



Australian Paediatric Surveillance Unit **NEWSLETTER** December 2018

Welcome to the December 2018 edition of the APSU's Rare Kids newsletter.

We hope that you find the newsletter interesting and informative and welcome your feedback at: SCHN-APSU@health.nsw.gov.au

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Looking ahead

Surveillance Studies under development

- Hypophosphatasia (HPP)
- X-Linked Hypophosphataemic Rickets (XLH)

Australian Paediatric Surveillance Unit Celebrating 25 Years of research, advocacy and care for children living with rare conditions

The APSU was founded in 1993 in recognition of the gap in knowledge about the epidemiology of rare childhood disorders in Australia. Through the APSU, paediatricians have made a significant contribution to closing that knowledge gap, and this has improved the health and well-being of children nationally.

In 25 years, over 300 researchers have used the APSU to conduct more than 69 studies on rare disorders including infections, genetic diseases and injuries. It has been a great pleasure to have been involved in the important work of the APSU.

In May we celebrated our 25 Year Anniversary and said farewell to A/Professor Yvonne Zurynski, our Director of Research. I thank her for 13 Years of dedicated service to leading and advancing the scope of APSU activities. I thank all Staff, Study Investigators, Committee members and Paediatricians throughout Australia for their contributions to the success of the APSU over the years and look forward to an on-going collaboration. We acknowledge with gratitude financial support from the Australian Department of Health

Professor Elizabeth Elliott

APSU Scientific Review Panel (SRP)

APSU thanks SRP members for their continued support of APSU activities through 2018: Professor Carol Bower, Dr Fiona Mackie, Dr David Burgner, Dr Mavis Duncanson, Dr David Lester-Smith and Professor Bin Jalaludin.

We extend a heartfelt and extra special thanks to the outgoing panel members, Associate Professor Yvonne Zurynski (13 Years), Professor Bin Jalaludin (18 Years), and Professor Carol Bower (21 Years) for their exceptional commitment in providing expert reviews, guidance and support essential to the success of APSU surveillance studies.



Professor Bin Jalaludin



Associate Professor Yvonne Zurynski



Professor Carol Bower

Surveillance Study Updates

Severe Injury Related to Disc Battery (SIRDB)

A year has passed since the SIRDB surveillance was launched on the APSU monthly report card. As at December 2018, **13 cases** have been notified with **most injuries having occurred in young children less than five years of age**.

Now that the festive season and school holidays are upon us, access to new toys and gadgets that contain button batteries is inevitable.

We encourage all APSU contributors to report any child less than 16 years of age with a newly diagnosed injury related to disc or button battery ingestion or insertion that required procedural intervention—either to remove the battery, to assess or to repair damage related to the battery to the APSU.

Please do not report cases where the battery has been ingested/inserted and it has passed/fallen out of the patient and the patient did not require a procedure to remove the battery or to assess or repair damage related to the battery.

This valuable information will assist in the review of manufacturing and packaging standards and codes for products and packaging containing disc batteries.



Links to recent related media articles:

The Conversation: 'Button batteries kill. Here's how we can prevent needless child deaths from battery ingestion' 09/08/2018

CHOICE: 'The hidden dangers of button batteries' 27/09/2018

The Sydney Morning Herald: "The walking dead": Toddlers who swallow button batteries' 19/08/2018

AFP REMINDER

Keeping Australia Polio Free — 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 certification of Australia by the WHO. The WHO indicators of surveillance performance include a target annualised non-polio AFP rate of >1/100 000 children under 15 years of age.

The APSU protocol and case report form can be found here: [APSU Protocol](#), [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.

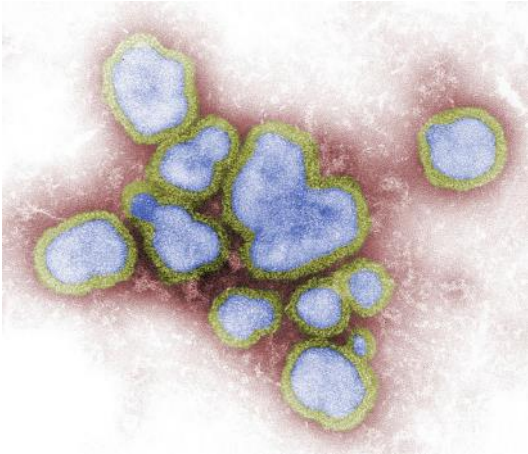
More details at: www.vidrl.org.au/laboratories/poliovirus-reference/specimen-referral

Please do not hesitate to contact the APSU if you have any questions about this surveillance.

