
Event Agenda

World Rett Syndrome Congress

Tue, Oct 01, 2024

4:30 PM - 6:00 PM

Private Event - Rett World Leaders' Forum

Location: By invitation only
Chair: Bill Callaghan, Claude Buda

Wed, Oct 02, 2024

7:30 AM - 8:45 AM

Attendee Registration

Location: Main Foyer and Registration Desk, Ground Floor, QT Hotel

8:00 AM - 5:00 PM

Accessible Changing Rooms

Location: Cloud Break Room, Level 2, QT Hotel

8:00 AM - 5:00 PM

Caregiver Retreat Center

Location: North Break Room, Level 2, QT Hotel

8:00 AM - 5:00 PM

Hangout Room

Location: Malibu Room, Level 2, QT Hotel

8:45 AM - 9:00 AM

Welcome for all Attendees

Location: Ballroom, Ground Floor, QT Hotel
Chair: Claude Buda ; Speaker: Margaret Brimble

9:00 AM - 9:30 AM

History of Rett syndrome

Location: Ballroom, Ground Floor, QT Hotel
Speaker: Alan Percy ; Chair: Margaret Brimble, Claude Buda

9:30 AM - 10:00 AM

Diagnostic challenges in Rett and Rett-related disorders

Location: Ballroom, Ground Floor, QT Hotel
Speaker: Tim Benke ; Chair: Margaret Brimble, Claude Buda

10:00 AM - 10:30 AM

Novel Insights into the Biology of MeCP2 and Rett Syndrome

Location: Ballroom, Ground Floor, QT Hotel
Speaker: Joe Zhou ; Chair: Margaret Brimble, Claude Buda

10:00 AM - 4:00 PM

Fully Accessible Changing and Showering Facility

Location: Bungalow Cabin, Level 2, QT Hotel

10:30 AM - 11:00 AM

MORNING TEA

Location: Break Area, Ground Floor, QT Hotel

11:00 AM - 11:30 AM

Transcriptional buffering and reverberating superbursts in Rett syndrome neurons

Location: Maui Room, Ground Floor, QT Hotel
Speaker: James Ellis ; Chair: Wendy Gold, Joe Zhou

11:00 AM - 11:45 AM

A word with Rett Syndrome Associations around the world

Location: Ballroom, Ground Floor, QT Hotel
Speaker: Bill Callaghan

11:30 AM - 12:00 PM

MECP2, Astrocytes, and Rett Syndrome

Location: Maui Room, Ground Floor, QT Hotel
Speaker: Qiang Chang ; Chair: Wendy Gold, Joe Zhou

