

PLEASE NOTE: *This program is subject to updates and changes – for latest updates visit www.luminesceallianceconference.org.au*

Wednesday 4 November 2026

Master of Ceremonies: Ben Apted, SPP

08:00 – 08:45	Arrival, registration and coffee	
08:45 – 09:00	**Opening Remarks, Celebrating 10 years of Luminesce Alliance,** *Kathryn Griener AO, Luminesce Alliance* **Welcome to Country,** *Aunty Lola Ryan, La Perouse Local Aboriginal Land Council*	
09.00 – 10.30	**Opening Plenary: Delivering greater health equity for the 2 million Australians and their families living with rare diseases** **Hearing Lived Experience: A Family Perspective on Rare Disease Care and Access** *Prof Wendy Gold, University of Sydney and Raelene and Brett Anslow* **Evolution of the rare disease journey – increasing access to fair and equitable treatment** *Prof Adam Jaffe, Head, Discipline of Paediatrics and Child Health School of Clinical Medicine, UNSW Sydney* **The Future Direction for Genomics Testing: A Global Perspective on Improving Access to Genomics Knowledge and Technology** *Tiffany Boughtwood, the Australian Health Genomics Commissioner, Genomics Australia* **PANEL** **Access to rare disease treatments and trials for paediatrics –solutions and enablers (30 min)** **Facilitator:** *Prof Adam Jaffe, UNSW Sydney* 1. *Trent Zimmerman, Alexion* 2. *Prof Andrew Wilson, University of Sydney* 3. *Prof Michelle Farrar, UNSW Sydney* 4. *Laura Collie, NSW Health* 5. *Prof Parmjot Bains, RNA Institute, UNSW Sydney* 6. *Meg Maack, Childhood dementia Initiative*	
10.30 – 11.00	**Morning tea - Posters, networking and trade display**	
11.00 – 12.00 **PARALLEL SESSIONS**	**LEVEL 4 - SEMINAR ROOM** **Led and Made in Australia: Advancing Research, Commercialisation and Sovereign Capability for the Next Generation of Therapeutics** **PRESENTATIONS - Commercialisation** • Bridging Research and Commercialisation: Lessons from Building Tessellate Bio - *Hilda Pickett, Children's Medical Research Institute* • Pathways to driving innovation and commercialisation - *Anne O'Neill, ANDHealth+*	**LEVEL 5 - The HTH HEART MEETING ROOM** **Precision Medicine in Practice - The Translational Impact of the Kids Advanced Therapeutic Program** **PANEL with audience Q&A** A world-first advanced therapy trial provides the backdrop for this discussion on the power of lived experience and community partnership. The panel will demonstrate how Sydney Children's Hospitals Network translates research into clinical care through its end-to-end innovation ecosystem. **Facilitator:** *Lani Attwood, Sydney Children's Hospitals Network.*

