



Australian Paediatric Surveillance Unit

rare kids

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Welcome to the **July 2025** APSU newsletter. In this edition, we highlight our most recent publications. These publications are made possible due to your contribution to our surveillance studies, whether you are responding that you have nothing to report each month, or reporting a case and completing the associated case report forms. Please take a moment to review our latest published findings.

Surveillance Study Update - data collection closing

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

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. **If you still have a response to submit to the anonymous survey, please complete the survey as soon as possible.**

The aim of the 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.

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.**

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.



Guy Eslick

The Australian Paediatric Surveillance Unit would like to extend a very warm and heartfelt Thank You to Guy Eslick who we farewelled in January 2025. We thank Guy for sharing his knowledge and expertise with both APSU staff and MD students. We wish you well with your future endeavours.

Thank You

Dr Tracey Tsang (25 December 1982 - 9 April 2025)

I write with profound sadness to acknowledge the unexpected and sudden death of Dr Tracey Tsang on 9 April 2025, aged 42 years, nine months after being diagnosed with a facial tumour. Tracey was a good friend, and I had the privilege of having her as a research colleague in the Specialty of Child and Adolescent Health at the University of Sydney for over 12 years.

Tracey was humility personified – and few who worked with her realised her exceptional talents. She graduated with a Bachelor of Applied Science at the University of Sydney with First Class Honours and was awarded the University Medal. She was a brilliant violinist, having achieved a prestigious Licentiate in Music, Australia, which is awarded to exemplary candidates and is considered a professional credential. She played first string in the SBS Youth Orchestra and latterly performing in a quartet, often at charitable fundraisers. If that was not enough, she was a black belt in martial arts and had represented Australia in international Kung Fu competitions.

Above all, however, Tracey was a dedicated Mum to her much-loved boys Jared and Dylan, and a supportive wife to Tim Stegeman through his many years of medical and anaesthetic study. At her funeral Tracey was praised as a wonderful friend and for her great sense of humour and penchant for good food.

Tracey also loved her work. Just days before her death we had extended her Senior Research Fellow contract, and she was looking forward to returning to work. She first came to work with me in 2013 after doing her PhD, on the role of anxiety in ADHD, in the adolescent unit at Westmead Hospital. During her work in my group at the Children's Hospital Westmead Clinical School, she supported and worked with Aboriginal leaders, post-graduate students and researchers on the Lililwan project – exploring the prevalence of Fetal Alcohol Spectrum Disorder (FASD) and early life trauma in the remote Fitzroy Valley of Western Australia. She was also a key researcher when we followed this cohort 10 years later in the Bigiswun Kid project.

Tracey's work advanced our knowledge about alcohol use in pregnancy and the effects of prenatal alcohol exposure (PAE), particularly FASD, and had been cited in clinical guidelines and policy. She published three seminal systematic reviews - on eye and vision abnormalities, ear and hearing abnormalities, and behavioural challenges in children with PAE and FASD. She also reported on motor skills, behaviour, speech, vision, facial dysmorphology and health outcomes in the Lililwan cohort. Tracey also played an important role in recording the results of an NHMRC-funded trial conducted in the Hunter New England region to improve the management of alcohol use in pregnancy.

She developed a national database for FASD with the Australian Paediatric Surveillance Unit and managed the FASD Registry Australia. She also contributed to the recent revision of the Australian Guidelines for the Diagnosis of FASD. Her recent work on estimating FASD prevalence in the general Australian population is to be published in June 2025. Her work on the impact of prenatal cannabis and polysubstance use on neurodevelopment in FASD, the genetics of FASD, and mental illness in FASD is ongoing.

Tracey's contribution to broadening our understanding of FASD, and improving the health and quality of life for children living with FASD, will have a lasting impact. We will miss her smile, her friendship, her enthusiasm, her expertise, and her dedication to her work.

Vale Tracey.

Elizabeth Elliott, Professor of Paediatrics and Child Health, Director APSU. May 2025



Publications update

APSU publications are made possible due to your ongoing contribution to our surveillance studies, whether you are responding that you have nothing to report each month, or reporting a case and completing the associated case report forms.

The APSU is grateful for your ongoing active participation in our surveillance studies and ensures that APSU contributors are acknowledged in every publication.

