Rare Youth Revolution Team

Have you ever been told you don’t look sick? Or maybe someone has asked you a question about your disability that has left you cringing inside.

Ceridwen Hughes, Shirlene Badger & Tom Almeroth-Williams

This discussion & short film highlights the reality of both the search for a diagnosis and the impact of the diagnostic moment.

Adam Pearson, Dagmar Bennett, Ross Lannon, Jordan Mossom, Graham Miller & Vicky Donald

How do we finesse the art of starting, maintaining and finishing conversations about complex subjects?

Prof. Stefan Marciniak, Dr Jenny Dickens, Eimear Rutherford & Nikita Zubkov

Some of the Cambridge Institute of Medical Research Team talk rare lung disease research.

Simone Manso, Rudy Benfredj, Marla Picone & Caroline Hargrove

How human intelligence and tech combined can help diagnose and treat earlier and can analyse social media to capture patient and caregiver perspectives.

Dr Melita Irving & Dr Lucy McKay

Join Melita and Lucy who’ll be extracting DNA live! Don’t worry, there won’t be any blood and gore around, just a few juicy strawberries and some washing up liquid!

10.45 – 11.15
RARE DISEASE MYTH BUSTERS AND QUIZ

12.00 – 12.45
THE DNA DOCTOR LIVE! UNDERSTANDING YOUR GENETIC CODE

13.15- 14.00
HOW DO WE START THIS CONVERSATION?
Rare Youth Revolution Team
The team is talking about growing up with rare conditions and managing mental health whilst going through life’s sometimes scary, but exciting, milestones in education, employment and relationships.

Dr Giles Yeo
Giles' research in rare diseases of obesity has given us new insight into normal variations of body weight. He believes understanding rare conditions brings benefit to broader society.

Dana Perella
Join Dana live for a cookie buttercream icing decorating lesson where she'll be telling us a bit more about her incredible fundraising mission for research.

Onno Faber & Dr Jason Mellad
Rare disease is a complex problem, and although every disease is different, as patients they find themselves in the same boat. Onno and Jason discuss solutions.

Cambridge Rare Disease Network’s children’s community performance
You are invited to join the kids as they emerge from social isolation to be together again.
MEETS DR MELITA IRVING: THE DNA DOC
Your friendly rare disease ologist!

HEALX: AI-POWERED, PATIENT-INSPIRED TREATMENTS
Treatments faster and cheaper

CAMBRIDGE STEM CELL INSTITUTE: STEM CELLS DISEASE AND YOU
Lab life with the stem cells experts

EPAG FOR EPICARE, RARE EPILEPSIES: THE BRAIN GAME
Myth busting and brain games

PUFF OF SMOKE: AN ILLUSTRATED DIAGNOSTIC JOURNEY
Crayonlegs comic graphic memoir

CONCEPTIONEERING: BUILDING A MORE ACCESSIBLE WORLD THROUGH TECHNOLOGY
Meet the robots and gizmos

WELLCOME-MRC INSTITUTE OF METABOLIC SCIENCE: METABOLIC TREASURE
Digging for rare metabolic treasures

ALLSTRIPES
Harnessing the power of community

MEDICS4RAREDISEASES
Spotting the zebras in medicine
COOKIES4CURES: FUNDING CURES ONE COOKIE AT A TIME
Get your apron on for some baking!

MICROSOFT RESEARCH: PROJECT TOKYO, DESIGNING FOR INCLUSIVITY
Design activities for human diversity

LIFEARC: THE CHARITY TURNING PROMISING SCIENCE INTO PATIENT BENEFITS
Accelerate scientific breakthroughs

WELLCOME GENOME CAMPUS: LEARN MORE ABOUT GENETIC COUNSELLING
Genetic counselling in action

REALLY REAL RESOURCES
Stock photography that challenging stigma & celebrating individuality and inclusivity

JORDAN MOSSOM: DAYTIME DISABILITY, A DOCUMENTARY PHOTOGRAPHY PROJECT
Muscular Dystrophy in pictures

SAME BUT DIFFERENT: RARE AWARE PHOTOGRAPHY AND "JOURNEY OF HOPE" FILM
Rare sculpture gallery unveiled!

