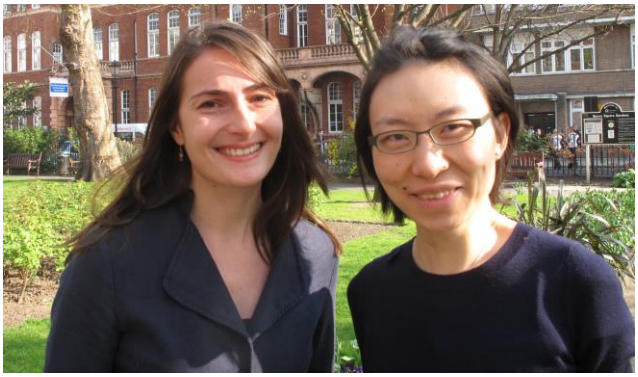
Jill is a registered nurse by training and worked in the Dementia Research Group at St Mary's and the National Hospital between 1993-1996 whilst completing her MSc in Gerontology. More recently Jill has been working for the Pick's Disease Support

Group (PDSG), a similar but much larger organisation to the FAD group, which works with people with progressive behavioural problems across the country. As a result Jill comes to us with a wealth of invaluable experience.

This appointment marks something of a departure for the Myrtle Ellis Fund, which now becomes the umbrella fund for all of the support groups run from the DRC, including us, the newly formed FAD support group, in addition to the longstanding Posterior Cortical Atrophy (PCA) and Primary Progressive Aphasia (PPA) support groups. These other groups support patients with degenerative illnesses who have problems predominantly affecting their visual or language skills respectively.

In addition to helping with the planning, fundraising and organisation of the groups, Jill will also be working with us to try to increase the availability of specialised support group care to individuals with FAD, PCA and PPA across the UK. Currently all of our meetings are held in London, and whilst many group members travel long distances to be present, many others are unable to attend. We envisage a role for our support groups in enabling people living with these conditions to be in touch with others within their local or regional communities who share similar experiences and challenges. The PDSG has shown that this is possible, co-ordinating multiple small local meetings in many regions of England, Scotland and Wales. It is a significant challenge, but one that we will try to tackle over the coming months and years.

We are also pleased to welcome Dr Yuying Liang, who will be joining Natalie and the team working on familial AD research at the Dementia Research Centre. Yuying is currently carrying out her clinical training in Neurology on the wards at the National Hospital for Neurology & Neurosurgery but will be taking up post as a Clinical Research Fellow in June 2011.



Natalie Ryan and Yuying Liang

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Jill and Yuying are looking forward to meeting many of you at the next meeting on 6th July 2011. We are sure that you will all make them very welcome.

NICE change guidance on drugs for Alzheimer's disease

The National Institute for Health and Clinical Excellence (NICE), covering England and Wales, has published new draft guidelines proposing increased access to medication for people with Alzheimer's disease. In 2005 NICE caused controversy by advising that drugs such as donepezil, galantamine and rivastigmine should be limited to people with 'moderate' Alzheimer's disease. However, the new guidelines back the use of these drugs also in people with 'mild' symptoms. The news is particularly important for people with familial AD as it will make it easier for them to have access to these medications in the early stages of the disease. These medications address the symptoms of Alzheimer's disease and are not a magic cure. However, many people who take them do report feeling sharper as a result.

Plans for disease modifying treatment trials for familial AD

The real challenge for the Alzheimer's disease research field is to find treatments that can modify the disease process in order to slow, delay or ideally stop the illness from developing altogether. Trials of such potential treatments have been taking place in patients with late onset sporadic AD but unfortunately people with familial AD have traditionally often been excluded from these trials due to their young age. In a bid to change this attitude and launch a proposal to design treatment trials specifically for familial AD, a meeting with the European Medicines Agency (EMA) was held in November 2010. At this meeting, the prospect of designing prevention trials for individuals from families affected by FAD was discussed.

