CPSP 15
CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM
1996 • 2011

2011 Results

CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

Canadian Paediatric Society

Public Health Agency of Canada
Agence de la santé publique du Canada

Mission Statement

To contribute to the improvement of the health of children and youth in Canada by national surveillance and research into childhood disorders that are high in disability, morbidity, mortality and economic costs to society, despite their low frequency.

Public Health Impacts of CPSP Studies 2005 to 2011

Acquired demyelinating syndromes (ADS) of the central nervous system

- **Findings:** Optic neuritis was the most common presentation
- **Public health impact:** Supports the need for increased awareness that ADS could be a first manifestation of multiple sclerosis

Congenital myotonic dystrophy (CMD)

- **Findings:** Neonatal mortality rate of 18%; CMD being a disorder of muscle immaturity, complication-free prolonged ventilation can result in improvement in strength and hypotonia state
- **Public health impact:** Reinforces the need for greater awareness, screening in pregnancy and genetic counselling, as 58% were index cases for the families

Early-onset eating disorders

- **Findings:** Incidence of 2.6 per 100,000 children five to 12 years of age
- **Public health impact:** Supports CPS statement for use of growth charts to assist early detection

Head injury secondary to suspected child maltreatment

- **Findings:** High mortality rate of 12%; over half involved infants were less than six months of age
- **Public health impact:** Supports the need for more programs to prevent abusive head injuries

Injuries associated with baby products

- **Findings:** Strollers involved in 63% of the 90 reported incidents
- **Public health impact:** Supports Health Canada's advisory warning about amputation/laceration hazard posed by strollers with hinge mechanisms

Medium-chain acyl-coenzyme A dehydrogenase deficiency

- **Findings:** High efficiency of newborn screening programs to detect asymptomatic patients
- **Public health impact:** Supports early detection to allow for simple preventive measures (e.g., avoidance of fasting, prompt management of acute illnesses)

Non-type 1 diabetes mellitus

- **Findings:** Number of new cases of paediatric type 2 diabetes was higher than expected; 95% were overweight/obese; important regional differences were identified
- **Public health impact:** Supports CPS and PHAC efforts in promoting healthy active living

Renal stone disease associated with melamine-contaminated products

- **Findings:** No cases found in Canada
- **Public health impact:** Demonstrates added value of the CPSP to conduct enhanced surveillance of emerging public health concerns, quickly and inexpensively

Severe iron-deficiency anemia (IDA)

- **Findings:** Nearly 200 confirmed cases, many with significant morbidity; risk factors included prolonged bottle-feeding and excessive cow's milk intake
- **Public health impact:** Supports the need for nutrition counselling to prevent IDA

Travel-related illnesses in paediatric travellers who visit with friends and relatives abroad

- **Findings:** Enteric fever, malaria, diarrheal diseases and hepatitis A comprised 75% of the cases; most parents did not seek pre-travel advice
- **Public health impact:** Supports the need for education and provision of anticipatory guidance on pre-travel advice

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Acknowledgements

The key strength of the Canadian Paediatric Surveillance Program (CPSP) is its commitment to the improvement of the health of children and youth in Canada and around the world. This would not be possible without the participation of Canadian paediatricians, subspecialists and other health care providers in the monthly collection of information on rare paediatric conditions, principal investigators who design studies and analyze the data to provide knowledge and educational solutions, and the guidance of the Steering Committee members. We thank them all.

We also thank IMPACT (Immunization Monitoring Program ACTive) centres for their role in the verification of the acute flaccid paralysis study data collected and for their support of the CPSP.

The strong partnership between the Canadian Paediatric Society (CPS) and the Public Health Agency of Canada (PHAC) allows the program to grow in Canada and to take a leadership role on the international scene.

Funding

Funding for the CPSP is required to support program management. The surveillance program is funded through a combination of government funds and unrestricted grants from Canadian charities, research institutions, hospitals and corporations. All funding is provided to maintain and expand the program.

We gratefully acknowledge the financial support received in 2011 from the Public Health Agency of Canada, Health Canada's Therapeutic Effectiveness and Policy Bureau, and the following non-governmental sources:

- Citizens United for Research in Epilepsy (CURE)
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- St. Michael's Hospital AHSC AFP Innovation Fund
- Talecris Biotherapeutics
- The Hospital for Sick Children Foundation
- University of Alberta

Foreword

Federal Minister of Health

The Honourable Leona Aglukkaq

I would like to congratulate the Canadian Paediatric Society for its contribution to improving the health and well-being of children and youth in Canada. As outlined in this report, the Society successfully monitors rare diseases and conditions affecting our young people through the Canadian Paediatric Surveillance Program (CPSP).

With the help of over 2,500 paediatricians and paediatric subspecialists, the CPSP gathers valuable information that helps us understand how these rare diseases affect children and youth and how treatments are working. This information also gives us insight into risk factors, prevention practices and the types of health policies best suited to address the needs of patients with these conditions.

I believe the success of the CPSP is due in part to the strong partnership between the Public Health Agency of Canada, the Canadian Paediatric Society and paediatricians across Canada who take the time to provide information and ongoing support.

The Government of Canada is proud to work with the Canadian Paediatric Society and its members in providing a healthier future for Canadian children and youth.

Chief Public Health Officer of Canada

Dr. David Butler-Jones

As Chief Public Health Officer of Canada, I congratulate the Canadian Paediatric Surveillance Program on the accomplishments described in its 2011 annual report. The year 2011 marks the fifteenth anniversary of the CPSP, an occasion to acknowledge the program's invaluable surveillance leadership role.

Through the CPSP, data on rare childhood diseases and conditions are collected monthly from more than 2,500 paediatricians, subspecialists and health care providers. This information helps us learn more about these diseases, determine what we can do to prevent them and decide what future health policies we need to consider.

I would like to thank the CPSP Steering Committee, Canadian Paediatric Society staff, the Public Health Agency of Canada staff and all the paediatricians for their steadfast commitment to the surveillance program. Their dedication and spirit of collaboration signify their commitment to helping the millions of children and youth in Canada and around the world who are living with a rare disease.

President of the Canadian Paediatric Society

Dr. Jean-Yves Frappier

As President of the CPS and as a founder of the Adolescent Medicine subspecialty at the Royal College of Physicians and Surgeons of Canada, I am very proud to be part of the CPSP and its achievements, both nationally and internationally. Through the CPSP, mental health issues affecting children and youth were studied, such as early-onset eating disorders, conversion disorder and the complications associated with the consumption of energy drinks.

The statistics of the CPSP's first 15 years are impressive and include over 2,500 participants, 49 studies and 26 one-time surveys. These statistics confirm the continued interest and support of Canadian paediatricians and paediatric subspecialists. The 47 study-related publications in peer-reviewed journals, such as *Paediatrics & Child Health, CMAJ, Pediatrics, Neurology* and *Diabetes,* attest to the ongoing quality of the research conducted, as well as the productivity and visibility of the program.

The CPSP, in its leadership co-chair role of INoPSU, is very active in encouraging collaboration among investigators, in preparing comparative studies resulting in publications and in promoting the medical and public health importance of the network.

The CPS is looking forward to many more years of timely, important and pertinent national epidemiological research for the benefit of our Canadian children and youth.

CPSP Chair

Dr. Kimberly Dow

The Canadian Paediatric Surveillance Program, this year celebrating its fifteenth anniversary, continues to strive for improvement in the health of children and youth in Canada through excellence in national surveillance and research.

Over the years the CPSP has vastly reduced the amount of time from the inception of a study research idea on rare diseases to the completion of data collection and the presentation/publication of study results in many different fields of paediatrics. Innovative feedback measures such as educational resources, *ADR Tips of the Month* and CPSP Highlights and Commentaries in *Paediatrics & Child Health,* have been highly praised by program participants.

This year saw the launch of our online database, e-CPSP, a giant step in both going green and accelerating the collection of data. I would encourage you to read this year's anniversary publication with special attention to study results, e-CPSP and the theme page on the impact of CPSP studies on public health.

Finally, I would like to thank all Canadian paediatricians who are contributing on a monthly basis to the success of our surveillance program. The program's achievements over the past fifteen years would simply not be possible without your support.

CPSP Steering Committee

Kimberly Dow, MD (Chair)	Canadian Paediatric Society
Claude Cyr, MD	Canadian Paediatric Society
Denis Daneman, MD	Paediatric Chairs of Canada
Marie Adèle Davis, MBA	Canadian Paediatric Society
Kevin Gordon, MD	Canadian Association of Child Neurology (Liaison)
Danielle Grenier, MD	Canadian Paediatric Society
W. James King, MD	Canadian Paediatric Society
Dorothy Moore, MD	IMPACT (Immunization Monitoring Program ACTive) (Liaison)
Paul Muirhead, LL.M.	Consultant
Alison Quartaro, BA	Canadian Paediatric Society
Jeff Scott, MD	Canadian Paediatric Society
Paul Thiessen, MD	Canadian Paediatric Society
Lesley Ann Turner, MD	Canadian College of Medical Geneticists (Liaison)
Anne-Marie Ugnat, PhD	Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada
Tom Wong, MD	Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada
Sandra Woods, MD	Canadian Paediatric Society

In November 2011, **Denis Daneman**, **Tom Wong**, and **Sandra Woods** completed their terms as members of the CPSP Steering Committee. We sincerely thank them for their contributions over the past years.

CPSP Working Group

Danielle Grenier, MD (Chair)	Canadian Paediatric Society
Melanie Laffin Thibodeau, BCom (Chair until March)	Canadian Paediatric Society
Marie Adèle Davis, MBA	Canadian Paediatric Society
Laurence Gillieson, BA	Canadian Paediatric Society
Alison Quartaro, BA	Canadian Paediatric Society
Anne-Marie Ugnat, PhD	Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada

Publications 2007–2011

Published papers related to studies

(See www.cps.ca/cpsp for a complete list of abstracts with hyperlinks.)

Acquired demyelinating syndromes of the CNS
Incidence of acquired demyelination of the CNS in Canadian children. Banwell B, Kennedy J, Sadovnick D, Arnold DL, Magalhaes S, et al. *Neurology* 2009; 72: 232-9

Acute flaccid paralysis
AFP surveillance in Canada. Macey J, Lipskie T. *Pan American Health Organization Immunization Newsletter*, Apr 2007; XXIX(2): 1-3

Child maltreatment
The Canadian Paediatric Surveillance Program: A framework for the timely data collection on head injury secondary to child maltreatment. Bennett S, Grenier D, Medaglia A. *Am J Prev Med* 2008; 34(4S): S140-2

Head injury secondary to suspected child maltreatment: Results of a Canadian national surveillance program. Bennett S, Ward M, Moreau K, Fortin G, King J, MacKay M, Plint A. *Child Abuse Negl* 2011; 35(11): 930-6

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Adverse events associated with paediatric use of complementary and alternative medicine: Results of a Canadian Paediatric Surveillance Program survey. Vohra S, Brulotte J, Le C, Charrois T, Laeeque H. *Paediatr Child Health* 2009; 14(6): 385-7

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Congenital rubella syndrome
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Acute neurological findings in a national cohort of neonates with severe neonatal hyperbilirubinemia. Sgro M, Campbell D, Barozzino T, Shah V. *J Perinatol* 2011; 31(6): 392-6. Epub 2010 Dec 9; doi:10.1038/jp.2010.137

Prevention of kernicterus – New guidelines and the critical role of family physicians. Shaw E, Grenier D. FP Watch, *Can Fam Physician* 2008; 54(4): 575-6

Lap-belt syndrome
The spectrum of seat belt syndrome among Canadian children: Results of a two-year population surveillance. Santschi M, Lemoine C, Cyr C. *Paediatr Child Health* 2008; 13(4): 279-83

Necrotizing fasciitis
Epidemiology and outcome of necrotizing fasciitis in children: An active surveillance study of the Canadian Paediatric Surveillance Program. Ihuoma E, Davies HD. *J Pediatr* 2007; 151(7): 79-84

Non-type 1 diabetes mellitus
Type 2 diabetes, medication-induced diabetes, and monogenic diabetes in Canadian children: A prospective national surveillance study. Amed S, Dean HJ, Panagiotopoulos C, Sellers EAC, Hadjiyanakis S, Laubscher TA, Dannenbaum D, Shah BR, Booth GL, Hamilton JK. *Diabetes Care* 2010; 33(4): 786-91

Surveillance – General
Active surveillance: An essential tool in safeguarding the health and well-being of children and youth (Commentary). Grenier D. *CMAJ* 2007; 177(7): 169-71

Beyond counting cases – Public health impacts of national paediatric surveillance units. Grenier D, Elliott EJ, Zurynski Y, Pereira RR, Preece M, Lynn R, von Kries R, Zimmerman H, Dickson NP, Virella D*. Arch Dis Child* 2007; 92: 527-33

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Vitamin D-deficiency rickets among children in Canada. Ward LM, Gaboury I, Ladhani M, Zlotkin S. *CMAJ* 2007; 177(2): 161-6

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(See www.cps.ca/cpsp for a complete list with hyperlinks.)

