

CTX

Cerebrotendinous Xanthomatosis

INTERNATIONAL WORKSHOP SERIES

Monday, September 1, 2025 | Kyoto, Japan



Introducing Our Featured Speakers



Akira Honda, MD, PhD
Professor of Medicine
Joint Research Center/Dept.
Gastroenterology
Tokyo Medical University Ibaraki Medical
Center, Japan



Yoshiki Sekijima, MD, PhD
Professor and Chairman
Department of Medicine (Neurology &
Rheumatology)
Shinshu University School of Medicine,
Japan

Thank You

Workshop Organizing Committee



Abbey R. Cook, BA
Patient Advocate
CTX Alliance



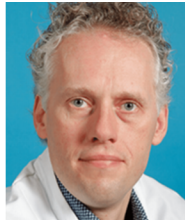
Andrea DeBarber, PhD
Oregon Health and
Science University, USA



Prof. Tzipora C. Falik-Zaccai
Galilee Medical Center,
Bar-Ilan University, Israel



Dr. Antonio Federico
University of Siena
Italy



Hidde Huidekoper, MD, PhD
Erasmus MC University
Medical Center, Netherlands



Robert D. Steiner, MD
University of Wisconsin,
Prevention Genetics, USA

Welcome to Kyoto and the 2025 CTX International Workshop Series! On behalf of the CTX Alliance and the organizing committee, it is our pleasure and privilege to host this collaborative meeting exclusively dedicated to cerebrotendinous xanthomatosis (CTX).



Monday, September 1, 2025

Workshops for Speakers, Organizers, and Advocates for Improved International Collaboration | The Prince Kyoto Takaragaikie

Welcome - Royal Room

8:15 – 8:30 am	Introductions, review of agenda, and key priorities
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Workshop #1 - Royal Room

CTX Clinical Severity Scoring Index

Session Leaders: Drs. Andrea DeBarber & Robert Steiner

8:30 - 10:00 am	Explore potential for CTX clinical severity score/improved standardization of symptoms to better understand phenotype-genotype correlations
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10:00 - 10:15 am	Break
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Workshop #2 - Royal Room

International CTX Patient Registry

Session Leaders: Dr. Hidde Huidekoper, Abbey Cook, and Jean Pickford

10:15 - 11:00 am	Background, Goals, Structure & Governance
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11:00 - 12:30 pm	Clinical & Patient Dataset Discussion
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Group Lunch - Rose Room

12:30 – 1:30 pm	Group Lunch
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Featured Speakers - Royal Room

1:30 -2:00 pm	Akira Honda, MD, PhD Japanese contributions to the biochemical understanding of CTX
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2:00 - 2:30 pm	Yoshiki Sekijama, MD, PhD Clinical experience of CTX in Japanese patient cohort
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Workshop #3 - Royal Room

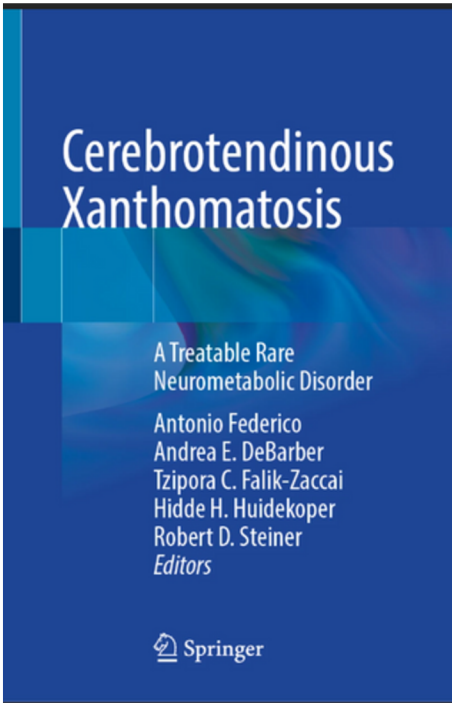
CTX Heterozygotes Research & Findings

Session Leaders: Drs. Antonio Federico & Tzipora Falik-Zaccai

2:30 - 3:45 pm	Explore emerging evidence of minor clinical findings in CTX heterozygotes and discuss potential investigative avenues
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3:45 - 4:00 pm	Wrap-up & Group Photo
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THANK YOU TO OUR MEETING SPONSOR



new! CTX BOOK

Features:

Updates on basic research and the clinical, biochemical and molecular genetic findings.

Chapters written by the main most of the experts in the field.

Focused on studies to improve our understanding of clinical, biochemical and genetic aspects.

The book has not yet been released. You may pre-order it now and it can be shipped when it is published near end of November.

Discounts available to meeting attendees. Contact the CTX Alliance for more information at ctxalliance@gmail.com.

The CTX Alliance provides education, support, advocacy, and promotes research for CTX patients, their families, and medical professionals who treat and study this rare disease.