

CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

# 2022 Results





## **Mission**

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.

## **Canadian Paediatric Surveillance Program Annual Results**

Surveillance is integral to the practice of public health. Public health surveillance, as defined by the World Health Organization, includes the systematic collection, collation, and analysis of data coupled with the timely dissemination of information for assessment and public health response. Integral to its public health mandate, the Canadian Paediatric Surveillance Program (CPSP) is committed to sharing valuable information obtained through its active surveillance of rare conditions in children and youth in Canada. Key results of CPSP multi-year studies and one-time surveys are published in this annual report. These results highlight important findings and inform health professionals, researchers, and policy makers in developing strategies to improve the health of children and youth in Canada.

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### **Project manager**

Melanie Laffin Thibodeau, Manager, Surveillance, CPSP and IMPACT

### **Scientific review**

Catherine Farrell, MD, Chair, CPSP Scientific Steering Committee

Sam Wong, MD, Medical Affairs Director, CPSP and Canadian Paediatric Society

### **Scientific and translation review**

Miriam Santschi, MD, Canadian Paediatric Society Representative, CPSP Scientific Steering Committee

### **Translation**

Dominique Paré, C. Tr., Traduction Le bout de la langue inc.

### **Layout and design**

John Atkinson, Fairmont House Design

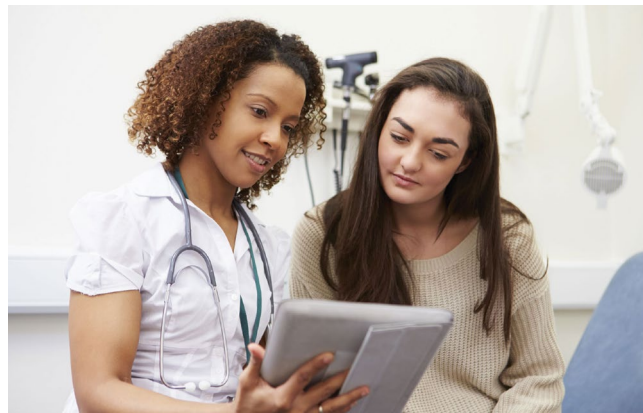
### **Editing and production**

Una McNeill, CPSP Consultant

# CPSP ADR Tips of the Month

The Canadian Paediatric Surveillance Program (CPSP) produces Adverse Drug Reaction (ADR) Tips of the Month that alert participants of new information regarding potential adverse drug reactions, including advice on how to recognize and best manage such events to improve outcomes for children and youth.

If you have seen an adverse drug reaction in your practice, please report the event as soon as possible to the CPSP. Case reports are valuable to the CPSP and Health Canada as they contribute to the ongoing monitoring of the benefit-risk profile of health products used in children and can thus result in changes to information in the product monograph and other risk mitigation measures.



## ADR Tip of the Month

### Infusion errors leading to fatal overdoses of *N*-acetylcysteine

The Institute for Safe Medication Practices Canada published a bulletin on fatal overdoses of intravenous (IV) *N*-acetylcysteine resulting from errors in pump programming.

Health care providers are reminded to:

- Review processes that support IV administration of *N*-acetylcysteine. Be aware of proper ordering and administration of IV *N*-acetylcysteine, as it is not a benign medication when administered incorrectly;
- Ensure accurate programming of the loading dose and maintenance doses. Some smart pumps have stepwise programming; however, others require manual interventions, thus increasing the possibility of infusion errors.

For more information:

<https://ismpcanada.ca/wp-content/uploads/ISMPCSB2022-i8-NAC-Alert-Infusion-Errors.pdf>

**Please report all suspected adverse drug reactions (ADRs).**

01/2023

## ADR Tip of the Month

### Cannabis and cannabis-drug interactions

Cannabis can inhibit or compete for several cytochrome P450 (CYP) isoenzymes, UDP-glucuronosyltransferases, and P-glycoproteins. These enzymes and transporters are involved in the metabolism and absorption of numerous medications, including commonly prescribed anticoagulants, antiplatelet agents, and antiepileptic drugs.

