



## FTD Support Group newsletter February 2019

# Next meeting – March 22nd

Welcome to the February 2019 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 meeting will be the Annual Seminar held on 22<sup>nd</sup> March 2019.

This will be an all day event where people living with FTD, their carers and professionals can come together to share their experiences. There will be some talks from experts in the field, which many of you will hopefully find very interesting and useful.

The seminar will include a brief overview of FTD and a talk on imaging the brain before a refreshments break. After, a Speech and Language Therapist will discuss speech therapy approaches to primary progressive aphasia and this will be followed by a talk on care and activities for those with FTD. After a lunch break we will hear about a carer's account of living with a partner with semantic dementia and there will be a talk about where we are with therapeutic trials in FTD. The seminar will end with a Q&A session with a neurologist from the Dementia Research Centre.

Details of the event are as follows:

### **Date and Time:**

Friday 22<sup>nd</sup> March 2019, 09:00 – 16:00

### **Location:**

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

An invitation will be sent out to all members with instruction on how to RSVP. For further enquires, please contact Hannah Carr by email at [Hannah.carr@ucl.ac.uk](mailto:Hannah.carr@ucl.ac.uk)

### ***Saying Goodbye***

We are sad to announce that Laura King has left Rare Dementia Support. Many of you will have spoken to Laura at the previous meetings as well as via email. She did an amazing job in organizing the meetings and we wish her well in her future endeavours. Now that Laura has left the team we ask that all FTD related enquiries are sent to either [Hannah.carr@ucl.ac.uk](mailto:Hannah.carr@ucl.ac.uk) or to [contact@raredementiasupport.org.uk](mailto:contact@raredementiasupport.org.uk)

## **The International Conference of Frontotemporal Dementias (ICFTD)**

In our last newsletter, we mentioned the ICFTD, which was taking place in November in Sydney, Australia. The team are back and have some brilliant feedback from the conference.

The lectures and seminars in ICFTD covered many aspects of FTD including genetic, pathological and molecular biomarkers, to clinical diagnosis and management. Many of the discussions and break-out sessions finished with a positive look to the future regarding treatments and clinical trials.

There was a great turn out from the Genetic FTD Initiative (GENFI) and Longitudinal Investigation of FTD (LIFTD) teams from UCL.



Dr Martina Bocchetta and Dr Ione Woollacott received prizes for presenting talks on their respective research interests. Both Martina's work, examining structural changes in the brain in patients with semantic dementia using magnetic resonance (MR) imaging, and Ione's research, covering potential markers in the cerebrospinal fluid (fluid found around the spinal cord and brain) of patients with genetic FTD, represent the importance of understanding how the brain and CSF change in FTD.

Lucy Russell, a PhD student and research assistant for the LIFTD study, presented her novel eye-tracking data examining changes in social cognition in behavioural variant FTD, research she is currently conducting at UCL.



Data blitzes – rapid, 3 minute long talks – were given by PhD students Katrina Moore and Elizabeth Gordon, and research assistant Mollie Neason. Both Katrina and Elizabeth presented promising data about how future therapeutic trials in FTD could be run; Katrina's new app, the GENFI-Cog, and Elizabeth's research investigating how MR imaging will be used in future clinical trials, are exciting steps forward towards the formation of an FTD therapeutic trial.

During the conference a 'Carer's Day', covering many aspects of what it means to care for a person with FTD, was held. Much information regarding the psychological, financial and emotional impact of being a carer, as well as advice on what help can be attained, and where this can be found, was discussed.

Attending ICFTD was an invaluable opportunity for all involved. Meeting international experts in the field of FTD, sharing research, discussing new findings and future avenues of investigation is vitally important in driving advances in FTD research, particularly as we move towards the development of new treatments for FTD.



11th International Conference  
on Frontotemporal Dementias

## Free Online Courses

Created out of Mind have created two new online courses around rare dementias, which are free to sign up to. Below we describe these courses and show how and when you can sign up to them.

### The Many Faces of Dementia

In this online course, you'll gain a unique insight into dementia through the stories, symptoms and science behind four less common diagnoses. You'll explore key issues in dementia care and research through the eyes of people affected by four less common conditions. World-leading experts at UCL show how research into the signs, stages, symptoms and causes of these forms can bring us closer to defeating dementia.

Estimated learning time is approximately 2 hours per week across 4 weeks, at your own pace.

