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From the Co-Chair

It has been some time since the last INoPSU newsletter and there is much news to report.

After the success of the INoPSU Symposium and business meeting in Melbourne in August 2013 (see page 2), INoPSU and member units have progressed steadily, contributing unique data on rare childhood conditions to influence clinical practice and policy. APSU, and CPSP have each started five new surveillance studies, BPSU has started four new studies while NZPSU has started three and if we look across all of INoPSU 22 new studies have begun since 2013.

The units have been very productive with at least 60 publications in the last 2 years and an important INoPSU paper on surveillance methodology used across the network for Acute Flaccid Paralysis to meet the WHO goals for poliovirus eradication.

We were all devastated to lose our good friend and Co-Chair of INoPSU, Dr Danielle Grenier in September 2014. In recognition of Danielle's enormous contribution to INoPSU, to rare disease surveillance and to paediatrics and child health, we have established The Danielle Grenier Prize for Excellence in Paediatric Surveillance, which will be awarded to the best presentation at each INoPSU scientific meeting. We would like to express our thanks to Melanie Laffin Thibodeau in the CPSP for all of her hard work and ongoing communication with INoPSU during a difficult time.

There have been many changes in leadership in the Netherlands, Portugal and New Zealand Units. Rob Rodriguez-Pereira from the Netherlands retired after many years leading the Netherlands Unit. We thank Rob for his valuable contribution to INoPSU and his strong leadership as convenor of the Network 2006-2008. Daniel Virella moved on from his role at the Portuguese unit. Daniel also ably led INoPSU as convenor from 2009-2012. Barry Taylor retired from his role in the NZPSU after leading NZPSU together with Nigel Dickson for many productive years. We wish Rob Barry and Daniel every success and happiness in the future. We warmly welcome Joana Kist-van Holth who will lead the Netherlands unit.

Finally, I too must move on from my role as Co-Chair of INoPSU. I certainly enjoyed the role enormously, especially working with my Co-Chair, Danielle Grenier, who I miss very much. We achieved much in a relatively short time, including the successful meeting in Melbourne, the 15 Year INoPSU Report, new INoPSU logo and website, new terms of reference and guidelines on establishing a new paediatric surveillance unit. I would like to thank Richard Lynn from the BPSU and everyone from INoPSU for their support.

In London this week, I handed over all matters relating to INoPSU to **Mirjam Maeusezahl** from the Swiss Paediatric Surveillance Unit. I have every confidence that Mirjam will bring new ideas and vitality to INoPSU. I look forward to being involved with INoPSU in the future.

- Yvonne Zuryski



Danielle Grenier Prize for Excellence in Paediatric Surveillance

In 2014 we lost our good friend and avid supporter of INoPSU, Danielle Grenier.

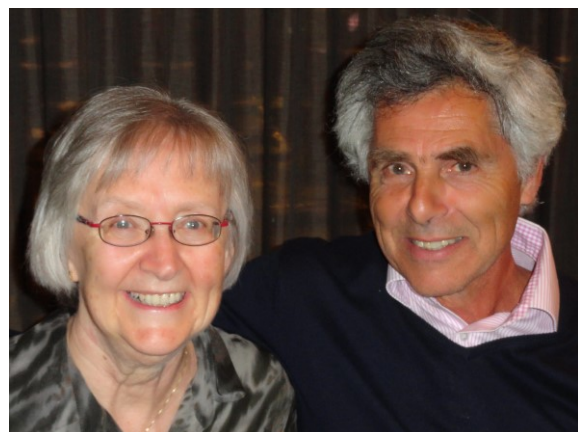
Danielle's leadership of the Canadian Paediatric Surveillance Program since its inception in 1996 was widely recognized in Canada and internationally. She was an influential figure in INoPSU, taking on the role of Co-Chair of the network from August 2012. Importantly, Danielle was a strong proponent of international collaboration, leading and contributing to international papers that reported data from INoPSU members. She regularly contributed to her local journal, *Paediatrics & Child Health*, often citing new results from surveillance studies undertaken by the CPSP, to influence paediatric clinical practice and policy. She was an outspoken advocate for child health and children's rights, using evidence to support her advocacy work. She also co-edited an important book: *Well Beings: A Guide to Health in Child Care*.