Physicians are reminded to ask patients about cannabis use (both medical and non-medical), and should consider possible drug-drug interactions in patients taking cannabis who experience otherwise unexplained toxicity or therapeutic failure.

Physicians should also report all suspected serious adverse events related to cannabis to the current CPSP studies on medical and/or non-medical (recreational) cannabis use.

For more information:

<https://www.canada.ca/en/health-canada/services/drugs-health-products/medeffect-canada/health-product-info-watch/october-2020.html#a41>

<https://www.cpsp.cps.ca/uploads/studies/Cannabis-used-for-medical-purposes-protocol.pdf>

**Please report all suspected adverse drug reactions (ADRs).**

01/2021

## ADR Tip of the Month

### Serious neuropsychiatric events associated with Singulair (montelukast)

Serious neuropsychiatric (NP) events have been reported in patients with and without a previous history of psychiatric disorder during Singulair treatment and after its discontinuation. NP events include, but are not limited to, agitation, aggression, depression, sleep disturbances, and suicidal thoughts and behaviours. The mechanisms underlying these events are not currently well understood.

Health care providers are reminded to:

- Consider risks, benefits, and potential alternative therapies before treating with Singulair
- Advise patients and caregivers to monitor for changes in behaviour and/or new NP symptoms during Singulair treatment

For more information:

<https://www.canada.ca/en/health-canada/services/drugs-health-products/medeffect-canada/health-product-info-watch/august-2020.html#a5.1>

**Please report all suspected adverse drug reactions (ADRs).**

09/2020

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# Foreword



Public Health  
Agency of Canada

Agence de la santé  
publique du Canada

## Message from the Federal Minister of Health

**The Honourable Mark Holland, P.C., M.P.**

It is my pleasure to introduce the *Canadian Paediatric Surveillance Program (CPSP) 2022 Results*. This annual report captures the ongoing efforts of the CPSP in monitoring important paediatric health issues. Gathering essential information and developing studies on emerging and rare conditions affecting children and youth is key in helping health professionals, researchers, and policy makers understand and address the needs of young Canadians.

A big thank you to the Canadian Paediatric Society, Health Canada, and the Public Health Agency of Canada for their continued commitment to improving the health and well-being of children and youth across the country. For more than 25 years, these organizations have worked together on this program which supports the development of better treatments, detection and prevention strategies, and ultimately, improves health outcomes for children in Canada. An example of the dedication to these goals is the program's ongoing surveillance pertaining to the long-term effects of COVID-19 on children's health, which could lead to the development of effective strategies to diagnose post-COVID-19 condition in children and youth.

The success of these studies would not be possible without the dedication of the 2,800 paediatricians and subspecialists from across Canada who continually shared data and intelligence on many rare and emerging childhood conditions and diseases – thank you to each of you.

As reiterated on February 7<sup>th</sup> 2023 through our plan for improving health care for Canadians, our government is unwavering in our commitment to supporting children's mental and physical health. That is why we're investing in timely access to a family health team or provider, a sustainable health workforce, shorter wait times, better mental health, and a modernized health system. In addition, we are addressing immediate pressures in paediatric hospitals and emergency rooms, and long wait times for surgeries, which will directly benefit the health of children and youth in Canada.

The well-being of our next generation is of utmost importance and that is why initiatives like the CPSP are critical to ensuring that children receive the best possible care.







# Message from the Chief Public Health Officer of Canada

## Dr. Theresa Tam

I would like to thank those experts involved in the Canadian Paediatric Surveillance Program (CPSP) and the Canadian Paediatric Society for their instrumental efforts to support the health and well-being of children and youth across the country. The CPSP would not be possible without the many paediatricians and paediatric subspecialists who have voluntarily contributed to the collection of data, despite competing demands of the COVID-19 pandemic and other continuing priorities.

The COVID-19 pandemic has shown us the importance of having robust surveillance data to help identify, monitor and understand potential and emerging health threats quickly and effectively. In this regard, the CPSP provides valuable data on the incidence of rare and emerging childhood conditions in Canada. The data collected through the CPSP provides researchers with a better understanding of the risk factors, prevention practices, impacts and effectiveness of treatments for rare and emerging childhood conditions. This information supports health care providers in improving patient care and helps communities to build better prevention and support programs.