- 11:45 AM - 12:25 PM** **An introduction to resources**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Bill Callaghan
- 12:00 PM - 12:20 PM** **Sex-specific single cell-level transcriptomic signatures of Rett syndrome disease progression**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Osman Sharifi ; Chair: Joe Zhou, Wendy Gold
- 12:10 PM - 12:25 PM** **Discussion: World Rett Syndrome and Related Groups**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Bill Callaghan ; Chair: Claude Buda
- 12:20 PM - 12:40 PM** **Rett syndrome cases caused by elusive structural variants within MeCP2**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Tomer Poleg ; Chair: Wendy Gold, Joe Zhou
- 12:25 PM - 12:45 PM** **Champion your child (or getting what you need in complex systems)**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Fiona Russo ; Chair: Dugald McBrayne
- 12:40 PM - 1:00 PM** **Molecular mechanisms and efficacy of KIT-13, a synthetic plasmalogen derivative, in mouse and cell-based models of Rett Syndrome**
Location: Maui Room, Ground Floor, QT Hotel
Speakers: Ounhee Ohgami, Masanori Honsho ; Chair: Joe Zhou, Wendy Gold
- 12:45 PM - 1:00 PM** **Discussion: Parent Support**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Fiona Russo ; Chair: Dugald McBrayne
- 1:00 PM - 2:00 PM** **LUNCH**
Location: Ground Floor, QT Hotel
- Lunch in Bazaar Restaurant (Level 1)**
 1:00 PM - 2:00 PM
 Location: Bazaar Restaurant, Level 1, QT Hotel
- Lunch in Stingray Restaurant (Ground Floor)**
 1:00 PM - 2:00 PM
 Location: Stingray Restaurant, Ground Floor, QT Hotel
- 2:00 PM - 2:30 PM** **Modeling neural network changes associated with Rett syndrome using induced pluripotent stem cell-derived brain organoids and assembloids**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Bennett Novitch ; Chair: Wendy Gold, Jeff Neul
- 2:00 PM - 2:40 PM** **Pain in Rett Syndrome – What We Know, Don’t Know, and Need to Know**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Frank Symons ; Chair: Paige Nues
- 2:30 PM - 2:50 PM** **In vivo Xenotransplantation model for MECP2 neurodevelopmental disorders**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Hilde Van Esch ; Chair: Wendy Gold, Jeff Neul
- 2:40 PM - 3:00 PM** **PainChek - Giving a voice to those who cannot tell you they’re in pain**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Jeff Hughes ; Chair: Paige Nues
- 2:50 PM - 3:10 PM** **Identification of novel molecules by which Mecp2 knock-out astrocytes exert a synaptotoxic action on neurons**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Angelisa Frasca ; Chair: Wendy Gold, Jeff Neul
- 3:00 PM - 3:30 PM** **Discussion: Pain and Rett Syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speakers: Frank Symons, Jeff Hughes ; Chair: Paige Nues

3:10 PM - 3:30 PM	NEAT1-mediated regulation of the mTOR pathway and mRNA localization impacts autophagy dysregulation in Rett syndrome Location: Maui Room, Ground Floor, QT Hotel Speaker: Edilene Soares ; Chair: Wendy Gold, Jeff Neul
3:30 PM - 4:00 PM	AFTERNOON TEA Location: Break Area, Ground Floor, QT Hotel
4:00 PM - 4:30 PM	Genotype-phenotype relationships in Rett syndrome Location: Maui Room, Ground Floor, QT Hotel Speaker: Helen Leonard ; Chair: Nicoletta Landsberger, Carolyn Ellaway
4:00 PM - 4:20 PM	Sleep issues in Rett Syndrome and their impact Location: Ballroom, Ground Floor, QT Hotel Speaker: Honey Huessler ; Chair: Becky Jenner
4:20 PM - 4:40 PM	Emotional, behavioural and automatic dysregulation in Rett Syndrome Location: Ballroom, Ground Floor, QT Hotel Speaker: Paramala Santosh ; Chair: Becky Jenner
4:30 PM - 6:00 PM	Poster Blitz Location: Exhibition Area, Level 1, QT Hotel
4:30 PM - 5:00 PM	Comorbidities Location: Maui Room, Ground Floor, QT Hotel Speaker: Aglaia Vignoli ; Chair: Nicoletta Landsberger, Carolyn Ellaway
4:40 PM - 5:00 PM	Anxiety-like behaviour in Rett Syndrome Location: Ballroom, Ground Floor, QT Hotel Speaker: Alan Percy ; Chair: Becky Jenner
5:00 PM - 5:20 PM	Discussion: Behaviours in Rett Syndrome Location: Ballroom, Ground Floor, QT Hotel Chair: Becky Jenner ; Speakers: Honey Huessler, Paramala Santosh, Alan Percy
6:00 PM - 10:00 PM	Cocktail Reception Location: Sunset Room, Level 1, QT Hotel

