RARE DEMENTIA SUPPORT

www.raredementiasupport.org

FAD Support Group Newsletter

December 2016

FAD Support Group Newsletter

Welcome to the December 2016 edition of the familial Alzheimer's disease (FAD) support group newsletter. We are currently trialling various different formats for the newsletter, and welcome your feedback on an ongoing basis. The seventh annual meeting of the FAD support group took place on Saturday April 30th 2016. As in the previous year, we joined with members from the familial frontotemporal dementia (fFTD) support group for a morning of equally relevant presentations, before breaking into disease specific groups for the afternoon sessions. We were pleased to see familiar faces at this meeting and indeed to have the opportunity to welcome new members to the group. Once again, the group was made up of people affected by FAD, 'at risk' family members, as well as the relatives and friends of people affected by this diagnosis. The theme of the support group meeting focussed on how people respond to having been given a genetic diagnosis: the information that is made available to them at the point when a family is given genetic results and how they begin to take that forward. After a break for lunch which afforded the opportunity to meet with other people in similar circumstances, and for informal discussion across both groups, Prof Nick Fox, Prof Seb Crutch and Dr Natalie Ryan facilitated a discussion group and took questions from the floor. Summaries of the presentations are listed in this newsletter and audio recordings are available to download at http://www.ucl.ac.uk/drc/support-groups/FAD-support-group. We would like to alert you to the date of our 2017 meeting, which is scheduled to take place on **Saturday 13th May 2017.** The venue will be different from that of previous years and we look forward to welcoming you to The Hub on the 5th Floor of the Wellcome Collection at 183 Euston Rd https://wellcomecollection.org/visit-us/getting-here. We will be in contact nearer the time with agenda and other details.

Drug Trial Update, Philip Weston, Clinical Research Associate, UCL

There are now probably more therapeutic trials aiming to find a medication that will stop or slow the progression of Alzheimer's disease in the brain than at any time in the past. Many of the best research groups from around the world are now working together with pharmaceutical companies for this common goal. The first results from the DIAN-TU trial, which several of our support group members participated in, are still awaited. However, even before the first results are available, there are already plans to roll out a third DIAN-TU treatment arm, using a drug that targets the disease in a slightly different way, in order to maximize our chances of finding an effective therapy. A trial published earlier in the year gave cause for optimism. In the study the drug aducanumab, which aims to remove amyloid (the sticky protein thought to be responsible for Alzheimer's disease) from the brain, was given to 165 people with mild Alzheimer's disease. The study found that, not only was aducanumab effective at reducing the amount of amyloid in the brains of participants, but it also reduced the rate at which their memory declined. Whilst this is only a preliminary study the results are encouraging. A larger trial is now planned, aiming to replicate these initial findings. Recent preliminary results from a much larger study using a different anti-amyloid drug (solanezumab) were more disappointing. The study involved over 2,00 people with mild/moderate Alzheimer's. Whilst there appeared to be a possible mild effect, no significant benefit was found. One theory for why this might have been is that the treatment was given too late in the disease. Solanezumab is also one of the drugs being used in DIAN-TU (a trial in FAD). Experts agree that in FAD individuals who have not yet developed significant symptoms, and so are earlier in the disease, may be more likely to gain a benefit. Further results from other trials are expected over the next 12 months, with researchers optimistic that an effective treatment will be found within the coming years.

Summary of FAD / fFTD Meeting, 2016

Summary of Joint FAD/fFTD Support Group Meeting, April 2016

Kirsty Macpherson, Research Assistant, UCL

Around 70 FAD and fFTD Support Group members attended our annual meeting on Saturday 30th April 2016. For the morning session both groups met together to hear four short talks, and in the afternoon we split into our two separate groups for a more informal discussion time. The agenda focussed on issues surrounding genetic testing and the impact of FAD on families and children. Thus it had a more personal focus compared to previous meetings which have included more scientific or practical content, and several attendees commented that they found this helpful in the context of their own situations. The presentations are summarised below and are all available to view on our website at http://www.raredementiasupport.org/fad/meetings/recordings.