Surveillance Study Updates

Severe Complications of Influenza 2018

The 2018 flu season is over and 20 confirmed cases with severe complications were reported to the APSU between the 1st June and the 30th September.



Influenza A virions Image credit: CDC/F.A.Murphy

Included were children aged < 15 years with laboratory confirmed influenza **AND** admitted to hospital **AND** who have at least one of the following complications:

pneumonia (confirmed on X-ray or microbiology), oxygen requirement, mechanical ventilation, laboratory proven secondary bacterial co-infection, encephalitis, encephalopathy seizures (including simple febrile seizure, prolonged or focal seizure or status epilepticus), transverse myelitis, polyneuritis, mononeuritis, Guillain-Barré syndrome, Reye syndrome, myocarditis, pericarditis, cardiomyopathy, rhabdomyolysis, purpura fulminans, disseminated coagulopathy, shock (requiring >40 ml/kg fluid resuscitation), acute renal failure or death, including death at presentation to hospital.

The most frequently reported complications included:

pneumonia (47.6%), Laboratory proven bacterial co-infection (23.8%), seizure (14.3%), laboratory proven viral co-infection (14.3%), encephalitis or encephalopathy (9.5%), rhabdomyolysis (9.5%), disseminated coagulopathy (9.5%), shock (requiring >40 ml/kg fluid resuscitation) (9.5%) and acute renal failure (9.5%).

Of the 20 cases, 1 died and 10 were admitted to a paediatric intensive care unit.

In the last 11 years, there have been 633 cases reported to the APSU with severe complications of influenza supporting current recommendations for vaccination.

Information about Influenza, vaccines and recommendations for vaccination can be found in the Australian Immunisation Handbook and can be viewed by following this link:

<https://immunisationhandbook.health.gov.au/vaccine-preventable-diseases/influenza-flu#accordion-para-8446-155031>

Staff Changes in the APSU

We bid farewell to **Associate Professor Yvonne Zurynski** after 13 years of dedicated service. Yvonne joined the APSU in 2005 taking on the role of Assistant Director. From 2016, Yvonne expertly guided the APSU as the Director of Research until her resignation in March this year. Yvonne has taken up a new position at the Australian Institute of Health Innovation, Macquarie University as the Associate Professor of Health System Sustainability and leads the coordinating unit of the NHMRC Partnership Centre in Health System Sustainability.

We miss Yvonne's expertise and hard work and thank her for her commitment and outstanding contribution to APSU. We wish Yvonne success in her new role.

We welcome **Carlos Nunez Miranda** to the role of Research Associate. Carlos has just completed his PhD in Cancer Epidemiology at The University of Sydney's School of Public Health.

We farewelled **Ingrid Charters** after spending the last 12 months supporting the APSU administrative functions (Ingrid's second term with APSU), and wish her success in her new role at The Children's Hospital Westmead.



Team APSU 2018

New Study Alert: Children Hospitalised with Severe Indoor Trampoline Park Injury

Indoor trampoline parks are increasingly popular, especially amongst children. Their proliferation across Australia has seen a rise in the number of injuries, including serious spinal injuries. More than 20 new centres have opened in Australia since 2013. Trampolines used in trampoline parks differ from domestic trampolines used in backyards across the country, both in design and patterns of use. They are generally large centres with multiple interconnected bouncing surfaces, foam pits and game areas (see pictures). They are designed to be crowded and dynamic, attracting birthday parties, social groups and families. Thus, the injury mechanisms and type differ. New voluntary safety standards have been developed for the industry in an attempt to reduce the number of injuries, however not all indoor trampoline parks have committed to these standards.



Given that paediatric injury from indoor trampoline parks is now increasingly recognised as an emerging public health and safety issue, [Dr Susan Adams](#) and [Dr Lisa Sharwood](#), who have both recently appeared in media reports about this issue, are leading this new APSU study with the aim of quantifying and characterising the scale and scope of paediatric injuries at a national level, so that more evidence based and informed injury prevention strategies can be developed.

Please **start reporting cases** of Severe Indoor Trampoline Park Injury Admitted to Hospital. The new study already appears on the recently distributed APSU November 2018 report card. The protocol and case report form have been uploaded to the APSU website: [Protocol](#), [Online Case Report Form](#), [Printable Case Report Form](#). Please complete the case details via the secure online case report form or simply download the PDF Printable Case Report Form, complete and email or fax back to the APSU.

Case definition: Please report any child aged up to and including 15 years who is admitted to hospital as a result of injury(ies) sustained while at an indoor trampoline park/facility.

Exclusions: Please don't report children injured on a domestic trampoline, or at an outdoor recreational trampoline facility, children discharged from emergency department and not admitted to hospital.

