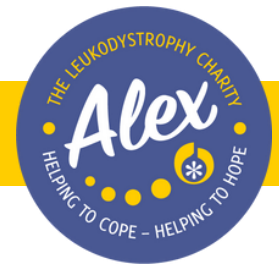


# Community Weekend Virtual Agenda



## Saturday Presentations

Time	Topic	Presenter
09:30-09:35	Alex TLC Introductions	Sara Hunt
09:35-09:55	Alex TLC Update	Sara Hunt
09:55-10:15	NHS England Inherited White Matter Disorder (IWMD) Service and Patient Registry	Dr Rahul Singh
10:15-10:35	Working with Alex TLC - NHSE IWMD Service & Registry	Helen Morris (Metabolic Support) & Toni Mees
10:35-10:55	Leukolabs - a UK Research Collaboration	Dr Noémie Hamilton
10:55-11:10	Q&A	
11:10-11:35	Break	
11:35-11:55	Gene Therapy/Bone Marrow Transplant	Dr Claire Horgan
11:55-12:15	Adrenomyeloneuropathy (AMN) - Symptoms and treatments for men	Dr Robin Lachman
12:15-12:35	Transplant for Advanced Cerebral ALD: Risk-Benefit	Dr Troy Lund
12:35-12:55	Support for severely symptomatic patients (adults)	Dr Charlie Wade & Prof. Jeremy Chattaway
12:55-13:10	Q&A	
13:10-14:00	Lunch	
14:00-14:20	The psychosocial impact on parents of having a child diagnosed with cerebral ALD	Dr Hilary Piercy
14:20-14:40	ALD: Monitoring (children)	Dr James Davison
14:40-15:00	Hematopoietic stem-cell transplantation (HSCT) in Adults with Adult Onset Cerebral ALD	Dr Wolfgang Kohler
15:00-15:15	Q&A	
15:15-15:45	Break	



# Community Weekend Virtual Agenda



## Sunday Presentations

Time	Topic	Presenter
09:30-09:35	Alex TLC Introductions	Karen Harrison
09:35-09:55	Summary of Saturday's Research Roundtable	Dr James Poulter (Leukolabs)
09:55-10:15	Sex-specific newborn screening for X-linked Adrenoleukodystrophy (ALD)	Dr Stephan Kemp
10:15-10:35	Alex TLC Newborn Screening Study	Genetic Alliance - Jennifer Jones
10:35-10:55	Gene Therapy for Adrenomyeloneuropathy (AMN)	Dr Florian Eichler
10:55-11:10	Q&A	
11:10-11:40	Break	
11:40-12:00	Genetics & Genetic Counselling	Dr James Poulter
12:00-12:20	Paediatric Symptom Management	Dr Alasdair Parker
12:20-12:40	ALD Monitoring - Personal Story	Kathleen O'Sullivan-Fortin
12:40-12:55	Q&A	
12:55-13:45	Lunch	
13:45-14:15	Minoryx Therapeutics S.L. Clinical Programme Update	Dr Arun Mistry, Minoryx Therapeutics
14:15-14:30	SwanBio Program Updates: investigating AAV gene therapy for AMN	Eileen Sawyer, SwanBio
14:30-15:00	VK0214 in Patients with AMN – Update	Dr Joel Neutel, Viking Therapeutics
15:00-15:15	Q&A	
15:15-15:45	Break	