Thu, Oct 03, 2024

8:00 AM - 9:00 AM	Late/Day Registrations Location: Main Foyer and Registration Desk, Ground Floor, QT Hotel
8:00 AM - 5:00 PM	Accessible Changing Rooms Location: Cloud Break Room, Level 2, QT Hotel
8:00 AM - 5:00 PM	Caregiver Retreat Center Location: North Break Room, Level 2, QT Hotel
8:00 AM - 5:00 PM	Accessible Hangout Room Location: Malibu Room, Level 2, QT Hotel
8:40 AM - 9:20 AM	Healing the microbiome of children with neurodevelopmental disorders including Rett syndrome using genomic technologies Location: Ballroom, Ground Floor, QT Hotel Speaker: Dr Heather Way ; Chair: Dionne Snyders
9:00 AM - 9:30 AM	Rett syndrome, MECP2 and therapeutic strategies Location: Maui Room, Ground Floor, QT Hotel Speaker: Rudolf Jaenisch ; Chair: Alan Percy, Helen Leonard

- 9:20 AM - 9:30 AM** **Discussion: Nutrigenomics**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Dionne Snyders ; Speaker: Dr Heather Way
- 9:30 AM - 10:00 AM** **Rett syndrome: Novel insights from preclinical studies**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Nicoletta Landsberger ; Chair: Alan Percy, Helen Leonard
- 9:30 AM - 9:50 AM** **Optimizing nutrition - Achieving potential**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Sue Thompson ; Chair: Sabrina Millson
- 9:50 AM - 10:10 AM** **Gut bacteria - Composition, activity and impact**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Kathleen Motil ; Chair: Sabrina Millson
- 10:00 AM - 10:30 AM** **Identifying and evaluating novel therapies in animal models of Rett syndrome**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Jeff Neul ; Chair: Alan Percy, Helen Leonard
- 10:00 AM - 4:00 PM** **Fully Accessible Changing and Showering Facility**
Location: Bungalow Cabin, Level 2, QT Hotel
- 10:10 AM - 10:30 AM** **Gastrointestinal (GI) Tract: From Top to Bottom**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Aglaia Vignoli ; Chair: Sabrina Millson
- 10:30 AM - 11:00 AM** **MORNING TEA**
Location: Break Area, Ground Floor, QT Hotel
- 11:00 AM - 11:30 AM** **CDKL5 Deficiency Disorder: Overview and updates**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Tim Benke ; Chair: Michela Fagiolini, Jenny Downs
- 11:00 AM - 11:20 AM** **Oral health in Rett syndrome: Risk factors, mouthcare and management**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Yvonne Lai ; Chair: Sabrina Millson
- 11:20 AM - 11:30 AM** **Discussion: Issues concerning the digestive system in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Sabrina Millson ; Speakers: Sue Thompson, Aglaia Vignoli, Kathleen Motil, Yvonne Lai
- 11:30 AM - 11:50 PM** **Investigating the role of extracellular vesicles as molecular biomarkers for CDKL5 deficiency disorder**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Antonia Gurgone ; Chair: Michela Fagiolini, Jenny Downs
- 11:30 AM - 11:50 AM** **North American Puberty Trends and Menstrual Management Strategies for Rett Syndrome Females**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Jane Lane Percy ; Chair: Pamela Roman
- 11:50 AM - 12:00 PM** **Discussion: Puberty and menstrual management in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Pamela Roman ; Speaker: Jane Lane Percy
- 11:50 AM - 12:10 PM** **FOXG1**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Eric Marsh ; Chair: Michela Fagiolini, Jenny Downs
- 12:00 PM - 12:20 PM** **Transitioning from paediatric to adult health care; Medical issues in adult Rett syndrome and related disorders**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Aglaia Vignoli ; Chair: Rajni Khajuria