Links to recent related media items:

[The Sydney Morning Herald: 'Jump in trampoline park injuries sparks calls for mandatory standard' 15/02/18](#)

[The Sydney Morning Herald: "Appalling": How to avoid unsafe trampoline parks 'in for a quick buck' 18/11/2018](#)

[The Project, Channel 10: 'Should Trampoline Parks Have Mandatory Safety Standards?' 20/11/2018](#)



Recent Events

Celebrating 25 Years of the APSU

On a very wet and windy Sunday in May, the APSU acknowledged 25 Years of achievements and impacts at The Charles Perkins Lecture Theatre, The University of Sydney, by hosting an informative day of talks and discussions.

Special thanks are extended to the speakers who graciously donated their time to participate in such a successful and interesting day:

- **Professor Paul Colditz** (*Chair, President, Paediatrics and Child Health, RACP*)
- **Professor Carol Bower** (*Chair, APSU SRP Chair*)
- **Mr Steve Waugh AO** (*Meeting the needs of children living with rare disease and their families*)
- **Professor Elizabeth Elliott AM FAHMS** (*Celebrating 25 years of APSU achievements*)
- **Associate Professor Yvonne Zurynski** (*Living with a rare disease—experiences of families and clinicians*)
- **Dr Sloane Madden** (*Early Onset Eating Disorders in young children: role of surveillance to support policy and care*)
- **Professor Natasha Nassar** (*Chair, Financial Markets Foundation for children Chair of Translational Childhood Medicine*)
- **Dr Marcel Zimmet** (*Fetal Alcohol Spectrum Disorder—from surveillance to policy*)
- **Professor Heather Jeffery AO** (*Sudden Unexplained Death in Australian Infants*)
- **Professor Helen Leonard** (*RETT Syndrome: from surveillance to genotype-phenotype characterisation*)
- **Professor John Christodoulou AM** (*Chair, Chair of Genomic Medicine, Murdoch Childrens Research Institute*)
- **Professor Cheryl Jones** (*Consequences of congenital infection: HSV, Rubella, Varicella, HIV, cCMV and Zika*)
- **Dr Anne Durkan** (*Long-term outcomes after atypical HUS*)
- **Associate Professor Julia Brotherton** (*Juvenile Onset Respiratory Papillomatosis*)
- **Professor Robert Booy** (*Severe Influenza in Australian Children*)
- **Dr Philip Britton** (*Encephalitis Study*)



Thank you to our sponsors for their support of the event:

Sydney Children's Hospital Foundation

and **Kids Research, The Sydney Children's Hospitals Network**



L to R: Carol Bower, Yvonne Zurynski, Sloane Madden, Paul Colditz, Steve Waugh, Lynette Waugh, Elizabeth Elliott



L to R: Steve Waugh, Lynette Waugh, John Christodoulou, David Dossetor, Heather Jeffery, Elizabeth Elliott



L to R: Julia Brotherton, Philip Britton, Robert Booy, Anne Durkan, David Dossetor, Elizabeth Elliott, Suzy Teutsch



L to R: Carol Bower, Yvonne Zurynski, Elizabeth Elliott



L to R: Natasha Nassar, Carol Bower, Helen Leonard

APSU Facts: Since 1993 APSU has...

Sent 369,999 report cards

Maintained a response rate of >90% each year

Studied 69 conditions

Collected detailed data on ~8,510 children with rare disease

Published ~ 350 journal publications and reports.

In 1993 990 clinicians reported by returning a report card in the post, in 2018, ~1570 clinicians reported to APSU, 95% by e-mail

