



# rare kids

Australian Paediatric Surveillance Unit

### Inside this issue:

- *Celebrating 30 Years* 2
- *EOI for APSU SRP* 3
- *Study update: Acute Flaccid Paralysis* 3
- *Study update: Severe Injury related to Button Battery* 4
- *Study update: Paediatrician experience of Subpoena or Court Testimony* 5
- *MD Student Spotlight* 6
- *FASDAR* 7
- *Recent presentations* 7
- *Current APSU SRP* 8
- *Contact the APSU* 8
- *25 Years of NZPSU* 8

Welcome to the APSU newsletter, in this edition, we remind Paediatrician’s of the importance of remaining vigilant for polio by reporting Acute Flaccid Paralysis cases to the APSU to contribute to maintaining Australia’s (and the Western Pacific Region) Polio Free accreditation.

We also highlight a new APSU study ‘Paediatrician’s experience with Subpoenas and Court Testimony related to suspected child maltreatment’ that has recently been included in our monthly surveillance.

An update for clinicians is included for the severe injury related to disc battery study. Awareness and campaigning for safety reforms has resulted in changes to the manufacturing of some disc batteries and our update includes important new information for you.

In addition, there is information on upcoming rare disease RACP webinars, student projects, and recent conference presentations. If you would like to view our most recent publications, please visit the publications library on the APSU website [www.apsu.org.au](http://www.apsu.org.au).



Guy Eslick  
APSU Director of Research

### A special thanks to ALL contributors to the APSU monthly surveillance system

APSU is keenly aware of the additional challenges faced by clinicians due to busy workloads and increased demands on your time. We greatly appreciate the diligence with which so many of you have continued to participate and support our monthly surveillance.



### Professor David Burgner

The Australian Paediatric Surveillance Unit would like to extend a very warm and heartfelt **Thank You** to Professor David Burgner. David has been a long standing member of the APSU Scientific Review Panel. His contribution to the APSU has been extremely helpful and highly valued .

Thank  
You

## 2023 marked 30 Years of Surveillance

### 30 years of surveillance is an enormous achievement for the Australian Paediatric Surveillance Unit.

We presented a session at the RACP Congress in May 2024 to highlight this important milestone. An article detailing 30 years of achievements and highlights has been published in the Archives of Disease in Childhood:

*Elliott EJ, Teutsch S, Nunez C, Morris A, Eslick GD; APSU Investigators and Contributors. Improving knowledge of rare disorders since 1993: the Australian Paediatric Surveillance Unit. Arch Dis Child. 2024 May 13:archdischild-2023-326116. doi: 10.1136/archdischild-2023-326116.*

Some key facts about the APSU:

- Established by Elizabeth Elliott in 1993
- **72** rare chronic and complex childhood diseases have been studied so far, including infectious, genetic, mental health, rare injuries, rare immune disorders
- Up to 16 different conditions studied simultaneously using standardised case definitions and datasets for each condition (demographics, diagnosis, treatment, complications, outcomes)
- Used by over **400** researchers (national groups of experts established for each condition)
- Often provides the first national incidence estimates for rare childhood conditions
- Outcomes support policy, clinical practice and lead to further research
- APSU staff have also attracted grants to enable activities other than surveillance:
  - Systematic reviews / rapid reviews
  - Surveys of Paediatricians (knowledge attitudes practice)
  - Clinical audits
  - Impacts on families and quality of life surveys
  - Health services utility and costs studies (detailed activity and costing data)
  - Establishing rare disease registries



**Do you have an interest in conducting a study through the Australian Paediatric Surveillance Unit?**

Contact the APSU team by email at [SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)  
to arrange a time to discuss your ideas and project requirements.



The APSU is calling for an  
Expression of Interest (EOI) to join our  
**Scientific Review Panel** in 2025

**Are you an experienced paediatrician / researcher  
with an interest in rare childhood conditions?**

**If so, we would like you to join our SRP!**

**For more information, please contact us at:**

[SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)

### Acute Flaccid Paralysis (AFP) Surveillance – Keeping Australia Polio-Free

**Did you know that despite being certified polio-free in 2000, Australia remains at real risk of importing polio?**

Wild-type poliovirus is still endemic in Afghanistan and Pakistan, and vaccine-derived polioviruses (VDP) are still circulating in many countries. There has been an outbreak of VDP in Indonesia for the past two years, with fears that it could spread to neighbouring countries, including PNG, and by its close proximity, to Australia.