- 12:10 PM - 12:40 PM** **MECP2 Duplication syndrome: early findings from the international MECP2 Duplication Database (MDBase)**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Helen Leonard ; Chair: Michela Fagiolini, Jenny Downs
- 12:20 PM - 12:40 PM** **The usefulness of the doing activities at their best**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Åsa-Sara Sernheim ; Chair: Rajni Khajuria
- 12:40 PM - 1:00 PM** **Communication, connection and community**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Elizabeth Lea ; Chair: Rajni Khajuria
- 12:40 PM - 1:00 PM** **Rett syndrome in males**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Alan Percy ; Chair: Michela Fagiolini, Jenny Downs
- 1:00 PM - 2:00 PM** **LUNCH**
Location: Ground Floor, QT Hotel
- Lunch in Bazaar Restaurant (Level 1)**
1:00 PM - 2:00 PM
Location: Bazaar Restaurant, Level 1, QT Hotel
- Lunch in Stingray Restaurant (Ground Floor)**
1:00 PM - 2:00 PM
Location: Stingray Restaurant, Ground Floor, QT Hotel
- 2:00 PM - 2:25 PM** **Microtubule dynamics dysfunction in X-linked neurodevelopmental disorders**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Shani Waninger ; Chair: Wendy Gold, Bennett Novitch
- 2:00 PM - 2:10 PM** **Discussion: Women with Rett Syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Rajni Khajuria ; Speakers: Aglaia Vignoli, Åsa-Sara Sernheim
- 2:10 PM - 2:30 PM** **Technology-assisted motor rehabilitation for people with Rett syndrome (TeMoRett)**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Paul Chojecki ; Chair: Claudia Petzold
- 2:25 PM - 2:50 PM** **Electrophysiological biomarkers**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Michela Fagiolini ; Chair: Wendy Gold, Bennett Novitch
- 2:30 PM - 2:50 PM** **Fear of movement in Rett syndrome - Its origins, evaluation, and treatment**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Meir Lotan ; Chair: Claudia Petzold
- 2:50 PM - 3:15 PM** **Using EEG to follow and predict outcomes in Rett syndrome**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Eric Marsh ; Chair: Wendy Gold, Bennett Novitch
- 2:50 PM - 3:00 PM** **Discussion: Perspectives on functional ability in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Claudia Petzold ; Speakers: Paul Chojecki, Meir Lotan
- 3:00 PM - 3:20 PM** **Wearable-based assessment of heart rate variability and its implications in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Paramala Santosh ; Chair: Tanja Rovagnati
- 3:15 PM - 3:35 PM** **Characterizing MeCP2 dose-sensitive biomarkers**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Christine Coquery ; Chair: Wendy Gold, Bennett Novitch
- 3:20 PM - 3:30 PM** **Discussion: Wearable-based assessment of heart rate variability and its implications in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Tanja Rovagnati ; Speaker: Paramala Santosh

- 3:30 PM - 4:00 PM** **AFTERNOON TEA**
Location: Break Area, Ground Floor, QT Hotel
- 4:00 PM - 4:30 PM** **An update on Trofinetide in Rett syndrome**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Alan Percy ; Chair: Carolyn Ellaway
- 4:00 PM - 4:20 PM** **Hip surveillance and care for Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Jenny Downs ; Chair: Jessica Cubillos Arellano
- 4:20 PM - 4:40 PM** **Rett syndrome: Curvature of the spine and bone issues**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Marielle van den Berg ; Chair: Jessica Cubillos Arellano
- 4:30 PM - 5:00 PM** **PTP1B inhibition - A mechanism-based approach to the treatment of Rett syndrome**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Nicholas Tonks ; Chair: Carolyn Ellaway
- 4:40 PM - 4:50 PM** **Discussion: Issues concerning the musculoskeletal system in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Jessica Cubillos Arellano ; Speaker: Marielle van den Berg
- 4:50 PM - 5:10 PM** **Perspectives of parents and physical therapists on physical therapy in Rett Syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Hanneke Borst ; Chair: Winnie Nordberg
- 5:00 PM - 6:00 PM** **Extended Poster Viewing**
Location: Exhibition Area, Level 1, QT Hotel
- 5:10 PM - 5:30 PM** **The Rett syndrome world of music: From a retrospective perspective**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Märith Bergström-Isacsson ; Chair: Winnie Nordberg
- 5:30 PM - 5:40 PM** **Discussion: Selected therapies**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Winnie Nordberg ; Speakers: Hanneke Borst, Märith Bergström-Isacsson
- 7:30 PM - 8:30 PM** **Introductions - "Everything I've never said" and "Danielle's Dad"**
Location: Ballroom, Ground Floor, QT Hotel
Speakers: Samantha Wheeler, Ben Boulton