	• Industry perspective: Australia's space in the global commercial therapeutics landscape - *Chris Alma, Platypus Bio* **PRESENTATIONS – Innovations and advanced technologies** • Scalable approaches to variant interpretation and therapeutic assessment in inherited retinal diseases. *Prof Robyn Jamieson, Children's Medical Research Institute* • From Promise to Practice: Translating Nanomedicine into Tomorrow's Therapies. *Prof Maria Kavallaris AM, Children's Cancer Institute* • New gene and cell transplantation paradigms to restore vision in blinding retinal diseases. *A/Prof Anai Gonzalez Cordero, Children's Medical Research Institute.* • A self-amplifying theranostic for the treatment of solid tumours in children. *Prof Philip Hogg, Centenary Institute*.	1. *Dr Kavitha Kothur, Sydney Children's Hospitals Network* 2. *Dr Boris Waldman, Parent and Patient Advocate, Foundation for Angelman Syndrome Therapeutics (FAST) Australia; Clinician Researcher, Specialist Anaesthetist* 3. *A/Prof Michelle Lorentzos, Sydney Children's Hospitals Network* 4. *Dr Janette Lee, Sydney Children's Hospitals Network* 5. *Dr May Aung-Htut, Murdoch University.*
12:00-13:00	**PANEL** **From Discovery to Patient Impact: Overcoming Commercialisation Barriers for Advanced Therapeutics in Australia** **Facilitator:** *Ben Apted, SPP* 1. *Chris Alma, Platypus Bio* 2. *Dr Hilda Pickett, Children's Medical Research Institute* 3. *Anne O'Neill, ANDHealth+* 4. *Prof Alec Welsh, UNSW Sydney*	**LEVEL 5 - The HTH HEART MEETING ROOM** **Enabling Equity & Access Centred Care** **PRESENTATIONS** Codesign example from Molecular Point-of-Care Testing Program - START (STREP A) respiratory POC project *Robert Monaghan, Kirby Institute and Prof Rebecca Guy, Kirby Institute* **PANEL** **Engaging First Nations Families: Co-design, Trust, and Culturally Safe Care** **Facilitator:** *Dr Kate Hetherington, UNSW Sydney* 1. *Prof Raghu Lingam, UNSW Sydney* 2. *Robert Monaghan, Kirby Institute* 3. *Prof Sue Woolfenden, The University of Sydney* 4. *Alunya Wilkinson, Parent Advocate*
13.00 – 14.00	**Lunch Session – LEVEL 4 - SEMINAR ROOM** **Beyond the Data: Research With, Not On** *Allen Stanley, Aboriginal Health Directorate, Sydney Children's Hospital Network* *This session explores how meaningful engagement with Aboriginal people and communities can strengthen research, policy, service design and evaluation outcomes. Drawing on practical experiences and approaches that align with ethical research guidelines and the principles underpinning Aboriginal Health Impact Statements, this session highlights the importance of self-determination, cultural safety, reciprocity and shared decision-making. Participants will learn how to move beyond consultation towards genuine partnership, ensuring Aboriginal voices and lived experience help shape decisions from the outset and contribute to more effective, culturally responsive and community-centered outcomes.*	



14:00-14:30 LEVEL 4	**From Data to Impact: Advancing Precision Medicine Through Smarter Trials and Global Collaboration- Great work so far, but where can we go from here to make it better?** *Dr Michael Cox, Martian Clinical Consulting*	
14.30 – 15.30 PARALLEL SESSIONS	**LEVEL 4 - SEMINAR ROOM** **From Cancer to Rare Disease: Translating Three Decades of Precision Progress** **1. Moderator Context Setting** Framing of the equity challenge and debate proposition. *Prof Adam Jaffe, UNSW Sydney* **2. Position Statements: Cancer vs Rare Disease** *Cancer perspective*: What made ZERO and national scale possible – *Prof Michelle Haber, Children's Cancer Institute* *Rare disease perspective*: Where systems currently fall short – *A/Prof (Elizabeth) Emma Palmer, Sydney Children's Hospitals Network* **3. Moderated Debate & Cross-Panel Discussion: Should resources currently invested in paediatric cancer research and care be redirected to paediatric rare diseases to achieve greater equity in precision medicine?** Cancer has benefited from sustained system-level investment in precision medicine, while rare diseases have not. Are these differences justified—and what would it take to close the gap? ***Rare Diseases team*** 1. *Prof Michelle Farrar, Sydney Children's Hospitals Network* 2. *A/Prof Michelle Lorentzos Sydney, Children's Hospitals Network* 3. *Kris Pierce, UNSW Sydney* 4. *Prof Natalie Taylor, UNSW Sydney* ***Cancer team*** 1. *Dr Richard Mitchell Children's Hospitals Network* 2. *Dr Kate Hetherington, UNSW Sydney* 3. *Prof Mark Cowley, Children's Cancer Institute* 4. *Prof Glenn Marshall, Children's Cancer Institute* **Synthesis & Closing Reflections** Key insights and practical takeaways.	**LEVEL 5 - The HTH HEART MEETING ROOM** **Conference Abstract oral presentations** **Chair:** *Dr Radek Szmyd, Children's Medical Research Institute* **Presentations** • Investigating hospital utilisation by children with rare diseases using administrative health data - *Dr Carolyn Arico, The University of Sydney* • Novel Targeted KCNT1 Small-Molecule Therapy achieves phenotype reversal in Epilepsy of Infancy with Migrating Focal Seizures -*Dr Kavitha Kothur, Children's Hospital Westmead and Kids Neuroscience Centre* • Characterising Toxicity of DFMO/AMXT1501 Polyamine Inhibition Therapy for Treatment of High-Risk Neuroblastoma -*Mrs Lara Knight, Children's Cancer Institute* • Unravelling whole-genome doubling based genomic instability in paediatric cancers - *Dr Piyushkumar Mundra, Children's Cancer Institute*
15.30 - 16.00	Afternoon tea	



