

National Cystinosis Patient Study Day

26th January, 2019: 40 Bull St, Birmingham B4 6AF

Time	Topic	Speaker
09.30– 09.45	Registration and coffee	-
09.45 - 10.00	Welcome and Introduction	Dr Graham Lipkin
10.00-10.15	The CNS role in Cystinosis clinic	Emily cooper
10.15-10.45	Update on the management of adults with cystinosis Adults	Dr Aude Servais
10.45- 11.15	Pregnancy and cystinosis	Dr Hannah Blakey Lauren Rowe
11.15-1130	Coffee	
11.30- 12.00	Update on the diagnosis and management of children with + cystinosis	Dr Amrit Kaur
12- 00-12.30	Eyes in Cystinosis Imaging the eye in cystinosis – looking through crystals	Dr Biswas
12-30 to 13.00	Lunch	
13.00 to 13-30	State of the art management of Fanconi Syndrome	Caroline Booth
13.30- 14.00	Swallowing and Speech challenges in Cystinosis	Katrina Emery
14.00 -14.15	The Rare Renal Disease Registry (RaDaR) Cystinosis update	Lesley fifer
14.15– 14.30	National Designation Update	Dr Lipkin/Game
14.30 – 14.50	Research and Innovations 1	Dr Barbara Mckensie
14.50 -15.10	Research and Innovations 2	Prof Stephen Waldek
15.10– 15.25	Coffee	
15.25-15.40	Cystinosis Foundation UK	TBA
15.40 to 15.55	Orphan Europe	Ken Vicary
15.55-16.10	Closing remarks	David Game