Fri, Oct 04, 2024

- 8:00 AM - 8:30 AM** **Late/Day Registrations**
Location: Main Foyer and Registration Desk, Ground Floor, QT Hotel
- 8:00 AM - 5:00 PM** **Accessible Changing Rooms**
Location: Cloud Break Room, Level 2, QT Hotel
- 8:00 AM - 5:00 PM** **Caregiver Retreat Center**
Location: North Break Room, Level 2, QT Hotel
- 8:00 AM - 5:00 PM** **Accessible Hangout Room**
Location: Malibu Room, Level 2, QT Hotel
- 8:30 AM - 8:50 AM** **Clinical development of trofinetide in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Jeff Neul ; Chair: Eric Marsh, Wendy Gold
- 8:50 AM - 9:10 AM** **A novel full-spectrum medicinal cannabis-derived clinical trial in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Carolyn Ellaway ; Chair: Eric Marsh, Wendy Gold

- 9:10 AM - 9:30 AM** **TSHA-102 - An investigational gene therapy for Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Suku Nagendran ; Chair: Eric Marsh, Wendy Gold
- 9:30 AM - 9:50 AM** **The Development of NGN-401, a self-regulating gene therapy for Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Stuart Cobb ; Chair: Eric Marsh, Wendy Gold
- 9:50 AM - 10:10 AM** **miRARE: An approach, a philosophy, and an expanding adventure**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Sarah Sinnett ; Chair: Eric Marsh, Wendy Gold
- 10:00 AM - 4:00 PM** **Fully Accessible Changing and Showering Facility**
Location: Bungalow Cabin, Level 2, QT Hotel
- 10:10 AM - 10:30 AM** **Discussion: Emerging therapies**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Eric Marsh, Wendy Gold ; Speakers: Sarah Sinnett, Jeff Neul, Carolyn Ellaway, Suku Nagendran, Stuart Cobb
- 10:30 AM - 11:00 AM** **MORNING TEA**
Location: Break Area, Ground Floor, QT Hotel
- 11:00 AM - 11:25 AM** **Gene editing and Rett syndrome**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Wendy Gold ; Chair: Eric Gowans, James Ellis
- 11:00 AM - 11:20 AM** **Rett syndrome: Sensory processing and regulation**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Gillian Townend ; Chair: Hanneke Borst
- 11:20 AM - 11:30 AM** **Discussion: Issues concerning the senses in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Chair: Hanneke Borst ; Speaker: Gillian Townend
- 11:25 AM - 11:50 AM** **ADAR-Mediated transcript modification for a common nonsense mutation in Rett syndrome**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Ronald Emeson ; Chair: Eric Gowans, James Ellis
- 11:30 AM - 11:50 AM** **Assessing communication**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Gillian Townend ; Chair: Paula Bozani Prunes
- 11:50 AM - 12:15 PM** **The use of antisense oligonucleotides as a potential therapeutic for MeCP2 disorders**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Ashley Anderson ; Chair: Eric Gowans, James Ellis
- 11:50 AM - 12:10 PM** **Autonomous communication**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Gayle Porter ; Chair: Paula Bozani Prunes
- 12:10 PM - 12:30 PM** **Self-determination in teenagers and (young) adults with Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Gerna Scholte ; Chair: Paula Bozani Prunes
- 12:15 PM - 12:40 PM** **A new view on Rett syndrome and its treatments through single-cell whole-brain imaging in model mice**
Location: Maui Room, Ground Floor, QT Hotel
Speaker: Lieselot Carrette ; Chair: Eric Gowans, James Ellis
- 12:30 PM - 1:00 PM** **The use of eye gaze technology in Rett syndrome**
Location: Ballroom, Ground Floor, QT Hotel
Speaker: Elizabeth Lea ; Chair: Paula Bozani Prunes

