

National Study Day Update on Care of Patients with Cystinosis

Queen Elizabeth Hospital, Birmingham
Tuesday, 1 October, 2013

9.30 to 10.00
Registration and light refreshments

Morning session
Chair **Dr Graham Lipkin**

10.00 to 10.15
Welcome and introduction to the day – Dr Graham Lipkin
Consultant Nephrologist, Queen Elizabeth Hospital, Birmingham

10.15 to 10.45
Overview of Cystinosis – Dr Stephen Waldek

10.45 to 11.15
Renal disease in the paediatric setting – Dr Sally Hulton
Consultant Paediatric Nephrologist, Birmingham Children's Hospital

11.15 to 11.45
Renal disease in the adult setting – Dr Graham Lipkin

11.45 to 12.10
Cystinosis and the Eye – Dr Elizabeth Graham
Consultant Ophthalmologist, St Thomas' Hospital, London

12.10 to 12.30
Patient transition and the Birmingham model – Mr Steven Wise
CNS Renal Metabolic Disease, Queen Elizabeth Hospital, Birmingham

12.30 to 13.30
Lunch and an opportunity to network

Afternoon session
Chair **Dr Stephen Waldek**

13.30 to 13.50
Problems with nutrition and swallowing – Dr Mark Bradbury
Consultant Paediatric Nephrologist, Royal Manchester Children's Hospital

13.50 to 14.20
Neurological and neuromuscular complications and their management – Dr Nick Davies
Consultant Neurologist, Queen Elizabeth Hospital, Birmingham

14.20 to 14.40
What's new in Cystinosis research – Prof Roz Anderson
Professor of Pharmaceutical Chemistry, University of Sunderland

14.40 to 15.00
Refreshment break

15.00 to 15.30
Endocrine and bone problems and their management – Dr Jeremy Kirk
Consultant in Paediatric Endocrinology, Birmingham Children's Hospital

15.30 to 16.00
Patients' perceptions of illness and treatment: applications to Cystinosis
Professor John Weinman – Professor of Psychology, Kings College, London

16.00 to 16.20
The patient's perspective and the role of the Cystinosis Foundation – Ami Froehlich
Secretary, Cystinosis Foundation UK

16.20 to 16.30
Closing remarks Dr Graham Lipkin



RECORDATI GROUP

For further details email

selgott@orphan-europe.com or steven.wise@uhb.nhs.co.uk

or telephone **07880 735 524**

A non-promotional meeting in partnership with Orphan Europe (UK) Limited

Graham Lipkin

University Hospitals 
Birmingham
NHS Foundation Trust



UNIVERSITY OF
BIRMINGHAM

Welcome

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- CME-registered
- Attendance Certificate
- Talk posted on Rare Renal

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