



2026 CONFERENCE

#LuminesceAlliance2026

4-5 November 2026 | UNSW Sydney

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THE UNIVERSITY OF SYDNEY



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Wednesday 4 November 2026

Master of Ceremonies: Ben Apted, SPP

08:00 – 08:45	Arrival, registration and coffee	
08:45 – 09:00	Welcome to Country, <i>Aunty Lola Ryan, La Perouse Local Aboriginal Land Council</i> Opening Remarks, Celebrating 10 years of Luminesce Alliance, <i>Kathryn Griener AO, Luminesce Alliance</i>	
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 <i>Prof Wendy Gold, University of Sydney and Raelene and Brett Anslow</i> Evolution of the rare disease journey – increasing access to fair and equitable treatment <i>Prof Adam Jaffe, Head, Discipline of Paediatrics and Child Health School of Clinical Medicine, UNSW Sydney</i> The Future Direction for Genomics Testing: A Global Perspective on Improving Access to Genomics Knowledge and Technology <i>Tiffany Boughtwood, the Australian Health Genomics Commissioner, Genomics Australia</i> PANEL Access to rare disease treatments and trials for paediatrics –solutions and enablers (30 min) Facilitator: <i>Prof Adam Jaffe, UNSW Sydney</i> <i>Trent Zimmerman, Alexion;</i> <i>Prof Andrew Wilson,</i> <i>Prof Michelle Farrar, UNSW Sydney;</i> <i>Laura Collie, NSW Health;</i> <i>Prof Parmjot Bains, RNA Institute, UNSW Sydney;</i> <i>Meg Maack, Childhood dementia.</i>	
10:30 – 11:00	Morning tea - Posters, networking and trade display	
11:00 – 12:00	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 - <i>Hilda Pickett, Children's Medical Research Institute</i> - Pathways to driving innovation and commercialisation - <i>Anne O'Neill, ANDHealth+</i> - Industry perspective: Australia's space in the global commercial therapeutics landscape - <i>Chris Alma, Platypus Bio</i>	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: <i>Lani Attwood, Sydney Children's Hospitals Network.</i>

	PRESENTATIONS – Innovations and advanced technologies - Scalable approaches to variant interpretation and therapeutic assessment in inherited retinal diseases. <i>Prof Robyn Jamieson, Children's Medical Research Institute</i> - From Promise to Practice: Translating Nanomedicine into Tomorrow's Therapies. <i>Prof Maria Kavallaris AM, Children's Cancer Institute</i> - New gene and cell transplantation paradigms to restore vision in blinding retinal diseases. <i>A/Prof Anai Gonzalez Cordero, Children's Medical Research Institute.</i> - A self-amplifying theranostic for the treatment of solid tumours in children. <i>Prof Philip Hogg, Centenary Institute.</i>	<i>Dr Kavitha Kothur, Sydney Children's Hospitals Network</i> <i>Dr Boris Waldman, Parent and Patient Advocate, Foundation for Angelman Syndrome Therapeutics (FAST) Australia; Clinician Researcher, Specialist Anaesthetist</i> <i>A/Prof Michelle Lorentzos, Sydney Children's Hospitals Network</i> <i>Dr Janette Lee, Sydney Children's Hospitals Network</i> <i>Dr May Aung-Htut, Murdoch University.</i>
12:00-13:00	PANEL From Discovery to Patient Impact: Overcoming Commercialisation Barriers for Advanced Therapeutics in Australia Facilitator: <i>Ben Apted, SPP</i> <i>Chris Alma, Platypus Bio</i> <i>Dr Hilda Pickett, Children's Medical Research Institute</i> <i>Anne O'Neill, ANDHealth+</i> <i>Prof Alec Welsh, UNSW Sydney</i>	Enabling Equity & Access Centred Care PRESENTATIONS Equity, Trust and Impact: Learning from Aboriginal Research Methodologies <i>Prof Michelle Dickson, Poche Centre for Indigenous Health</i> Codesign example from Molecular Point-of-Care Testing Program - START (STREP A) respiratory POC project <i>Robert Monaghan, Kirby Institute and Prof Rebecca Guy, Kirby Institute</i> PANEL Engaging First Nations Families: Co-design, Trust, and Culturally Safe Care Facilitator: <i>Dr Kate Hetherington, UNSW Sydney</i> <i>Prof Raghu Lingam, UNSW Sydney</i> <i>Prof Michelle Dickson, The University of Sydney</i> <i>Robert Monaghan, Kirby Institute</i> <i>Prof Sue Woolfenden, The University of Sydney</i> <i>Alunya Wilkinson, Parent Advocate</i>
13.00 – 14.00	Lunch Session – Beyond the Data: Research With, Not On <i>Allen Stanley, Aboriginal Health Directorate, Sydney Children's Hospital Network</i> <i>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.</i>	
14:00-14:30	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? <i>Dr Michael Cox, Martian Clinical Consulting</i>	

