RARE DEMENTIA SUPPORT

Dear FAD Support Group Members, March 2018

Welcome to the March 2018 edition of the FAD Support Group newsletter – there is a mixture of news, research updates and contributions from family members and we hope it is of interest. There are also invitations to the FAD support group meeting in London this May and to the international family conference in July in Chicago (see end of the newsletter).

Upcoming Support Group Meeting

The next **FAD Support Group Meeting**, is on **Saturday 12th May 2018** - please do come along if you can – and feel free just to come to some of the meeting. The agenda, not yet finalised, will include a talk on familial Alzheimer's disease research from Dr O'Connor, an update on potential treatments and new trials and a question and answer session with Prof Nick Fox.

At this meeting we would also like to acknowledge the huge contribution that many of you have made to raising public awareness of young onset and familial Alzheimer's disease. Support group members have been interviewed for newspaper and magazine articles, television documentaries, films and books and have shared their stories at events in person and globally via the internet. This is having a real impact on awareness. We plan to have a discussion session on 'sharing stories' at our meeting in May. We hope this will be an open discussion - if anyone is happy to share a few words about their experiences of interacting with the media, do let Ivanna know at ivanna.pavisic.15@ucl.ac.uk. Please also let Ivanna know if you have shared your story in the press and are happy for a link to the article to be placed on the 'sharing stories' section of the FAD support group website.

Date & Time: Saturday 12th May 2018, 10:30 – 15:00

Location: The Hub, 5th floor, Wellcome Collection, 183 Euston Road, London NW1 2BE. (Come through the main entrance, head up the initial set of stairs and just past the visitors' reception desk you will see some lifts on the left. Take the lift to the 5th floor and we will guide you to the room).

Directions: https://wellcomecollection.org/visit-us/getting-here

RSVP: To register your place, please RSVP to Laura King l.king@wellcome.ac.uk – ideally by May 8th. This will help us with guest registration and catering provisions for the sandwich lunch. Let us know if you have any special dietary requirements.

Help with travel expenses: we have had a small donation to help with travel costs for this meeting –please let Laura know if a contribution towards travel expenses would help to make it possible for someone to attend the meeting.

If there is a specific topic that you would like to see discussed at future meetings, please do not hesitate to email Ivanna with suggestions – we'd love to hear from you – or mention it in person.

Dementia Research Centre | UCL Institute of Neurology
8-11 Queen Square | London | WC1N 3BG

Some welcomes and goodbyes

We would like to introduce some new staff members. Laura King has recently joined us as the Rare Dementia Support Administrator. Laura will be arranging meetings for the support groups that fall under the Rare Dementia Support umbrella – including FAD. If you, or someone else, would like any information about these meetings, please contact Laura at l.king@wellcome.ac.uk

Ivanna Pavisic is a research assistant and PhD student at the Dementia Research Centre, who has been studying dementia over the past three years. She completed her Biology degree at Université de Lausanne in Switzerland and her Master's in Translational Neurology at UCL. She is one of the psychologists carrying out cognitive testing for the research study on familial Alzheimer's disease FAD at UCL as well as the Dominantly Inherited Alzheimer's Network (DIAN) study. She is aiming towards a PhD on improving the understanding of progression and diagnosis of dementias like familial Alzheimer's disease. Ivanna works at Queen Square and has taken on the role as FAD Support Group Facilitator. If you would like information about FAD generally, or have any questions that Ivanna may be able to help with, please contact her at ivanna.pavisic.15@ucl.ac.uk or on 07388 220323.

Antoinette O'Connor has taken over from Dr Phil Weston as a Clinical Research Associate at the Dementia Research Centre, with Phil now carrying out his clinical neurology training in London. Antoinette is responsible for the day-to-day organisation of UCL's research study on familial Alzheimer's disease as well as contributing to the DIAN study and helping with the FAD support group. She also works in the Queen Square cognitive clinic; a clinic that receives referrals from across the UK. She graduated from medicine from University College Cork in Ireland in 2012. She became interested in dementia while working as a care assistant during her degree. She completed basic medical training in Cork and began specialist training in neurology in 2015. She has taken time out from clinical training in Ireland to undertake research (and a PhD) in familial Alzheimer's disease.