**A/Professor Anne Morris and Dr Suzy Teutsch are the current APSU representatives on the Australian Polio Expert Panel (PEP), meeting every 2 months to review Australian AFP cases.**

PEP member, Dr Eppie Yiu, recently published an informative article: Leung R, Yiu EM. **Practical approach to the child presenting with acute generalised weakness.** J Paediatr Child Health. 2024 Feb-Mar;60(2-3):41-46. doi: [10.1111/jpc.16536](https://doi.org/10.1111/jpc.16536).

**Your help to report children aged <15 years with AFP is crucial for identifying suspected cases of polio and ensure that Australia remains polio-free.**

In 2023, AFP cases identified through APSU surveillance and the Paediatric Active Enhanced Disease Surveillance (PAEDS) surveillance system and cases reported directly to the National Enterovirus Reference Laboratory (NERL), contributed to Australia’s Polio-free certification status by the WHO Western Pacific Region.

A total of 94 children with suspected AFP were reported, 82 of whom were confirmed with non-polio AFP. The AFP case rate was 1.71cases per 100,000 children aged <15 years, meeting the WHO target of one non-polio AFP case per 100,000. This case rate has been consistently achieved in Australia for the past 16 years.

The APSU would like to thank all Contributors who have reported AFP cases in 2023 and 2024, especially those located outside of major cities and/or PAEDS hospitals, including John Hunter Children’s Hospital, Gold Coast University Hospital, Townsville Hospital, University Hospital Geelong, and Royal Hobart Hospital,

Your efforts towards achieving Australia’s goal of remaining Polio-free are very much appreciated!



**The Polio Expert Panel encourages all paediatricians to continue reporting all cases of AFP to the APSU.**

High quality acute flaccid paralysis (AFP) surveillance is essential to maintain polio-free status.

The APSU protocol, online and PDF case report forms can be found here:

[APSU AFP Protocol, ONLINE or PDF Case Report Form](#)

**Two stool samples for testing to exclude polio virus should be collected within 14 days of the onset of paralysis and sent to the National Polio Reference Laboratory.**

More details at: [www.vidrl.org.au/laboratories/poliovirus-reference/specimen-referral](http://www.vidrl.org.au/laboratories/poliovirus-reference/specimen-referral)



### Severe injury related to disc battery (study commenced December 2017)

#### Important information for clinicians: In August 2024,

Energizer® launched a new design for their 20mm batteries with bitterant on one side (like the Duracell® battery) as well as a blue indicator dye that is triggered by moisture. This has the potential to expedite diagnosis, though there are still likely to be logistic challenges in getting children to a definitive point of care for battery removal.

It is important to note that absence of blue dye does not mean no battery has been ingested. It remains unclear how well this system will work in real life, and the majority of button batteries (both Energizer® and other brands) do not have the indicator.

**Deliberate self harm:** Button batteries (and other batteries) are increasingly becoming a tool for deliberate self harm, particularly amongst young girls and women, who ingest them or insert them into their vagina. Batteries with sufficient residual charge are also capable of causing severe caustic burns and fistulisation into adjacent structures. Many of these patients are frequent representers to health services.

Collation of these deliberate ingestion/insertion cases will facilitate advocacy for safer inherent battery design such that caustic damage does not occur. **The APSU case definition does not exclude deliberate BB exposures.**



Recent publications from the APSU surveillance study on Severe Injury related to Disc Battery by MD Student Christopher Tran:

⇒ Tran C, Nunez C, Eslick GD, Barker R, Elliott EJ. **Complications of button battery ingestion or insertion in children: a systematic review and pooled analysis of individual patient-level data.** World Journal of Pediatrics. 2024 Aug 22:1-2.

⇒ Tran C, Nunez C, Eslick GD, Barker R, Elliott EJ. **Button battery exposure in children: a systematic review and meta-analysis.** Injury Prevention. 2024 Oct 4.

#### Key findings from the complications of button battery ingestion or insertion in children: a study of 439 paediatric cases.

##### Most common presenting symptoms:

- Feeding/swallowing difficulties (48%)
- Respiratory difficulties (35%)
- Pain (29%)
- Upper GI upset (29%)

##### Most common complications:

- Oesophageal mucosal damage (26%)
- Tracheoesophageal fistula (23%)
- Aortooesophageal fistula (7%)
- Death (6%)

##### Risk of complications identified:

- Age ≤2 years was associated with common complications including tracheoesophageal fistula (TOF) (aOR 3.56 95% CI:1.94–6.52), oesophageal stenosis (aOR 1.84 95% CI:1.01–3.35), vocal cord palsy (aOR 4.35 95% CI:1.48–12.77); and death (aOR 2.46 95% CI:1.04–5.85).
- Battery exposure >6 hours was associated with TOF (aOR 3.95 95% CI:1.59–9.85), vocal cord palsy (aOR 0.40 95% CI:0.17–0.97); and death (aOR 7.71 (95% CI:1.02–58.37).

