

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

10:00 Registration- North Lobby		Refreshments & Networking		East Lobby
10:20	Welcome - <i>Opening Remarks</i>	<b>Vicky Ford, MP:</b> 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)	<b>Professor Patrick Chinnery (BR-TR):</b> What is the NIHR BioResource? <b>Professor Allan Colver:</b> Transition is about becoming a young adult, not the medical condition <b>Dr Patrick Yu Wai Man:</b> Genetic Eye Disease – Light at the End of the Tunnel? <b>Maria Kokocinska &amp; Janet Turberville-Greenley:</b> Creating the world’s first children’s centre for rare disease		The Light
11:30 Hot drinks will be available in each of the training rooms				Trg rooms
11:35	<b>Rm: Waldo Williams 2</b>	<b>Rm: Ada Salter 3</b>	<b>Rm: Waldo Williams 1</b>	<b>Rm: Ada Salter 1 &amp; 2</b>
	<b>Social Media</b> Getting the best out of your social media with <i>Genetic Alliance UK &amp; Pompe Disease Patient</i>	<b>Working with Industry</b> <i>Exploring ways to work with pharmaceutical &amp; biotech industries with Findacure &amp; The Gaucher Association</i>	<b>Genomics</b> <i>The power of genomics in diagnosing rare diseases with East of England Genomics Medicine Centre</i>	<b>Data and Research</b> <i>Why data is central to research with IT Director of NIHR BioResource for Translational Research</i>
12:30 Lunch- one hour		Refreshments, Discussions, Displays & Networking		East Lobby
13:00	<b>Optional:</b> Discussions for patients, carers & patient support groups representatives	<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	<b>Rm: Ada Salter 3</b>	<b>Rm: Waldo Williams 2</b>	<b>Rm: Ada Salter 1 &amp; 2</b>	<b>Rm: Waldo Williams 1</b>
	<b>Social Media</b>	<b>Working with Industry</b>	<b>Genomics</b>	<b>Data and Research</b>
14:30	Consent Panel	<b>Q &amp; A session</b> <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 &amp; legality of consent, use &amp; access to data, children’s &amp; family consent, transitioning to adult consent, dynamic consent and the impact of withdrawing consent?</i>		The Light
15:10 Break Tea & Coffee		Refreshments & Networking		East Lobby
15:25	Cardiovascular Research Centre University of Leicester	<b>Dr David Adlam and Becks Breslin, Chair of BeatSCAD:</b> Patients and Researchers collaborate to solve SCAD		The Light
15:40	University College London and Great Ormond Street Hospital	<b>Professor Paul Gissen, Head of ‘Genetics and Genomic Medicine’ academic programme at UCL and Honorary Consultant in Paediatric Metabolic Diseases at GOSH:</b> Gene therapy for Inherited metabolic disorders		
15:55	Closing Remarks	<b>Professor John Bradley:</b> 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**