We are extremely grateful to the FAD support group members who joined us to make a short film on 'Living with familial AD' last autumn. In this film, several individuals who are at risk of familial AD described how the disease has affected them and their families and how they feel about participating in research and potentially taking part in treatment trials in the future. The film, which will feature on the UK FAD support group website we are building, was shown at the EMA meeting and provided us with a valuable way of representing the views of the people who would enter such treatment trials if they were established.
Nick Fox was at the EMA meeting; here he describes how the day went:

"Familial AD and trials in at-risk individuals finally made it on to the agenda of the European Medicines Agency. At a meeting in their sparkling modern offices in London's Canary

Wharf, European and US scientists and researchers from industry spent a day with the official regulators of European Medicines and trials to find new treatments. This was the first time ever that familial AD was considered by a regulatory authority and it began the discussion about the goal of offering treatments and ultimately prevention trials to families with autosomal dominant Alzheimer's disease.

The meeting began with a group of us setting out the injustice of families being excluded from participating in trials because of their age or family history, even though these families have, in many ways, contributed immeasurably to the progress of Alzheimer's disease research over the past two decades. The European Medicines Agency was surprised by the interest in the meeting, which was completely oversubscribed. The Agency had arranged for familial AD to be considered on the same day with Huntington's disease, another familial condition where there is great interest in starting treatment earlier and in particular when individuals are still completely well and asymptomatic.

Despite the novelty of the approach, the response from the regulators was remarkably positive, including a suggestion that, given the relatively limited number of individuals who could participate in trials of therapies for familial AD, one successful trial might be sufficient for regulatory approval. Commonly, two such trials are needed.

One key issue that came up was how to handle individuals who wanted to take part in the trial because of a family history but who did not want to know their genetic status. The regulators in particular were concerned that people who were gene-negative (did not carry the gene), should not be exposed to a drug with potential side effects. Equally, if only those people who were gene-positive were given the active treatment (as opposed to the placebo) then if anybody developed side effects, they would know they carried the gene even though they had chosen not to learn about their genetic status.

The meeting ended with a very positive message but with recognition that some detailed design questions need to be worked out. Exploring the opinions of the people who would enter these trials will be a key part of this process.

Launch of a web Forum specifically for FAD families

February 2011 saw the launch of the ADAD (Autosomal Dominantly Inherited Alzheimer's Disease) Forum: a website designed to connect family members affected by FAD from all over the world. The Forum allows individuals to communicate with each other through message boards. It also provides opportunities to access

information and engage in discussions about a variety of issues, including the prospect of treatment trials for FAD. If you would like to participate in the Forum, please visit their website at http://www.alz.org/_adad/. The website address is confidential so should only be distributed to individuals associated with FAD, but if there are other members of your family who you think might benefit from accessing it; please do pass it on to them.

How is it for you?

Every individual and family affected by familial AD is unique, but you may sometimes find that you have shared similar thoughts or experiences. We have created this section of the newsletter to give members of the group the opportunity to share their story. Here, one of our group members tells us how familial AD has affected her life:

"When I was a little girl my auntie wasn't well, I never asked what was wrong. I'll never forget my mum telling me years later all about our family history of Alzheimer's disease. I grew up hating that word but never did it cross my mind that my mum would one day be ill.

I was 16 when my mum was diagnosed. My brothers and I treated her like nothing was wrong, so she said the same thing over and over again but each time we would react just as if it was the first time we heard it. Looking back we were all trying to make her feel normal. It was hard but we could always make her laugh and reassure her that everything was ok. By that time I believed that one day I would be ill like mum, so many family members had fallen prey to the disease there is no chance I could escape it.

It took us three years to finally have the test done, all thanks to my mum donating her brain. My cousins weren't so lucky - because they were never asked or advised to donate their mum's brain for research, they hadn't known that she was ill because of a faulty gene.

I have changed since having the test done, I don't think about it too much because I know what is ahead of me. I want to get the most out of life and have fun along the way. Life really is too short, value every day and take nothing for granted."

If you or your relatives would like to share your own experiences, thoughts or opinions, feel free to send them to Natalie so that other group members can benefit from hearing your story.

We hope to see many of you at the next FAD support group meeting on July 6th. Please call Natalie on 02076912303 ext. 723856 or email ryan@drc.ion.ucl.ac.uk to register for the event.