Does active surveillance of serious and life-threatening adverse drug reactions improve reporting? Zimmerman M, Grenier D, Levitt M. *Paediatr Child Health* 2011; 16(9): 532-4

Early-onset neonatal sepsis: It is not only group B streptococcus. Sgro N, Yudin MH, Lee S, Sankaran K, Tran D, Campbell D. *Paediatr Child Health* 2011; 16(5): 269

The Canadian Paediatric Surveillance Program: Celebrating 15 years of successful paediatric surveillance. Ugnat A-M, Grenier D, Laffin Thibodeau M, Davis MA. *Paediatr Child Health* 2011; 16(4): 203-5

What happens when you mix a transplant with respiratory syncytial virus? Robinson JL, Grenier D. *Paediatr Child Health* 2011; 16(1): 12

Presentations in 2011

(See www.cps.ca/cpsp for a complete list of presentations with hyperlinks.)

National

Early-onset neonatal sepsis and meningitis
Early-onset neonatal sepsis in industrialized countries. Sgro M. Global Health Symposium – Group B streptococcal sepsis in newborns: An international expert panel discussion on the global burden and opportunities for prevention, The Hospital for Sick Children, Toronto, in October (oral)

Neonatal sepsis and the changing patterns of infection. Sgro M. Paediatric Update Session. Canadian Paediatric Society Annual Conference, Quebec City, in June (oral)

Kernicterus
Chronic bilirubin encephalopathy continues to occur in Canada. Sgro M, Campbell D, Shah V. Canadian Paediatric Society Annual Conference, Quebec City, in June (oral)

Paediatric myasthenia
Paediatric myasthenia: first year of active national surveillance. Kolski H. 46th Annual Congress of the Canadian Neurological Sciences Federation, Vancouver, in June (oral)

Severe iron-deficiency anemia in infants and young children
The landscape of severe iron-deficiency anemia in Canada. Wong S. Paediatric Update Session, Canadian Paediatric Society Annual Conference, Quebec City, in June (oral)

Surveillance – General
Paediatric surveillance – A core medical and public health function. Grenier D, Davis MA. Children's Hospital of Eastern Ontario, Ottawa, in June (oral)

Can active surveillance improve reporting of serious and life-threatening drug reactions? The Canadian experience. Grenier D, Davis MA, Zimmerman M, Laffin Thibodeau M. Canadian Paediatric Society Annual Conference, Quebec City, in June (poster)

International

Surveillance – General
Taller de vigilancia epidemiológica pediatría. Grenier D, Mercer R. *I Conferencia de Actualizatión en Pediatría – ALAPE 2011*, Panama, in April (oral)

¿Una vigilancia estricta puede mejorar el reporte de reacciones adversas a medicamentos? Grenier D, Zimmerman M. *XIII Congreso Nacional de Pediatría, CoNaPeMe*, Guadalajara, in May (oral)

Can active surveillance improve reporting of serious and life-threatening adverse drug reactions? The Canadian Paediatric Surveillance Program experience. Grenier D, Davis MA, Ugnat A-M, Zimmerman M. Laffin Thibodeau M, Quartaro A. 5th Europaediatrics, Vienna, in June (poster)

Does active surveillance of adverse drug reactions improve reporting? The CPSP experience. Grenier D, Zimmerman M. International Network of Paediatric Surveillance Units (INoPSU) Conference, Montreux, in September (oral)

Injuries associated with baby products. Grenier D, Fréchette M, McFaull S, Skinner R, Ugnat A-M. International Network of Paediatric Surveillance Units (INoPSU) Conference, Montreux, in September (oral)

Public Health Impacts of the International Network of Paediatric Surveillance Units. Grenier D. *Congreso Nacional de Pediatría*, Albufeira, in October (oral)

Travel-related illnesses in paediatric travelers who visit friends and relatives abroad
Travel-related illnesses among pediatric VFRs in Canada. Crockett M, Hui C, Kuhn S, Ford-Jones L, Grondin D, Keystone J. 60th Annual Meeting of the American Society of Tropical Medicine and Hygiene, Philadelphia, in December (oral)

Surveillance at Work

Overview

The importance of surveillance to the practice of medicine cannot be overstated. Through the ongoing, systematic collection of data, the burden of disease can be determined, interventions to prevent the occurrence of a disorder can be assessed, and information collected can be used in the development of health policy. Surveillance takes research data into action.

According to Statistics Canada, in September 2011 the Canadian population was 34,482,779, and 7,841,284 individuals were 0–19 years, which represents approximately 23% of the Canadian population. Although individually uncommon, rare diseases affect thousands of these children and youth and typically have lifelong impacts. The actual incidence of many of these disorders is not readily available, and yet is essential for improved clinical care, advocacy and health service planning.

The CPSP provides an innovative means to undertake paediatric surveillance and increase awareness of childhood disorders that are high in disability, morbidity, mortality and economic cost to society, despite their low frequency. Preference is given to studies that have strong public health importance or could not be undertaken any other way. All studies in the program must conform to high standards of scientific rigour and practicality, and the CPSP assures the confidentiality of all information collected. To enhance data capture on individual studies, the program works collaboratively with other professional groups, such as psychiatrists, pathologists/coroners, and adult endocrinologists. The program also offers an opportunity for international collaboration, through the International Network of Paediatric Surveillance Units (INoPSU), with other paediatric surveillance units worldwide.

Process

The CPSP Steering Committee oversees the program and reviews new study proposals. Upon initiation of a new study, practising Canadian paediatricians, paediatric subspecialists and other health care providers receive a summary of the protocol, including the case definition and a brief description of the condition. This serves to educate and increase awareness of conditions under surveillance while providing a uniform basis for reporting. The CPSP uses a two-tiered reporting process to ascertain and investigate cases: an initial 'check-off' form and a detailed questionnaire. Case ascertainment is undertaken by comparing selected study results with cases reported to the Hospital Discharge Abstract database of the Canadian Institute of Health Information (CIHI) and by investigating duplicate reports and comparing data with relative programs or centres. To date, case ascertainment has been excellent.

Reporting

The 'check-off' form, listing the conditions currently under surveillance, is mailed monthly to participants. For each condition, respondents are asked to indicate the number of new cases seen in the last month, including 'nil' reports. A 'nil' report is very important in active surveillance; the CPSP cannot simply assume that no reply means no cases. In October 2011, the program launched eCPSP, an electronic platform giving participants the opportunity to receive their monthly forms online.

Participants report all cases meeting the case definitions, including suspect or probable cases. This sometimes leads to duplicate reports but avoids missed cases. The list of studies conducted by the program since 1996 can be accessed at www.cps.ca/cpsp.

TABLE 1 – Initial response rates (%) and number of participants for 2011

Provinces/territories	Reporting rates (%)	Number of participants
Alberta (AB)	79	315
British Columbia (BC)	74	268
Manitoba (MB)	86	118
New Brunswick (NB)	78	29
Newfoundland and Labrador (NL)	76	52
Nova Scotia (NS)	89	96
Northwest Territories (NT)	100	2
Nunavut (NU)	100	2
Ontario (ON)	77	1,007
Prince Edward Island (PE)	100	7
Quebec (QC)	79	594
Saskatchewan (SK)	76	49
Yukon (YT)	100	1
Canada	**79**	**2,540**

Confidentiality is maintained by using only non-nominal patient information, such as the date of birth and sex of the child. This anonymous information is used to exclude duplicates and is sent to the original respondent to request case-specific information.

Once the detailed questionnaire is returned to the CPSP, it is forwarded to the investigator for analysis. If further information is required to confirm or exclude a case, the program manager contacts the respondent on behalf of the investigator.

Participants who do not reply every month receive reminders. In addition, information on the monthly compliance rates and the number of cases reported is mailed quarterly to all participants to keep them informed of progress. In 2011, the national reporting rate was 79% (Table 1) and the response rate for completion of detailed questionnaires, 85% (Table 2).

Participant workload

The monthly reporting system is simple and the follow-up study questionnaires are easy to complete. As only non-nominal, non-identifiable data are collected through the CPSP, respondents do not hesitate to provide clinical information.

In 2011, the majority of participants (87%) had 'nil' cases to report. The importance of zero reporting must be re-emphasized. Table 3 illustrates the number of cases reported by respondents in 2011. As studies come and go, the workload shifts to different subspecialties. Through the years, studies with national collaborative networks have been very successful. The 2011 study with the most reports was severe iron-deficiency anemia in infants and young children.

TABLE 2 – 2011 detailed questionnaire completion rates as of May 1, 2012

Studies/conditions	Reported cases*	Pending	% Completion rate
Acute flaccid paralysis	48	6	88
Adrenal suppression	34	11	68
Adverse drug reactions – serious and life-threatening	40	6	85
Conversion disorder in children and youth	35	15	57
Early-onset neonatal sepsis and meningitis	108	21	81
Langerhans cell histiocytosis	33	4	88
Neonatal hyperbilirubinemia – severe (2011-2013)	53	9	83
Paediatric myasthenia	22	0	100
Periodic fever syndromes	27	3	89
Persistent albuminuria in the paediatric population with type 2 diabetes mellitus	34	0	100
Respiratory syncytial virus (RSV) infections in paediatric transplant patients	15	1	93
Severe iron-deficiency anemia in infants and young children	115	12	89
Travel-related illnesses in paediatric travellers who visit friends and relatives abroad	9	0	100
Total number of cases (all studies)	**573**	**88**	**85**

* Excluding duplicate and excluded cases

TABLE 3 – Number of cases reported by respondents in 2011

Number of cases	% Respondents
0	87
<5	13
5–10	0.9
>10	0.1

The CPSP is extremely grateful that the majority of participants faithfully complete the detailed questionnaires subsequent to reporting cases. This demonstrates that they appreciate the enormous value of the scientific data collected and reinforces the Steering Committee's insistence on short, precise and pertinent detailed questionnaires.

To thank paediatricians and paediatric subspecialists for their tremendous commitment and support, names of participants who completed the initial reporting forms for all months in 2011 and/or returned one or more detailed questionnaires were entered in draws for various prizes.

Investigators' corner

The CPSP provides investigators, through its timely, active surveillance system, an innovative means of obtaining non-nominal, national data on low-frequency diseases and conditions from over 2,500 participants. The program is committed to a high case ascertainment rate and, due to follow-up reminders to non-respondents, obtains a response rate of 85% on detailed questionnaires (Table 2). The CPSP offers an opportunity for international

collaboration with other paediatric surveillance units worldwide and a chance to make a difference in the health and well-being of Canadian children and youth.

Individual researchers are encouraged to submit proposals for new studies that meet the Criteria for Inclusion, and follow the Format for Submission, available on the CPSP website at www.cps.ca/cpsp. The Steering Committee reviews submissions at its spring and fall meetings, giving preference to studies that have either strong scientific and public health importance or those that could not be undertaken any other way. Following the review, studies must receive ethical approval and have external funding arrangements in place before final acceptance to the program. Researchers interested in obtaining more information about the program are encouraged to visit the website or contact the manager of surveillance at cpsp@cps.ca.

One-time survey questions

The CPSP is also available to investigators as a cost-effective tool to survey participants on a one-time basis in order to identify the prevalence of a problem or to answer a specific question. Once approved by the CPSP Steering Committee, the one-time survey is sent to all participants with the monthly initial reporting form. Collected results are forwarded to the investigator for data analysis.

Results of the 2011 one-time survey questions are found on pages 38-44, and the list of surveys completed to date can be accessed at www.cps.ca/cpsp.

Glossary of terms for tables of cases in each study results
Reported: Reports of cases received
Duplicates: Cases reported by more than one participant
Excluded: Cases not meeting the case definition
Pending: Detailed reports not received or not yet confirmed
Confirmed: Cases verified as meeting the case definition

CPSP Principal Investigators

Surveillance studies in 2011

Dr. Shalini Desai
Acute flaccid paralysis

Dr. Ellen Goldbloom
Adrenal suppression

Margaret Zimmerman
Adverse drug reactions – serious and life-threatening

Dr. Christina Grant
Conversion disorder in children and youth

Dr. Michael Sgro
Early-onset neonatal sepsis and meningitis and *Neonatal hyperbilirubinemia – severe (2011–2013)*

Dr. Bruce Crooks
Langerhans cell histiocytosis

Dr. Hanna Kolski
Paediatric myasthenia

Dr. Paul Dancey
Periodic fever syndromes

Dr. Elizabeth Sellers
Persistant albuminuria in the paediatric population with type 2 diabetes mellitus

Dr. Joan Robinson
Respiratory syncytial virus infections in paediatric transplant patients

Dr. Patricia Parkin
Severe iron-deficiency anemia in infants and young children

Dr. Maryanne Crockett
Travel-related illnesses in paediatric travellers who visit friends and relatives abroad

Surveillance Studies in 2011

Acute flaccid paralysis

January 1996 to December 2013

S Desai[1], T Smith

Highlights 2011

- Vigilant surveillance of acute flaccid paralysis (AFP) is essential in light of ongoing transmission of wild poliovirus in countries around the world.
- Neurological investigations (MRI, EEG, etc.) occur in 91% of all AFP cases.
- Guillain-Barré syndrome (GBS) is the most frequent diagnosis for AFP in Canada.
- Canada's AFP surveillance continues to work towards World Health Organization (WHO) targets for AFP detection, stool specimen collection and follow-up for residual paralysis.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Acute onset of focal weakness or paralysis characterized as flaccid (reduced tone) without other obvious cause (e.g., trauma) in children less than 15 years of age. Transient weakness (e.g., postictal weakness) does not meet the case definition.