She will be very much missed by everyone from INoPSU, and we will always remember her exceptional clinical skills, her passion for research, epidemiology and evidence based practice. Most of all we will remember Danielle's sparkling enthusiasm for INoPSU, her friendship and her positive influence on us all.

In recognition of her enormous contribution to INoPSU, we will give a prize in her name to the best presentation at each INoPSU Scientific meeting: **The Danielle Grenier Prize for Excellence in Paediatric Surveillance**.



Danielle at the ICP 2013 Melbourne Australia



Danielle and Rob Rodriguez Pereira, Director of the Netherlands Paediatric Surveillance Unit at the INoPSU dinner Melbourne 2013

Congratulations to the British Paediatric Surveillance Unit on their 30th Anniversary!



From everyone at INoPSU, our heartfelt congratulations to the BPSU on their 30th Anniversary!

BPSU was the first national surveillance unit designed specifically to collect data on rare childhood conditions. The methodology was innovative 30 years ago and it continues to be used by at least 11 national surveillance units across the world. BPSU has provided vital and unique data on 110 rare childhood diseases, and has been proactive in using these data to inform clinical practice and public health policy.

Congratulations to all paediatricians for contributing to the many successes of the BPSU and for continuing to participate in BPSU surveillance. A special congratulations and thank you to Richard Lynn who has managed the BPSU for many years through good times and bad and still always managed to find time to contribute to INoPSU.

As the late Sir Cyril Clarke, BPSU chairman, stated in 1991:

“British and Irish paediatricians can feel justly proud of themselves as pioneers and as key enactors in this unique reporting system”

BPSU, we thank you for your innovative approach and significant leadership over the last 30 years and we look forward to your continued success!

For more information on the BPSU please visit their website: www.rcpch.ac.uk/bpsu

Congratulations to the Swiss Paediatric Surveillance Unit on their 20th Anniversary!

SPSU – The Swiss Paediatric Surveillance Unit is celebrating its 20th Anniversary this year! Happy anniversary and may your success continue long into the future!

Events

International Congress of Paediatrics Vancouver, Canada 17-22 August 2016

<http://www.ipa2016.com>



BPSU 30th Anniversary Conference and Rare Disease Day Tea Party: Rare Diseases in Paediatrics – From Birth to Transition, Tuesday 23rd February 2016

For further information please follow this link www.rcpch.ac.uk/bpsu/rdc16 or contact the BPSU richard.lynn@rcpch.ac.uk or jacob.avis@rcpch.ac.uk or <http://www.rcpch.ac.uk/bpsu>