The first talk was from Dr Jonathan Rohrer, Consultant Neurologist and researcher at the Dementia Research Centre, UCL, who gave us an introduction and background to issues associated with genetic testing. Presymptomatic genetic testing is available for individuals who have a parent affected by FAD or fFTD, and who therefore may have inherited the genetic mutation causing the disease. Dr Rohrer explained the process of genetic testing, which includes a period of genetic counselling to help the individual think through all the implications of getting tested and make an informed decision about whether it is right for them. He also mentioned the implications of genetic test results for insurance (for more details see the talk by Phil Cleverly at our 2015 meeting, available on our website) and he outlined the research studies and drug trials that are currently available for people at risk of FAD and fFTD. Finally he gave us a brief explanation of preimplantation genetic diagnosis (PDG), which aims to help couples conceive an unaffected pregnancy by using in vitro fertilisation (IVF) technology. Clearly genetic testing and PDG raise complex personal and ethical issues and this was reflected in the questions and discussion which followed the talk.

Next we heard from Alison Metcalfe, Professor of Health Care Research and Vice Dean for Research at the Florence Nightingale Faculty of Nursing and Midwifery, King's College London. Based on her work with families affected by a range of genetic conditions, she spoke about talking to children and young people about familial Alzheimer's Disease / familial Frontotemporal Dementia. A lot of her insights and observations were to do with communication within families, including factors that can make communication difficult and strategies that can improve communication. She talked about the various stages of development in a child's understanding of genetic risk and their emotional reactions to that, and she discussed the barriers that can hinder parents from talking to their children about genetic issues. She reflected on the pros and cons of discussing genetic risk, from the perspective of both the parent and the child. Her overall message was that good communication helps families to cope and leads to stronger relationships, and she gave a range of practical tips to facilitate this.

Our third talk was from Professor Pat Sikes and Dr Mell Hall from the University of Sheffield. The title of their presentation was '*Diagnosis and Beyond*: children and young people's perceptions of navigating parental dementia'. As part of their research, they interviewed children, teenagers and young adults who have a parent with dementia. They shared some quotes from these interviews, giving us an insight into young people's perspectives on the diagnostic process and their experiences of the unpredictable disease trajectory. Finally we heard from an fFTD Support Group Member who told her personal story of genetic testing: why she decided to get tested, what the process was like and how she has reacted to the result. It was a privilege to hear her account. As she emphasised, everyone is different and there is no right way to approach things, but we all benefited greatly from the opportunity to hear her story.

Research Update & Upcoming Events

Research Update – News from AAIC in Toronto
Philip Weston, Clinical Research Associate, UCL

A large amount of new Alzheimer's research was presented at this year's annual Alzheimer's Association International Conference (AAIC) held in Toronto, with many studies involving FAD families. As well as drug trials (discussed above), work continues that aims to better understand the changes that occur in the brain during Alzheimer's, especially in the very early stages prior to the onset of symptoms. Methods to detect and track these early changes continue to improve. Such work is very important to 1) help us develop better targeted treatments, 2) have reliable methods to diagnose people early, and 3) to be able to assess whether a drug is having a beneficial effect.

Results from a new type of PET scan, which detects the protein tau (the second protein involved In Alzheimer's disease), look very promising. This new type of scan has attracted a lot of interest, and is now also being used in research at UCL. Findings from various new blood tests and spinal fluid tests to detect Alzheimer changes were also presented. Development of a blood test, which could be used to measure the effect of new treatments would of course be very useful, and may well be available in the near future.

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.

Free Online Dementia Course Features Dedicated FAD Module

We are delighted to announce that a free online course has been developed by colleagues here at UCL, featuring a whole module dedicated to FAD, and is due to start on 27th February 2017. Throughout the course, learners discover some of the key issues in dementia care and research by exploring four less common forms of dementia through the eyes of people affected by the condition, and world-leading experts at UCL. This course is presented by experts from the UCL Institute of Neurology and Division of Psychiatry who are highly regarded for their work as scientists and clinicians. Importantly, course participants hear from people who have been diagnosed with dementia, and people who care for a family member with dementia to get a better understanding of the impact that a diagnosis of dementia brings.