Results

There were 58 notifications of AFP through the CPSP to the Public Health Agency of Canada with onset in 2011, which included 35 confirmed cases. Approximately 51% of all reports came from the CPSP network and 49% from IMPACT. Five AFP reports were excluded because they did not meet the case definition: four based on age criteria and one based on diagnosis. The 35 confirmed cases represent a non-polio AFP detection rate of 0.62/100,000 in children less than 15 years of age (Table 2). As documented in previous years, Canada's annual AFP incidence rate has been artificially low due to delays in receiving detailed case report forms in the reporting calendar year. As this study is ongoing, AFP delayed reporting occurs and the figures are adjusted accordingly once detailed case report forms have been received.

TABLE 1 – AFP cases in 2011

Reported	Duplicates	Excluded	Pending	Confirmed
58	8	5	10	35

In 2011, AFP cases ranged in age from one week to 14 years (median 5 years, mean 5 years), and were fairly evenly distributed across age groups. A total of 51% of AFP cases were male and 49% were female.

Among the reported AFP cases in 2011, documentation of age-appropriate polio immunization was found to be incomplete: 15 cases (43%) had documented receipt, one case (3%) was recorded as "up-to-date" with no further information and the remaining 19 cases (54%) included no information on immunization. Vaccine uptake rates of inactivated poliovirus vaccine (IPV) in Canada are approximately 80% for four doses or more among 7 year olds.

Investigation for polio virus, other enteroviruses or *Campylobacter*

Virological investigation included testing of stool specimens for 14 cases (40%), cerebrospinal fluid (CSF) for 20 cases (57%) and throat swabs for 12 cases (34%). Where stool was collected, 86% had an adequate sample taken within 14 days from the onset of paralysis. In the remaining cases, stool collection was later, when the sensitivity of enterovirus isolation is lower. Overall, 34% (n=12) of cases had an adequate stool sample collected within 14 days of the onset of paralysis (Table 2). None of the samples collected in 2011 were positive for polioviruses. Testing was also conducted for *Campylobacter* in 15 cases (43%) and was not isolated in any of the samples.

Neurological investigations

In 2011, approximately 91% of cases underwent at least one type of neurological investigation (CSF examination, nerve conduction studies/electromyography, MRI/CT scan) with CSF exams and MRI/CT scans used most

frequently in 77% and 80% of cases respectively. Of those cases that had a test, approximately 70% had abnormal CSF chemistry results, 89% had abnormal electromyography and/or nerve conduction studies and 68% had abnormal MRI or CT scans.

As observed in previous years, the majority of AFP cases (22, 63%) were diagnosed as GBS, three of which were Miller-Fisher variant. The remaining 13 cases were diagnosed as transverse myelitis (n=3), botulism (n=2) and other (n=8).

Hospitalization and outcome

All confirmed AFP cases reported in 2011 required hospitalization. Except in four cases with unknown length of stay, length of hospital stay ranged from one to 29 days (median 10 days, mean 12 days). Outcome at the time of the initial report was documented in 33 cases (94%): six (18%) fully recovered, 25 (76%) partially recovered with residual weakness or paralysis and two (6%) had not fully recovered. There were no deaths. Only 16 cases (46%) had clinical outcome reported at 60 days, including 12 cases who had fully recovered, two with partial recovery (i.e., some residual weakness or paralysis) and two had not recovered or outcomes were pending.

TABLE 2 – Number of AFP cases, non-polio AFP incidence rate (per 100,000 population <15), percentage of cases with adequate stool sample and percentage of cases with follow-up exam 60 days after paralysis onset, Canada 1996–2011

Year	Number of cases	Incidence rate	% with adequate stool sample*	% with 60 days follow-up
1996	27	0.45	18.5	70.4
1997	35	0.59	28.6	45.7
1998	43	0.72	25.6	46.5
1999	60	1.01†	33.3	33.3
2000	64	1.09†	45.3	37.5
2001	52	0.89	36.5	38.5
2002	44	0.75	31.8	34.1
2003	44	0.76	34.1	22.7
2004	38	0.66	44.7	28.9
2005	53	0.93	26.4	32.1
2006	39	0.69	20.5	43.6
2007	50	0.89	42.0	46.0
2008	42	0.75	33.3	42.9
2009	59	1.05†	30.5	49.2
2010	46	0.82	34.8	54.3
2011	35	0.62	34.3	45.7

* Adequate stool sample refers to one stool sample taken within 14 days of paralysis onset
† WHO target met

Discussion

The majority of cases of poliomyelitis are asymptomatic; a small percentage of cases, approximately 4–8%, may manifest as a nonspecific fever and sore throat. Approximately 1% of cases develop paralytic poliomyelitis. Symptoms of this form of polio include severe muscle pain and stiffness of the back and neck; rapid onset of asymmetric acute flaccid paralysis may occur. There is usually a fever present at the onset of illness and the paralysis depends on the location of nerve cell infection. If poliomyelitis is suspected in a patient, further consultation with a neurologist and infectious diseases consultant would be prudent.

Based on the current 2011 AFP case data, Canada failed to meet WHO quality assurance criteria for non-polio AFP incidence rate (1.0/100,000), stool sampling (80%) or 60 day follow up (80%). The recommended target for non-polio AFP incidence has only been met three times since AFP surveillance began in 1996 (1999, 2000 and 2009). The targets for stool testing and 60 day follow-up have never been met.

Canada's consistently lower than expected AFP rates over the years could be a result of under-detection of cases, in combination with delayed reporting, or could be a true reflection of lower baseline levels for non-polio AFP in Canada. The low rates of stool sampling may be a result of diagnostic practices used in Canada. Given that most AFP cases are diagnosed as either GBS or transverse myelitis, physicians may favour neurological investigations where results are known quickly. With respect to 60 day follow-up, most AFP cases are not admitted to acute care hospitals for over 60 days, resulting in data gathering difficulties.

The Public Health Agency of Canada and the CPSP have undertaken a study to compare the AFP surveillance systems used by countries that are part of the International Network of Paediatric Surveillance Units. It is expected that the result of this study will help to target improvements to the AFP surveillance system in Canada. In addition, efforts will continue towards improving the data collection form, evaluating the functionality of the AFP surveillance systems and exploring ways of supplementing the AFP data system used in Canada.

Global Polio Eradication Initiative (GPEI)
www.polioeradication.org
In 2011, there were 650 cases of wild poliovirus reported which represents a decrease of 48% from the 2010 global case count. In addition, India, one of four remaining endemic countries, reported only one case of polio and has now reported no new cases in over a year. However, the three other endemic countries (Afghanistan, Pakistan, Nigeria) continued to experience persistent transmission throughout 2011 along with Chad, Angola and the Democratic Republic of Congo. As a result of ongoing transmission, seven countries had new outbreaks of polio in 2011; most notably China after over 10 years without any wild poliovirus cases.

The Independent Monitoring Board, which monitors the progress of the GPEI, released a report in October 2011 warning that current funding gaps and program deficiencies were threatening the goal of stopping polio transmission in 2012. The WHO's Executive Board subsequently declared polio eradication a "programmatic emergency for global public health" and planned to table this resolution at the 65th Session of the World Health Assembly in May, 2012.

Reference

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Acknowledgements

The contribution of Kelly Mansfield is greatly appreciated.

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Adrenal suppression

April 2010 to March 2012

A Ahmet[1], E Goldbloom[1], S Abish, S Benseler, E Cummings, H Huynh, A Mokashi, A-M Ugnat, W Watson

Highlights 2011

- In the second year of surveillance, 16 cases of symptomatic adrenal suppression (AS) were confirmed while 17 are still under review.
- Adrenal crisis, a condition with significant morbidity, was confirmed in one case.
- The most common presentations were growth failure and non-specific symptoms.
- The predominant type of glucocorticoid (GC) treatment in most of the cases reported was inhaled corticosteroids. Many were treated with more than one form of GC (e.g., inhaled and intranasal).
- There were no reported cases of AS for children being treated with intranasal GCs alone.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report any new patient less than 18 years of age treated with any form of glucocorticoid therapy with evidence of adrenal suppression defined as:

➤ Adrenal crisis, an acute critical illness out of proportion in severity to the current illness and manifested by any of the following:
- Hypotension/shock
- Decreased level of consciousness/lethargy
- Unexplained hypoglycemia or hyponatremia
- Seizure
- Death

or

➤ Symptomatic* adrenal insufficiency with supportive biochemical evidence

* Signs/symptoms can include anorexia, weakness, fatigue, lethargy, fever, gastrointestinal symptoms (nausea, vomiting, constipation, diarrhea, abdominal pain), morning headache, hypoglycemia, myalgia, arthralgia, psychiatric symptoms and growth failure.

Exclusion criteria

Adrenal insufficiency unrelated to GC therapy, including adrenocorticotropic hormone (ACTH) deficiency due to hypothalamic or pituitary gland abnormalities, and primary adrenal disorders, such as:
- Congenital adrenal hyperplasia
- Autoimmune adrenalitis or polyglandular syndromes
- Adrenal hypoplasia congenita
- ACTH resistance syndromes
- Metabolic disorders (adrenoleukodystrophy, peroxisome biogenesis disorders, cholesterol metabolism, mitochondrial disorders)
- Infectious disorders (sepsis, tuberculosis, fungal infections, viral infections)
- Infiltrative/destructive causes (hemorrhage, amyloidosis, sarcoidosis, metastases)
- Drugs inhibiting steroid biosynthesis (e.g., ketoconazole, etomidate, suramin, aminoglutethimide, metyrapone)

Results

Demographics

In the second year of surveillance, 16 cases of symptomatic AS have been confirmed to date. Ten (63%) were male. The mean age at diagnosis of AS was 7.3 years (range 2.5–15.9). All were Caucasian. The underlying conditions requiring GC treatment included: asthma alone (13 cases, 81%); asthma, atopy and subglottic stenosis (one case, 6%); arthritis (one case, 6%); and vasculitis (one case, 6%). Eight (50%) cases were from Quebec, six (38%) were from Ontario and two (13 %) were

TABLE 1 – AS cases in 2011

Reported	Duplicates	Excluded	Pending	Confirmed
62	3	26	17	16

from western provinces. The confirmed cases presented to a physician's office or clinic (13 cases, 81%), on the inpatient unit (one case, 6%), and to the emergency department (two cases, 13%). One patient who presented to the emergency department was transferred to the intensive care unit.

Glucocorticoid therapy
Fourteen children received inhaled corticosteroids, as solo therapy (n=6) or in combination with oral GC (n=1), intranasal GC (n=2), intranasal and short course oral GC (n=4) or oral and topical (n=1). Two children received primarily systemic GCs: a combination of intravenous and oral GCs (n=1) and oral only (n=1). The specific types, doses and treatment durations of GCs were variable and were not consistently reported. The most commonly reported inhaled corticosteroid was fluticasone, usually in doses of 500 mcg/day for months to years.

Presentation
Of the 16 confirmed cases of symptomatic AS, the most common presentations were growth failure and non-specific symptoms (e.g., fatigue, nausea, myalgia). One case (6%) had adrenal crisis. The presenting symptoms and signs of the remaining cases are described in Table 2.

TABLE 2 – Presenting symptoms and signs (n=16)

	Number of cases (%)
Adrenal crisis	1 (6)
Growth failure alone	5 (31)
Growth failure and non-specific symptoms*	2 (13)
Non-specific symptoms	6 (38)
Cushings	2 (13)

* Non-specific symptoms included one or more of fatigue, lethargy, nausea, anorexia, vomiting, abdominal pain or myalgia.

Physical activity
The underlying condition requiring GC therapy caused a decrease in physical activity in five (31%) children. The GC therapy caused a decrease in physical activity in one (6%) child. Five (31%) children experienced a weight gain on GC therapy.

Outcome and management
After confirmation of AS, 15 (94%) children were treated with GC replacement and 12 (75%) were seen by or referred to an endocrinologist. One (6%) child was hospitalized for three days (adrenal crisis), two of which were in the intensive care unit. The other 15 children (94%) were managed as outpatients.

Conclusion

The minimal estimated incidence of symptomatic AS to date is approximately 20 cases per year in the Canadian paediatric population. The majority of the reported cases involved inhaled corticosteroids. Physicians must be aware of the potential side effects of asthma therapy and frequently revisit GC doses to ensure that patients are being treated with the lowest effective dose to reduce the risk of AS.

A large proportion of patients presented with growth failure or non-specific symptoms. This underlines the importance of close monitoring of children's growth and potential symptoms associated with AS. The lack of consistent, specific signs and symptoms of AS means that many cases may not be recognized without proactive screening.

Over the past 21 months, this CPSP study has provided an ideal format for data collection to estimate the frequency and morbidity of paediatric AS in Canada. It has also been an effective tool in raising awareness about this condition and contributing to the recognition of children at risk of AS.

Publications and presentations

Goldbloom EB, Ahmet A. Adrenal suppression: An under-recognized complication of a common therapy. *Paediatr Child Health* 2010; 15(7): 411–2

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Adverse drug reactions – serious and life-threatening

January 2004 to December 2013

M Zimmerman[1]

Highlights 2011

- The study confirmed 29 suspected paediatric adverse reaction (AR) cases.
- Product groups most commonly associated with suspected adverse reactions were psychoanaleptics, antibacterial agents, antiepileptics and immunosuppressants.
- The quality of clinical information gathered via the CPSP is considered to be good to excellent as per the quality grading scale used by the World Health Organization (WHO).

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report serious and life-threatening adverse reactions* in an infant or child up to the age of 18 years, associated with the use of prescription, non-prescription, biological (immunoglobulin) products, complementary medicines (including herbals) and radiopharmaceutical products.