- 12:40 PM - 1:00 PM** **First cohort data from the REVEAL adolescent/adult and pediatric studies of TSHA-102 gene therapy for Rett syndrome**
 Location: Maui Room, Ground Floor, QT Hotel
 Speaker: Suku Nagendran ; Chair: Eric Gowans, James Ellis
- 1:00 PM - 2:00 PM** **LUNCH**
 Location: Ground Floor, QT Hotel
- Lunch in Bazaar Restaurant (Level 1)**
 1:00 PM - 2:00 PM
 Location: Bazaar Restaurant, Level 1, QT Hotel
Lunch in Stingray Restaurant (Ground Floor)
 1:00 PM - 2:00 PM
 Location: Stingray Restaurant, Ground Floor, QT Hotel
- 2:00 PM - 2:30 PM** **Bioengineering adeno-associated viruses (AAVs) for effective gene therapy: advances and applications in Rett syndrome**
 Location: Maui Room, Ground Floor, QT Hotel
 Speaker: Andrea Perez Iturralde ; Chair: Rudolf Jaenisch, John Christodoulou
- 2:00 PM - 2:20 PM** **Discussion: Communication and Rett syndrome**
 Location: Ballroom, Ground Floor, QT Hotel
 Chair: Paula Bozani Prunes ; Speakers: Gillian Townend, Gayle Porter, Gerna Scholte
- 2:20 PM - 2:40 PM** **Breathing and swallowing dysfunction in Rett syndrome**
 Location: Ballroom, Ground Floor, QT Hotel
 Speaker: Jan "Nino" Ramirez ; Chair: Paula Gödke
- 2:30 PM - 3:00 PM** **Nanoparticle platforms for therapeutic applications**
 Location: Maui Room, Ground Floor, QT Hotel
 Speaker: Frank Caruso ; Chair: Rudolf Jaenisch, John Christodoulou
- 2:40 PM - 3:00 PM** **In what way does a mouse model of Rett syndrome provide knowledge about lung efficiency/health in the disorder?**
 Location: Ballroom, Ground Floor, QT Hotel
 Speaker: Monica Justice ; Chair: Paula Gödke
- 3:00 PM - 3:30 PM** **AFTERNOON TEA**
 Location: Break Area, Ground Floor, QT Hotel
- 3:00 PM - 3:20 PM** **Pneumonia**
 Location: Ballroom, Ground Floor, QT Hotel
 Speaker: Michelle Caldecott ; Chair: Paula Gödke
- 3:20 PM - 3:30 PM** **Lung health and the use of a PEP device**
 Location: Ballroom, Ground Floor, QT Hotel
 Speaker: Marielle van den Berg ; Chair: Paula Gödke
- 3:30 PM - 4:00 PM** **The Rett syndrome multidisciplinary clinic: Over 20 years of experience in Sydney, Australia**
 Location: Maui Room, Ground Floor, QT Hotel
 Speaker: Carolyn Ellaway ; Chair: Jeff Neul, Jenny Downs
- 3:30 PM - 3:45 PM** **Discussion: Issues concerning the respiratory system in Rett syndrome**
 Location: Ballroom, Ground Floor, QT Hotel
 Chair: Paula Gödke ; Speakers: Jan "Nino" Ramirez, Monica Justice, Michelle Caldecott, Marielle van den Berg
- 3:45 PM - 3:45 PM** **FYI - Early Finish Today!**
 Location: Ballroom, Ground Floor, QT Hotel
- 4:30 PM - 6:00 PM** **Sea World Gala Dinner Bus Services**
 Location: Bus Pickup Area, Ground Floor, QT Hotel