14.30 – 15.30 PARALLEL SESSIONS	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 <i>Cancer perspective:</i> What made ZERO and national scale possible – Prof Michelle Haber, Children's Cancer Institute <i>Rare disease perspective:</i> 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 Prof Michelle Farrar, Sydney Children's Hospitals Network A/Prof Michelle Lorentzos Sydney, Children's Hospitals Network Kris Pierce, UNSW Sydney Prof Natalie Taylor, UNSW Sydney Cancer team Dr Richard Mitchell Children's Hospitals Network Dr Kate Hetherington, UNSW Sydney Prof Mark Cowley, Children's Cancer Institute Prof Glenn Marshall, Children's Cancer Institute Synthesis & Closing Reflections Key insights and practical takeaways.	Conference Abstract oral presentations Chair: Dr Radek Symyd, 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	What Will Cancer Precision Therapeutics Look Like in 2030? Risks and readiness for researchers, clinicians, and families.	Diagnostic odyssey journey - Variants of unknown significance Chair: Kris Pierce, UNSW Sydney

	PRESENTATIONS • Cancer horizon scan - International perspectives <i>Prof Louis Chesler, Children's Cancer Institute</i> • What's Ahead - Mapping the Functional Cancer Landscape: Proteomics and the 2030 Horizon <i>Rebecca Poulos, Children's Medical Research Institute</i> • The Biology of Response and Resistance <i>Prof Matt Dun, University of Newcastle</i> • Liquid Biopsy Innovation in Brain Cancer: Hype or hope? <i>Dr Marion Mateos, Children's Cancer Institute</i> PANEL Early Detection & Monitoring, How Does Cancer Care Change? Facilitator <i>Dr Richard Mitchell, Sydney Children's Hospital, Randwick</i> 1. <i>Dr Kate Hetherington, UNSW Sydney</i> 2. <i>Lucy Jones, NBL Australia</i> 3. <i>Prof Louis Chesler, Children's Cancer Institute</i> 4. <i>Dr Noemi Fuentes-Bolanos, Sydney Children's Hospitals Network</i> 5. <i>Lani Attwood, Sydney Children's Hospitals Network</i> 6. <i>Marylyn Ritchie, Chief AI Officer, and Director AI Center for Health Innovation and Informatics, Medical University of South Carolina</i>	PRESENTATIONS • Searching for Answers: A Family's Experience of the Diagnostic Odyssey <i>Prof Wendy Gold, The University of Sydney and Emma Maly</i> • Functional analysis for precision treatment of Telomere Biology Disorder patients. <i>Prof Tracy Bryan, Cancer Institute NSW</i> • gEnomics4newborns: integrating Ethics and Equity with Effectiveness and Economics for genomic newborn screening <i>A/Prof Sarah Norris, The University of Sydney</i> • Equitable solutions to rare disease genetic diagnosis <i>Dr Lisa Ewans, Sydney Children's Hospitals Network</i> PANEL Who Owns Genomic Data? Building a National, Equitable Approach to Resolution and Reanalysis Facilitator: <i>Dr Lisa Ewans, Sydney Children's Hospitals Network</i> 1. <i>Tiffany Boughtwood, Genomics Australia</i> 2. <i>A/Prof Sarah Norris, The University of Sydney</i> 3. <i>Prof Kristine Barlow-Stewart, Children's Cancer Institute</i> 4. <i>Prof Sandra Cooper, The University of Sydney</i> 5. <i>Dr Lucinda Freeman, University of Technology Sydney</i>
17.30	Dinner attendees meet at Conference Registration Desk	
17.40	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