* Noxious and unintended severe response to a health product, which occurs at any dose and results in emergency observation, hospitalization, persistent or significant disability or death.

Exclusions

Do not report reactions to medical devices, blood products (platelets, red cells and single-donor plasma), vaccines, poisonings or self-administered overdoses.

Results

From January 1 to December 31, 2011, 44 cases of suspected serious adverse drug reactions (ADRs) were reported and 29 cases were confirmed as meeting the case definition. In comparison, 42, 67, 68 and 45 reports were received via the CPSP in 2010, 2009, 2008 and 2007 respectively. The quality of clinical information gathered via the CPSP is considered to be good to excellent as per the quality grading scale used by WHO.

TABLE 1 – Serious and life-threatening adverse drug reaction cases in 2011

Reported	Duplicate	Excluded	Pending	Confirmed
44	0	8	7	29

Of the 29 confirmed cases, 15 were male and 14 were female. The age range was from one month to 17 years. Table 2 provides a comparison of the age distribution of confirmed AR reports from 2007 to 2011.

TABLE 2 – Annual comparison of age distribution of confirmed cases

	2011 (n=29)	2010 (n=32)	2009* (n=51)	2008 (n=40)	2007 (n=45)
Up to 5 years of age	9	6	14	15	9
6 to 12 years	7	15	16	14	16
13 to 17 years	13	10	21	11	18
Not reported	0	1	0	0	2

* The 2009 number of cases has been adjusted to reflect delayed reports not included in the *CPSP 2009 Results*.

All 29 cases were classified as serious (more than one reason for seriousness was reported in 15 cases). Table 3 shows a comparison of the reasons for seriousness received in the past five years. Information regarding patient outcome was provided for 24 of the 29 confirmed cases as follows: recovered (n=18), not yet recovered (n=4), recovered with sequelae (n= 1), death (n=1).

Suspected health products

Table 4 lists the health products described in the 29 AR reports, sorted by number of reports received per each individual product. In 23 reports, a single product was suspected of the causing the reaction(s). Two

suspected products were reported in six cases. The classes of health products most frequently suspected of causing adverse reaction(s) were psychoanaleptics (n=7; four cases with psychostimulant agents used for the treatment of attention deficit and hyperactivity disorders and three cases with antidepressants) followed by antibacterial agents (n= 6), antiepileptics (n=4) and immunosuppressants (n=3). The most frequently involved health product classes have varied somewhat each year; however, the top four classes have generally included these classifications. Additional information regarding the reported confirmed AR reports is accessible online at www.cps.ca/cpsp.

TABLE 3 – Annual comparison of reasons for seriousness of confirmed cases

	2011 (n=29)	2010 (n=32)	2009 (n=51)	2008 (n=40)	2007 (n=45)
Death	1	0	1	3	0
Life-threatening	11	6	14	12	9
Hospitalization	18	19	28	18	18
Disability	4	2	3	0	0
Medically important condition*	15	17	21	12	11

* A medically important reaction is defined as one that may not be immediately life-threatening or result in death or hospitalization but may jeopardize the patient or may require intervention to prevent one of these other outcomes from occurring.

Conclusion

The classes of health products most frequently suspected of causing adverse reaction(s) in 2011 were psychoanaleptics, followed by antibacterial agents, antiepileptics and immunosuppressants. All of these classes of health products are used frequently in the treatment of paediatric patients.

The ongoing sharing of adverse reaction reports through the CPSP is key to enhancing the safety of health products for children.

TABLE 4 – Suspected health products reported in AR reports (n=29) in 2011

Suspected health product	# Time reported (n=36)
Infliximab	3 (n=3)
Atomoxetine, carbamazepine, methylphenidate hydrochloride (extended release)*, ibuprofen, drospirenone/ethinyl estradiol†	2 each (n=10)
Ceftriaxone, cefuroxime, citalopram, diphenydramine, doxycycline, fentanyl, flecainide, indomethacin, ifosfamide, isoniazid, ketamine, lamotrigine, linezolid, meropenem, methotrexate, midazolam, risperidone, romiplostim, succinylcholine, sulfasalazine, trazodone, valproic acid, venlafaxine	1 each (n=23)

* All reported as Concerta®.

† Combination products containing two active ingredients (Yaz®, Yasmin®)

Publications and presentations

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Grenier D, Zimmerman M. ¿Una vigilancia estricta puede mejorar el reporte de reacciones adversas a medicamentos? *XIII Congreso Nacional de Pediatría, CoNaPeMe*, Guadalajara, May 2011. (Oral presentation)

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Conversion disorder in children and youth

September 2011 to August 2013

C Grant[1], C Krasnik[1], J Cairney, A Chapman, M Connolly, S Findlay, O Jamoulle, A Kam, E Lipman, R MacNay, B Meaney

Highlights 2011

- The majority of confirmed conversion disorder (CD) cases are female which is consistent with the literature.
- The average age of confirmed cases is 13.7 years with a range of 9–16 years.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report any new patient less than 18 years of age with suspected or diagnosed conversion disorder* defined as the persistent appearance of symptoms/signs that affect the patient's:

- Voluntary motor function (e.g., weakness, abnormal gait or movements, difficulty with swallowing or loss of speech) **and/or**
- Sensory function (e.g., loss or diminished sensation of touch, sight, or hearing) **and/or**
- Non-epileptic seizures ("pseudoseizures" or "psychogenic seizures") and suggest a neurological or medical disease/condition **and**
- May be accompanied by psychological factors at presentation
- Cause significant distress and/or impairment in daily activities, such as self-care, school, play, peer and family relationships and/or activities **and**
- Cannot be adequately explained by a medical condition, substance abuse, or other mental disorder according to the clinical judgment of the treating physician after a comprehensive physical exam and appropriate investigations
- Show no evidence that they have been intentionally produced

* If the diagnosis is uncertain or awaiting confirmation, the case should still be reported.

Exclusion criteria

Patients who have predominantly or exclusively symptoms that are secondary to substance abuse; intentionally produced; secondary to pain disorder, somatization disorder or fatigue; due exclusively to another psychiatric disorder, such as depression, psychosis or tic disorder diagnosed by a child psychiatrist

Results

In the first four months of surveillance, 46 CD cases were reported, meeting the expected study target of a total of 200 cases over two years. With only 11 cases confirmed to date, it is premature to report on detailed results. In the literature, CD is reported more frequently in females. So far, 91% of confirmed cases are females with an average age of 13.7 years (range 9–16). The presenting complaints vary widely, including altered sensation, loss of consciousness, visual changes and dizziness. The majority of confirmed cases required hospitalization with an average length of stay of six days (range 2–19). Analysis of the 33 pending cases will provide a better description of clinical features at presentation, associated features, such as comorbid psychiatric or medical illness and family history of psychiatric illness, the pattern and severity of illness, associated psychosocial features and the current management of children and youth with CD.

TABLE 1 – CD cases from September 1 to December 31, 2011

Reported	Duplicate	Excluded	Pending	Confirmed
46	1	1	33	11

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Early-onset neonatal sepsis and meningitis

Neonates less than seven days of age

January 2011 to December 2012

M Sgro[1], DM Campbell, S Lee, K Sankaran, D Tran, M Yudin

Highlights 2011

- In the first year of surveillance, 61 cases of early-onset neonatal sepsis and meningitis (NSM) were confirmed.
- Antibiotic prophylaxis during labour was given to 33% of mothers.
- Group B *Streptococcus* and *E. coli* accounted for the vast majority of cases.
- There appear to be very few cases of sepsis caused by other types of bacteria.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report any neonate less than seven days of age presenting with one of the following:

- Positive blood culture*

and/or

- Positive cerebrospinal fluid (CSF) culture* from a lumbar puncture (LP)

Neonates with possible nosocomial infections should also be reported.

* Culture growth includes bacterial or fungal pathogens

Exclusion criteria

- Neonates who are asymptomatic with positive culture, such as coagulase-negative *Staphylococcus*, Diphtheroids, *Corynebacterium* spp., *Bacillus* spp., *Propionibacterium* spp., *Aerococcus* spp., *Micrococcus* spp.
- Positive CSF from a drain, reservoir, shunt or intracranial surgical procedure

Results

In the first year of surveillance, 109 cases of early-onset neonatal sepsis and meningitis were reported. Of these, 61 were confirmed, seven were excluded for not meeting the case definition, one was a duplicate and 40 are pending review. The 61 confirmed cases were predominantly from Ontario (n=19) and Quebec (n=18), while six other provinces each reported less than seven cases (BC, AB, MB, NB, NS, NL).

TABLE 1 – NSM cases in 2011

Reported	Duplicate	Excluded	Pending	Confirmed
109	1	7	40	61

All included infants were born between 24 and 41 weeks gestation, with a mean gestational age of 35 weeks and a mean birth weight of 2,697 g (range 568–4,290). The male to female ratio is 1.1:1 (32 males, 29 females). Maternal group B *Streptococcus* status was positive in 15 cases (25%), negative in 26 cases (43%) and unknown in 20 cases (33%); however, 20 mothers (33%) received antibiotic prophylaxis.

TABLE 2 – Breakdown of positive bacterial cultures (n=61)

Bacterial Organism	Frequency (%)
Coagulase-negative *Staphylococci*	4 (7)
E. coli	17 (28)
E. faecalis	1 (2)
Group B *Streptococcus*	30 (49)
H. influenzae	2 (3)
S. bovis	1 (2)
S. epidermidis	2 (3)
S. pneumoniae	2 (3)
S. pyogenes	1 (2)
S. viridans	1 (2)

During the surveillance, bacteria were confirmed primarily from blood cultures (n=56); however, positive cerebral spinal fluid cultures were also reported in five cases. Initial data analysis suggests that group B *Streptococcus* (49%) and *E. coli* (28%) were the most commonly reported positive bacterial cultures. There appear to be very few cases of positive cultures caused by other bacterial organisms.

Understanding the neonatal infection pattern in Canada is of paramount importance with regards to both maternal intrapartum antibiotic guidelines and neonatal management.

Publications and presentations

Sgro M, Yudin MH, Lee S, Sankaran K, Tran D, Campbell DM. Early-onset neonatal sepsis: it is not only group B streptococcus. *Paediatr Child Health* 2011; 16(5): 269

Sgro M. Early-onset neonatal sepsis in industrialized countries. Global Health Symposium – Group B streptococcal sepsis in newborns: An international expert panel discussion on the global burden and opportunities for prevention, The Hospital for Sick Children, Toronto, October 2011. (Oral presentation)

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Langerhans cell histiocytosis

July 2009 to June 2012

B Crooks[1], D Dix, L Parker, S Weitzman

Highlights 2011

- The study confirmed 18 new Langerhans cell histiocytosis (LCH) cases in 2011 and a total of 40 confirmed cases to date.
- The average age at diagnosis is 4 years 5 months (range: birth to 16 years, 4 months).
- Patients often experience delay to diagnosis of up to 60 weeks and see multiple health care professionals.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report any new patient presenting from birth to the 18th birthday with:

- Clinical LCH features that may include unexplained bone pain and soft tissue swelling, diabetes insipidus and hypothalamic-pituitary dysfunction, proptosis, recurrent otitis or otorrhoea, maculopapular rash or seborrhoeic dermatitis or napkin dermatitis resistant to treatment, interstitial pneumonitis or sclerosing cholangitis

and

- Either a) or b)

  a) Biopsy-proven LCH, with lesional cells containing:
  - Birbeck granules demonstrated on electron microscopy and/or
  - CD1a positive cells and/or
  - Langerin-positive cells and/or
  - S100 positive cells with characteristic H&E histopathology

  b) Lytic bony lesions or pituitary/hypothalamic lesions characteristic of LCH without biopsy where:
  - Risks of biopsy are considered too hazardous due to site of lesion
  - Lesion has shown characteristic spontaneous regression

Results

For this study, national surveillance of LCH is conducted using three parallel methods: the CPSP, the C17 network of paediatric haematology/oncology centres and the other allied specialty physicians (orthopaedics, neurosurgery, ENT, dermatology, ophthalmology, endocrinology and pathology). In 2011, 24 cases of LCH were reported to the CPSP. Of these, 18 were confirmed. Only two cases were reported via the alternate pathway and not through the CPSP. Neither is confirmed.

TABLE 1 – LCH cases in 2011

Reported	Duplicate	Excluded	Pending	Confirmed
24	2	0	4	18

Of the 18 confirmed cases, 14 were males and four were females. The main ethnicity reported was Caucasian and others included South Asian, Native American and Middle Eastern. There were six cases from Ontario and Quebec, respectively. The remaining cases were in four provinces (BC, AB, MB, NS). The mean age at diagnosis was 4 years 5 months (range: birth to 16 years, 4 months). Presenting features were varied. There were 10 cases of single-system bony disease: the orbit (n=4), the skull (n=3), the long bones (n=2) and the vertebra (n=1). Three cases presented with polyuria/polydipsia, two of whom had multisystem disease, and one had skull-based disease. Multisystem disease occurred in three cases involving young infants. Three patients presented with solitary skin disease. Those with skin disease had extended times from onset to diagnosis (12 to 60 weeks).

Treatment was by curettage alone (n=3), observation (n=3), non-steroidal anti-inflammatory drugs (NSAIDs) (n=1) and steroid and vinblastine (n=9). Two further cases failed initial treatment with steroid/vinblastine and

received cytarabine and cladribine, with or without 6-mercaptopurine and/or dexamethasone. No clinical trials for LCH therapy were open during 2011. All cases survived.

