

Social Media Messages for Rare Disease Day Cambridge Lecture held on 28.02.19

NIHR BioResource Retweeted



NIHR Cambridge BRC @CambridgeBRC · Feb 28

Countdown has begun to the [@NIHRBioResource](#) / [@camraredisease](#) free [@rarediseaseday](#) talk tonight in Cambridge. Meet researchers Dr Jagtar Singh Nijjar, Dr Isabelle Delon, Dr Tomasz Matys & Dr James Thaventhiran. Not too late to book but hurry bit.ly/2TYED2B



NIHR BioResource @NIHRBioResource · Feb 28

Our director Nathalie & Jo from [@camraredisease](#) were on the radio last week talking about rare disease research & tonight's lecture at [@CUH_NHS](#). You can still listen to their interview which also features Allison, whose son has r(20) ow.ly/JCWR30nRXN1 (listen at 21.07 in)



NIHR BioResource Retweeted



RACC-UK@RACC_UK · Feb 28

We're off to Cambridge! #RareDiseaseDay2019 #RareDiseaseDay #rareiseaseawareness #rareiseaseadvocate #autoinflammatory #periodicfevers @camrareisease @NIHRBioResource



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Ring20UK @Ring20UK · Feb 28

Some of the aspirations for the future mentioned by Baroness Nicola Blackwood @nicolablackwood #RareDiseaseDay @NIHRBioResource @camrareisease



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Ring20UK @Ring20UK · Feb 28

Kicking off our evening event here in Cambridge for the Rare Disease Lectures with Laura Mader from @PLRH

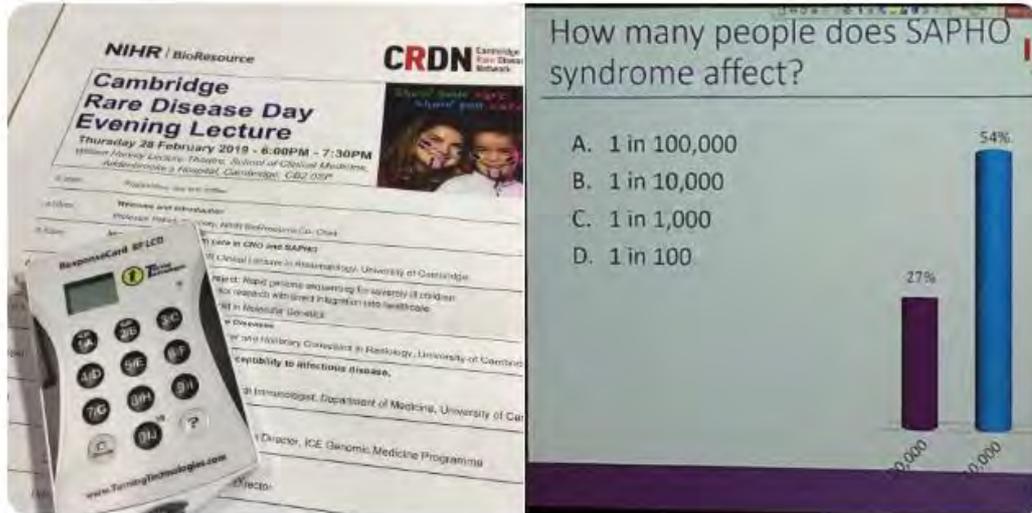


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Mito Research Cambridge @cam_mito · Feb 28

I didn't know there was going to be a test 😊 great interactive tools to keep the audience engaged at the Cambridge Rare Disease Evening @NIHRBioResource @camraredisease



2 6

Jagtar Singh Nijjar Retweeted



NIHR BioResource @NIHRBioResource · Feb 28

@JagtarNijjar talks about his research journey to start finding a treatment for CNO and his research began with meeting a mother of a patient at a previous rare disease lecture #rarediseaseday



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Jennifer Martin @Jen_omics · Feb 28

It's question time!! The panel take questions from the audience @camraredisease @NIHRBioResource #RareDiseaseDay #genomics #rarediseaseday2019



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Dr. Louise Gaynor @DrLGaynor · Feb 28

Looking forward to hearing about the rare disease research taking place in Cambridge! @NIHRBioResource @camraredisease #rarediseaseday