This year's report captures the growing concern about post COVID-19 condition, as surveillance results reveal that it can also impact children and youth. The persistence of symptoms in some individuals can have significant impacts on physical, social and emotional well-being, and can affect the ability to carry out daily activities. This highlights the importance of continued monitoring and research into the long-term effects of COVID-19 and the need for appropriate care and support for those affected by post COVID-19 condition. It will be interesting to see the results of this ongoing surveillance in the coming years as more data are collected. Moreover, the CPSP is examining indirect effects of the COVID-19 pandemic, such as the incidence of first-time hospitalizations for anorexia nervosa throughout the pandemic and adverse events related to virtual care. These are some of the many diverse mental and physical health conditions captured by the surveillance system. The CPSP also continues to monitor other rare or emerging diseases and conditions, including serious adverse events related to recreational cannabis use, congenital syphilis and hypoglycemia during treatment of acute lymphoblastic leukemia.

As Canada's Chief Public Health Officer, I commend the Canadian Paediatric Society on the release of the *Canadian Paediatric Surveillance Program 2022 Results* report. It provides valuable insights into the state of child health in Canada and makes vital contributions to the health and future of our youngest people living in Canada.



# Message from the President of the Canadian Paediatric Society

## Dr. Mark Feldman

I would like to thank my colleagues from across Canada who, despite working through the trials and tribulations that the COVID-19 pandemic has placed on their practices, have continued to diligently and voluntarily report cases of rare conditions and emerging health concerns to the Canadian Paediatric Surveillance Program (CPSP). These efforts are so valuable, and so appreciated — the data collected is used to inform national clinical guidelines and to guide public health decisions and policies.

Unsurprisingly, the unintended consequences of the pandemic continue to affect our children and youth. This impact can be seen in the interim study results on first-time hospitalizations for anorexia nervosa during the pandemic (page 22). The study shows that the pandemic was a precipitating factor in many hospitalizations for anorexia nervosa, and close to 40% of new admissions were among children 11 to 13 years of age. Despite eating disorders having one of the highest mortality rates of any mental health condition affecting children and youth, patients can fall through the cracks of paediatric care, as eating disorders are complex biopsychosocial illnesses that do not fit neatly into the silos of mental or physical health. Preliminary study results were included in the [Canadian Paediatric Society's written submission to the Standing Committee on the Status of Women](#) and support the need for urgent and dedicated action now.

Other study and survey results, on topics such as congenital syphilis (page 19) and severe/life-threatening opioid, stimulant, or sedative use (page 52), demonstrate the many areas of child and youth health that must be prioritized in the coming years. The results from the CPSP study on serious and life-threatening events associated with non-medical cannabis use (page 41) have demonstrated that the most common primary case presentation continues to be poisoning and intoxication, involving mainly children less than 13 years of age and cannabis in edible form. These results were used to inform the [Canadian Paediatric Society's written submission to the Cannabis Act legislative review](#).

I urge all my fellow colleagues to take a moment to read the results that have been generated thanks to the time you have taken to report these cases. Again, this data goes a long way to helping us better understand the effects that these rare conditions and serious adverse events are having on the health of our children and youth. Armed with this information, we are better positioned to advocate for timely access to needed services and treatments.

I also take this opportunity to thank our partners at the Public Health Agency of Canada and Health Canada. Without their continued support and collaboration, this important work would not be possible.





# Message from the Chair of the Canadian Paediatric Surveillance Program

## Dr. Catherine Farrell

First, I would like to thank my colleagues from across Canada for their continued dedication to reporting cases to the Canadian Paediatric Surveillance Program (CPSP). As busy paediatricians and paediatric subspecialists, I recognize that completing a CPSP clinical questionnaire(s) at the end of a busy workday isn't always a top priority; and yet, thanks to their efforts, the Program continues to achieve high response rates.