Currently, 40 LCH cases have been confirmed during the first 2.5 years of this study. Case acquisition will close in July 2012. Only four cases have been reported via the alternate pathways. Additional efforts will be made to collect further cases and outstanding data. Most cases involve bony disease. The time from onset to diagnosis appears to be long, and patients see multiple health care professionals.

Publications and presentations

Crooks B, Grenier D. Langerhans cell histiocytosis: A complex recurrent disease. *Paediatr Child Health* 2010; 15(2): 69–70

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Neonatal hyperbilirubinemia – severe (2011–2013)

Infants 60 days or less

March 2011 to February 2013

M Sgro[1], T Barozzino, DM Campbell, T Longpre, M Ofner, V Shah

Highlights 2011

- In the first 10 months of surveillance, 22 cases of severe neonatal hyperbilirubinemia were confirmed. The mean reported peak bilirubin level was 461 μmol/litre.
- ABO incompatibility was the most common cause of severe hyperbilirubinemia followed by G6PD deficiency and other antibodies.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report any infants 60 days of age or less with unconjugated hyperbilirubinemia and who have had:

- Peak serum total bilirubin > 425 μmol/L **or**
- Neonatal exchange transfusion

Exclusion criteria

Infants who have had exchange transfusion for well-documented Rh isoimmunization disease or who were born at less than 35 weeks gestational age.

Results

In the first 10 months of surveillance, 57 cases of severe neonatal hyperbilirubinemia were reported in infants 60 days of age or less. Of these, 22 were confirmed, six were excluded for not meeting the case definition and 29 are under review. There have been no duplicate reports thus far.

TABLE 1 – Severe neonatal hyperbilirubinemia cases from March 1 to December 31, 2011

Reported	Duplicate	Excluded	Pending	Confirmed
57	0	6	29	22

As expected from the inclusion criteria, the mean gestational age was 38 weeks (range 36–41) with a birth weight of 3,262 g (range 2,569–3,770). Of the confirmed cases, most were reported from Ontario (n=8) and Quebec (n=6). The remaining cases were from British Columbia, Alberta, Saskatchewan and Nunavut. The female to male ratio is 1.2:1 and all infants were breast-fed.

The cause of severe hyperbilirubinemia was identified in about half (12/22) of the confirmed cases. ABO incompatibility (n=8) was the most common cause followed by G6PD deficiency (n=2) and other antibodies (n= 2). The mean reported peak bilirubin level was 461 μmol/litre (range 301–604), compared to the 468 μmol/litre (range 137–773) found in the 2002–2004 CPSP study. Phototherapy was required in 20 confirmed cases, of which four received intravenous immunoglobulin and two needed exchange transfusion. Two infants were reported to have received no treatment. Data from this study will allow for comparison with two previous CPSP studies, namely severe neonatal hyperbilirubinemia (2002–2004) and kernicterus (2007–2009). The goal of this specific surveillance study is to look at rates of severe hyperbilirubinemia/kernicterus pre-and post-introduction of the 2007 Canadian Paediatric Society's position statement, *Guidelines for detection, management and prevention of hyperbilirubinemia in term and late preterm newborn infants (35 or more weeks' gestation)*, and to comment on the effectiveness of the guidelines.

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Paediatric myasthenia

January 2010 to December 2011 – Final report

H Kolski[1], J Vajsar[1]

Highlights

- In two years of national surveillance, 57 cases of paediatric myasthenia (PM) were confirmed.
- A high index of suspicion is required to diagnose PM; a significant percentage of patients (33% with generalized symptoms and 56% with exclusively ocular symptoms) demonstrated normal titres of acetylcholine receptor antibodies.
- There appears to be a significant overlap with other autoimmune disorders, particularly thyroid diseases.
- PM is a treatable disease; readily available treatments include pyridostigmine, prednisone and intravenous immunoglobulin (IVIG).
- Early recognition and management of PM helps to avoid unnecessary testing, prevents the progression of symptoms and lessens morbidity and mortality.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report any child less than 18 years of age with at least one of the following clinical features:

- Fluctuating ptosis (unilateral or bilateral) **and/or**
- Fluctuating extraocular muscle weakness (unilateral or bilateral) **and/or**
- History of skeletal muscle weakness or fatigue

and any of the following supportive tests:

- Tensilon™ test (edrophonium) (or other acetylcholinesterase inhibitor) demonstrating reversal of weakness
- Elevated acetylcholine receptor or MuSK (muscle specific kinase) antibody levels
- Abnormal nerve conduction studies (demonstrating defect in neuromuscular junction transmission) or single fiber EMG

Exclusion criteria

- Underlying primary muscle disease
- Underlying metabolic disease
- Transient neonatal myasthenia

Results

In two years of national surveillance, 57 confirmed cases of PM were reported from Alberta, Manitoba, Ontario, Quebec and Newfoundland. Three cases were excluded: two for insufficient information and one for wrong diagnosis. The completion rate of the detailed questionnaires was 100%. There were 34 generalized and 18 purely ocular reports of PM in children. There were 14 incident cases in 2010 and six in 2011: 13 generalized and seven ocular. Overall, the median age of onset was 10 years (range birth to 17) for the generalized form compared to three and a half years (range 18 months to 11 years) for the ocular subtype. The ratio of male to female was 1:1.1 in the generalized group and 1:2.6 in the younger ocular group. Positive acetylcholine receptor titres were found in 22/33 (67%) of generalized cases and 8/18 (44%) ocular patients. A high index of suspicion is therefore required to diagnose PM; a significant percentage of patients did not have elevated screening acetylcholine receptor antibodies. In these cases, further precise diagnostic evaluation was required. There were five reports of congenital myasthenic syndrome.

TABLE 1 – PM cases from January 1, 2010 to December 31, 2011

Year	Reported	Duplicate	Excluded	Pending	Confirmed
2010	39	2	0	0	37
2011	25	2	3	0	20
Total	**64**	**4**	**3**	**0**	**57**

Initial treatments
For the 34 patients presenting with generalized symptoms, early treatment course information was available for 33 patients. All were started on pyridostigmine; improvement was noted in 100%. Eighteen patients received steroids; improvement was cited in 17/18 (94%). Of those tried on IVIG, improvement was reported in 17/21 (81%).

For the 18 patients with exclusively ocular presentations, 17 had prescribed medications listed. Improvement occurred in 15/17 (88%) patients started on pyridostigmine. All 10 patients started on prednisone improved. IVIG was reported to help one out of two patients.

Associated conditions
There appears to be a high association of PM with thyroid disorders. Two antibody positive patients were concurrently diagnosed with Grave's disease. Another patient had elevated antimicrosomal antibodies. Four patients had a family history of Hashimoto's/thyroid disease.

Conclusion

This study represents the largest descriptive series of paediatric myasthenia in North America. It provides valuable information about clinical characteristics and raises awareness regarding the diagnosis. A high index of suspicion is required even in patients with normal titres of acetylcholine receptor antibodies. PM is a treatable disease. Children generally respond promptly to readily available treatments including pyridostigmine, prednisone and IVIG. Early recognition and management of PM helps to avoid unnecessary testing, prevents the progression of symptoms and lessens morbidity and mortality.

Publications and presentations

Kolski H, Vajsar J, Grenier D. Paediatric myasthenia: A moving target. *Paediatr Child Health* 2010; 15(4): 226

Kolski H. Paediatric myasthenia: first year of active national surveillance. 46th Annual Congress of the Canadian Neurological Sciences Federation, Vancouver, June 2011. (Oral presentation)

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Periodic fever syndromes

September 2011 to August 2014

P Dancey[1], S Benseler, M Gattorno, A Junker, R Laxer, P Miettunen, L Turner

Highlights 2011

- Periodic fever, aphthous stomatitis, pharyngitis and adenitis (PFAPA) was the most commonly reported periodic fever syndrome (PFS) during the initial four months of surveillance.
- Familial Mediterranean fever and undefined PFS were also reported.
- Most patients have seen multiple physicians before receiving a diagnosis.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report any patient less than 18 years of age presenting with a newly diagnosed periodic fever syndrome (autoinflammatory syndrome) meeting the criteria outlined below.

Inclusion criteria

Patients must have one of the following diagnoses (see protocol for specific details outlined in the appendix and for characteristic features in the table; the protocol can be accessed at www.cps.ca/cpsp):

- Familial Mediterranean fever (FMF)
- Tumor necrosis factor receptor-associated periodic syndrome (TRAPS)
- Hyperimmunoglobulinemia D syndrome (HIDS)
- Cryopyrin-associated periodic syndromes (CAPS), including familial cold autoinflammatory syndrome (FCAS), Muckle-Wells syndrome (MWS), and neonatal-onset multisystem inflammatory disease (NOMID)
- Periodic fever, aphthous stomatitis, pharyngitis and adenitis (PFAPA)
- Periodic fever syndrome – undefined

Exclusion criteria

- Detailed clinical assessment and investigations compatible with infections, malignancy, or the classical inflammatory or autoimmune rheumatic diseases (e.g., systemic lupus erythematosus, systemic juvenile idiopathic arthritis, inflammatory bowel disease)
- Febrile attacks with regular periodicity and low neutrophil counts, suggestive of cyclic neutropenia

Results

During the initial four months of surveillance, 25 cases of PFS were reported. Of the 11 confirmed cases, eight were PFAPA, two were FMF and one was undefined PFS. The average age at diagnosis was four years old (range 1–7). No cases of TRAPS, CAPS or HIDS have been reported to date. This may reflect the rarity of these conditions, but also the requirement for genetic testing confirmation causing a delay in the final reporting. Most cases have been evaluated by more than two physicians before receiving a diagnosis (range 1–4). The majority of reporting physicians are general paediatricians, in addition to rheumatologists and geneticists. Further progress through the course of this three-year surveillance study should clarify the full spectrum and incidence of PFS cases in Canada.

TABLE 1 – PFS cases from September 1 to December 31, 2011

Reported	Duplicate	Excluded	Pending	Confirmed
25	1	0	13	11

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Persistent albuminuria in the paediatric population with type 2 diabetes mellitus

April 2010 to March 2012

S Hadjiyannakis[1], E Sellers[1], S Amed, A Dart, H Dean, R Dyck, J Hamilton, V Langlois, C Panagiotopoulos, A-M Ugnat

Highlights 2011

- Persistent albuminuria was confirmed in 16 children less than 18 years of age with type 2 diabetes mellitus (T2DM).
- Children of Aboriginal heritage appear to be disproportionally affected.
- A family history of diabetes-related renal disease and exposure to pre-gestational or gestational diabetes is frequently found.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report any patient up to 18 years of age with type 2 diabetes mellitus
and
persistent microalbuminuria or macroalbuminuria, defined as 2/3 positive samples at least one month apart over a 3–6 month period.

Canadian Diabetes Association definition of diabetes:

- Fasting plasma glucose (FPG) ≥7.0 mmol/L* or
- Random plasma glucose ≥11.1 mmol/L* or
- Two-hour plasma glucose ≥11.1 mmol/L* after a standard oral glucose tolerance test

* Requires a second, confirmatory test if child is asymptomatic

Diagnosis of T2DM will be based on the following clinical features:

- Obesity (body mass index >95th percentile for age and gender)
- Family history of T2DM in a first or second degree relative(s)
- Belonging to a high-risk ethnic group (e.g., Aboriginal, African, Hispanic, South-Asian)
- A history of exposure to diabetes in utero (diagnosed before or during pregnancy)
- Evidence of insulin resistance: acanthosis nigricans, polycystic ovarian syndrome, hypertension, dyslipidemia
- Absence of diabetes-associated autoantibodies when available

TABLE 1 – Definition of albuminuria*

	Urine albumin to creatinine ratio (ACR)†	24-hour urine collection for albumin
Microalbuminuria	2.0–20.0 mg/mmol (male) 2.8–28.0 mg/mmol (female)	30–300mg/day (male or female)
Macroalbuminuria	>20.0 mg/mmol (male) >28.0 mg/mmol (female)	>300 mg/day (male or female)

* Persistent albuminuria defined as 2/3 positive samples over a 3–6 month period, samples must be at least one month apart
† Confirmation with either first-morning urine sample or overnight urine collection

Results

Of the 16 confirmed cases during 2011, 12 (75%) were female and 14 (88%) were in children of self-declared Aboriginal heritage (13 First Nations, one Métis). A regional variation was noted with 75% of cases from Manitoba, 19% from northwestern Ontario and 6% from Nova Scotia.

TABLE 2 – Persistent albuminuria in children with T2DM cases in 2011

Reported	Duplicate	Excluded	Pending	Confirmed
21	0	0	5	16

The mean age at diagnosis of albuminuria was 13.6 years (range 9.8–17.7) (male 16.1; female 11.7 years). Associated co-morbidities were common, with dyslipidemia the most frequently reported in 9/16 cases (56%), hypertension in 8/16 (50%), and non-alcoholic liver disease in 3/16 (19%). Frequent findings included exposure to pre-gestational diabetes (6/16, 38%), exposure to gestational diabetes (3/16, 19%) and a family history of diabetes-related renal disease (9/16, 56%).