We are delighted to welcome Laura, Ivanna, and Antoinette, who join Dr Natalie Ryan and Prof Nick Fox in the familial Alzheimer's disease support group team. Sadly, we said "goodbye" to Rachel Crane however, we are pleased that the reason is that she has a place on a clinical psychology doctorate course in Leeds - a great achievement. Rachel had this personal message for you:

"I have thoroughly enjoyed my time working for Rare Dementia Support and getting to know you all in various capacities, whether this was at a support group meeting, via email or the support group enquiry line. Although I am leaving the team, I do hope to return to this area once I am a fully qualified clinical psychologist. I will always have a special interest in rare dementias and hope I can continue to raise awareness to health professionals and highlight the need for specialist support services for those affected by a rare dementia diagnosis. One of the many things I have learnt, aside from the social and emotional benefits of disease-specific support groups, is the exchange of valuable personal information you all share with one another at support group meetings. It has highlighted the impact a rare dementia diagnosis can have on an individual, their friends and family. The experiences you have shared with me have made me passionate about returning in a clinical role to continue raising awareness about dementia not just being about memory; dementia can be non-memory led, young-onset, and/or inherited.

I will always hold fond memories of Rare Dementia Support and would like to thank you again - I feel very privileged that you have shared your journey with me."

Research Updates

Drug Trial Update, Dexter Penn, Clinical Research Fellow, UCL

Researchers all over the world continue to investigate different targets to maximize our chances of finding an effective treatment for Alzheimer's disease. In the DIAN-TU trial, the focus is on individuals at risk of familial Alzheimer's disease (FAD) or those mildly affected by FAD. One of the drugs in DIAN-TU (Gantenerumab) has shown potential and higher doses will now be investigated. Preparations are well underway to add a new treatment (a 3rd Arm) to the trial. This new drug will target the disease in a different way and be given in tablet form over 4 years. Approximately 200 subjects will be enrolled globally and there is an allocation to recruit 10 people locally at Queen Square.

Technology and Dementia, AAIC 2017 in London, Dexter Penn

The Technology and Dementia Pre-Conference at the 2017 Alzheimer's Association International Conference (AAIC) showed off cutting edge applied science to improve diagnosis and care of people living with dementia. There were many fantastic presentations including an adorable robotic seal called Paro designed to ease mood problems in severe dementia. There was also a very interesting project which uses the voice recognition capability in Amazon's Alexa Echo to allow patients to perform memory tests at home – potentially saving them travelling in for assessments

Personally, the thing that really stood out was the complexity involved in designing technology for people living with dementia. The concept of person centred design is crucial - and a panel discussion at the conference left a big impression on me. Designing technology that improves lives is difficult in cognitively normal people and is even more challenging in people living with dementia. One researcher from the US made a great point that "good design may not be enough…". Great technology needs to engage users or there will not be benefits in quality of life. An open dialogue is needed to avoid barriers around cost, privacy and user support. Prof Dröes from Amsterdam reiterated that users must be at the heart of what we do - understanding the lived experience of service users helps researchers to make sure that technology actually works for the people they are designed to help.

More news from AAIC 2017 in London, Antoinette O'Connor, Clinical Research Associate, UCL

Last year's AAIC brought over 5,600 researchers from around the world to London to discuss the latest progress in the field. A large amount of research was presented – and many studies involved FAD families. A key theme was the identification of biological signals called biomarkers. Researchers are focusing on biomarkers to distinguish different dementias; detect early changes; predict decline; and/or monitor disease progression and response to treatment. Phil Weston presented research from UCL on a blood test that may help detect early changes in Alzheimer's disease. Promising research was presented on positron emission tomography (PET) brain scans to detect tau protein (a protein that builds up in Alzheimer's disease). This type of scanning is now being used in research at UCL.

The importance of research into care is increasingly recognised and several talks and posters focused on how to improve dementia care. The Lancet Commission on dementia prevention,

intervention, and care was unveiled with recommendations on risk reduction and care interventions. This is just a tiny snapshot of the huge body of work that was discussed over the five-day conference. All the researchers who presented work at AAIC were extremely grateful to the FAD family members who participate, without whom the research would not be possible.