New studies commenced 2013 - 2015

Unit	Date Commenced	Surveillance study Title	Link to study protocol
APSU	1/09/14	Childhood Interstitial Lung Disease	http://www.apsu.org.au/studies/current/
	1/04/15	Chronic Fatigue Syndrome	http://www.apsu.org.au/studies/current/
	1/12/14	Fetal alcohol spectrum disorders (FASD)	http://www.apsu.org.au/studies/current/
	1/06/14	MECP2 Duplication syndrome	http://www.apsu.org.au/studies/current/
	1/7/14	22q11.2 Deletion Syndrome	http://www.apsu.org.au/studies/current/
BPSU	1/7/14	Enterovirus and parechovirus meningitis	http://www.rcpch.ac.uk/bpsu/neoentero
	1/10/14	Exchange blood transfusion	http://www.rcpch.ac.uk/bpsu/ebt
	1/3/15	Nutritional rickets	http://www.rcpch.ac.uk/bpsu/rkt
	1/4/15	Type 2 Diabetes	http://www.rcpch.ac.uk/bpsu/t2d
CPSP	1/01/13	Childhood Lyme disease	http://www.cpsp.cps.ca/surveillance/study-etude/childhood-lyme-disease
	1/01/14	Childhood tuberculosis	http://www.cpsp.cps.ca/surveillance/study-etude/childhood-tuberculosis
	1/01/14	Hypoglycemia in low-risk term newborns	http://www.cpsp.cps.ca/surveillance/study-etude/hypoglycemia-in-low-risk-term-newborns
	1/01/15	Listeria in the newborn and early infancy	http://www.cpsp.cps.ca/surveillance/study-etude/listeria-in-the-newborn-and-early-infancy
	1/01/15	Sudden unexpected death in epilepsy	http://www.cpsp.cps.ca/surveillance/study-etude/sudden-unexpected-death-in-epilepsy
NZPSU	1/01/14	Supratherapeutic paracetamol ingestion	http://www.otago.ac.nz/nzpsu/otago064430.pdf
		Pleural Empyema	http://www.otago.ac.nz/nzpsu/otago071841.pdf
		Serious Adverse Drug Reactions	http://www.otago.ac.nz/nzpsu/otago054241.pdf
ESPED	01/01/13	Kawasaki disease in children < 18 years	http://www.esped.uni-duesseldorf.de/
	01/01/13	Leigh syndrome / Leigh-like syndrome	
	01/07/13	Pertussis in the first 12 month of life	
	01/01/14	Severe combined Immundeficiency	
	01/01/14	Vein of Galen aneurysmal malformation	
	01/01/14	Volvulus without malrotation in very low birth weight infants (<1500g)	
	01/09/14	Invasive infections with multiresistant bacteria in hospitalized children and adolescents	
	01/01/15	Juvenile and congenital myasthenic syndrome	
	01/01/15	Stroke in newborns and childhood	
	01/03/15	Tuberous sclerosis complex	
	01/07/15	Type I Interferonopathies	
	01/01/16	Acute liver failure II	
SPSU	1/1/13	Pertussis	http://www.bag.admin.ch/k_m_meldesystem/00737/index.html?lang=de
	1/3/13	Kawasaki disease	http://www.bag.admin.ch/k_m_meldesystem/00737/index.html?lang=de
	1/7/13	Mycoplasma pneumonia Encephalitis	http://www.bag.admin.ch/k_m_meldesystem/00737/index.html?lang=de
	1/12/13	Tuberculosis	http://www.bag.admin.ch/k_m_meldesystem/00737/index.html?lang=de

INoPSU Publications 2013-2015

INOPSU

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APSU

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4. Ko DWH, Zurynski Y, Gilbert GL, and members of the APSU GBS study group. (2015). Group B streptococcal disease and genotypes in Australian infants. *Journal of Paediatrics and Child Health*. Feb 4. doi: 10.1111/jpc.12830. [Epub ahead of print]
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6. Khandaker G, Zurynski Y, Ridley G, Buttery J, Marshall H, Richmond PC, Royle, J, Gold, M, Walls, T, Whitehead, B, McIntyre, P, Wood, N, Booy, R, Elliott, EJ. (2014). Clinical epidemiology and predictors of outcome in children hospitalised with influenza A (H1N1) pdm09 in 2009: a prospective national study. *Influenza Other Respir Viruses*, 8(6):636-45.
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For other APSU publications please see www.apsu.org.au

BPSU

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25. Knowles, R., Oerton, J., An update on the British Paediatric Surveillance Unit study on congenital hypothyroidism. *FootPrint - Issue 9 - March 2013.*
26. Oddie S J., Craven, Deakin V., Westman, J., Scally, A., Severe neonatal hypernatraemia: a population based study. *Arch Dis Child Fetal Neonatal Ed* 2013;0:F1-F4
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For other BPSU publications please see <http://www.rcpch.ac.uk/bpsu>

CPSP

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For other CPSP publications please see <http://www.cpsp.cps.ca>

ESPED

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For other ESPED publications please see <http://www.esped.uni-duesseldorf.de>

NZPSU

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Netherlands

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SPSU

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INoPSU website: <http://www.inopsu.com>

You will find latest news, events and information about all National Paediatric Surveillance Units including weblinks to the individual units

Australian Paediatric Surveillance Unit (APSU)

British Paediatric Surveillance Unit (BPSU)

Belgium Paediatric Surveillance Unit (BePSU)

Canadian Paediatric Surveillance Programme (CPSP)

German Paediatric Surveillance Unit (ESPED)

Greece and Cyprus Paediatric Surveillance Unit (GCPSU)

Netherlands Paediatric Surveillance Unit (NSCK)

New Zealand Paediatric Surveillance Programme (NZPSU)

Swiss Paediatric Surveillance Unit (SPSU)

Welsh Paediatric Surveillance Unit (WPSU)

Portuguese Paediatric Surveillance Unit (PPSU)

Irish Paediatric Surveillance Unit (IPSU)

Greece and Cyprus Paediatric Surveillance Unit (CPSU)