16:00 – 17:30 **PARALLEL SESSIONS**	**LEVEL 4 - SEMINAR ROOM** **What Will Cancer Precision Therapeutics Look Like in 2030? *Risks and readiness for researchers, clinicians, and families*.** **PRESENTATIONS** • Cancer horizon scan - International perspectives *Prof Louis Chesler, Children's Cancer Institute* • What's Ahead - Mapping the Functional Cancer Landscape: Proteomics and the 2030 Horizon *Dr Rebecca Poulos, Children's Medical Research Institute* • Liquid Biopsy Innovation in Brain Cancer: Hype or hope? *Dr Marion Mateos, Children's Cancer Institute* **PANEL** **Early Detection & Monitoring, How Does Cancer Care Change?** **Facilitator** *Dr Richard Mitchell, Sydney Children's Hospital, Randwick* 1. *Dr Kate Hetherington, UNSW Sydney* 2. *Lucy Jones, NBL Australia* 3. *Prof Louis Chesler, Children's Cancer Institute* 4. *Dr Noemi Fuentes-Bolanos, Sydney Children's Hospitals Network* 5. *Lani Attwood, Sydney Children's Hospitals Network*	**LEVEL 5 - The HTH HEART MEETING ROOM** **Diagnostic odyssey journey - Variants of unknown significance** **Chair:** *Kris Pierce, Rare Diseases NSW* **PRESENTATIONS** • Searching for Answers: A Family's Experience of the Diagnostic Odyssey *Prof Wendy Gold, The University of Sydney and Emma Maly* • Functional analysis for precision treatment of Telomere Biology Disorder patients. *Prof Tracy Bryan, Cancer Institute NSW* • gEnomics4newborns: integrating Ethics and Equity with Effectiveness and Economics for genomic newborn screening *A/Prof Sarah Norris, The University of Sydney* • Equitable solutions to rare disease genetic diagnosis *Dr Lisa Ewans, Sydney Children's Hospitals Network* **PANEL** **Who Owns Genomic Data? Building a National, Equitable Approach to Resolution and Reanalysis** **Facilitator:** *Dr Lisa Ewans, Sydney Children's Hospitals Network* 1. *Tiffany Boughtwood, Genomics Australia* 2. *A/Prof Sarah Norris, The University of Sydney* 3. *Prof Kristine Barlow-Stewart, Children's Cancer Institute* 4. *Prof Sandra Cooper, The University of Sydney* 5. *Dr Lucinda Freeman, University of Technology Sydney*
17.30 **17.40**	**Dinner attendees meet at Conference Registration Desk** **Dinner attendees escorted to restaurant**	
18:00 – 21:00	**Conference dinner**	