'Brains in a Dish' public engagement project –Charlie Murphy, Created out of Mind, Wellcome Collection

Artist Charlie Murphy, science writer Phillip Ball, BBC Medical correspondent Fergus Walsh and Prof Nick Fox have each donated a skin biopsy to Dr Selina Wray's dementia research study and are reflecting on each stage of the cell transformations process from their various perspectives. They are also interested in speaking to people who have previously donated skin biopsies as part of the research study to hear their perspectives on this kind of research, and on the "Brains in a Dish" project. Thank you to those who have spoken to them already. If anyone else would like to meet with the team over the next five months, please get in touch.

The project hopes to stimulate curiosity about the healthy and ageing brain, and explore how research can increase our understanding of degenerative brain diseases. It is part of the 'Created out of Mind' residency at the Hub at Wellcome Collection.

http://www.createdoutofmind.org/people-and-perceptions Contact: c.murphy@wellcome.ac.uk

Contributions from members

Jess Fleig, My general experience with dementia and taking part in research

I decided to take part in dementia research when I was 19-years old. When I first got in touch with Rare Dementia Support and the Dementia Research Centre (DRC) I was nervous and unsure of what I was looking for. I only knew that my dad had familial Alzheimer's disease and I could get it too. I spoke to the renowned Professor Nick Fox who ensured I got onto the international DIAN observational study and local study. At that stage, although I was no stranger to dementia, it was only then that I started to come to terms with the fact that I had a 50 percent chance of developing it in my 30s or 40s. I found the research study to not only be extremely interesting, but also quite therapeutic and enjoyable for the most part (I have still never met someone who enjoyed a lumbar puncture though-but it is bearable!) The psychology tests and tasks I always viewed as a bit of a competition with myself, and I try to outdo myself every year. The MRIs I find quite relaxing and it is always enjoyable talking to the wonderful staff and meeting others involved in research. The researchers have sent me links to the results of the studies I have taken part in (at a group level) so I can see exactly what I have contributed to, and it is the most wonderful feeling. One thing I have learnt along the way is to always negotiate with the new employer days off for dementia research without it affecting your holiday time-it can take a lot of your annual leave otherwise but it is so vital to society that I have found employers are usually very understanding.

I was hit with a dilemma exactly a year ago this month- whether to continue with the dementia research. I had gone through six months of genetic counselling because I was determined to find out if I had the gene that would guarantee I would inherit Alzheimer's like so many members of my family. I am relieved to say I did not have the gene. Of course there are many complex emotions that come with it, especially when you have other relatives who potentially do have the gene. I wondered whether

to continue with research- was I denying anyone else a place on the study? Was it worth the risks of a lumbar puncture every couple of years? Would I even be of any use to the study anymore?

Luckily I spoke to the staff at the DRC and they were so helpful, explaining how I was still useful to the research as a control participant. I figured any way of helping to forward dementia research is one worth doing, even if I am less useful than if I had the gene. There is nothing more important than helping to search for trends and biomarkers that could lead to scientific discoveries which will aid the dementia community. I also have so much awe for those who take part in DIAN-TU, the familial Alzheimer's drug trial, as well as other experimental drug trials. Without these selfless people we would not be making such vital steps towards a cure. And last but not least… Thank you to the DRC for being such a wonderful therapy for me over the past seven years.

Joseph Jebelli, In Pursuit of Memory (John Murray, 2017) ISBN 978-1-47363-573-9**, £20**

This is a book that fills an important gap in the array of Alzheimer's publications. It provides a history of the scientific quest to understand the disease, accessible explanations of the current state of research and the whole narrative is further enriched by the inclusion of personal stories from researchers, carers, those with the illness and even the author himself. It is these stories, often inspirational and very moving, that will guarantee this book a lot longer shelf life than many of the others and make it so useful to all who are interested in Alzheimer's, as carers or interested individuals

After an initial introduction in which the author tells of his own personal encounter with Alzheimer's through his granddad and his professional training as a neuroscientist, the book moves on to detail the initial work of Alois Alzheimer in identifying the condition at the start of the twentieth century. The book then takes us through growing understanding of the condition over the century (with tremendous leaps over the years 1990-2010) and provides discussion of the current Tau and Amyloid Cascade Hypotheses about the nature of the condition. As a trained neuroscientist, Jebelli is able to write with clarity and simplicity about the science of Alzheimer's.

