



Congenital Hyperinsulinism Family

Meeting Day

Brisbane Marriott Hotel
515 Queen Street, Brisbane QLD 4000
Brisbane, Australia

August 4 -6, 2023

Organized by:
Congenital Hyperinsulinism International and Queensland Children's Hospital

Sponsored by Rezolute

August 4, 2023

18.00 – 20.00

Dinner Meet and Greet

August 5, 2023

8.30

Conference Registration

9.00 – 9.15

Welcome and Overview of the Day

Louise Conwell, Paediatric Endocrinologist, Queensland Children's Hospital; Associate Professor, Faculty of Medicine, University of Queensland
Julie Raskin, CEO, Congenital Hyperinsulinism International

9.15 - 9.45

Living with Hyperinsulinism – Participant Introductions and Sharing

10.00 – 10.45

Congenital Hyperinsulinism Care in Queensland

- Congenital Hyperinsulinism Explained (Diagnosis, Genetics, Subtypes, Current Treatment Options)
Louise Conwell (15 minutes)
- Newborn Hypoglycaemia Screening
Helen Liley, Neonatal Paediatrician, Mater Mothers Hospital, Brisbane; Professor, Faculty of Medicine, University of Queensland (10 minutes)
- CHipping the Pancreas Out
Craig McBride. Paediatric Surgeon, Queensland Children's Hospital; Senior Lecturer, University of Queensland; Associate Professor, Griffith University, Queensland(15minutes)

10.45 – 11.05

Networking Break

11:05– 11:55

Ongoing Management of Congenital Hyperinsulinism and its Consequences

- Hypoglycaemia Despite Treatment, Activities of Daily Living (Exercise, Play, School), Sick Days, Technology – Continuous Glucose Monitoring, Growth and Development, Diabetes, Exocrine pancreatic insufficiency, Transition to Adult care, Psychosocial Burden
Louise Conwell

Karen Bragg, Clinical Nurse Consultant, Credentialed Diabetes Educator, Queensland Children's Hospital

Shawn Tadjell, Clinical Nurse (Endocrinology), Queensland Children's Hospital

- Future treatments for congenital hyperinsulinism
Louise Conwell

11.55 – 12.30

Diet and Feeding

- Should diet play a role in managing congenital hyperinsulinism by HI type? If so, how?
- What are strategies to help with feeding issues?

Michelle Fuery, Paediatric and Endocrine Dietitian, Queensland Children's Hospital

Louise Conwell

12.30 – 13.15

Ask the Experts and Advocates

Moderator Julie Raskin

Possible Question Topics:

Challenges to Managing HI in infants and Toddlers

HI and Growth and Development

When Hypoglycaemia is Still an Issue

More on Genetics

Dealing with Highs and Lows

Transition from Pediatric to Adult Care

Issues with Access to Care

Rare Disease Advocacy

Devices

Sick Days

HI Global Registry

13.15 – 14.15

Lunch

14.15 – 15.15

CHI Patient Advocacy

- CHI HI Global Registry and Collaborative Research Network

Julie Raskin

- CHI Support and Awareness Program

Jennifer Schmitt, Chief Operating Officer, CHI

- Discussion of Advocacy Needs in Australia

Facilitators: Erin Greaves and Margaret Maher

15.10 – 15.45

Networking Break and Group Photo

15.45 – 17.00

Clinical Research

- The Role of Patient Advocacy in Research

Julie Raskin

- Queensland Children's Research

Craig Munns, Paediatric Endocrinologist, Queensland Children's Hospital; Professor of Paediatrics, Faculty of Medicine and Director, Child Health Research Centre, University of Queensland.

- RZ358 and the SunRize Study

Davelyn Hood, MD, MBA

Loredie Lugos

- "Let's Talk about Clinical Research Discussion" with Panelists

Moderated by Julie Raskin. Panelists including Louise Conwell, Davelyn Hood, Loredie Lugos, and Craig Munns

18.00 – 21.00

Dinner and Evening Conversations

August 6

10.00

Visit to South Bank Parklands, Brisbane

(We will leave the Marriott together and board the City Cat Ride Ferry to get there. Participants may return from the Parklands on their own, at their leisure)