MUSCLEHELP FOUNDATION: DISCOVER THE VIRTUAL #POWEROF657
The magic of Muscle Dreams!

EASTERN AHSN: TURNING GREAT IDEAS INTO POSITIVE HEALTH IMPACTS
Share your biggest challenges with innovators

CAMBRIDGE SCIENCE CENTRE & EAR SWITCH
Communication re-imagined!
POSTERS & FILMS

TIMOTHY SYNDROME
Increased awareness of Timothy Syndrome can connect patient families, inspire conversations, lead to new paths for research and save lives by Timothy Syndrome Alliance (TSA)

GO MAKE MEMORIES
Raise awareness of the ultra-rare and devastating group of genetic conditions, Niemann-Pick disease by Niemann-Pick UK (NPUK)

POSTER: GENE THERAPY AT A GLANCE & FILM: GENE THERAPY ANIMATION
Learn more about gene therapy and how it may be used to treat rare diseases by Orchard Therapeutics

POSTER: INVESTIGATING THE SMITH-MAGENIS SYNDROME POPULATION IN THE UK & FILM: SMITH-MAGENIS SYNDROME THROUGH OUR LOGO
Discover more about Smith-Magenis Syndrome by Smith-Magenis Syndrome Foundation UK

PITT-HOPKINS SYNDROME & FILM: PITT-HOPKINS AWARENESS DAY 2020
Pitt-Hopkins Syndrome poster and Pitt-Hopkins Awareness Day 2020 film by Pitt Hopkins UK

POSTERS

SCALING A REAL-WORLD EVIDENCE PLATFORM FOR LYSOSOMAL STORAGE DISEASES
Real-world evidence to facilitate rare disease research by AllStripes Research

MEETING THE UNMET NEEDS FOR SALIVARY GLAND CANCER RESEARCH IN THE UK AND BEYOND
A unique collaboration addressing unmet needs in the UK and beyond by Salivary Gland Cancer UK

BEHÇET’S UK DIAGNOSTIC ODYSSEY
The difficulty with diagnosing Behçet’s; a complex, debilitating and lifelong condition by Behçet’s UK

PLAYING VASCULITIS CLUEDO
Do you have enough clinical curiosity? by Vasculitis UK

FILMS

KAY’S STORY
Kay Parkinson journey from rare disease parent and founder of Alstrom Syndrome UK, to CEO of CRDN then onto founding the RDNN by Rare Disease Nurse Network

VOICES OF GENETIC COUNSELLORS: SO MUCH MORE THAN JUST A TEST
Four genetic counsellors from across England recalling particularly difficult cases they have dealt with in their careers, which have left a lasting impact on them by Anna Middleton

MUSIC OF LIFE: WHAT IS A GENE?
A unique collaboration between healthcare, academia and filmmaking has led to the development of a new metaphor to describe genomics concepts by Wellcome Genome Campus Connecting Science

LIVING IN THE SHADOW OF HUNTINGTON’S DISEASE
We explain what Huntington’s is & how it’s inherited by The Huntington’s Disease Association

FIGHT LIKE A CHAMP1ON
A big thank you to the researchers helping our community by CHAMP1 Research Foundation

YBRP AND THE QUEST TO A CURE
A collaborating with researchers from St. Jude Children’s Hospital and Andlit Therapeutics by The Yellow Brick Road Project
CRDN
Cambridge Rare Disease Network

SAYS
THANK YOU!
DANKE!
MERCI!
Grazie!
GRACIAS!
DANK JE WEL!

to all our:
speakers, exhibitors,
volunteers and to
every single attendee

as well as to all our generous sponsors...

Evolution Education Trust

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AND IN A UNPRECEDENTED YEAR...

RAREfest20 wouldn't happen without you!