

SESSION ONE - Basic Science and Mechanisms - Friday Afternoon - 26th April 2019

Chair of Session One		Dr Paddy Harrison, University College Cork			
Start Time	Finish Time	Speaker	Presentation Title	Institution	Country
1:45 p.m.	2:00 p.m.	Welcome Address - by Professor Elena Levchenko and Anne Marie O'Dowd			
2:00 p.m.	2:30 p.m.	Dr Olivier Govaere	Metabolite cysteamine regulates immune tolerance upon lipid-induced oxidative stress in non-alcoholic fatty liver disease	Newcastle University	UK
2:30 p.m.	3:00 p.m.	Dr Koenraad Veys	Allogeneic HSCT transfers wild-type cystinosis to nonhematological epithelial cells in cystinosis: First human report	University of Leuven	BE
3:00 p.m.	3:30 p.m.	Comfort break			

SESSION TWO - Clinical Science - Friday Afternoon - 26th April 2019

Chair of Session Two		Dr Katharina Hohenfellner			
Start Time	Finish Time	Speaker	Presentation Title	Institution	Country
3:30 p.m.	4:00 p.m.	Professor Craig Langman - The Isaac A Abt MD Professor of Kidney Diseases	Non-traditional approaches to the myopathy of nephropathic cystinosis	Feinberg School of Medicine, Northwestern University Head, Kidney Diseases, The Ann and Robert H Lurie Children's Hospital of Chicago	USA
4:00 p.m.	5:00 p.m.	Christian Koeppel	Galileo-training as therapeutic approach to enhance motor performance and life quality in Cystinosis - presentation of clinical data and the Galileo-Study-	Department for Pediatric Orthopedics and Neuro-Orthopedics, Schoen Klinik Muenchen Harlaching	DE
		and Christine Knerr	Logopedic findings in patients with Cystinosis	Logopedics, SPZ, Traunstein	DE
		Professor Dieter Haffner	Bone disease in nephropathic cystinosis	Hannover Medical School Children's Hospital	DE
5:00 p.m.	5:30 p.m.	Poster session - guided poster session for patients/families			

5:30 p.m. 7:00 p.m. Welcome Reception - mingling between families and scientists

SESSION THREE - Therapeutics - Saturday morning - 27th April 2019

Chair of Session Three		Professor Donald Cairns, Robert Gordon University			
Start Time	Finish Time	Speaker	Presentation Title	Institution	Country
9:00 a.m.	9:30 a.m.	Emeritus Professor Herbie (David Richard) Newell	Novel small molecule cysteamine-based therapies for the treatment of cystinosis	Newcastle University	UK
9:30 a.m.	10:00 a.m.	Professor Paul Goodyer	Update on new drug therapy for cystinosis	Montreal Children's Hospital	CA
10:30 a.m.	10:30 a.m.	Dr Manoe Janssen	Drug combination improves metabolic profile of cystinotic kidney cells	Utrecht University	NL
10:30 a.m.	11:00 a.m.	Dr Laura Rita Rega	Genistein treatment for renal disease in cystinosis	Bambino Gesù Hospital, Rome	IT
11:00 a.m.	11:30 a.m.	Comfort break			

SESSION FOUR - General Public Patient Engagement - Saturday morning - 27th April 2019

Chair of Session Four		Professor Elena Levchenko, University of Leuven			
Start Time	Finish Time	Topic			
11:30 a.m.	12:15 p.m.	Oral presentations by PhD students/Early stage researchers			
12:15 p.m.	12:30 p.m.	Prize for best presentation Prize for best poster			
12:30 p.m.	1:00 p.m.	Poster session - guided poster session for patients/families Extended break to allow mingling between families and scientists			
1:00 p.m.	2:00 pm	Lunch			

SESSION FIVE – Transitional Care Strategies / Social Impact - Saturday afternoon - 27th April 2019

Chair of Session Five		Dr Tara Raftery, Temple Street Children's Hospital			
Start Time	Finish Time	Speaker	Presentation Title	Institution	Country
2:00 p.m.	2:30 p.m.	Dr Suja Somanadhan	Social impact of Cystinosis disease	University College Dublin	IE
2:30 p.m.	3:00 p.m.	Dr Hannah Blakey	Pregnancy in Women with Cystinosis	Institute of Translational Medicine (ITM), Birmingham	UK
3:30 p.m.	3:50 p.m.	Anne Marie O'Dowd	Family perspective	Cystinosis Ireland	IE
3:50 p.m.	4:15 p.m.	Comfort break			

SESSION SIX – Clinical aspects of Cystinosis - Saturday afternoon - 27th April 2019

Chair of Session Six		Dr Shu-Dong Zhang, University of Ulster			
Start Time	Finish Time	Speaker	Presentation Title	Institution	Country
4:14 p.m.	4:45 p.m.	Dr Brendan Keating	Using these genetic data-sets to understand transplant complications and thus improve treatment for transplant patients	Division of Transplantation Department of Surgery, University of Pennsylvania, Penn Transplant Institute Philadelphia, PA 19104	USA
4:45 p.m.	5:15 p.m.	Dr Ahmed Reda	Unraveling the mechanism of azoospermia in male cystinosis patients	Katholieke Universiteit	BE
5:15 p.m.	5:30 p.m.	Closing Remarks	Mr Mick Swift	Cystinosis Ireland	IE

7:30 p.m. Workshop Gala Dinner