



# Better Together

## CNE INTERNATIONAL CONFERENCE 2024

CYSTINOSIS FOUNDATION UK & CYSTINOSIS NETWORK EUROPE

[www.cystinosis-europe.eu](http://www.cystinosis-europe.eu)

We are delighted to present the outline agenda for the CNE International Conference 2024  
Scientific meeting, 25<sup>th</sup> July 202, Manchester, UK.

*The details below are for information only and may be subject to change.*

Register for the conference through our  
[dedicated portal here](#)

Thursday 25<sup>th</sup> July

Time	Speaker	Topic
<b>Session 1</b>		
09:00	David Game	Overview and introduction
09:15	Elena Levtchenko	Hot Topics and Key Research Developments Update
<b>Session 2 Pathophysiology of Cystinosis</b>		
09:30	Roos Masereeuw	Organoids, tubuloids development
09:50	Alessandro Luciani	Pathophysiology of kidney dysfunction/proximal tubule dysfunction
10:10	Rik Gijbers	Muscle research update
10:30	Break	
<b>Session 3 Advances in Diagnosis &amp; Treatment</b>		
10:50	Herbie Newell	Cysteamine Pro- drug Trial
11:10	Jennifer Hollywood	mTor inhibitor/autophagy-therapy
11:30	Francesco Emma/team	Dietary effects
11:50	Paul Goodyer	mRNA updates
12:10	Paul Grimm	Update on Stem cell Therapy
12:30	Anuj Chauhan	Cysteamine contact lens research update
12:50	Discussion/Q&A	

<b>13:00</b>	Lunch	Meet the charities/funding opportunities/networking lunch
<b>Session 4</b>	<b>Clinical: Muscle/Bone and Guideline Development</b>	
<b>14:00</b>	Katharina Hohenfellner	IMPACT update
<b>14:20</b>	Alex Rossor	Neuromusclar disease: Lessons from other metabolic disorders
<b>14:40</b>	tbc	Swallowing dysfunction / dysphagia
<b>15:00</b>	Dieter Haffner	Bone Disease in cystinosis
<b>15:20</b>	Georgios Kaltsakas	Respiratory issues/non invasive ventilation
<b>15:50</b>	Break	30 minutes tea break for poster viewing
<b>16:10</b>	David Game	Organisation of Care. NHS England National Designation Centres
<b>16:30</b>	Katharina Hohenfellner	Update on clincial guideline development
<b>16:50</b>	Discussion & Q&A	
	<b>Closing Session</b>	
<b>17:00</b>	tbc	Research overview commentary
<b>17:30</b>	Close	

Conference organising committee:

**Dr Graham Lipkin, Scientific Chairperson,**  
*Consultant nephrologist, Queen Elizabeth Hospital Birmingham*  
 Prof Elena Levtchenko, *Amsterdam UMC*  
 Dr Koenraad Veys, *KU Leuven*  
 Dr David Game, *Adult Nephrologist, Guy's & St Thomas' Hospital, London* RDG Lead  
 Dr Ruth Davis, *Cystinosis Ireland research committee*

**Mr Will Newman, Organising Committee Chairperson,** *Cystinosis Foundation UK*  
 Ms Alex Hutchinson, *Cystinosis Foundation UK*  
 Mr Neil Sugden, *Cystinosis Foundation UK*  
 Ms Karen McCullagh, *Cystinosis Network Europe*  
 Ms Denise Dunne, *Cystinosis Support Europe*