5:00 PM - 10:00 PM

SEA WORLD GALA DINNER

Location: Sea World Resort - Waiting Area

Buses Arrival Zone at Sea World

5:00 PM - 6:00 PM

Location: Sea World Resort - Carpark

Waiting Area - with Childrens' Characters

5:05 PM - 6:00 PM

Location: Sea World Resort - Waiting Area

Dolphin Show

6:00 PM - 6:20 PM

Location: Sea World - Dolphin Beach Stadium

Welcome to Country

6:20 PM - 6:35 PM

Location: Sea World - Dolphin Beach Stadium

Respite / Quiet area

6:30 PM - 10:00 PM

Location: Sea World - Shark Bay

Dinner Gala

7:00 PM - 10:00 PM

Location: Sea World - Main Dinner Area

Sat, Oct 05, 2024

8:00 AM - 8:45 AM

Late/Day Registrations

Location: Main Foyer and Registration Desk, Ground Floor, QT Hotel

8:00 AM - 12:00 PM

Accessible Changing Rooms

Location: Cloud Break Room, Level 2, QT Hotel

8:00 AM - 12:00 PM

Caregiver Retreat Center

Location: North Break Room, Level 2, QT Hotel

8:00 AM - 12:00 PM

Accessible Hangout Room

Location: Malibu Room, Level 2, QT Hotel

9:00 AM - 9:30 AM

Seizures and seizure-like episodes in Rett syndrome

Location: Ballroom, Ground Floor, QT Hotel

Speaker: Alexandra Johnson ; Chair: Pedro Rocha

9:30 AM - 9:45 AM

Discussion: Seizures and seizure-like episodes in Rett syndrome

Location: Ballroom, Ground Floor, QT Hotel

Chair: Pedro Rocha ; Speaker: Alexandra Johnson

9:45 AM - 9:50 AM

I have Rett syndrome

Location: Ballroom, Ground Floor, QT Hotel

Speaker: Jacinta Rome

9:50 AM - 10:20 AM

Sibling panel

Location: Ballroom, Ground Floor, QT Hotel

Chair: Stuart Rome, Bill Callaghan ; Speakers: Kye Kanemura, Julius Kortekaas, Emily Osborne, Te Buda, Alice Davies

10:00 AM - 2:00 PM

Fully Accessible Changing and Showering Facility

Location: Bungalow Cabin, Level 2, QT Hotel

10:20 AM - 10:30 AM

Discussion: Sibling Panel

Location: Ballroom, Ground Floor, QT Hotel

Chair: Stuart Rome, Bill Callaghan ; Speakers: Jacinta Rome, Kye Kanemura, Julius Kortekaas, Emily Osborne, Te Buda, Alice Davies

10:30 AM - 11:00 AM

MORNING TEA

Location: Break Area, Ground Floor, QT Hotel

11:00 AM - 11:20 AM

What parents/carers want others to know about living with Rett syndrome

Location: Ballroom, Ground Floor, QT Hotel

Speakers: Paige Nues, Liz Davies, Trish Donnelly ; Chair: Stuart Rome

11:20 AM - 11:40 AM

Rare disease registries: Why do we need them?

Location: Ballroom, Ground Floor, QT Hotel
Speaker: John Christodoulou ; Chair: Alan Percy

11:40 AM - 12:00 PM

Clinical trials in Australia

Location: Ballroom, Ground Floor, QT Hotel
Speaker: Robyn Langham ; Chair: Carolyn Ellaway

12:00 PM - 12:10 PM

The future of Rett syndrome from the clinical perspective

Location: Ballroom, Ground Floor, QT Hotel
Speaker: Jeff Neul ; Chair: Tim Benke, John Christodoulou

12:10 PM - 12:20 PM

The future of Rett syndrome from the preclinical and basic research perspective

Location: Ballroom, Ground Floor, QT Hotel
Speaker: Joe Zhou ; Chair: Tim Benke, John Christodoulou

12:20 PM - 12:40 PM

Therapies wrap up

Location: Ballroom, Ground Floor, QT Hotel
Speakers: Joe Zhou, Jeff Neul ; Chair: Tim Benke, John Christodoulou

12:40 PM - 1:00 PM

Congress Closing Ceremony

Location: Ballroom, Ground Floor, QT Hotel

1:00 PM - 2:00 PM

LUNCH

Location: Ground Floor, QT Hotel

2:00 PM - 3:30 PM

Informal Networking

Location: Ballroom, Ground Floor, QT Hotel

3:30 PM - 4:00 PM

AFTERNOON TEA

Location: Break Area, Ground Floor, QT Hotel