Preliminary results indicate that persistent non-orthostatic albuminuria in youth with T2DM does occur in Canada and that children of Aboriginal heritage appear to be disproportionally affected. National surveillance for the prevalence of albuminuria in children with T2DM is necessary to define the spectrum and extent of the problem. This is important for predicting the burden of illness and for planning screening and intervention programs. This data will be useful for paediatricians, community physicians, community health professionals, policy makers and program planners. Furthermore, the data will provide a baseline prevalence estimate for future comparison. Identification of the population of children with T2DM and persistent albuminuria will facilitate research to understand the etiology and prevention of this significant complication.

Publications and presentations

Sellers E. Renal disease in youth with type 2 diabetes: Need for early detection. *Paediatr Child Health* 2010; 15(5): 256–7

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Respiratory syncytial virus infections in paediatric transplant patients

September 2010 to August 2013

JL Robinson[1], U Allen, I MacLusky

Highlights 2011

- The incidence of severe respiratory syncytial virus (RSV) infections in paediatric solid organ or haematopoietic stem cell transplants appears to be low.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report all inpatients and outpatients less than 18 years of age who have:

- Laboratory-confirmed RSV infection

and

- Received solid organ transplantation or haematopoietic stem cell transplantation within the two previous years

Results

Ten cases of paediatric transplant patients with RSV infections were confirmed in 2011. Of these, four cases were nosocomial: two in liver recipients (11 days and 6 months post-transplant respectively), one in a kidney recipient (63 days post-transplant) and one in an allogeneic haematopoietic stem cell recipient (16 days post-transplant). None of these four cases required ventilation.

TABLE 1 – RSV infections in paediatric transplant patients cases in 2011

Reported	Duplicate	Excluded	Pending	Confirmed
17	0	5	2	10

Three cases were community-acquired infections that were not severe. One case occurred 10 months post-transplant in an allogeneic haematopoietic stem cell recipient who was not admitted to hospital. Two cases occurred in kidney recipients: one at 55 days post-transplant was admitted to hospital but not ventilated; the second at 20 months post-transplant was not admitted.

The final three cases survived severe RSV infections and required ventilation for: three days (lung recipient, 33 days post-transplant), six days (liver recipient, five months post-transplant) and 21 days (allogeneic haematopoietic stem cell recipient, 22 days post-transplant).

The incidence of severe RSV infections in paediatric solid organ or haematopoietic stem cell transplant patients appears to be low. As RSV prophylaxis is available, gathering data on the incidence and morbidity associated with RSV infection in Canadian transplant recipients is of utmost importance to establish potential costs and benefits of palivizumab in this population.

Publications and presentations

Robinson JL, Grenier D. What happens when you mix a transplant with respiratory syncytial virus? *Paediatr Child Health* 2011; 16(1): 12

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Severe iron-deficiency anemia in infants and young children

October 2009 to September 2011 – Final report

P Parkin[1], S Zlotkin[1], M Belletrutti, M Carcao, J Grabowski, A-M Ugnat, S Wong

Highlights

- Severe iron-deficiency anemia (IDA) continues to occur in Canada, with 195 confirmed cases in two years.
- Dietary factors such as prolonged bottle-feeding, excessive cow's milk and/or inadequate iron-enriched food intake were involved.
- Asian and Aboriginal populations were over-represented in the study sample, accounting for 36% and 12% of the confirmed cases, respectively.
- Significant morbidity is associated with severe IDA, including developmental delay, heart failure, cerebral thrombosis and health care utilization.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

Report all otherwise healthy infants and young children from six to 36 months of age with severe iron-deficiency anemia defined as: Hemoglobin <80 g/L and low mean corpuscular volume (MCV; below normal for age) **plus one or more of the following:**

- Low ferritin
- Low iron
- High transferrin receptor
- High free-erythrocyte protoporphyrin
- Correction of anemia with iron therapy

Exclusion criteria

- Chronic disease known to be associated with anemia
- Diseases associated with malabsorption
- Conditions associated with blood loss, such as trauma, surgery and frequent bloodletting
- Known congenital hemoglobinopathy
- Known disorders of clotting
- Blood loss due to acute or chronic disease causing gastrointestinal bleeding

Results

Throughout the two years of surveillance, 340 cases of severe IDA were reported in infants and young children. Sixty-five cases were excluded for the following reasons: not meeting inclusion criteria for anemia (n=19), age (n=14), confirmatory biochemical laboratory test such as ferritin (n=4), date of diagnosis (n=13) and presence of a disease known to be associated with anemia (n=2); inability to locate chart/patient by respondent (n=13); reported by lab with no details of case known (n=1); and child excluded by physician (n=1). Two children were excluded for more than one reason. A total of 195 cases were confirmed. The reporting rate for completion of the detailed questionnaire was 84%. The estimated incidence of severe IDA in infants aged 12 to 36 months is 12/100,000 (Statistics Canada, 2006 Census), which may be an underestimate.

TABLE 1 – Severe IDA cases from October 1, 2009 to September 30, 2011

Year	Reported	Duplicate	Excluded	Pending	Confirmed
2009*	38	0	14	6	18
2010	152	8	23	24	97
2011†	150	14	28	28	80
Total	**340**	**22**	**65**	**58**	**195**

* October 1, 2008 to December 31, 2009
† January 1, 2011 to September 30, 2011

The mean age of patients was 18 months (range 6–36). Where information was provided, almost half of the cases' mothers were Caucasian (82/182, 45%), 65 (36%) were Asian, 21 (12%) were Aboriginal and 14 (8%) were other

ethnicities. This suggests an over-representation of the overall Asian population, which is 12% of the Canadian population (Statistics Canada, 2006 Census). The Aboriginal population is also over-represented in this study, as Aboriginals represent 4% of the Canadian population (Statistics Canada, 2006 Census). However, in this survey Aboriginals might be under-reported, as very few paediatricians are working in remote northern communities.

The median hemoglobin level was 55 g/L (interquartile range [IQR] 45–67), median MCV was 51.9 fL (IQR 49.1–55.0) and median serum ferritin was 3.8 μg/L (IQR 2–8).

Of the 195 infants, 154 (79%) were receiving cow's milk at diagnosis of IDA; their mean daily consumption was 1.1 L (38 oz), with a range of 200 mL to 2.4 L (7–81 oz). Inadequate intake of iron-enriched foods was reported in 89 infants (46%). Current or previous breast-feeding was found in 124 infants (64%). Of those children over 12 months of age, 111/140 (79%) reported using the bottle during the day and 60% reported using the bottle in bed. Presenting signs that prompted the physician to request laboratory investigations included pallor (n=126), poor weight gain (n=20), developmental delay (n=13), poor energy (n=45), fever (n=29), irritability (n=37), infectious illness (n=58), underweight (n=15), edema (n=11), pica (n=13) and poor feeding (n=10). Almost one-quarter (23%) had complications, particularly developmental delay (n=33), evidence of heart failure (n=9) and cerebral thrombosis (n=2). In all cases, the attending physician prescribed oral iron supplementation and provided dietary counselling. Hospital admission was needed in 83 cases (43%); of these, 25 required a blood transfusion and 42 had a consultation with a paediatric hematologist. Transfusions for children with IDA are usually reserved for severe anemia with complications. The median reported hemoglobin level in children requiring a blood transfusion in this study population was 36 g/L (IQR 28–46).

Conclusion

The results from these 24 months of surveillance demonstrate that severe IDA is being reported in Canadian infants and young children and is associated with significant morbidity. Dietary factors likely played an etiologic role in most confirmed cases, including inadequate intake of iron-enriched foods and high consumption of cow's milk. Primary prevention through nutrition counselling of young children may lead to reductions in severe IDA. Secondary prevention through screening young children, especially those with high risk factors, for early stages of iron deficiency before the onset of anemia should be an area for future research.

Publications and presentations

Parkin P, Zlotkin S. Why is this tachypneic child so pale? *Paediatr Child Health* 2010; 15(3): 135–6

Wong S. The landscape of severe iron-deficiency anemia in Canada. Paediatric Update Session. Canadian Paediatric Society Annual Conference, Quebec City, June 2011. (Oral presentation)

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Travel-related illnesses in paediatric travellers who visit friends and relatives abroad

March 2009 to February 2011 – Final report

M Crockett[1], L Ford-Jones, D Grondin, C Hui, J Keystone, S Kuhn

Highlights

- During the two years of surveillance, 91 confirmed cases of significant travel-related illnesses (TRIs) occurred among paediatric travellers who visited friends and relatives abroad (VFRs).
- Enteric fever ("typhoid fever") and malaria were the most common types of travel-related illnesses.
- A majority of confirmed cases did not obtain pre-travel advice.
- Almost three-quarters of the cases required hospitalization with an average length of stay of 12 days.

Background and objectives

The complete protocol can be accessed at www.cps.ca/cpsp.

Case definition

A travel-related illness is acquired while travelling abroad and symptoms may develop during travel or following the child's return to Canada. A VFR traveller may be a foreign-born child or the Canadian-born child of foreign-born parents who is travelling to a country of origin to visit friends and relatives. The diagnosis is made on clinical and/or laboratory criteria.

Report all children living in Canada less than 18 years of age who acquire significant travel-related illnesses while travelling abroad as VFR travellers.

Exclusion criteria

- Children who develop travel-related illnesses but did not travel to visit friends and relatives
- Children who acquire non-specific mild travellers' diarrhea and respiratory infections, not requiring hospitalization

Results

During the two years of surveillance, 129 cases were reported. The study confirmed 91 cases of TRIs in paediatric VFRs (Table 1). Among these, 42 (46%) were reported from Ontario, 14 (15%) from British Columbia, 12 (13%) from Quebec, 11 (12%) from Alberta, 10 (11%) from Manitoba and the remaining cases were from Saskatchewan and Prince Edward Island. The regions of travel and the types of TRIs acquired by paediatric VFRs are summarized in Tables 2 and 3 respectively.

TABLE 1 – TRIs in paediatric VFRs cases from March 1, 2009 to February 28, 2011

Year	Reported	Duplicate	Excluded	Pending	Confirmed
2009*	51	3	8	7	33
2010	68	6	4	9	49
2011†	10	0	1	0	9
Total	**129**	**9**	**13**	**16**	**91**

* March 1 to December 31, 2009
† January 1 to February 28, 2011

The majority (81%) presented with fever. Diarrhea (42%), vomiting (18%), abdominal pain (16%), cough (16%), headache (12%), rash (9%) and jaundice (9%) were also common symptoms. The majority of patients with TRIs were initially seen in the emergency department (64%) as compared to the physician's office or clinic (36%). The interval of time between the beginning of travel and the onset of symptoms ranged from a few days to several months with an average of 62 days due to the long duration of travel for some children. The interval of time between the onset of symptoms and the physician visit varied depending on the type of travel illness, as did the time between the onset of symptoms and diagnosis.

The average duration of travel was approximately 7 ½ weeks. Almost all VFR children travelled to urban areas with 49% travelling exclusively to urban areas and 42% to both rural and urban areas. Only 9% travelled

exclusively to rural locations. The majority of confirmed cases (79%), whose type of accommodation was known, stayed in family homes, only 19% of which were documented to have air conditioning and/or insect screens. Other risk factors included ingestion of food from street vendors (18%), unsafe water (19%), unpasteurized dairy products (5%) and uncooked or unpeeled fruits and vegetables (22%).

TABLE 2 – Region of travel associated with TRIs*

Asia	56
Africa	20
Central/South America	10
Middle East	5
Europe	1

* Some travellers developed TRIs following travel to more than one country.

Among the 91 confirmed cases, 24 obtained pre-travel advice and 45 did not; in 22 cases it was unknown whether any advice was received. Of those who received pre-travel advice (n=24), eight obtained it from a travel clinic physician, five from a paediatrician, four from a family doctor and seven respondents did not specify from whom they received advice.

TABLE 3 – Types of TRIs acquired by paediatric VFRs

Enteric fever (suspected, confirmed)	36 (3, 33)
Malaria	17
Severe diarrheal illness	12
Hepatitis A	11
Parasitic infections	9
Symptomatic TB disease	5
Dengue	3
Respiratory disease (including H1N1)	3
Non-typhoidal *Salmonella* bacteremia	2
Measles	1
Brucellosis	1
UTI (multi-drug resistant organism)	1

Of those who obtained pre-travel advice, 11 patients were not compliant with the advice given regarding vaccines (n=2) or antimalarials (n=9). In eight cases it was unknown whether the advice was given correctly and not followed or was inappropriate. Four cases did not receive recommended pre-travel vaccines and/or antimalarial medications for their destinations according to recognized travel medicine guidelines. One primary vaccine failure was reported in a case with enteric fever; however, the effectiveness of typhoid vaccines is known to be only about 70%.

More than 70% of patients with TRIs required hospitalization (n=65) with an average length of stay of 12 days (mean=12, median=6). Of note, two patients required admissions of approximately three months duration. Three patients were critically ill at presentation: one presented with hypotension due to malaria and two presented with septic shock secondary to *Salmonella* species bacteremia. Four patients required admission to intensive care units. Four children were left with significant sequelae and there was one death due to septic shock.

Conclusion

There were 91 confirmed cases of significant TRIs among paediatric VFRs during the surveillance period from 2009–2011. These numbers likely under-represent the burden of TRIs among paediatric VFRs because the case definition excludes mild respiratory and gastrointestinal illnesses that do not require hospitalization.

The results of this surveillance study are consistent with information regarding TRIs among adults, given that paediatric VFRs generally travelled for at least several weeks, stayed in family homes, and ingested unsafe food and water. The majority (62%) of TRIs in this study sample occurred in children who travelled to Asia. Only one-quarter of the paediatric VFRs sought travel advice and, among those who did, several were not compliant with pre-travel recommendations and some received advice that did not follow standard travel medicine guidelines.