2025

- Bull, L.J., Eslick, G.D., Teutsch, S.M., & Elliott, E.J. **Assessing Psychological Harms on Parents and Primary Caregivers of Children Living with a Rare Disease: A Systematic Review of the Scope and Validity of Surveys Utilized.** Clin Child Fam Psychol Rev (2025). doi.org/10.1007/s10567-025-00533-7
- Tsang TW, Rosenblatt DH, Parta I, Elliott EJ. **Estimating the Prevalence of Fetal Alcohol Spectrum Disorder in Australia.** Drug and Alcohol Review. 2025 Jun 4. doi.org/10.1111/dar.14082
- Teutsch SM, Nunez CA, Morris A, Eslick GD, Elliott EJ, on behalf of Chief Investigators of APSU. **Australian Paediatric Surveillance Unit (APSU) Annual Surveillance Report 2023.** Communicable Diseases Intelligence (2018). 2025, 49: doi.org/10.33321/cdi.2025.49.019
- Jobling JM, Teutsch SM, Eslick GD, Elliott EJ. **Impact on the family of a child's rare disease: a large cross-sectional study.** Rare. 2025 Feb 7:100066. doi.org/10.1016/j.rare.2025.100066
- Tsoi KY, Sharwood LN, Eslick GD, Nunez C, Morris A, Williams N, Erskine C, Adams S. **Evaluating Paediatric Injury Hospitalisations From Indoor Trampoline Parks Across Australia: A Multi-Centre Study.** Journal of Paediatrics and Child Health. 2025, 61(3):457-464. doi.org/10.1111/jpc.16770

2024

- Tran C, Nunez C, Eslick GD, Barker R, Elliott EJ. **Button battery exposure in children: a systematic review and meta-analysis.** Injury and Prevention. 2024. doi.org/10.1136/ip-2024-045339.
- 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. doi.org/10.1007/s12519-024-00833-y
- Berkhout A, Yeoh DK, Teutsch S, Morris A, Nourse C, Clark JE, Blyth CC, Jones CA; APSU Neonatal HSV Study Advisory Group. **Herpes simplex virus in infancy: Evaluation of national surveillance case capture.** Journal of Paediatrics and Child Health. 2024. Oct 60 (10):526-530, doi.org/10.1111/jpc.16596.
- Elliott EJ, Teutsch S, Nunez C, Morris A, Eslick GD. **Improving knowledge of rare disorders since 1993: the Australian Paediatric Surveillance Unit.** Archives of Disease in Childhood. 2024 109(12):967-979, doi.org/10.1136/archdischild-2023-326116.
- Tsang TW, Allen T, Turner A, Bowyer J, Fitzpatrick J, Latimer J, Oscar J, Carter M, Elliott EJ. **Ophthalmic Findings in Aboriginal Children with High Rates of Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorder: The Lililwan Project.** Ophthalmic Epidemiology. 2024 Mar 25:1-8. doi.org/10.1080/09286586.2024.2331539.



APSU Scientific Review Panel (SRP)

Thanks are extended to our ongoing SRP members: Dr Mavis Duncanson (NZ), 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



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

Are you interested in conducting a study through the APSU?

Contact the APSU by email at SCHN-APSU@health.nsw.gov.au to arrange a time to discuss your ideas and project requirements with the APSU team.

REMINDER TO ALL APSU CONTRIBUTORS:

Please respond to the monthly report card email—even if you don't have a case to notify. The "nothing to report" response provides information about participation in the scheme, is a mechanism for assessing completeness of case ascertainment and ensures that the scheme provides good quality data.

Visit our website at: www.apsu.org.au

Find current and past study related material, as well as our publications library

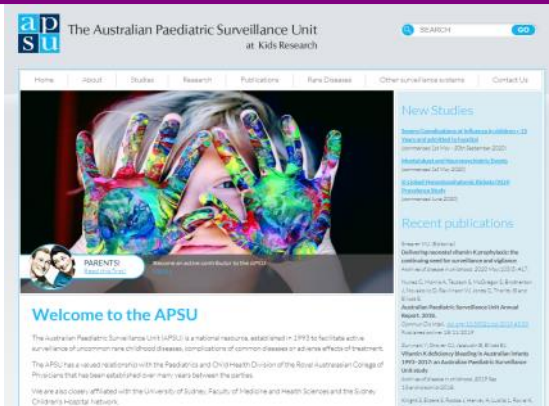
Is there something we can do better?

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



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REDCap Online Reporting: APSU Contributors can now complete case report forms ONLINE through our data capture and 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 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

Changed your contact details? Please let us know your new details by emailing us at: 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