NIHR | BioResource **CRDN** Cambridge Rare Disease Network

Cambridge Rare Disease Day Evening Lecture

Thursday 28 February 2019 - 6:00PM - 7:30PM
 William Harvey Lecture Theatre, School of Clinical Medicine, Addenbrooke's Hospital, Cambridge, CB2 0SP

Show your rare Show you care

5.30pm	Registration, tea and coffee
6.00pm	Welcome and Introduction Professor Patrick Chinnery, NIHR BioResource Co- Chair
6.10pm	Improving patient health care in CNO and SAPHO Dr Jagtar Singh Nijar, NIHR Clinical Lecturer in Rheumatology, University of Cambridge
6.20pm	Next Generation Children Project: Rapid genome sequencing for severely ill children. A model for translational genomics research with direct integration into healthcare Dr Isabelle Delon, Clinical Scientist in Molecular Genetics
6.30pm	Imaging in the diagnosis of Rare Diseases Dr Tomasz Matys, University Lecturer and Honorary Consultant in Radiology, University of Cambridge
6.40pm	Whole Genome Sequencing for susceptibility to infectious disease, potential for patient benefits Dr James Thaventhiran, Consultant Clinical Immunologist, Department of Medicine, University of Cambridge
6.55pm	Q&A Discussion with all speakers Facilitator: Dr Gemma Chandratillake, Course Director, ICE Genomic Medicine Programme



Gemma Chandratillake @GemmaChand · Feb 28

Now James Thaventhiran talking about #rarediseases that lead to susceptibility to infection and how the lower rates of infectious diseases in the west mean that we don't see the family history we'd expect in a genetic disorder @camraredisease @NIHRBioResource #raredisease2019



CRDN

Cambridge Rare Disease Network @camraredisease · Feb 27
One day to go! #ShowYourRare #RDD2019 @rarediseaseday To everyone taking part, in whatever way you can tomorrow, to raise awareness, showcase best examples of good practice & come together with a united voice. Thank you & we're with you! bit.ly/CamRDD19 @CambridgeBRC



Rare Disease Day Cambridge Lecture
Thursday 28 Feb 2019 from 6.00pm to 7.30pm

doors open at 5.30pm, following the talks there is a networking and drinks reception until 8.00pm

Jointly hosted by:
NIHR BioResource
Cambridge Rare Disease Network

Featured Speakers

- Dr Jagtar Singh Nijjar
NIHR Clinical Lecturer in Rheumatology at the University of Cambridge
- Prof Ken Smith
Professor of Medicine and Head of the Department of Medicine at the University of Cambridge
- Dr Isabelle Delon
Clinical Scientist at the EMEC Genomic Laboratory
- Dr Tomasz Matys
Lecturer and Honorary Consultant in Radiology at the University of Cambridge



PLRH @plr_h_cambridge · Feb 28
Tonight! Really looking forward to this great event - thanks @camraredisease @NIHRBioResource @CambridgeBRC :)



28 February 2019 from 6.00pm to 7.30pm
NIHR Cambridge BRC @CambridgeBRC
Come & meet Cambridge researchers Dr Jagtar Singh Nijjar, Dr Isabelle Delon, Dr Tomasz Matys & Dr James Thaventhiran at our free @rarediseaseday talk on 28 Feb. Great chance to meet researchers & network ...

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NIHR BioResource Retweeted



Eastern AHSN @TheEAHSN · Feb 28

We're delighted to be attending this later, so please come and say hello! There's so much amazing work going on in the area, it promises to be a fascinating evening.