They will be able to understand how dementia affects people by watching video interviews, look deeper into the topics by reading articles, interact through activities and questions, and also learn from others on the course by taking part in the discussions that accompany each step. Over 8,500 people took part in the first run of this course in March 2016, and we hope to replicate this success as we repeat the course next year.

Visit www.futurelearn.com/courses/faces-of-dementia to watch the trailer, register for free and join the conversation.

Everybody is welcome to take part in this course, so please use the opportunity to raise awareness of rare dementias by sharing the invitation with anyone who might be interested. We would also like to take this opportunity to thank our support group members who participated in the videos for the course.

DIAD Family Conference

The DIAD Family Conference 2017

What is the DIAD family conference?

In 2015, Washington University and the Alzheimer's Association organised the first international **Dominantly Inherited Alzheimer Disease (DIAD) Family Conference**. The conference brought together families living with DIAD, researchers, regulators and pharmaceutical companies for an unprecedented day of information sharing, dialogue and support.

The considerable success of the 2015 DIAD Family Conference led to a call for this to be an annual event, with the next one having taken place on 23rd July 2016 in Toronto, Canada. This conference once again provided a forum for interactive dialogue about research, trial design, drug development and other concerns raised by basic and clinical researchers and families, thus providing an opportunity for scientists to learn from each other, for regulators and pharmaceutical companies to hear from families, and for families to gain valuable information and support, helping to foster their critical participation in research.

The 2017 DIAD Family conference will be held on **Saturday 15th July 2017 at University College London, UK**. The planning committee is busy organising a meeting that will inform and inspire families living with dominantly inherited Alzheimer's disease. With UCL as hosts and key collaborators, the London location means that UK families have a unique opportunity to get to the event. We are keen to support our group members to be as actively involved as possible and are trying to identify how travel funding can be best used. In order for the conference organisers to determine how much assistance could be offered for travel, they need to gauge how much interest there is in attending the conference.

To learn more about past conferences, please visit the website at https://dian-tu.wustl.edu/en/DIAD-family-conference/.

Details of registration will be circulated directly by the conference organisers shortly.

We look forward to welcoming as many of you as possible to the event on 15th July 2017!!

UCL

DIAN
Dominantly Inherited Alzheimer Network

Other News

Welcome to the Team…

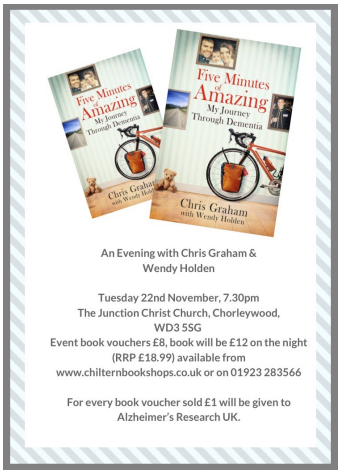
My name is Rachel Crane and I have recently joined the Rare Dementia Support Service as a "Group Facilitator and Psychology Research Assistant", based at the Dementia Research Centre. Having completed a psychology degree from the University of Leicester in 2009, I have subsequently worked in both physical and mental health services, as either an Assistant Psychologist or Research Assistant, within the NHS. These services include Memory Clinic, Specialist Brain Injury Rehabilitation, Improving Access to Psychological Therapies (IAPT), National Institute of Health Research projects, as well as secondary care psychological therapies services.

I have a strong research interest in dementia, specifically rare dementias. As a health professional working in this field, I have witnessed the psychological impact a diagnosis can have on the individual, alongside their family and friends. My experience has highlighted how difficult it can be to get a diagnosis of a rare dementia, and how limited people are with being able to access specialist support services. Outside of work, I am into my fitness and enjoy walking my black Labrador called Lola. I am also a proud auntie to my niece and nephew who keep me on my toes!

I am very much looking forward to meeting you all at future support group meetings and/or liaising over the telephone or via email.