In this study, the majority of paediatric VFRs required hospitalization for their TRIs with an average length of stay of 12 days (mean=12, median=6), while two patients required admissions of approximately three months duration. This demonstrates that in addition to the significant morbidity experienced by paediatric VFRs in Canada, there are also significant associated costs to the health care system. Furthermore, the majority of the TRIs were potentially preventable if appropriate pre-travel advice had been obtained and followed. This study highlights the need to develop education and advocacy strategies to ensure that pediatric VFR travellers are able to access and comply with travel health advice in order to minimize their risk of acquiring travel-related illnesses. In particular, further research is needed to evaluate the barriers and facilitators to accessing and adhering to pre-travel services and recommendations for pediatric VFRs.

Publications and presentations

Crockett M. Canadian children who travel abroad: What are the risks? *Paediatr Child Health* 2009; 14(3): 175–6

Crockett M, Hui C, Kuhn S, Ford-Jones L, Grondin D, Keystone J. Travel-related illnesses among paediatric VFRs in Canada. American Society of Tropical Medicine and Hygiene. 60th Annual Meeting, Philadelphia, December 2011. (Oral presentation)

Crockett M. Travel-related illnesses in Canadian children. Canadian Paediatric Society Annual Conference, Vancouver, June 2010. (Poster presentation)

Crockett M, Hui C, Kuhn S, Ford-Jones L, Keystone J. Travel-related illnesses in Canadian children (TRIP study). Infectious Diseases Society of America Annual Meeting, Philadelphia, October 2009. (Poster presentation)

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Survey Questions

Accidental or intentional methadone exposure in children and young infants

October 2011

L Lewington[1], A Ornstein[1], SM Marcus, C Shaffer, A Vulliamy

Methadone is a synthetic opioid agonist widely used in methadone maintenance treatment (MMT) programs for people with opioid dependency, and less commonly used as analgesia for palliative care and chronic pain. It is dispensed as a brightly colored solution in a juice-like dilutant that must be refrigerated. Methadone presence in the home may precipitate accidental ingestion by a child mistaking the suspension for juice, or intentional exposure by a caregiver giving it to a child as a sedative. Sadly, ingestion of only 0.5 mg/kg of methadone can be lethal for a child.

A one-time CPSP survey was done to evaluate and raise awareness of accidental and intentional paediatric methadone exposure, and to capture the number of observed cases in Canada in a 12-month period.

The survey response rate was 25% (642/2,559). Of these, 27 (4%) respondents reported caring for at least one child with suspected or confirmed methadone exposure within the preceding 12 months; 78% identified one or two cases, 15% identified three or four cases and 7% identified between five and 10 cases. Perceived clinical outcomes are presented in Table 1. Only 15 of the 27 respondents who had seen a case indicated that a child welfare authority was notified. Of note, the same case may have been reported by more than one respondent.

Forty percent of respondents were unaware that methadone might be intentionally given to a child by a caregiver as a sedative and 27% were unaware that even a small dose can be potentially lethal in children. Only 45% knew the importance of counselling caregivers about safe storage of methadone in the home.

TABLE 1 – Perceived clinical outcomes of suspected/confirmed methadone ingestions (n=27 reports)

Perceived clinical outcomes	Frequency (%)
Not serious	11 (41)
Serious - Hospitalization - ICU admission - Death	15 (46) 8 (30) 5 (19) 2 (7)
Data not reported	1 (4)

The results of this survey confirm that methadone ingestion in children is rare but can be lethal. Although less than 5% of all respondents had cared for methadone-exposed children, of those who had, 22% cared for multiple children (3–10 cases). This suggests that exposure may not be so very rare. The survey confirmed that paediatricians need more education about the risks and consequences of child methadone exposure as less than half of the respondents were aware that methadone may be intentionally given to a child as a sedative. Methadone exposure may be an under-recognized form of child maltreatment as just over half of the respondents who had seen a case indicated that a report to a child welfare authority was made. A targeted surveillance program would aid in further defining this issue in Canada.

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Behaviours and practices towards food allergies

January 2011

M Ben-Shoshan[1], M Desjardins[1], G Shand

A one-time survey was mailed to all 2,573 CPSP participants to assess the attitudes of Canadian allergists and paediatricians (non-allergists) towards non-controversial and controversial issues related to food allergy and food-induced anaphylaxis. Since accessibility to allergy specialists is variable across Canada and usually limited outside urban areas, paediatricians are playing a major role in the care of patients with allergic diseases. However, attitudes of allergists and non-allergists may differ for both non-controversial and controversial issues. The survey aimed to identify knowledge gaps that need to be bridged through appropriate educational programs. There were 533 CPSP responses, 25 from allergists and 508 from paediatricians (response rate 21%). Through parallel surveillance, 89 additional allergists were recruited from their medical association, the Canadian Society of Allergy and Clinical Immunology (CSACI). Overall, 114 allergists answered the survey.

Non-controversial issues

According to the 2010 Canadian consensus guidelines on the management of anaphylaxis in the primary care setting, the preferred route of epinephrine administration is intra-muscular (IM). In addition, although not mentioned in the consensus guideline, most experts now agree that for those with egg allergy, MMR immunization does not need to be given in a hospital setting as long as the immunization provider has an emergency kit containing epinephrine and is familiar with its use.

The survey revealed that 93% of allergists believe IM is the preferred route of epinephrine administration, versus 71% of paediatricians. Among allergists, less than 3% prefer the subcutaneous route. A smaller proportion of allergists compared to paediatricians require MMR immunization in a hospital facility in children with egg allergy (4% versus 12%).

Controversial issues

The appropriate age of introduction of allergenic foods remains controversial. The 2008 American Academy of Pediatrics' revised position statement stipulated that there was no convincing evidence to support delaying the introduction of solid foods beyond the age of 4–6 months, including allergenic foods like egg white, in order to prevent food allergies. Also, there are no guidelines regarding the optimal timing for epinephrine administration during an allergic reaction, but it is clear that a delay in initiating therapy may result in increased morbidity and mortality in cases progressing to anaphylaxis. Hence, we queried physicians on these issues to assess their actual recommendations.

The survey revealed that allergists were less likely than paediatricians to recommend delayed introduction of egg white to children with and without a family history of atopy (with family history: 43% versus 61%; without family history: 22% versus 50%). When managing food-induced anaphylaxis, respondents tend to administer epinephrine to patients with allergic reactions involving generalized or systemic symptoms. Yet, more than 25% would not give epinephrine even when the patient has breathing difficulties or symptoms consistent with hypotension.

Conclusion

For non-controversial issues, a greater proportion of allergists adhere to current guidelines or literature recommendations. Surprisingly, 25% of respondents, regardless of their subspecialty, would not administer epinephrine for severe anaphylaxis, a situation in which it is clearly indicated. Future education programs need to address these gaps to avoid unnecessary restriction of MMR immunization and ensure prompt delivery of epinephrine when there is a concern that the allergic reaction may progress to anaphylaxis. These recommendations should be continuously updated to reflect advances in care. Finally, more research is required to determine best practices regarding appropriate age of introduction of allergenic foods.

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CPSP resource use

April 2011

A Quartaro[1]

The CPSP provides supplemental resources to participants that include:
- A monthly educational tool on adverse drug reaction topics entitled *ADR Tip of the Month*
- Quarterly updates that summarize reported cases by region
- Biannual educational articles on study topics

A one-time survey was conducted to assess the use of the supplementary resources mailed to CPSP participants. Questions touched on were how frequently they read the supplemental CPSP resources, how helpful they found the material to be and how they disseminated the resources. The survey also asked for feedback on how the CPSP could make the resources more relevant to paediatric practice.

All 2,559 participants were sent the survey; the response rate was 27% (688/2,559). Results reaffirmed the importance of CPSP supplemental resources for program participants. Of the respondents, 65% (444/688) stated that they always read the *ADR Tip of the Month*; another 23% (158/688) read it sometimes. More than three-quarters (80%) of respondents said they read the quarterly updates and educational resources sometimes or always.

Interestingly, 82% of respondents found the ADR tips to be either very helpful (40%) or fairly helpful (42%). Certain groups of subspecialists did not find the tips to be particularly relevant to their practice. Respondents who shared the ADR information did so by posting to notice boards, circulating the hard copy to colleagues, presenting to students, discussing with colleagues and sharing with parents.

When asked about quarterly reports, 77% of participants responded that they always or sometimes read this resource; 63% felt this resource was either very or fairly helpful.

Educational resources are sent to participants twice per year, the latest having been sent five months prior to the survey being distributed. Respondents rated this resource as being fairly helpful (44%) and very helpful (28%).

The results of this survey confirm the high value that CPSP participants place on supplemental resources and the usefulness of ADR tips to provide paediatricians with timely information relevant to practice.

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Complications associated with energy drinks

March 2011

A Boutin[1], J Harvey[1], D Taddeo[1], J-Y Frappier

A one-time survey was conducted among all 2,510 CPSP participants to assess their screening practices regarding the use of energy drinks among children and youth. The survey also collected data on related complications encountered in the past 12 months and the reasons for the use of energy drinks mentioned by patients.

The survey response rate was 30%. Among the 741 respondents, 64% were general paediatricians, 35% were subspecialists and 1% did not specify their status.

Almost half of the respondents (46%) said they do not screen for the use of energy drinks: 57% were subspecialists and 41% were general paediatricians. Only 4% of respondents said they always screen for energy drink consumption while just under half (49%) screen occasionally. One percent did not answer.

Sixty-seven respondents (9%) reported they encountered patients with caffeine-related complications in the last 12 months: 52% were general paediatricians and 47% were subspecialists, including emergency medicine specialists (n=8), cardiologists (n=6) and adolescent medicine specialists (n=5). Fifty of these 67 respondents encountered less than five children and youth with complications. Fifteen percent of those who screen for energy drink use reported having seen patients with complications compared to only 2% of those who do not screen. Eighty-eight percent of those reporting complications were physicians who screen for the use of energy drinks. The types of reported complications are shown in Table 1.

Thirteen out of 43 respondents (30%) who answered the question regarding the amount of energy drinks consumed at a time (during a short period) reported having seen children and youth who were drinking three or more cans/containers. Seventeen out of 37 respondents (46%) who answered the question regarding the amount consumed per day reported having seen children and youth who were drinking three or more cans/containers.

Among the physicians who reported complications (n=67), 28% reported that children and youth who presented with complications associated with energy drinks had also consumed alcohol and 26% reported the use of other drugs (psychostimulants 30%, cannabis 20%, amphetamine 10%). The majority of these respondents (78%) had seen the children and youth in an office setting.

The reasons physicians gathered from children and youth for the use of energy drinks are shown in Table 2.

This one-time survey has some limitations, such as low response rate, assumed causal relationship of complications to energy drink use and, to a lesser extent, incomplete data submissions. However, the results show that 96% of respondents do not, or only occasionally, screen for energy drink use. Those who screen are finding possible complications associated with the use or abuse of

TABLE 1 – Physicians reporting complications associated with energy drinks among children and youth (n = 67)

Complications	Frequency (%)
Nervousness	35 (52)
Restlessness	34 (51)
Tachycardia	33 (49)
Palpitations	29 (43)
Insomnia	28 (42)
Headaches	20 (30)
Nausea	16 (24)
Arrhythmia	11 (16)
Hypertension	10 (15)
Vomiting	4 (6)
Vertigo	4 (6)
Diarrhea	2 (3)
Seizures	1 (1.5)
Euphoria	1 (1.5)
Hallucinations	1 (1.5)
Death	1 (1.5)
Others	9 (13)

TABLE 2 – Physicians reporting reasons for energy drink use among children and youth (n = 64)

Reasons	Frequency (%)
Increase alertness	46 (72)
Peer pressure	25 (39)
Sport performance	16 (25)
Increase attention	7 (11)
Exam performance	6 (9)
Decrease alcohol effect	5 (8)
Weight loss	3 (5)
Others*	21 (33)

* Energy, pleasure, preference, social reasons

these drinks. Indeed, the results reveal potentially serious complications reported by 9% of respondents, mainly from those who screened.

Hopefully, this survey will increase awareness of potential health hazards associated with the use of energy drinks and the importance of screening, especially when confronted with certain symptoms.

Survey results also support initiatives to ensure that energy drinks no longer be labelled as natural health products, but rather managed as food, requiring the display of nutritional, ingredients and caffeine information. A maximum caffeine level for these products should also be set.

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Necrotizing enterocolitis in infants

May 2011

R McCormick[1], M Raizenne, A-M Ugnat

An outbreak of necrotizing enterocolitis (NEC) in premature infants in the United States associated with the consumption of SimplyThick®, a thickening product, occurred in May 2011. Designed in partnership with the Public Health Agency of Canada, a one-time survey was sent to all CPSP participants to measure whether clinicians recommend the use of a thickening product for infants younger than one year and to document if Canadian cases of NEC were seen in the previous six months.

The survey response rate was 28% (741/2,660). Seventeen percent of respondents indicated having seen an infant hospitalized with NEC in the previous six months. Of those respondents, 77% had seen less than five cases, 12% reported five to 10 cases, and 9% reported more than 10 cases. Of note, 2% did not specify the number of cases seen.

