

CTX Session Agenda Presented by the CTX Alliance

This session will be available through Virtual Access streaming and will be recorded.

Registration for Virtual Access is required.

Recordings will be posted to YouTube in early July.



Friday, June 24

Time	Presentation	Speaker(s)
9:00 AM – 9:05 AM	Introductions and Welcome	Jean Pickford, Dr. Andrea DeBarber
9:05 AM – 9:30 AM	Overview of CTX – Biochemical Basis, Diagnosis, Clinical Symptoms and Treatment	Dr. P. Barton Duell
9:30 AM – 9:55 AM	Literature Review – Functional and Symptomatic Management in CTX	Dr. Brian Wishart
9:55 AM – 10:20 AM	Evidence to Support Similar Progression of CTX within Families	Dr. Penelope Bonnen
10:20 AM – 10:45 AM	Chenodeoxycholic Acid Therapy in Cerebrotendinous Xanthomatosis Patients during Pregnancy	Dr. Tzipora Falik-Zaccai
10:45 AM – 11:10 AM	Systematic Evidence Review – Lessions for Implementation of Newborn Screening for CTX Diagnosis and Management of Newborns with CTX	Dr. Austin Larson
11:10 AM – 11:35 AM	Results of Pilot Study Screening 20,000 Newborns for CTX and Progress Toward Adding CTX to Dutch NBS Panel	Dr. Frederic Vaz
11:35 AM – 12:00 PM	Update on Prospective Pilot Study Screening New York State Newborns for CTX	Dr. Joseph Orsini
12:00 PM – 1:30 PM	Closed lunch for CTX Family session attendees, in-person only	