09:00–10:30	Plenary - Across Borders and Lifecourse: Lessons from Global Evidence to Local Care Pragmatic, Embedded, Affordable: Trials That Changed Practice <i>Dr Michael Harhay (virtual), Deputy Director of the Division of Epidemiology and Director of the Center for Clinical Trials Innovation, University of Pennsylvania</i> Big Data, Real Patients: AI/ML Strategies for EHR-Linked Biobanks <i>Prof Marylyn Ritchie, Chief AI Officer, and Director AI Center for Health Innovation and Informatics, Medical University of South Carolina</i> NSW Health Perspective <i>Dr Kim Sutherland, Office for Health and Medical Research (OHMR), NSW Health</i> PANEL From Paediatrics to Adult Care: The Lifelong Impact of Research Facilitator: <i>Emeritus Prof Leslie White, Children's Cancer Institute</i> <i>A Prof Michelle Lorentzos, Sydney Children's Hospitals Network</i> <i>Tiffany Boughtwood, Genomics Australia</i> <i>Dr Kim Sutherland, OHMR, NSW Health</i> <i>Dr Marylyn Ritchie, Medical University of South Carolina</i> <i>Dr Michael Harhay, University of Pennsylvania (virtual)</i>
10.30 – 11.00 Morning tea	Therapeutic Innovation Australia (TIA) Poster Session - Co-designing Rare Passports for people living with rare and undiagnosed conditions <i>Jackson Horton, UNSW Sydney</i> - Interrogating the mechanisms of gene dysregulation in a paediatric cancer cohort <i>Navya Shukla</i> - Implementing Genomic Newborn Screening: ELSI Insights from Parents and Midwives <i>Jessica Lu, Sydney Children's Hospitals Network</i> - Body Mapping for Inclusive Consumer-Led Knowledge Generation in Genetic Health Research <i>Amy Griffiths, University of Technology Sydney</i> - Maternal immune activation, childhood infection and neurodevelopmental disorders: a population-based cohort study <i>Wen-qiang He, The University of Sydney</i> - SIBS-ONLINE: An Australian pilot for siblings of children with severe neurological conditions <i>Maddison C Smith, UNSW Sydney</i> - Towards Inclusive Paediatric Precision Medicine: Linguistically Diverse Families' Experiences of ZERO2 <i>Rebecca Daly, UNSW Sydney</i> - Curio: A Generative AI Toolkit for Molecular Reporting to Support Precision Medicine in Paediatric Cancer <i>Ali Afrasiabi, Children's Cancer Institute</i> 'Ready Steady School' A personalised website to promote school engagement among students with cancer <i>Dr Sarah Ellis, UNSW Sydney</i> - Sigverse: streamlining the analysis and interpretation of mutational signatures in precision medicine <i>Sam El-kamand, Children's Cancer Institute</i> - Building policy impact from FASD research: lessons from the FASD-CRE <i>Prof Elizabeth Elliot, The University of Sydney</i> - Bridging natural history and disease modelling to treat ciliary-related inherited retinal dystrophy <i>Nadya Andhika, Children's Cancer Institute</i> - NF-KAM enables tumour-informed ctDNA detection in minutes through alignment-free variant tracking <i>Dr Wenhan Chen, Children's Cancer Institute</i> - Antisense oligonucleotide-mediated splice disruption facilitates functional assessment of a candidate disease variant <i>Georgia Jimenez, The University of Sydney</i> - Parents' experiences of cancer surveillance for their child with genetic cancer risk <i>Jacqueline Hunter</i>

