



# Australian Paediatric Surveillance Unit 1993 - 2018



## *Celebrating 25 years of research, advocacy and care for children living with rare conditions*

**Sunday 13<sup>th</sup> of May 2018**

**Charles Perkins Centre Lecture Theatre,  
The University of Sydney**

9:00 – 9:30 *Coffee and registration*

### **Session 1**

**Professor Carol Bower** *Welcome*

**Professor Elizabeth Elliott** *Celebrating 25 years of achievements for the APSU*

**A/Professor Yvonne Zurynski** *Living with a rare disease – experiences of families and clinicians*

**Mr Steve Waugh** *Meeting the needs of children living with rare disease and their families*

**Dr Sloane Madden** *Early onset eating disorders in young children – role of surveillance to support policy and care*

11:00 – 11:30 *Morning tea*

### **Session 2**

**Dr Marcel Zimmet** *Fetal Alcohol Spectrum Disorders – from surveillance to policy*

**A/Professor Yvonne Zurynski and  
Professor Elizabeth Elliott** *Female Genital Mutilation – do Paediatricians see this rare injury?*

**Professor Heather Jeffery** *Sudden Unexplained Death in Australian Infants*

**Professor Helen Leonard** *Rett Syndrome: From surveillance to genotype-phenotype characterisation*

12:30 – 13:30 *Lunch and awards presentation*

### **Session 3**

**Professor Cheryl Jones** *Consequences of congenital infection: HSV, Rubella, Varicella, HIV, cCMV & Zika*

**Dr Anne Durkan** *Long-term outcomes after atypical HUS*

**A/Professor Julia Brotherton** *Juvenile Onset Respiratory Papillomatosis*

**Professor Robert Booy** *Severe influenza in Australian children*

**Dr Philip Britton** *Encephalitis Study*

15:00-16:00 *Wrap up – Wine and cheese*

**A satellite meeting of the Royal Australasian College of Physicians Congress 14<sup>th</sup> – 16<sup>th</sup> May**