Results showed that almost one-third (30%) of respondents have recommended the use of a thickening product for infants younger than one year. There was no question in the survey asking if the infant was premature or full term. Two cases of NEC in infants after the use of SimplyThick® were reported. One case, a premature infant (gestational age 27 4/7 weeks) who presented with NEC at 33 5/7 weeks, is deceased. The other case was alive and still in hospital at the time of the survey. Demographic information, including gestational age and age at presentation, was not available.

For a one-time survey, without reminders, a 28% response rate is in keeping with what is found in the literature. Clinicians would recall NEC cases as these are very sick infants requiring intensive care. Through a well-established surveillance network, public health authorities were able to rapidly collect information on an emerging issue.

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Sudden unexplained death in children with epilepsy

August 2011

EJ Donner[1]

Mortality rates in children with epilepsy exceed those of the general population. While many deaths may be explained by the underlying cause of seizures or co-morbid conditions, a proportion of deaths in children with epilepsy remain unexplained. The phenomenon of sudden unexpected death in epilepsy (SUDEP) refers to the death of a person with epilepsy that is sudden, unexpected and unexplained. Autopsy does not reveal a cause of death. SUDEP deaths may be witnessed or unwitnessed and may occur with or without evidence of a recent seizure.

The incidence of SUDEP in adults is estimated to be 1 death per 1,000 people with epilepsy per year, with rates approaching 1 per 100 person years in individuals with medically refractory seizures. The incidence of SUDEP in children has not been explored adequately; the limited literature suggests lower rates than in adults, ranging from 0.2 to 0.4 per 1,000 person years. These incidence rates are generally believed to be an underestimate, as it is widely acknowledged that poor awareness of SUDEP among health care practitioners and people with epilepsy results in low case ascertainment.

The CPSP conducted a one-time survey to determine whether a gap in knowledge of SUDEP exists among Canadian paediatricians and inform strategies for a prospective study of SUDEP among Canadian children. The survey was circulated to all CPSP participants and the response rate was 34% (866/2,570). Of the respondents, 78% (674/866) reported that they had cared for children with epilepsy in the preceding 24 months. Among these paediatricians, only 56 % (380/674) knew that children with epilepsy are at an increased risk of sudden unexplained death compared to children without epilepsy. Only 33% (225/674) of paediatricians caring for children with epilepsy were aware of the term SUDEP.

Fourteen paediatricians reported knowledge of a case of SUDEP. Of the 11 cases for which details of the death investigation process were reported, five children (45%) did not undergo autopsy, suggesting inadequate investigation of deaths in children with epilepsy. The survey methodology does not permit accurate incidence calculations.

This survey identifies poor awareness of SUDEP among Canadian paediatricians and highlights the need for educational initiatives to support future studies involving SUDEP case collection. Accurate incidence data will require prospective surveillance of SUDEP in children. More information about SUDEP may be found at www.sudepaware.org.

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International Developments

The International Network of Paediatric Surveillance Units (INoPSU), established in 1998, continues to enhance collaboration between national paediatric surveillance units. Currently, there are 12 national paediatric surveillance units worldwide that are full members of INoPSU: Australia, Britain, Canada, Cyprus/Greece, Germany, Ireland, Latvia, Netherlands, New Zealand, Portugal, Switzerland and Wales. The British Ophthalmological Surveillance Unit is an associate member, and the Belgian Paediatric Surveillance Unit is an affiliate member.

2011 highlights

The 7th INoPSU meeting was held in Montreux, Switzerland on September 1–2, 2011, and coincided with the Swiss Paediatric Society scientific meeting. Seventeen representatives from eight different INoPSU units were present (www.inopsu.com). The two-day meeting comprised a one-day scientific meeting, followed by the INoPSU business meeting.

The scientific program included the following presentations:

- The Swiss Paediatric Surveillance Unit: highlights of 15 years of operation
- The Belgian Paediatric Surveillance Unit "PediSurv"
- The BPSU: 25 years of informing vaccination policy
- The importance of engaging with patient support groups: education, research and influencing national policy on rare diseases in Australia
- Injuries associated with baby products, Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP), and CPSP data results
- Alcohol coma admissions in the Netherlands
- The 3rd national survey on childhood celiac disease in the Netherlands: still changing epidemiology and clinical presentation
- Shaken baby syndrome in Switzerland: results of a prospective follow-up study, 2002–2007
- Haemolytic uraemic syndrome in Switzerland: twelve years prospective surveillance
- Guillain-Barré/Fisher syndrome surveillance in the UK: is there a temporal association with influenza infection or vaccination?
- Vitamin D deficiency rickets in Australia: need for screening and early treatment in high risk groups
- Can active surveillance improve reporting of serious and life-threatening adverse drug reactions? The CPSP experience
- Severe hyperbilirubinaemia of the newborn: a problem in Switzerland?
- A lasting legacy? A BPSU study case review to evaluate public health impact

The business meeting focused on the roles of INoPSU, its benefits to members and the importance of good governance and financial accountability. The request for membership by the Belgium Paediatric Surveillance Unit was approved and the unit was formally welcomed to INoPSU. The network now has added a third level of membership, "associate," to the two current levels, full and affiliate. The new level will allow individuals and groups who have an interest in rare paediatric conditions to join INoPSU. Other INoPSU decisions include affirming BPSU as the administrative centre, re-developing the website, raising the profile of activities and producing collaborative international publications. Yvonne Zurynski from Australia and Danielle Grenier from Canada are the INoPSU co-chairs.

The 8th INoPSU meeting celebrating the 15th anniversary of the Australian Paediatric Surveillance Unit will be held in conjunction with the International Paediatric Congress (www.ipa-world.org) in Melbourne, Australia, August 24–29, 2013.

Publications from INoPSU members

Australian Paediatric Surveillance Unit (APSU)

Khandaker G, Marshall H, Peadon E, et al. Congenital and neonatal varicella: impact of the national varicella vaccination programme in Australia. *Arch Dis Child* 2011;96:453-6. doi:10.1136/adc.2010.206037

Lim A, Cranswick N, South M. Adverse events associated with the use of complementary and alternative medicine in children. *Arch Dis Child* 2010. doi:10.1136/adc.2010.183152

British Paediatric Surveillance Unit (BPSU)

Knowles RL, Friend H, Lynn R et al on behalf of the BPSU. Surveillance of rare diseases: a public health evaluation of the British Paediatric Surveillance Unit. *J Public Health* 2011. doi:10.1093/pubmed/fdr058

Reading R, Hughes G, Hill J, Debelle G. Genital herpes in children under 11 years and investigations for sexual abuse. *Arch Dis Child* 2011;96:752-7. doi:10.1136/adc.2010.205971

Lynn RM, Viner RM, Nicholls DE. Ascertainment of early onset eating disorders: A pilot for developing a national child psychiatric surveillance system. *Child Adol Mental Health* 2011. doi:10.1111/j.1475-3588.2011.00613.x

Adalat S, Dawson T, Hackett S, Clark J. Surveillance of toxic shock syndrome in the paediatric population in the UK. *Arch Dis Child* 2011;96:A5. doi:10.1136/adc.2011.212563.9

Townsend CL, Peckham CS, Tookey PA. Surveillance of congenital cytomegalovirus in the UK and Ireland. *Arch Dis Child* 2011;96:A46. doi:10.1136/adc.2011.212563.101

Further publications can be found at www.inopsu.com.

INoPSU conference, Montreux, Switzerland, September 2011

RESEARCH OPPORTUNITIES

Call for New Studies

Wanted
Investigators to initiate new CPSP studies

The program
- Well established, timely and cost-effective
- Multi-faceted surveillance, capable of collecting reliable data in a variety of fields
- Effective at monitoring low-frequency, high-impact diseases and conditions

Track record
- 79% response from approximately 2,500 paediatricians
- 85% data completion rate

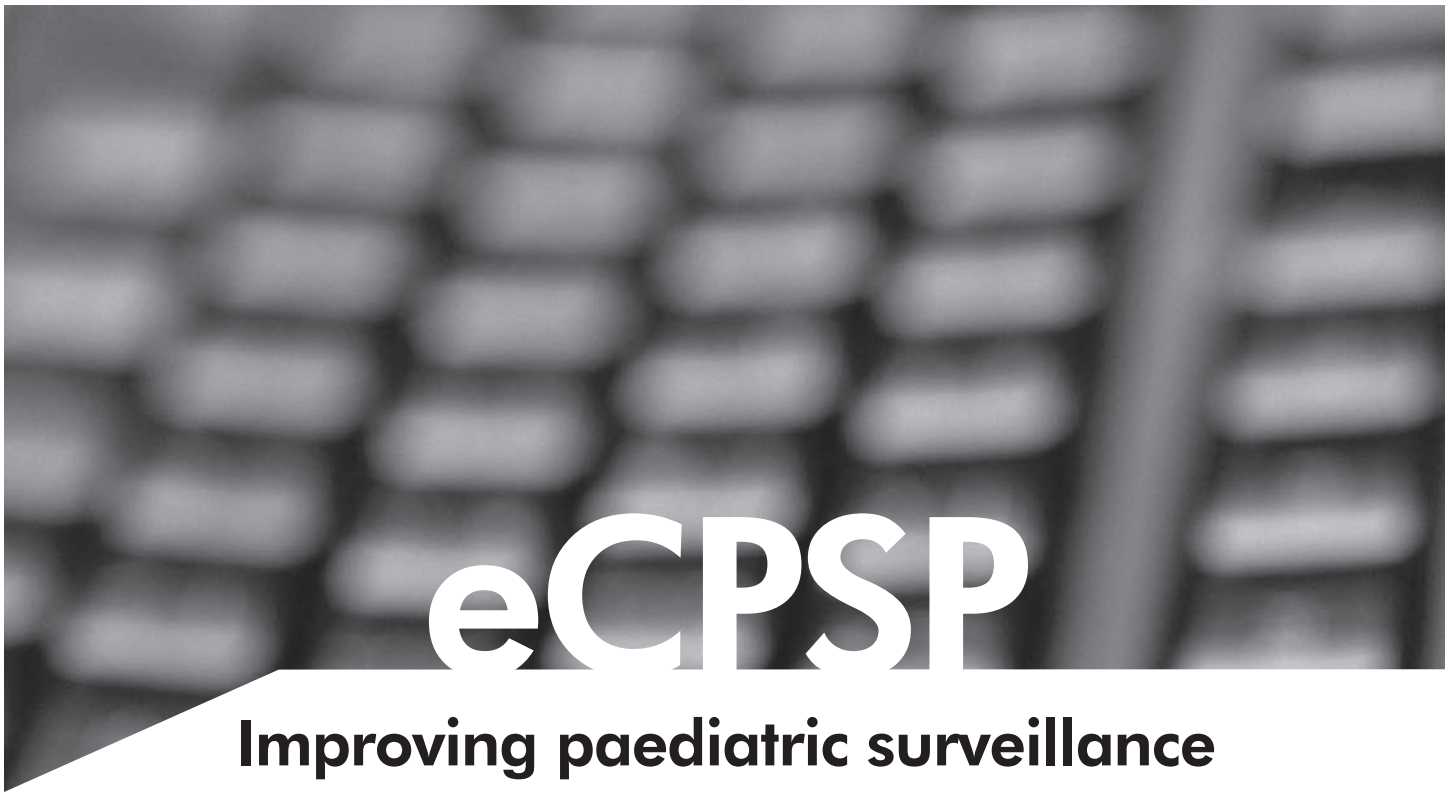
Study ideas
- Adverse neonatal outcomes of delivery or labour in water
- Bronchiectasis – non-cystic fibrosis
- Celiac disease
- Chylothorax
- Congenital syphilis
- Cyberbullying
- End-stage renal disease in early infancy
- Gonorrhea, syphilis, chlamydia and trichomonas infections
- Group A streptococcal toxic/septic shock
- Hallucinations with psychostimulants
- Hypercalcemia/nephrocalcinosis
- Life-threatening and lethal poisoning
- Marijuana-induced psychosis
- Moderate and severe encephalopathy
- Polyposis syndromes in children
- Systemic lupus erythematosus
- Tick-borne encephalitis
- Underdiagnosed cyanotic congenital heart disease

If you are interested in these or other studies, or for more program information, please contact 613-526-9397 ext. 239 or e-mail cpsp@cps.ca.

CPSP 15
CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM
1996 • 2011

"Fifteen years of success and still growing and improving! Over the years the CPSP has become an important collaborative tool for research, health policy development and the active surveillance of less common paediatric disorders. The hundreds of Canadian child care specialists who participate monthly in the program ensure that the CPSP is an effective way to foster continuing medical education on a wide spectrum of clinical conditions that might otherwise go largely unrecognized."

Dr. Bryce Larke, past Chief Medical Officer of Health, Whitehorse, Yukon Territory, and past member of the CPSP Steering Committee from 2004 to 2010



eCPSP

Improving paediatric surveillance

Launched November 2011

eCPSP is

- Greener
- Simple – a monthly hyperlink is sent to you
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- Easy – no log-in or passwords are required
- Accessible – reporting is possible from anywhere you have Internet access
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Update

As of May 1, 2012:

- There are 1,278 (49%) online participants
- 47% online participants report the first day they receive the e-mail

Next phases

- Performance monitoring
- Recruitment of off-line participants to online reporting
- Development of online one-time surveys
- Development of online detailed questionnaires

If you are not already signed up as an online participant, please switch today! E-mail us at cpsp@cps.ca and provide your preferred e-mail address.

CPSP
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For more information on the Canadian Paediatric Surveillance Program or a French version of this report, please contact:

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