11.00 - 12:30 PARALLEL SESSIONS	One Patient Record, Infinite Research Potential: Single Digital Patient Record (SDPR) and the Rise of Learning Health Systems Translation of PEACH to SDPR – utilising SDPR to improve equity – Imagine what else we can do <i>Prof Karen Zwi, UNSW Sydney</i> PRESENTATION- special launch Introducing Luminesce Alliance proposal <i>Impact for Kids NSW</i>. <i>Joe Connell, dandolopartners</i> PANEL Impact for Kids: Better Outcomes for Children. Greater Returns for NSW Facilitator: <i>Joe Connell, dandolopartners</i> <i>Prof Tom Snelling, The University of Sydney</i> <i>Prof Raghu Lingam, UNSW Sydney</i> <i>Dr Kate Hetherington, UNSW Sydney</i> <i>Prof Sue Woolfenden, The University of Sydney</i> <i>Prof Mark Cowley, Children's Cancer Institute</i> PANEL From Recruitment to Real-World Evidence: Single Digital Patient Record (SDPR) and the Future of Clinical Trials Facilitator: <i>Joe Connell, dandolopartners</i> <i>Prof Tracey O'Brien, Cancer Institute NSW</i> <i>Prof Tom Snelling, The University of Sydney</i> <i>Prof Raghu Lingam, UNSW Sydney</i> <i>Emeritus Prof Richard Henry, Luminesce Alliance</i> <i>Dr Michael Harhay, University of Pennsylvania (virtual)</i>	Inside the Drug Discovery Pipeline: Pathways to Paediatric Therapies Chair: <i>A/Prof Antoine de Weck, Children's Cancer Institute</i> PRESENTATIONS The THINK Model: Advancing Drug Development Through Medicinal Chemistry and Collaborative Design <i>Dr Kieran Stockton, Monash University</i> Navigating Drug Discovery: Partners and Pathways <i>Prof Brendon Monahan, MedChem Australia, Monash University</i> Sustainable funding mechanisms amenable to childhood cancer drug discovery <i>Paul Curnow, Akaysa</i> PANEL Bridging Discovery and Delivery: Partners, Pathways, and Paediatric Drug Development Facilitator: <i>A/Prof Antoine de Weck, Children's Cancer Institute</i> <i>Dr Michael Cox, Martian Clinical Consulting</i> <i>Prof Brendon Monahan, MedChem Australia, Monash University</i> <i>Dr Kieran Stockton, Monash University</i> <i>Paul Curnow, Akaysa</i> <i>Dr Julia Warning, MoH, NSW Health</i>
12.30 - 13.30	Lunch	
13.30 - 15.00 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 <i>Grantly Mailes, Gecko Consulting</i> Scaling AI Responsibly and Safely: Lessons from International Best Practice <i>Aurelie Jacquet, Ethical AI Consulting</i> AI and democratisation of data from health system <i>Prof Tom Snelling, University of Sydney, Sydney Children's Hospitals Network</i>	Conference Abstract oral presentations CHAIR: <i>Fran Evesson, The University of Sydney</i> Providing Enhanced Access for Child Health Services (PEACH): an implementation evaluation <i>Isabella Devine, UNSW Sydney</i> Defining Childhood Dementia to Advance Research, Policy, and Care: A Global Consensus Project using Delphi Methodology <i>Gail Hilton, Childhood Dementia Initiative</i>

	PreAls.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	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. Dr Marylyn Ritchie, Medical University of South Carolina 4. Prof Tom Snelling, The University of Sydney 5. Prof Mark Cowley, 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. Kathryn Greiner, Luminesce Alliance 5. Emeritus Prof Leslie White, Children's Cancer Institute 6. Dr Michael Cox, Martian Clinical Consulting 7. Dr Marylyn Ritchie, Medical University of South Carolina	