- Females were at increased risk of aorto-oesophageal fistula (aOR 3.24 95% CI:1.37–7.67); or death (aOR 1.89 95% CI:0.91–3.91).
- Unwitnessed events were associated with oesophageal stenosis (aOR 2.53 95% CI:1.12–5.76).

##### Recommendations:

- Mandate safer battery design
- Supervision
- Public and health professional awareness and education

## Surveillance Study Updates

### Paediatricians experience with Subpoena and Court Testimony related to suspected child maltreatment

Providing medical evidence in court can be a stressful experience, even for experienced forensic paediatricians. Exposure to and empathic engagement with traumatised patients coupled with the stress of legal proceedings and providing evidence in court can contribute to adverse psychological outcomes for paediatricians, including secondary traumatic stress and burnout.

In June 2024 the APSU launched the **Paediatricians experience with Subpoena and Court Testimony related to suspected child maltreatment** study on the monthly surveillance report card.

The aim of this project is to explore the impacts on paediatricians of receiving subpoenas and testifying in court in cases of child maltreatment. Anecdotal evidence suggests that many paediatricians find child maltreatment work, receiving subpoenas and testifying in court to be challenging and stressful. Little is currently known about the positive and negative impacts of this work on Australian and New Zealand paediatricians.

Dr Alyce Horstman from the Victorian Forensic Paediatric Medical Service (VFPMS) and PhD candidate, Monash University Department of Forensic Medicine is leading the study.

Unlike other conditions currently listed on the monthly report card, your participation and survey responses will remain anonymous.

More detailed information can be found on the APSU website on our [Current Studies](#) page where you can find links to the Participant Study Information Sheet and links to the online and printable case report forms.



Image by Gerd Altmann from Pixabay

### RACP Specialty Society Webinar Series 2024

RACP first piloted the Specialty Society webinar service in 2017 with 10 Specialty Societies to explore opportunities for collaboration between Specialty Societies and the College in delivering Continuing Professional Development resources to RACP members. Following the successful pilot, the webinar series program has continued since 2018.

Login to watch live or recorded sessions here: [www.racp.edu.au/fellows/resources/specialty-society-webinar-series](http://www.racp.edu.au/fellows/resources/specialty-society-webinar-series)

APSU will be presenting the following sessions:

Speaker	Webinar topic	Scheduled date	Webinar start time (AEDT)
Professor Elizabeth Elliott	The Australian Paediatric Surveillance Unit: achievements in research, advocacy and care for children living with rare conditions for over 30 years	Tuesday 19th November 2024	6pm
Dr Carlos Nunez	APSU Surveillance of Rare injuries in Children	Tuesday 26th November 2024	6pm
Dr Suzy Teutsch	Infectious Disease Surveillance by APSU	Tuesday 3rd December 2024	6pm

### MD Student Spotlight: Lochlan Bull

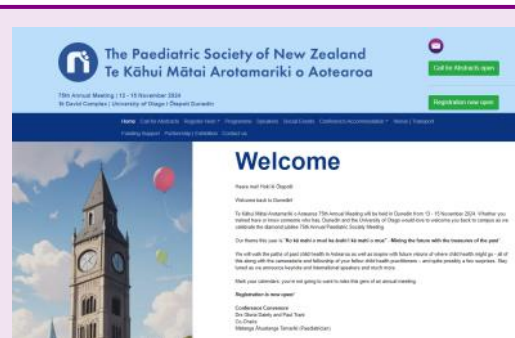
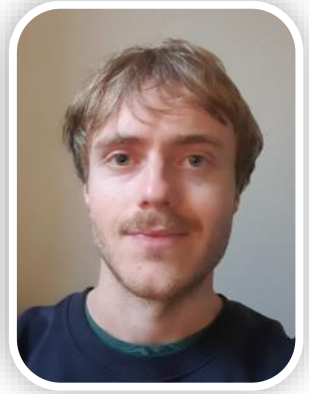
Fourteen weeks ago, I took my first steps into the world of research as a third-year medical student from the University of Sydney. Among the many moments of feeling like a fish out of water in medical school, completing a research project in three months was a particularly daunting requirement of the curriculum. However, the chance to contribute to the research community also evoked a sense of enthusiasm and determination. I stumbled at first, and a couple more times along the way, but I put one foot in front of the other and eventually finished a systematic review of the psychological impacts on parents of children with a rare disease.