An interesting chapter on 'The Alzheimer's Gene (Chapter 5) looks at the rarer genetic form of the disease and the implications for research of having a known gene(s). In this chapter the benefits of such knowledge are clearly spelt out but through a sensitive series of interviews with Carol (a known carrier of the APP Gene which in her family causes an early-onset Familial Alzheimer's Dementia; FAD) so to is the human cost. Issues such as getting tested for the gene, implications for children and whether such families can be involved in a research programme without knowing their genetic status are teased out not in a lecture theatre or research lab but in the personal life of a remarkable woman.

It is the many remarkable individuals we encounter in this book that will remain with the reader long after the book has been finished. Jebelli states that ' in writing this book I have witnessed extraordinary minds catapulting neuroscience into unimaginable futures. And I have seen breathtaking acts of human courage and sacrifice. We are now closer than ever to a cure'. By the time the reader puts the books down they will be truly assured of his first two claims but perhaps not quite as optimistic in his assertion of a cure. Containment and control (a bit like diabetes) one senses are certainly nearer.

This is an excellent reassuring and inspiring book for carers, those just diagnosed with the illness and any with a desire for greater understanding of Alzheimer's. It helps to strip away some of the ignorance and misunderstanding about dementia and also diminish a few of the fears that all of us who live with Alzheimer's face daily.

Finally - an apology! We are very sorry if you were affected by the problems we had with our phone and email systems a few months ago. Thank you for your patience with these frustrating issues. Fortunately, phones and emails are now working again.

We hope to see as many of you as can make it at our meeting on **Saturday 12th May**. If you want to get in touch before then, please do so.

With Best Wishes

The FAD Support Group Team

Below is a message from DIAN and the US Alzheimer's Association

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DIAD Family Conference 2018

The Dominantly Inherited Alzheimer Network Trials Unit (DIAN-TU) and the Alzheimer's Association are pleased to announce the 2018 conference for families impacted by dominantly inherited Alzheimer's disease (DIAD) will be held on **July 21st in Chicago, USA,** and will offer attendees information, support and opportunities to share insights with each other.

The Conference is for individuals from all over the world who have a DIAD mutation, those at-risk of a mutation, and family & friends who support at-risk individuals. We value your privacy and will ensure that you will not be required to disclose any private information at the conference.

Registration is open to all. For financial assistance, certain criteria below must be met. In addition, if the number of registrants exceeds capacity, **priority will be given to first-time attendees.**

Registration begins on **March 6th at 8pm** UK time **& closes when capacity is reached**.

1. Use this link to register: **https://tinyurl.com/yajdhn5g** Registration code is: **family18**

2. When you finish registration, you will receive an email confirming this. Please understand that this does **not** confirm a spot at the conference. You will receive an email by **March 30th** to let you know if you have a place at the conference or if you are on a waiting list. Those on the waiting list will be contacted if additional space becomes available but may not receive travel support.

Attendance and travel support criteria:

Travel support is available to conference attendees with, or at-risk for, DIAD, plus one support person (someone not at-risk, but who is directly affected by the disease, such as a spouse, sibling, etc) for each at-risk person. The support person **must** attend the conference to receive travel reimbursement. Support persons whose symptomatic family member cannot travel may also be eligible for travel support but should contact us at diad-fc@email.wustl.edu for confirmation.

This year, support for up to **four family members** (eligible parents plus eligible adult children) is available. Additional family members may register, but travel support is not available.

- For attendees from the UK: US **$1000 per person** for travel expenses
- 2 nights hotel accommodation

Please contact your site coordinator if you need assistance registering – or contact DIAN Expanded Registry at 001(844) 342-6397 or dianexr@wustl.edu with any questions.
Jennifer Petranek, will be responsible for much of the coordination of the DIAD Family Conference.