Thursday 5 November 2026

Master of Ceremonies: Joe Connell, dandolopartners

08:00–09:00	Registration
8:45-09:00	**Day 2 Welcome, Celebrating 10 years of Luminesce Alliance,** *Kathryn Griener AO, Luminesce Alliance*
09:00–10:30	**Plenary - Across Borders and Lifecourse: Lessons from Global Evidence to Local Care** **Pragmatic, Embedded, Affordable: Trials That Changed Practice** *Dr Michael Harhay (virtual), Deputy Director of the Division of Epidemiology and Director of the Center for Clinical Trials Innovation, University of Pennsylvania* **Big Data, Real Patients: AI/ML Strategies for EHR-Linked Biobanks** *Prof Marylyn Ritchie, Chief AI Officer, and Director AI Center for Health Innovation and Informatics, Medical University of South Carolina* **NSW Health Research and Innovation** *Dr Kim Sutherland, Office for Health and Medical Research (OHMR), NSW Health* **PANEL** **From Paediatrics to Adult Care: The Lifelong Impact of Research** **Facilitator:** *Emeritus Prof Leslie White, Children's Cancer Institute* 1. *A Prof Michelle Lorentzos, Sydney Children's Hospitals Network* 2. *Tiffany Boughtwood, Genomics Australia* 3. *Dr Kim Sutherland, OHMR, NSW Health* 4. *Dr Michael Harhay, University of Pennsylvania (virtual)*
10.30 – 11.00 Morning tea	**Therapeutic Innovation Australia (TIA) Poster Session** 1. Co-designing Rare Passports for people living with rare and undiagnosed conditions *Jackson Horton, UNSW Sydney* 2. Interrogating the mechanisms of gene dysregulation in a paediatric cancer cohort *Navya Shukla* 3. Implementing Genomic Newborn Screening: ELSI Insights from Parents and Midwives *Jessica Lu, Sydney Children's Hospitals Network* 4. Body Mapping for Inclusive Consumer-Led Knowledge Generation in Genetic Health Research *Amy Griffiths, University of Technology Sydney* 5. Maternal immune activation, childhood infection and neurodevelopmental disorders: a population-based cohort study *Wen-qiang He, The University of Sydney* 6. SIBS-ONLINE: An Australian pilot for siblings of children with severe neurological conditions *Maddison C Smith, UNSW Sydney* 7. Towards Inclusive Paediatric Precision Medicine: Linguistically Diverse Families' Experiences of ZERO2 *Rebecca Daly, UNSW Sydney* 8. Curio: A Generative AI Toolkit for Molecular Reporting to Support Precision Medicine in Paediatric Cancer *Ali Afrasiabi, Children's Cancer Institute* 9. 'Ready Steady School' A personalised website to promote school engagement among students with cancer *Dr Sarah Ellis, UNSW Sydney* 10. Sigverse: streamlining the analysis and interpretation of mutational signatures in precision medicine *Sam El-Kamand, Children's Cancer Institute* 11. Building policy impact from FASD research: lessons from the FASD-CRE *Prof Elizabeth Elliott, The University of Sydney* 12. Bridging natural history and disease modelling to treat ciliary-related inherited retinal dystrophy *Nadya Andhika, Children's Cancer Institute* 13. NF-KAM enables tumour-informed ctDNA detection in minutes through alignment-free variant tracking *Dr Wenhan Chen, Children's Cancer Institute* 14. Antisense oligonucleotide-mediated splice disruption facilitates functional assessment of a candidate disease variant *Georgia Jimenez, The University of Sydney*

	15. Parents' experiences of cancer surveillance for their child with genetic cancer risk *Jacqueline Hunter*	
11.00 - 12:30 **PARALLEL SESSIONS**	**LEVEL 4 - SEMINAR ROOMS 1/2** **One Patient Record, Infinite Research Potential: Single Digital Patient Record (SDPR) and the Rise of Learning Health Systems** Single Digital Patient Record (SDPR) Update: Advancing Secure, Real-Time Integration Across Care, Research and Discovery *Natasha Eaton, Single Digital Patient Record Implementation Authority* Translation of PEACH to SDPR – utilising SDPR to improve equity – Imagine what else we can do *Prof Karen Zwi, UNSW Sydney* **PRESENTATION- special launch** The first public presentation of *Impact for Kids: Better Outcomes for Children. Greater Returns for NSW*, a landmark proposal demonstrating the impact and future potential of a decade of investment in Luminesce Alliance paediatric translational research. *Joe Connell, dandolopartners* **PANEL** **Impact for Kids** **Facilitator**: *Joe Connell, dandolopartners* 1. *Prof Tom Snelling, The University of Sydney* 2. *Prof Raghu Lingam, UNSW Sydney* 3. *Dr Kate Hetherington, UNSW Sydney* 4. *Prof Sue Woolfenden, The University of Sydney* 5. *Prof Mark Cowley, Children's Cancer Institute* **PANEL** **From Recruitment to Real-World Evidence: Single Digital Patient Record (SDPR) and the Future of Clinical Trials** **Facilitator:** *Joe Connell, dandolopartners* 1. *Maria Mury, Cancer Institute NSW* 2. *Prof Tom Snelling, The University of Sydney* 3. *Prof Raghu Lingam, UNSW Sydney* 4. *Emeritus Prof Richard Henry, Luminesce Alliance* 5. *Dr Michael Harhay, University of Pennsylvania (virtual)* 6. *Natasha Eaton, Single Digital Patient Record Implementation Authority*	**LEVEL 4 - SEMINAR ROOMS 3/4** **Inside the Drug Discovery Pipeline: Pathways to Paediatric Therapies** **Chair:** *A/Prof Antoine de Weck, Children's Cancer Institute* **PRESENTATIONS** • The THINK Model: Advancing Drug Development Through Medicinal Chemistry and Collaborative Design *Dr Kieran Stockton, Monash University* • Navigating Drug Discovery: Partners and Pathways *Prof Brendon Monahan, MedChem Australia, Monash University* • Philanthropy and childhood cancer drug discovery – *Nadya Landey, Children's Cancer Institute* • Beyond Good Science: Three Things That Carry a Paediatric Therapy to Patients – *Ben Apted, SPP* **PANEL** **Bridging Discovery and Delivery: Partners, Pathways, and Paediatric Drug Development** **Facilitator:** *A/Prof Antoine de Weck, Children's Cancer Institute* 1. *Dr Michael Cox, Martian Clinical Consulting* 2. *Prof Brendon Monahan, MedChem Australia, Monash University* 3. *Dr Kieran Stockton, Monash University* 4. *Prof Ian Street, Children's Cancer Institute* 5. *Dr Julia Warning, MoH, NSW Health*
12.30 – 13.30	**Lunch**	
13.30 – 15.00	**LEVEL 4 - SEMINAR ROOMS 1/2**	**LEVEL 4 - SEMINAR ROOMS 3/4**