NIHR BioResource @NIHRBioResource

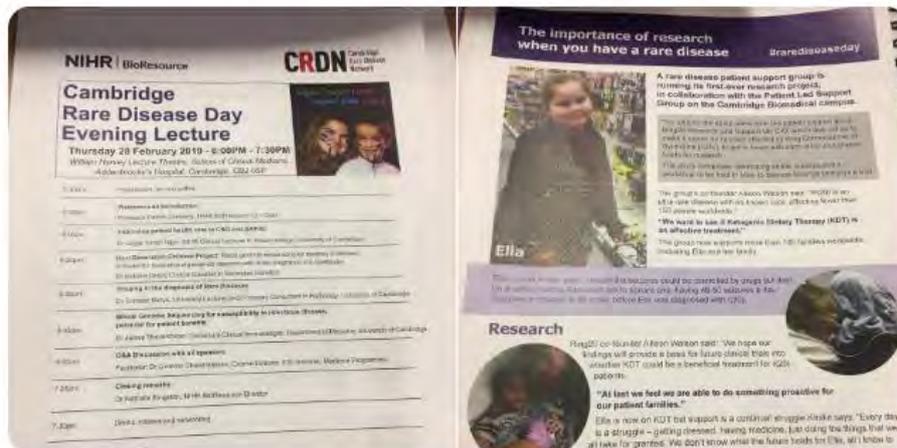
We're hosting a @rarediseaseday evening lecture at @CUH_NHS with @camraredisease on 28 Feb, 6pm-7.30pm. We have talks from Cambridge researchers in rheumatology, genomics, immunology & radiology...

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Ring20UK @Ring20UK · Feb 28

Here's our speakers for tonight at the Cambridge Rare Disease Day Evening Lecture and Ella, or r(20) poster girl #RareDiseaseDay @NIHRBioResource @camraredisease



NIHR BioResource **CRDN** **Cambridge Rare Disease Day Evening Lecture**
Thursday 28 February 2019 - 6.00PM - 7.30PM
Winton Theatre, Addenbrooke's Hospital, Cambridge, CB2 0QQ

The importance of research when you have a rare disease #rarediseaseday

Ella

Research

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Gemma Chandratillake @GemmaChand · Feb 28

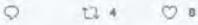
.@IsaDelon now talking about the next generation children's project, a rapid genomic diagnostic project in the NICU and PICU #rarediseaseday2019 @camraredisease @NIHRBioResource



ImPaHCS Retweeted

NIHR Cambridge BRC @CambridgeBRC · Feb 28

Cambridge's Dr Jagtar Singh Nijjar explains how his team is helping 2 improve patient health care in rare diseases CNO and SAPHO @ImPaHCS #SAPHO #CNO @NIHRBioResource @camraredisease @rarediseaseday



Jennifer Martin @Jen_omics · Feb 28

Describing brain imaging!

#RareDiseaseDay #brain @camraredisease @NIHRBioResource



Cambridge Rare Disease Network Retweeted



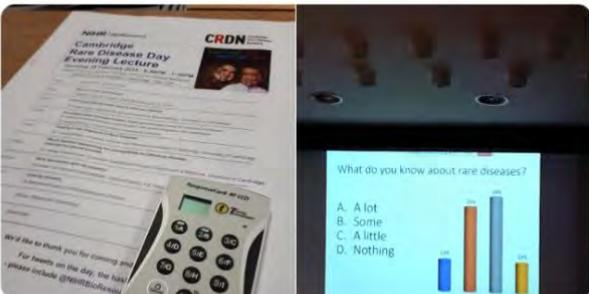
NIHR Cambridge BRC @CambridgeBRC · Feb 28

Patient groups have a lot of influence / power & now is the time to act: Prof Chinnery says that Minister For Innovation Nicola Blackwood herself has a rare disease and is fully supportive of new National genomic Healthcare strategy @rarediseaseday @camraredisease @NIHRBioResource



Libbie Read @LibbieRead · Feb 28

Gotta love interactivity! Fun voting system @camraredisease and @NIHRBioResource lecture for #RareDiseaseDay



Thomas Hiemstra @Thomas_Hiemstra · Feb 25

Great to meet up with @Ring20UK @camraredisease on @cambridge105 this morning to talk about @rarediseaseday @CambridgeBRC @plr_h_cambridge Thursday 28th 17:30 at #SchoolOfMedicine #Addenbrookes



Rare Disease Day Cambridge Evening Lecture 2019...