It has been informative, but often challenging, to learn about the difficulties faced by those caring for a child with a rare disease and their unmet psychological needs. However, I am hopeful that there will be more support and understanding of the family burden

associated with rare diseases in the coming years. I am also motivated to carry what I have learnt with me as I continue my medical training.

I am very grateful to the APSU for allowing me to contribute to this area of research, and to my supervisors, A/Prof Guy Eslick and Dr Suzy Teutsch, who provided invaluable support and guidance over the fourteen weeks with twice-weekly Zoom calls and very prompt replies to my innumerable emails and draft reports.

Although I started the fourteen weeks with some trepidation, I am finishing it with the same enthusiasm and interest that got me through it and look forward to my next research endeavour.



Our Paediatric colleagues in Aotearoa New Zealand are hosting their **75th Annual Paediatric Society Meeting** in beautiful **Dunedin**.

**13 - 15 November 2024**

The theme this year is "**Ko kā mahi o muri ka ārahi i kā mahi o mua**" - **Mining the future with the treasures of the past**".

Visit their web page for all the details [here](#).

### MD Student Spotlight: Summer Page

I completed an MD project with the APSU looking at congenital anomalies in children with FASD. I enjoy research and was excited for this project, although my lack of experience in epidemiology or paediatrics left me nervous that I may have bitten off more than I could chew.



My primary supervisor, Dr Tracey Tsang, offered wonderful guidance and anticipated the areas I would need assistance with, making my transition into this new field feel seamless. Throughout the project,

my co-supervisors A/Prof Guy Eslick and Prof Elizabeth Elliott were welcoming and incredibly supportive.

This project taught me about FASD, disease surveillance, and congenital anomaly classification systems and improved my skills in data collection and analysis. More importantly, it opened my eyes to how versatile a medical degree can be. I want to incorporate research into my career, but the clinical focus of the first two years of medicine left me unsure how feasible it would be to add research on top of a clinical load.

My experience during this project and learning about my supervisors' careers has shown me that it is not only possible, but also important, to include research in a medical career. Looking forward, I am very excited to do so.



## The World Congress on Alcohol and Addictions 2024



Dr Carlos Nunez (left) presenting with Prof Elizabeth Elliott (right)

The World Congress on Alcohol and Addictions was hosted by the International Society for Biomedical Research on Alcoholism, Melbourne, 23–26 September 2024.

Carlos Nunez presented the Mechanism for national surveillance of FASD: the Australian Paediatric Surveillance Unit (APSU)

Prof Elizabeth Elliott chaired The First 1000 Days theme and gave a plenary highlighting the impact of prenatal exposures on child outcomes.

FASD DIAGNOSIS: FAMILY EXPERIENCE OF THE DIAGNOSTIC PROCESS & IMPACT OF THE DIAGNOSIS ON FAMILIES



DR MARCEL ZIMMET

ISBRA 2024

SESSION 41: FETAL ALCOHOL SPECTRUM DISORDER (FASD) IN AUSTRALIAN CHILDREN, SURVEILLANCE AND EPIDEMIOLOGY



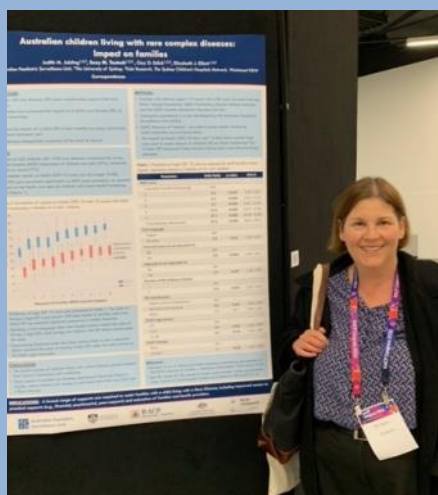
Dr Carlos Nunez (left) with Dr Marcel Zimmet (right)

## Fetal Alcohol Spectrum Disorder Australian Register (FASDAR)

Complementary to the APSU FASD project is the FASD Australian Registry (FASDAR), for which we are seeking patient referrals. FASDAR aims to improve the diagnosis, treatment and prevention of FASD in Australian children, by informing clinical, diagnostic and treatment guidelines, policies and programs to improve outcomes for children and their families. FASDAR also supports research studies and clinical trials. We are seeking help from clinicians to invite patients with FASD (aged <15 years at diagnosis) to register with FASDAR by providing them the Participant Information and Consent Forms, and seeking their consent to participate, or inviting them to contact us directly. The Participant Information and Consent Forms are can be found on the FASDAR website: [www.fasdregistry.org.au/parents/carers/](http://www.fasdregistry.org.au/parents/carers/)



## RACP Conference 2024



Suzy Teutsch (left) with her poster on Australian children living with rare complex diseases: Impact on families, at the RACP Congress 2024, ICC Sydney.

