



## FTD support group newsletter October 2018

# Next meeting – Dec 10th

Welcome to the October 2018 edition of the FTD Support Group newsletter. We aim to give you some insight into what the team have been up to since the last newsletter, and inform you of our upcoming meetings.

### **Our Next Meeting – save the date!**

The next FTD Support Group Meeting will be held on 10<sup>th</sup> December 2018.

During the morning session Martha Foiani from the UCL FTD team will talk about her PhD research work in the new UK Dementia Research Institute. She will be followed by Sara Tookey, who is a Clinical Psychology trainee and is working with our team to develop an FTD-focused carer support programme. She is keen to hear from carers who would like to be interviewed about their experiences as she develops the programme.

After a lunchbreak the afternoon session will include a Q+A with Dr Jonathan Rohrer – we are always keen to hear questions from people in advance so please do email them before the meeting.

For those of you who will be attending for the first time, we will also be running a pre-meeting at 10.30 to provide a brief introduction to FTD and the Rare Dementia Support Groups. This will hopefully prepare you for the meeting and ensure that it is not as overwhelming!

If you are subscribed to our newsletter mailing list you will likely receive an invitation to this event in due course. However, details of the event are as follows:

### **Date and Time:**

Monday 10<sup>th</sup> December 2018, 11:00 – 14:00, arrival from 10:30am.

### **Location:**

6<sup>th</sup> Floor, Wellcome Trust, Gibbs Building, 215 Euston Road, London, NW1 2BE

If you would like to attend, we ask that you RSVP so that we are aware of the number of people to expect. If you could RSVP to Laura King at [laura.king@ucl.ac.uk](mailto:laura.king@ucl.ac.uk), or leave a message for Hannah Carr on 07341 776 317. When you RSVP please also inform us of any special dietary requirements you may have as provisions for a light sandwich lunch will be provided.

### **Saying Hello**

We would like to introduce our new FTD Support Group Facilitator, Hannah Carr, who has taken over from Jessica Collins. Hannah has previously worked at Southern Health NHS Foundation Trust in mental health clinical trials and has recently joined the team. In her role Hannah will be assisting in conducting neuropsychological assessments for some of the studies we are currently running at the Dementia Research Centre. Hannah will be at the next FTD Support Group Meeting and is excited to meet you some of you there!

## Our new website

As some of you may have noticed, the FTD pages on the Rare Dementia Support website have been rather bare whilst they have been under construction.

The team have been working hard to update these pages to ensure they provide useful and up to date information on FTD.

These pages are now starting to be populated and are accessible at this link:

<http://www.raredementiasupport.org/ftd-frontotemporal-dementia/>

The new pages will be full of information about FTD, and living with a diagnosis.

We will also have similar pages for PPA and familial FTD.

We would like to make this as helpful as we can and so we are keen to hear from people about what they would like on the website – please email us with all of your ideas, or talk to us at the next support group meeting.

The UCL FTD team also run the FTD talk website at [www.ftdtalk.org](http://www.ftdtalk.org) which is also undergoing some changes at the moment to provide regular research updates.

## International Conference on FTD

Many members of the UCL FTD team will be heading out to Sydney in November for the International Conference on FTD.

The conference will bring together researchers from around the world to share their research. This is the first time that the ICFTD will be based in the Southern Hemisphere and demonstrates the global reach of FTD research.

Our team will be presenting their research at the meeting including work from the large international GENFI study which we run. We will hear about forthcoming trials and feed back at the next meeting.

There will also be a carer day during the meeting which will have UK representation from Rare Dementia Support.



[www.raredementiasupport.org/ftd-frontotemporal-dementia/](http://www.raredementiasupport.org/ftd-frontotemporal-dementia/)



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### WELCOME

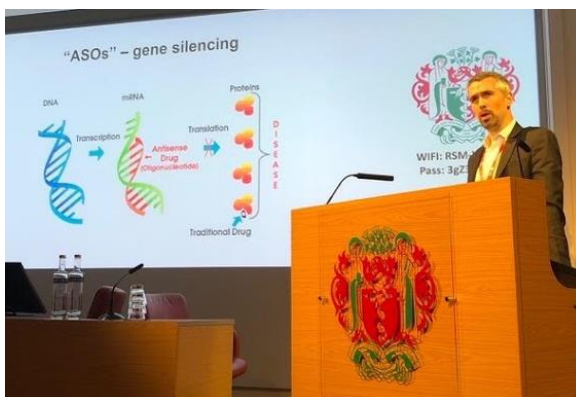
Welcome to the Frontotemporal Dementia Support Group, a service which is provided by the charity Rare Dementia Support, RDS, to support people affected by Frontotemporal Dementia, FTD. The pages here provide information about FTD, and about our FTD Support Groups, links to FTD Support Group newsletters, and information about our previous and forthcoming FTD Support Group meetings. For information about Rare Dementia Support, visit our homepage.

Medicine and Me is a collection of events held by the Royal Society of Medicine in London. They aim to provide updates on numerous conditions and give a direct voice to patients and their carers so that they can discuss their concerns about a condition and reflect on the impact of diagnosis, investigation and management.

On 24<sup>th</sup> September 2018 the Royal Society of Medicine in conjunction with the UCL FTD team ran a session of Medicine and Me focusing on living with FTD. At this event, there were some brilliant talks from carers and family members from the FTD community.

We also heard from a number of clinicians including Dr Rachele Shafei from UCL who helped organize the event. She, along with Jonathan Rohrer, Anna Volkmer and Jason Warren provided insight into what FTD is, how to manage the behavioural and language symptoms and gave further information on the genetics of FTD.

Carers and those at risk of FTD also shared their inspiring stories. Their stories encouraged participation from the audience and it was interesting to hear about a range of experiences of those who are caring for someone with FTD.



We understand that meetings can often be hard to attend by all – especially those who are not local to London. If you are unable to attend this meeting we are able to provide slides from the talks that are scheduled to occur at the meeting and we wish to remind you that you are always more than welcome to contact the Rare Dementia Support Team for advice and support on your journey with FTD at any time.

To contact the team please email:

[contact@raredementiasupport.org](mailto:contact@raredementiasupport.org)

or alternatively leave a voicemail message on: 07341 776 317

and Hannah will try to get back to you as soon as possible.

### Other upcoming meetings

As well as the FTD Support Groups, the Rare Dementia Support team also run a variety of other meetings. Below are a list of these and when they are going to be held:

Bereaved Carers' Support Group Meeting – Thursday 15<sup>th</sup> November 2018, 11:00 – 14:00, Seminar at the Hub, Wellcome Collection

Joint Carers' Support Group Meeting – Monday 19<sup>th</sup> November 2018, 11:00 – 14:00, 6<sup>th</sup> floor conference suite, Wellcome Trust

Primary Progressive Aphasia (PPA) Support Group Meeting – 8<sup>th</sup> January 2019, 11:00 – 14:00, 6<sup>th</sup> floor conference suite, Wellcome Trust

If you are interested in attending any of these events please RSVP to Laura King at [laura.king@ucl.ac.uk](mailto:laura.king@ucl.ac.uk)

Finally, we wanted to remind you that you are always welcome to contact the Rare Dementia Support Team for advice and support on your journey with FTD, at [contact@raredementiasupport.org](mailto:contact@raredementiasupport.org).