

# National Cystinuria Patient Day

Saturday April 22<sup>nd</sup> 2017

**Robens Suite, 29<sup>th</sup> Floor Tower Wing Guy's Hospital, London.**

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|---------------|---------------------------------------------------------------|
| 9.30 - 10.15  | Registration - water, tea, coffee, biscuits                   |
| 10.15-10.30   | Welcome – Kay Thomas                                          |
|               | Update on RADAR recruitment and news - Tiopronin issues       |
| 10.30         | Matthew Lewis – History and research ideas                    |
| 10.50         | David Game - Why do I need to see a Nephrologist?             |
| 11.10         | Matthew Bultitude - What does the surgeon do?                 |
| 11.30         | Break - water !                                               |
| 12.00         | Shabbir Moochhala – Exciting research                         |
| 12.30         | Rachel Mein - Will my children get it?                        |
| <b>13.00</b>  | <b>LUNCH</b>                                                  |
| 14.00         | Patient experts                                               |
|               | 1 Patient story                                               |
|               | 2 Presentation of cystinuria Facebook group                   |
| 14.30 - 16.00 | Discussion in breakout groups                                 |
|               | 1 Patient stories/experience/self help                        |
|               | 2 Surgical models – try to be a stone surgeon!                |
|               | 3 Diet – what should I eat / drink – preventing future stones |
| 16.00-16.30   | Summary of talks, future research / meetings.                 |