

'Think Research' Rare Diseases Patient Day Agenda
Wednesday 21 March 2018 at Friends House, London

10:00 <i>Registration- North Lobby</i>		Refreshments & Networking	East Lobby		
10:20	Welcome - <i>Opening Remarks</i>	Vicky Ford, MP: Chair of the All Party Parliamentary Group (APPG) on Rare, Genetic and Undiagnosed Conditions and member of the Science and Technology Select Committee	The Light		
10:30	NIHR BioResource for Translational Research (BR-TR)	Professor Patrick Chinnery (BR-TR): What is the NIHR BioResource? Professor Allan Colver: Transition is about becoming a young adult, not the medical condition Dr Patrick Yu Wai Man: Genetic Eye Disease – Light at the End of the Tunnel? Maria Kokocinska & Janet Turberville-Greenley: Creating the world's first children's centre for rare disease	The Light		
11:30 <i>Hot drinks will be available in each of the training rooms</i>					
11:35	Rm: Waldo Williams 2 Social Media Getting the best out of your social media with <i>Genetic Alliance UK & Pompe Disease Patient</i>	Rm: Ada Salter 3 Working with Industry <i>Exploring ways to work with pharmaceutical & biotech industries with Findacure & The Gaucher Association</i>	Rm: Waldo Williams 1 Genomics <i>The power of genomics in diagnosing rare diseases with East of England Genomics Medicine Centre</i>	Rm: Ada Salter 1 & 2 Data and Research <i>Why data is central to research with IT Director of NIHR BioResource for Translational Research</i>	
12:30	<i>Lunch- one hour</i>		Refreshments, Discussions, Displays & Networking		
13:00	<i>Optional: Discussions for patients, carers & patient support groups representatives</i>	<i>There will be informal group discussions held in the last 30 minutes of the lunch break. This is an opportunity to chat to fellow members whilst eating your lunch about topics that you're interested in. Feel free to join one of these groups.</i> <i>If there are any specific topics you would like to discuss (e.g. technology, problems you have encountered etc.) you can suggest them on Eventbrite.</i>	The Light back of the room		
13:30	Rm: Ada Salter 3 Social Media	Rm: Waldo Williams 2 Working with Industry	Rm: Ada Salter 1 & 2 Genomics	Rm: Waldo Williams 1 Data and Research	
14:30	Consent Panel	Q & A session <i>How will the new data consenting laws affect rare disease patients and research? In the digital age what should consent look like?</i> <i>Why do we need to consent and re-consent, ethics & legality of consent, use & access to data, children's & family consent, transitioning to adult consent, dynamic consent and the impact of withdrawing consent?</i>		The Light	
15:10	<i>Break Tea & Coffee</i>		Refreshments & Networking	East Lobby	
15:25	Cardiovascular Research Centre University of Leicester	Dr David Adlam and Becks Breslin, Chair of BeatSCAD: Patients and Researchers collaborate to solve SCAD		The Light	
15:40	University College London and Great Ormond Street Hospital	Professor Paul Gissen, Head of 'Genetics and Genomic Medicine' academic programme at UCL and Honorary Consultant in Paediatric Metabolic Diseases at GOSH: Gene therapy for Inherited metabolic disorders			
15:55	Closing Remarks	Professor John Bradley: NIHR Director of Cambridge Biomedical Research Centre and NIHR BioResource for Translational Research			

"Same But Different" photography exhibition will be on display in The Light

Today's event is a joint collaboration with:

**NIHR Cambridge Biomedical Research Centre and
NIHR BioResource for Translational Research**