Thursday 28 February 2019 at the Clinical School, Cambridge Doors open at 5.30pm. Talks are between 6pm to 7.30pm, followed by a drinks reception until cambridgebrc.nihr.ac.uk



Gemma Chandratillake @GemmaChand · Feb 28

.@JagtarNijjar giving a lovely background to his talk at our #raredisease2019 event of how his research came about through a #raredisease2017 event and a question from a mum @camraredisease @NIHRBioResource

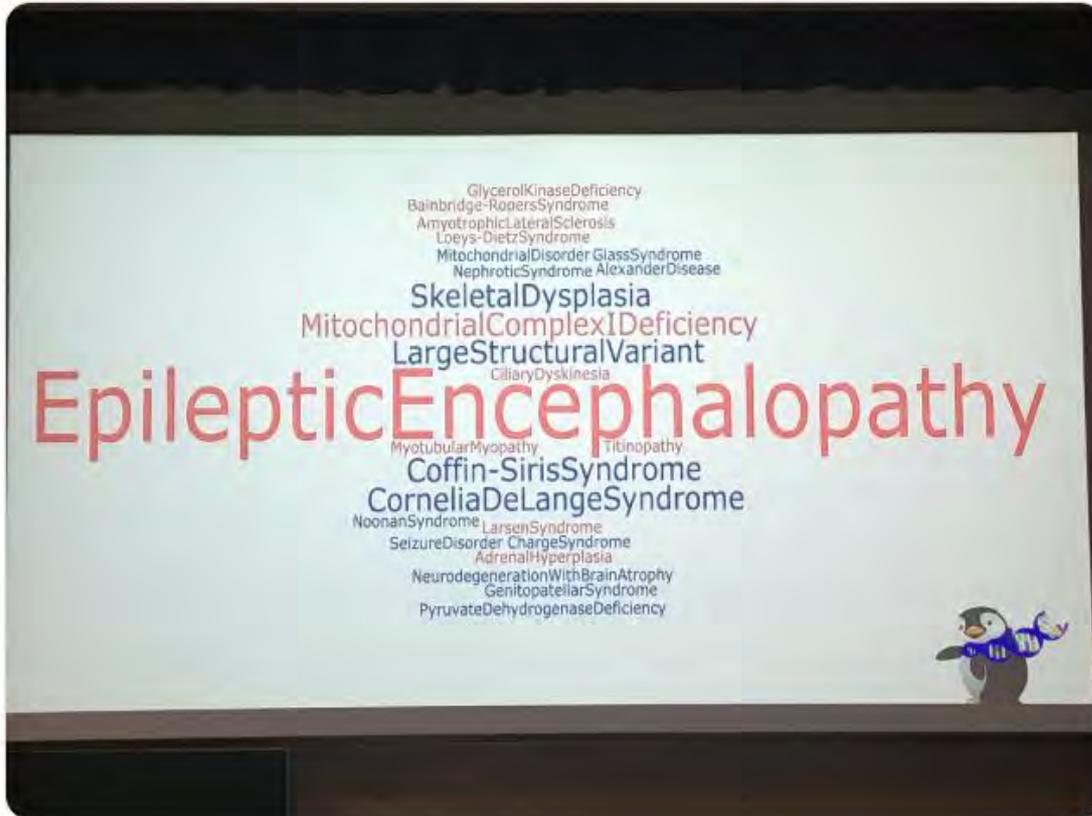




Ring20UK @Ring20UK · Feb 28

Dr Isabelle Delon explains about the Next Generation Children Project. Great to see Epileptic Encephalopathy listed front and centre, however WGS can't detect ring chromosomes- one of the ultra-rare epileptic encephalopathies.

#RareDiseaseDay @NIHRBioResource @camraredisease



Cambs Lupus Group @CambsLupus · Feb 28

See you there!

PLRH @plrh_cambridge

Tonight! Really looking forward to this great event - thanks @camraredisease @NIHRBioResource @CambridgeBRC :) twitter.com/CambridgeBRC/s...

NIHR BioResource Retweeted



NIHR Cambridge BRC @CambridgeBRC · Feb 28

Over 300 genes described as causing infection - but these r rare in the west where we don't have family histories to help work out what's going wrong. Recurrent infections can be caused by 1 or more of these genes

@camraredisease @NIHRBioResource @rarediseaseday



NIHR BioResource @NIHRBioResource · Feb 28

Dr Nathalie Kingston closes the event and thanks everyone for coming and hope it gives an insight of some of the rare disease research @CUH_NHS



↳ NIHR Cambridge BRC Retweeted



Nathalie Kingston @NatK1ngston · Feb 22

Talking Rare Diseases with @BBCcharlie and Jo Balfour from @camraredisease ahead of our #cambridge event with @NIHRBioResource - What about a fab way to end the week! #RareDiseaseDay on 28th Feb, it is all about #Awareness



BBC Cambridgeshire