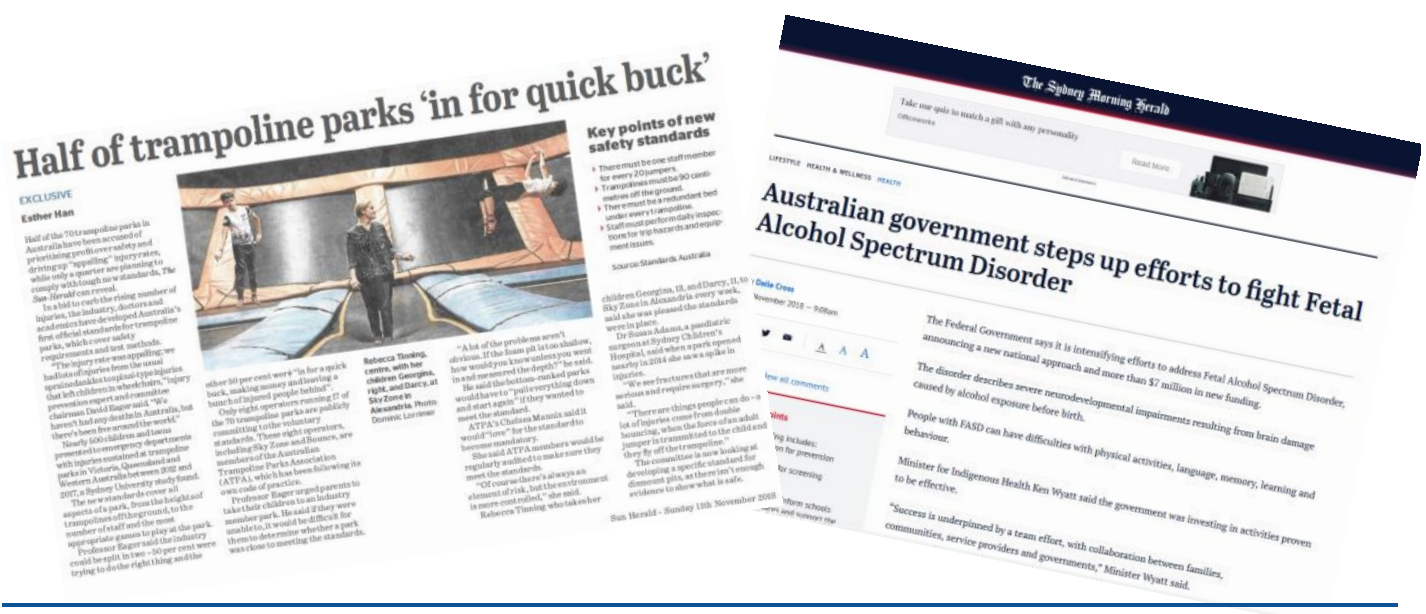
Key Publications and Media for

Key Publications:

- [Novakovic D, Cheng AT, Zurynski Y, Booy R, Walker PJ, Berkowitz R, Harrison H, Black R, Perry C, Vijayasekaran S, Wabnitz D. A prospective study of the incidence of juvenile-onset recurrent respiratory papillomatosis after implementation of a national HPV vaccination program. The Journal of infectious Diseases. 2018 Nov 9;217\(2\):208-12.](#)
- [Suzy Teutsch, Yvonne Zurynski, Elizabeth Elliott, and all chief investigators of APSU surveillance studies. Australian Paediatric Surveillance Unit Annual Report, 2017. Communicable Diseases Intelligence. PII:S2209-6051\(18\)00006-4. Published online: 12/09/2018](#)
- [Bartlett AW, Hall BM, Palasanthiran P, McMullan B, Shand AW, Rawlinson WD. Recognition, treatment, and sequelae of congenital cytomegalovirus in Australia: An observational study. Journal of Clinical Virology. 2018.](#)

Media:

- [The Sydney Morning Herald: 'Jump in trampoline park injuries sparks calls for mandatory standard' 15/02/18](#)
- [The Conversation: 'Button batteries kill. Here's how we can prevent needless child deaths from battery ingestion' 09/08/2018](#)
- [The Sydney Morning Herald: "The walking dead": Toddlers who swallow button batteries' 19/08/2018](#)
- [CHOICE: 'The hidden dangers of button batteries' 27/09/2018](#)
- [The Sydney Morning Herald: "Appalling": How to avoid unsafe trampoline parks 'in for a quick buck' 18/11/2018](#)
- [The Project, Channel 10: 'Should Trampoline Parks Have Mandatory Safety Standards?' 20/11/2018](#)
- [The Sydney Morning Herald: 'Australian government steps up efforts to fight Fetal Alcohol Spectrum Disorder 22/11/2018](#)



Upcoming Events



The First International RCPCH Conference in the MENA region
29th — 31st January 2019, Cairo EGYPT

www.rcpchmena-eg.org

Royal Australian College of Physicians Congress

“Impacting health along the life course”

6th — 8th May 2019, Auckland NEW ZEALAND

www.racpcongress.com.au



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RedCap Online Reporting Clinicians are now able to complete most case report forms online through our data capture management system (RedCap). Simply click on the link provided in the monthly report card email to complete the form. Links to the current APSU protocols and case report forms can be found in the monthly email report card and are also available for download on the [APSU website](http://www.apsu.org.au). 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 90 clinicians out of 1600 still receiving the yellow report card we would like to make responding easier for you.

Not currently an APSU Contributor? We would very much like you to become a member of the APSU and to contribute data to support our unique national surveillance effort.

Changed your contact details? Please let us know your new details.

To start responding via email, to join the APSU or to notify us of your changed contact details please contact us on: SCHN-APSU@health.nsw.gov.au

We're on the Web

www.apsu.org.au

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