Five Minutes of Amazing, My Journey Through Dementia - Book Launch

Jill Walton was privileged to be able to attend the launch of Chris Grahams book, 'Five minutes of amazing' on 22nd November 2016. Chris has a diagnosis of FAD and his story poses a profound question - do we accept the hand that fate deals us, or do we battle to make the most of the life we have and help others in the process? Chris Graham has emphatically chosen the latter. Having lived through a troubled childhood, Chris joined the British Army at a young age and found that the life of a soldier provided him with a much-needed sense of stability. However, his world was turned upside down when, at just 34 years of age, he was diagnosed with a form of early onset dementia. This brutal disease had already claimed the life of his father at 42, along with several other members of his family, and tragically had already confined his brother to a nursing home at the age of 43. In his brother's life, Chris could see a terrifying window into his own near future.



Chris, though, is an extraordinary human being. He decided overnight to stand up to this disease and do something to leave his mark before it was too late. And so it was that last year, Chris embarked on an awareness-raising 16,000-mile solo cycle around North America, armed only with his bike, a sense of humour, and some good old-fashioned British grit. Leaving his ever-supportive wife Vicky and baby son Dexter at home, he took on huge challenges - for instance, the fear that the ability to discern left from right might leave him at any point while navigating an entire continent - and made it home in time for Christmas, determined to spending however long he has left pouring his love and attention into his family life.

Five Minutes of Amazing is both the story of Chris' epic journey and of his fight against the disease increasingly being recognised as the defining disease of our generation. Inspiring and heart-rending in equal measure, it's as important as it is moving, and it will touch everyone who reads it.

The Nuffield Council on Bioethics held a meeting in June 2016 to enable a discussion with people affected by genetic conditions about their views on testing in pregnancy. The Council is investigating the ethical issues raised by a new kind of test – non-invasive prenatal testing (NIPT) – that can test for a range of genetic conditions safely and accurately early in pregnancy.

A support group member attended this meeting in June 2016, held with family members of people with genetic conditions and representatives of charities for people with genetic conditions to discuss their experiences and views on developments in non-invasive prenatal testing (NIPT).

Whilst the majority of the discussion focussed on conditions other than inherited dementia, the potential that this testing offers to families with an identifiable genetic cause of Alzheimer's disease or frontotemporal dementia is applicable and relevant.

Of particular interest in respect of the support group remit, was the recognition that it can be useful for people with a rare condition and their families to meet others in the same situation, for example to find out about the condition and the different ways that it affects people. Clearly, this is something we hope the support groups do make possible for members.

In Their Shoes – interactive dementia awareness workshops in secondary schools

Emma Harding and Rachel Woodbridge, PhD Students

The 'Seeing What They See' study is a collaborative interdisciplinary project based at the Dementia Research Centre, UCL. The social science stream which they have been working on is headed up by Brunel University, London. Brunel University, London recently launched a new initiative, the Student Public Engagement Fund, offering students the chance to apply for grants of up to £700 for community projects relating to their subject areas, working alongside the Brunel Volunteers Service. They applied to do interactive workshops in secondary schools with 14-18 year olds to get them talking about dementia, develop their understanding and to do some myth-busting of some common assumptions about dementia. The key messages they included in their application were:

- That dementia is about more than memory, for example, it can also cause word finding difficulties and perceptual problems
- That each person with a dementia diagnosis is different with a unique profile of strengths and difficulties
- That there is never just one person in any dementia journey, i.e. that family members and friends are also living with dementia

They have been busy designing the sessions and recruiting student volunteers to help run them. Their key aims are for the sessions to be informative, interactive and to a degree experiential. They hoped that by simulating some of the lesser known symptoms of dementia, they might be able to help the students to be more empathetic to people they may know or come across who have a diagnosis of a dementia.

The last stop in finalising the session plan was to ask for expert input and feedback at a support group meeting in which they got some invaluable ideas and suggestions from members which they have now incorporated. One of these was to look at ways they could package up a toolkit so that other schools further afield can run the sessions. They are in the process of running the first of ten sessions and will continue these into the new year.