Carlos Nunez (right) with his poster on Complications of button battery exposure in children: Systematic Review and pooled analysis of individual patient-level data, at the RACP Congress 2024, ICC Sydney.



## APSU Scientific Review Panel (SRP)

Thanks are extended to our ongoing SRP members: Dr Mavis Duncanson (NZ), Dr Fiona Mackie, Dr David Lester-Smith, Dr Tasneem Karim, Dr Anne Morris and Prof Elizabeth Elliott. **EOI to join the SRP are currently open**, please contact APSU for further information at email: [SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)

## Upcoming Events

### Celebrating 25 Years of the New Zealand Paediatric Surveillance Unit

Tuesday 12th November 2024

St Margaret's College, University of Otago, Dunedin NZ  
and online (contact email [nzpsu@otago.ac.nz](mailto:nzpsu@otago.ac.nz) for details)

Sessions include:

- Australian PSU, 30 years on including topics in common with NZPSU, Prof Elizabeth Elliott
- NZPSU — 1997 to 2016, A/Prof Nigel Dickson
- NZPSU — 2017 to 2023, Dr Mavis Duncanson

#### 'Since the beginning—NZPSU research that made a big difference'

- AFP and Polio NZ, Dr Mavis Duncanson
- Perinatal HIV NZ, Dr Lesley Voss
- Severe adverse drug reactions, A/Prof David Reith
- Congenital syphilis, A/Prof Emma Best
- Acute Hepatitis, Dr Helen Evans
- Ricketts, Professor Ben Wheeler

### The Paediatric Society of New Zealand

Te Kāhui Mātai Arotamariki  
o Aotearoa

are hosting the

### 75th Annual Meeting

in beautiful Dunedin.

13 - 15 November 2024

The theme this year is

"Ko kā mahi o muri ka ārahi i kā mahi o  
mua"

- *Mining the future with the treasures of  
the past*"

Visit their web page for all the conference  
details [here](#).

### We're working hard to bring you a better experience

on our website: [www.apsu.org.au](http://www.apsu.org.au)

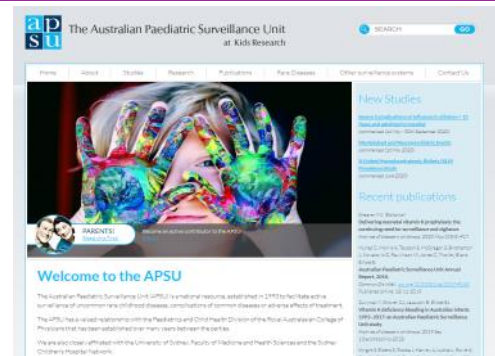
Is there something we can do better?

Do you have any suggestions you would like to share with us?

Is there a resource you would like to see included?

Please contact us with your thoughts and suggestions at:

[SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)



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### Disclaimer

The information contained in Rare Kids Newsletter is provided in good faith from sources believed to be accurate and true at the time of publication. The material is provided for general information only and does not constitute professional advice. The APSU does not expect or invite any person to act or rely on any statement, opinion or advice contained herein.

**REDCap Online Reporting:** APSU Contributors can now complete case report forms ONLINE through our data capture management system REDCap. Simply visit our [Current Studies page on the APSU website](#) and click on the relevant links to access Study Information Sheets (includes Case Definition), printable Case Report Forms and links to ONLINE Case Report Forms specific to each study. If you have any difficulties accessing the links or would like more information about completing the forms online, please contact us.

**Still returning the yellow card by post?** If you are one of the remaining 70 of 1500 clinicians still receiving the yellow report card by post, we would like to make responding easier for you. To start responding via email, please contact us at: [SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)

**Changed your contact details?** Please let us know your new details by emailing us at: [SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)

**Not currently an APSU Contributor?** We would very much like clinicians in paediatric and child health to become a member of the APSU and to contribute data to support our unique national surveillance effort. To join the APSU, please contact us by email at: [SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)