

Draft Programme

National Cystinuria Patient Day

Saturday March 30th 2019

Venue: Robens Suite, 29th Floor Tower Wing, Guy's Hospital, London

- 9.30 **Registration - water, tea, coffee, biscuits**
- 10.00 **Welcome**
Kay Thomas, Urologist, Guy's and St. Thomas' Hospital, London
- 10.05 **Update on RADAR recruitment and news**
Richard Coward, Nephrologist, Bristol Royal Hospital for Children
- 10.15 **History of cystinuria and research ideas**
Matt Lewis, Director of Metabolic Profiling, Imperial College London
- 10.30 **Patient Stories (30mins)**
- 11.00 **Break – water!**
- 11.10 **Why do I need to see a Nephrologist?**
David Goldfarb, Nephrologist, NYU
- 11.30 **What does the surgeon do?**
Matthew Bultitude, Urologist, Guy's and St. Thomas' Hospital
- 11.45 **The problem with urinary cystine measurements**
Shabbir Moochhala, Nephrologist, Royal Free Hospital
- 12.00 **Break – Water!**
- 12.10 **What should I eat and drink? Dietary advice for the cystine patient**
Rachel Davies, Senior dietician, Guy's and St. Thomas' Hospital
- 12.30 **What's new and exciting in research for cystinuria?**
John Sayer, Nephrologist, Newcastle
- 12.45 **Ask the Experts ... questions and answers**
All Faculty
- 13.00 **LUNCH**
- 13.45 **Updates from America**
David Goldfarb, Nephrologist, NYU
- 14.00 **Genetics ... Why do I have it and will my children get it?**
Kay Thomas, Urologist, Guy's and St. Thomas' Hospital, London
- 14.15 **Discussion in breakout groups (all faculty to assist)**
 1 Patient stories/experience/self-help [**Lead: David Game**]
 2 Surgical models – try to be a stone surgeon! [**Lead: M Bultitude**]
 3 Diet – preventing future stones [**Lead: Rachel Davies**]
- 15.45 **Summary and close.**