For more information about the 'Seeing What They See' project please visit our website:

https://www.ucl.ac.uk/dementia-vision

For more information about our workshops please contact:

emma.harding@ucl.ac.uk or *Rachel.woodbridge@brunel.ac.uk*

Other News and Updates

Young Onset Dementia Network

Rare Dementia Support is part of the collaborative Steering Group for the Young Dementia Network. As such, we are excited to announce the launch of the Young Dementia Network following the Young Onset Dementia Conference in September 2016. Tessa Gutteridge, Chair of the Young Dementia Network Steering Group, said: "We know first-hand the impact of dementia on younger people and their families and how isolating it can be. We believe that everyone affected should be well informed, feel connected to others and enabled to live life to the full. We are creating a Network. A community that includes people living with young onset dementia, their family and friends, as well as organisations and professionals who work in the fields of dementia and social care."

The Young Dementia Network will:

- Provide opportunities for members to share experiences, knowledge and to learn from each other.
- Encourage improved young onset services across the UK and influence and inform national and local policies.

Why join?

Joining the Young Dementia Network is free of charge and whilst there is no obligation to participate in activities and events, there will be lots of opportunities for you to become involved if you wish.

Joining will give you:

- Access to young onset dementia information, guidance and tools
- Regular newsletters including young onset specific information, events and research
- Events around the UK and online
- Opportunities to raise awareness of young onset dementia.

To join the network visit:
www.youngdementiauk.org

Alzheimer's Research UK Update

It's been a busy few weeks at Alzheimer's Research UK as we launched our Santa Forgot Christmas Campaign which has got millions of people talking about Alzheimer's and the need for research into new treatments. Through the support of the public, we continue to fund the most innovate research.

In October our funding helped a UCL team, led by Prof Nick Fox, study clinical and genetic information from over 60 families with familial Alzheimer's. Their research revealed new insights into how the specific genetic change responsible for familial Alzheimer's can influence each person's experience of the disease. You can read more on our blog. Over the coming months, we're also expecting some breaking clinical trial results in Alzheimer's and we'll keep you updated with all of the latest announcements at www.alzheimersresearchuk.org.

Fundraising Updates

Rare Dementia Support Fundraising

Professor Nick Fox, Director, Dementia Research Centre

I wanted to write to you personally to tell you about a new fund for Rare Dementia Support. This was recently established within The National Brain Appeal, the charity fundraising for The National Hospital of Neurology and Neurosurgery, of which the Dementia Research Centre is part. Funding for Rare Dementia Support will allow us to continue providing support groups, newsletters and access to advice and information to people affected by one of the following types of rare dementia: frontotemporal dementia (FTD & fFTD), primary progressive aphasia (PPA), posterior cortical atrophy (PCA) and familial Alzheimer's disease (FAD). Previously, the service was funded by donations to the FTD Support Group Fund and the Myrtle Ellis Fund which have both now been incorporated into the new fund. Creating one central fund enables us to increase our fundraising effort and extend the service we provide at the Dementia Research Centre. Our vision is for everyone affected by a form of rare dementia to have the opportunity to access specialist information and support, as well as contact with other people with a similar condition. It costs over £35,000 a year to provide current levels of support for the five rare dementia support groups - this includes 13 London and 50 regional meetings a year, a part-time support nurse co-ordinator and all other associated expenses. Over 2,000 people are currently on support group databases receiving emails and newsletters with around 1,000 attendees across all meetings. In addition, travel and accommodation bursaries are available to help patients and carers attend meetings. If you are interested in receiving further updates or would like to support the fund, please get in touch with louise.knight@uclh.nhs.uk. On behalf of the team at Dementia Research Centre and all who have benefitted from access to this service, thank you for taking the time to read this letter.