PARALLEL SESSIONS	**AI, Research & Clinical Practice - Turning complex data into better care** **PRESENTATIONS** • What It Takes to Scale Responsible AI: Global Lessons for System Change *Grantly Mailes, Gecko Consulting* • Scaling AI Responsibly and Safely: Lessons from International Best Practice *Aurelie Jacquet, Ethical AI Consulting* • AI and democratisation of data from health system *Prof Tom Snelling, University of Sydney, Sydney Children's Hospitals Network* • precAIs.ai - routine clinical trial data and possibilities unlocked by AI *Prof Mark Cowley, Children's Cancer Institute* • From Vision to Execution: Making Paediatric Cancer Data Accessible and Meaningful with AI, *Dr Ah-Jung Jeon, Children's Cancer Institute*	**Conference Abstract oral presentations** **CHAIR:** *Fran Evesson, The University of Sydney* • Providing Enhanced Access for Child Health Services (PEACH): an implementation evaluation - *Isabella Devine, UNSW Sydney* • Defining Childhood Dementia to Advance Research, Policy, and Care: A Global Consensus Project using Delphi Methodology - *Gail Hilton, Childhood Dementia Initiative* • Population-Based Newborn Screening Scoping Study For Duchenne Muscular Dystrophy In New South Wales And The Australian Capital Territory, Australia - *Sarah Shin, Sydney Children's Hospitals Network* • Genomic Mainstreaming in Paediatric Rare Disease at The Children's Hospital Westmead, an 18-month audit - *Fu Wan Sit, The University of Sydney* • EPIC-CP: a mixed-methods pilot RCT of social prescribing for caregivers of children with cerebral palsy - *Sandra Takchi, The University of Sydney* • **Rapid fire:** Bicultural and Bilingual Research Assistants: Reflections and Lessons Learned - *Sandra Takchi, The University of Sydney* • **Rapid fire:** Targeting MYCN-associated vulnerabilities through LSM4 disruption and dual BCL2/AURKA inhibition - *Sahar Mafi, Children's Cancer Institute* • **Rapid fire:** From Lived Experience to Laboratory Evidence for Xeroderma Pigmentosum - *Yvette Walker, XP Support Group Australasia*
15.00 - 15.30	**Afternoon tea**	
15:30 – 16:30	**PANEL: Can we achieve the promise of AI in the health system - a traditionally risk averse environment?** **Facilitator:** *Joe Connell, dandolopartners* 1. *Grantly Mailes, Gecko Consulting* 2. *Aurelie Jacquet, Ethical AI Consulting* 3. *Prof Tom Snelling, The University of Sydney* 4. *Dr Ah-Jung Jeon, Children's Cancer Institute* **CLOSING PANEL: Reflections, Collaborations and What's next** **Facilitator**: *Joe Connell, dandolopartners* 1. *Prof Roger Reddel, Children's Medical Research Institute* 2. *Prof Louis Chesler, Children's Cancer Institute* 3. *Prof Annemarie Hennessy, The University of Sydney* 4. *Prof Sean Emery, UNSW Sydney* 5. *Kathryn Greiner, Luminesce Alliance* 6. *Dr Michael Cox, Martian Clinical Consulting*	