Course start date: **18<sup>th</sup> February 2019.**

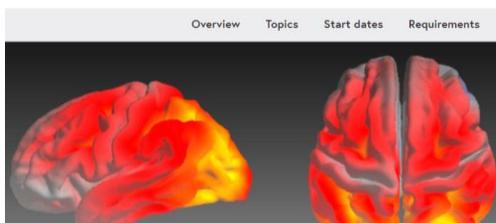
Sign up at:

<https://www.futurelearn.com/courses/faces-of-dementia>

ONLINE COURSE

### The Many Faces of Dementia

Gain a unique insight into dementia through the stories, symptoms and science behind four less common diagnoses.



### Dementia and the Arts: Sharing practice, developing, understanding and enhancing lives

Explore, challenge and shape your perceptions of dementias through science and the creative arts. Creating a society that supports and includes those living with a dementia is a major challenge – and opportunity. In this

online course you will discover how the arts can create common ground between people, and in doing so, learn what we can all do to improve the quality of life and care for people living with different dementias.

Estimated learning time is approximately 2 hours per week across 4 weeks, at your own pace. Each of the 4 weeks will showcase current best practice, explain the limits of our current understanding, and set ambitious goals for enhancing the lives of anyone affected by one of these conditions.

Sign up for free or choose the paid upgrade to gain 8 CPD points recognised by the Royal Society of Public Health (RSPH).

Course start date: **21<sup>st</sup> January 2019.**

Sign up at:

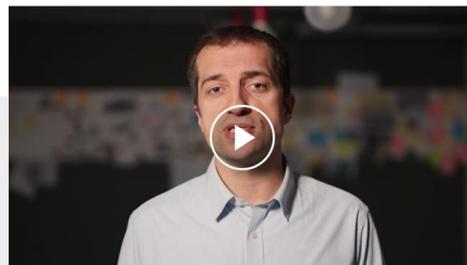
<https://www.futurelearn.com/courses/dementia-arts/3>

ONLINE COURSE

### Dementia and the Arts: Sharing Practice, Developing Understanding and Enhancing Lives

Explore, challenge and shape your perceptions of dementia through science and the creative arts

Drawing on the work of the [Created Out of Mind](#) project during its residency at the Wellcome Collection, this course will expand your perceptions of the dementias and the diverse role of the arts in all our lives.



[View transcript](#)

[Download video: standard or HD](#)

## **Other upcoming meetings**

Below is a list of the upcoming Rare Dementia Support meetings in 2019:

**Posterior Cortical Atrophy (PCA) Support Group Meeting** – Friday 1<sup>st</sup> March 2019 - 6<sup>th</sup> Floor Conference Suite, Wellcome Trust

**Primary Progressive Aphasia (PPA) Support Group Meeting** – Wednesday 3<sup>rd</sup> April 2019 – 6<sup>th</sup> Floor Conference Suite, Wellcome Trust

**Carers Support Group Meeting** – Tuesday 7<sup>th</sup> May 2019 - 6<sup>th</sup> Floor Conference Suite, Wellcome Trust

**FTD Support Group Meeting** – Thursday 4<sup>th</sup> July 2019 - 6<sup>th</sup> Floor Conference Suite, Wellcome Trust

**PCA Support Group Meeting** – Friday 5<sup>th</sup> July 2019 - 6<sup>th</sup> Floor Conference Suite, Wellcome Trust

**PPA Support Group Meeting** – Tuesday 23<sup>rd</sup> July 2019 - 6<sup>th</sup> Floor Conference Suite, Wellcome Trust

These meetings are subject to change and please keep an eye on our website's calendar

(<http://www.raredementiasupport.org/meetings/>) for any changes.

For more information on these events you can also email the team at [contact@raredementiasupport.org.uk](mailto:contact@raredementiasupport.org.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).

Yours,  
The FTD Support Group Team

## **DISCLAIMER**

*Please note that you assume full responsibility and risk in the use of information contained on our website, in our newsletters, at support group meetings and in subsequent correspondence. Our support group based correspondence is generic in nature and we are limited in our ability to offer specific advice via this means. We aim to ensure that all information is as accurate as possible but we accept no responsibility for any errors, omissions or inaccuracies, or for any adverse consequences of any kind arising from the use of support group based content. Our regional group facilitators are volunteers. They may refer to regional facilitator guidelines from RDS but are not governed by RDS. They operate independently and with best intention and you assume full responsibility for your contact and engagement with them and in the regional groups they facilitate. Please see the clinician responsible for your care, a social services representative, or your GP if you have specific needs which require attention. Any medical decisions should be taken in discussion with an appropriate health care professional.*