Thank you…

Many thanks to everyone who has supported the fund for Rare Dementia Support this year. The service is entirely funded by donations and your fundraising, so it is no exaggeration to say we couldn't do it without you! Special mentions to **Richard and Simon Watson** and the Longfei Taijiquan Association for raising almost £2,000 in July split between Rare Dementia Support and FTD Research; 10 year old **Lucas Church-Wood** whose grandma has FTD and who took on a mud run this summer; **Lisa Wilkinson** who organised a trifle challenge in memory of her father, Neil Wilkinson; **Laura Harris** whose mother has PPA and who is selling apples to raise FTD awareness; **Chris Hardy** who raised almost £4,000 with the Ironman Wales in September; **Jill Walton and Martin Reeves** who took part in the Royal Parks Foundation Half Marathon in October and between them have raised over £6,000. Thanks also goes to **Ellen O'Neill** and friends from Aquinas Grammar School who ran the Belfast Marathon in May and raised £800.

David Baddiel, whose father has FTD, also did a special charity performance of his West End show 'My Family: Not the Sitcom' on 23 September and a bucket collection for the two final weeks of all performances. £8285 was raised and is being divided between Rare Dementia Support, Alzheimer's Society and Unforgettable Foundation.

In 2017, **James Westcott** is running the Bath half and London marathons, with fundraising to be split between Rare Dementia Support and the Motor Neurone Disease Association. James's father, who died in 2014, had fFTD and later also developed Motor Neurone Disease. To support James and help him reach his £5000 target go to bit.ly/JamesWrunning

If you are interested in participating in a challenge, organising a fundraising event of your own or making a donation to the fund for Rare Dementia Support, please email louise.knight@uclh.nhs.uk or phone 020 3448 4724. You can donate online via JustGiving – go to bit.ly/RDSfund and please share the link with anyone you know who also wants to support the fund. You can also text **RDSF84** followed by the amount you would like to donate to **70070.**

RARE DEMENTIA SUPPORT

London Meetings

Joint FAD and fFTD London Support Group Meeting - 13th May 2017

Date: Saturday 13th May 2017
Time: The meeting will run from 11am until approx. 3pm, with coffee available from 10.30am and lunch provided
Location: The Wellcome Collection, 183 Euston Rd, London. NW1 2BE.
Directions: https://wellcomecollection.org/visit-us/getting-here

Agenda: The agenda will include a focus on drug trial research into treatment for FTD.

More details to follow in due course. Please RSVP to Janette Junghaus (j.junghaus@wellcome.ac.uk) or telephone 07341 776 317.

Dates for your 2017 diary…

Joint Carer's Support Group Meeting - 6th February 2017

Sara Wilcox will be presenting at our Joint Carer's Support Group meeting on **6th February 2017.** Sara started her career at the Court of Protection managing cases from application to winding up. She then worked in the community in Ealing as an advocate, and then at the Alzheimer's Society where she was their Legal and Welfare Officer for 5 years. Sara has extensive experience of helping people navigate the legal aspects of the dementia journey – paying for care, managing money, gifting, deprivation of assets, and welfare benefits, for example. Her charity, *Pathways Through Dementia,* operates a legal helpline and delivers talks and training to a range of audiences. Topics which will be covered during this meeting include: Paying for Care, the role of the Court of Protection – Lasting Powers of Attorney and Deputyship, Welfare Benefits and relevant community care laws such as the Mental Capacity Act, and the Care Act.

Bereaved Carer's Support Group Meeting - 29th March 2017

To register interest at any of the above meetings, please email Janette Junghaus (j.junghaus@wellcome.ac.uk) or telephone 07341 776 317.

Rare Dementia Support Rare Dementia Support runs specialist support group services for individuals living with, or affected by, one of five rare dementia diagnoses: frontotemporal dementia (FTD), posterior cortical atrophy (PCA), primary progressive aphasia (PPA), familial Alzheimer's disease (FAD) & familial frontotemporal dementia (fFTD). Our vision is for all individuals with or at risk of one of these rarer forms of dementia to have access to specialist information, support and contact with others affected by similar conditions. Rare Dementia Support is a Fund held by the National Brain Appeal (registered charity number: 290173). Rare Dementia Support activities are charitably funded—for information on how to make a donation please go to go to bit.ly/RDSfund.