



Better Together

CNE INTERNATIONAL CONFERENCE 2024

CYSTINOSIS FOUNDATION UK & CYSTINOSIS NETWORK EUROPE

We are delighted to present the outline agenda for the CNE International Conference 2024, hosted by Cystinosis Foundation UK, in Manchester England. The details below are for information only and may be subject to change.

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

Thursday 25th July

18:30 Meeting Together

Families are welcome to join us for a welcome reception and buffet. Make new connections and renew old friendships as we welcome you to the start of our family conference.

Friday 26th July

09:00 Learning Together

This session will give an overview of what cystinosis is and some of the clinical and research history of the condition.

Speakers will include Prof Dr Elena Levtchenko and Dr Stephen Jenkins.

10:30 Refreshment break

11:00 Sharing Together

Parallel break out sessions will allow parents of different age groups to gather and discuss topics of particular interest and importance. Discussions will be facilitated by a parent or adult with cystinosis and a professional (clinician / researcher).

12:00 Lunch (included in registration)

13:00 Better Treatments

This session will provide an update on the research currently being performed internationally in cystinosis. Updates will include CF 10 prodrug; everolimus; contact lens cysteamine therapy delivery; mRNA therapies; and treatment centres in the UK through the NHS system. Following the updates there will be time for discussions and questions for the speakers.

Speakers include: Prof Herbie Newell; Dr Jennifer Hollywood; Prof Anuj Chauhan; Dr Paul Goodyer; Dr David Game.

15:30 Refreshment break

16:00 Poster presentations

Up and coming researchers in the field of cystinosis will be displaying posters explaining their work throughout the conference. Selected speakers will have an opportunity to present and explain their work to our families with families having the opportunity to vote on the best presentation.

17:00 Close / Free evening

This evening there is no formal activity planned and you will have the opportunity to explore Manchester.

19:00 Adults and partners social gathering

This is a private event for our adults with cystinosis and their partners to gather for a social outing.

Saturday 27th July

09:00 Better Treatments continued

This session will be an opportunity to learn more about gene therapy, a new technology which has become noteworthy in our community. Following an introduction from Prof Paul Grimm on what stem cell and gene therapies are, Jordan Janz, the first patient to

take part in the University College San Diego study under Dr Stephanie Cherqui, will discuss his experience of the clinical trial and what it has meant for him.

10:30 Refreshment break

11:00 Groups Together

Parallel break out sessions will allow people with particular interest in specific aspects of life with cystinosis to gather and discuss their thoughts and experiences in a facilitated group.

12:00 Lunch (included in registration)

13:00 Better Health

This session will discuss living with cystinosis and the wider health implications including exercise, eye care and fertility, with an update from the IMPACT exercise study from Dr Katharina Hohenfellner.

14:45 Refreshment break

15:15 Living Better

This patient panel will be an exciting and informative session for all. A panel of adults with cystinosis will introduce themselves and share how living with cystinosis is part, but not all, of their lives.

As families join the conference and community we are aware that events like meeting here in Manchester will present a lot of information about the disease itself, treatments and research. The “Living Better” panel aims to give a reflection of what real life is like for an adult with cystinosis – how it is a part but not all of who they are and that it is possible to build normal and great lives while having to take therapies, live with the effects of cystinosis and get on with day to day living.

16:30 Closing remarks and announcement of prize winner

19:00 Have a Hoolie! (included in registration)

All our attendees are welcome to join us for our closing dinner and party. Let your hair down and celebrate our wonderful community.

Childcare is available on Friday and Saturday for children aged up to 12 years with activities planned for teens and adolescents too.

Translation is available from English to Dutch, French, German, Italian, Spanish, Turkish, and Russian.