In 2022, the CPSP initiated three new studies including post-COVID-19 condition, hypoglycemia during treatment of acute lymphoblastic leukemia, and adverse events related to virtual care. In addition, four one-time surveys were sent to participants on the following topics: button battery ingestions; severe/life-threatening opioid, stimulant, or sedative use; home-based phototherapy; and potential adverse events among breastfeeding infants exposed to maternal cannabis use. I invite you to take some time to read through the various reports and learn about the key, and sometimes alarming, results.



I would also like to take this opportunity to thank Dr. Charlotte Moore Hepburn, who completed her term as the Canadian Paediatric Society's Director of Medical Affairs in 2022. Over the past seven years, she made many outstanding contributions to the CPSP. Her leadership, spirit of innovation, attention to detail, and tenacity allowed the Program to flourish, gain momentum, and acquire greater recognition, despite the challenges associated with the COVID-19 pandemic. I extend a warm welcome to Dr. Sam Wong, who took on the role of Director of Medical Affairs in late 2022. I look forward to working with him in the years to come, aiming to ensure the CPSP continues its leadership in the areas of surveillance and research on rare paediatric conditions and diseases, and emerging issues of health concern for our children and youth.

Finally, I would like to thank our partners at the Public Health Agency of Canada and Health Canada for their continued support, leadership, and expertise.

# Acknowledgements

The key strength of the Canadian Paediatric Surveillance Program (CPSP) is its commitment to improve the health of children and youth in Canada and around the world. This focus 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, the investigators who design studies and analyse the data to provide knowledge and educational solutions, or the guidance of the Scientific Steering Committee members. We thank them all.

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

The strong partnership between the Canadian Paediatric Society, the Public Health Agency of Canada, and Health Canada 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 support 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 2022 from the Public Health Agency of Canada's Centre for Surveillance and Applied Research, Health Canada's Marketed Health Products Directorate, and the following non-governmental sources:

- Bethanys Hope Foundation
- CHEO Research Institute
- Children's Hospital Research Institute of Manitoba sponsored studies grant from Novo Nordisk Inc.

# Canadian Paediatric Surveillance Program Scientific Steering Committee

Catherine Farrell, MD  
Jill Borland Starkes, MD  
Peter Buck, DVM, MSc

Paul Dancey, MD  
Marie Adèle Davis, MBA  
Elizabeth Donner, MD  
Joanne Embree, MD  
Geneviève Gravel, MPH

Sabrina Heyde, JD  
Melanie Laffin Thibodeau, BCom  
Joanna Lazier, MD  
Charlotte Moore Hepburn, MD  
Shaun Morris, MD  
Jay Onysko, MA  
Stephen Parker, MPH

Jorge Pinzon, MD  
Anne Rowan-Legg, MD  
Chelsea Ruth, MD  
Miriam Santschi, MD  
Patrick Seitzinger, MD  
Sam Wong, MD

Canadian Paediatric Society (Chair)  
Canadian Paediatric Society  
Centre for Food-borne, Environmental and Zoonotic Infectious Diseases,  
Public Health Agency of Canada  
Paediatric Chairs of Canada (Liaison)  
Canadian Paediatric Society  
Canadian Association of Child Neurology (Liaison)  
IMPACT (Immunization Monitoring Program ACTive) (Outgoing Liaison)  
Centre for Communicable Diseases and Infection Control,  
Public Health Agency of Canada  
Consultant  
Canadian Paediatric Society  
Canadian College of Medical Geneticists (Liaison)  
Canadian Paediatric Society (Outgoing Medical Affairs Director)  
IMPACT (Immunization Monitoring Program ACTive) (Incoming Liaison)  
Centre for Surveillance and Applied Research, Public Health Agency of Canada  
Centre for Immunization and Respiratory Infectious Diseases,  
Public Health Agency of Canada  
Canadian Paediatric Society  
Canadian Paediatric Society  
Canadian Paediatric Society  
Canadian Paediatric Society  
Canadian Paediatric Society (Resident Representative)  
Canadian Paediatric Society (Incoming Medical Affairs Director)

The CPSP Scientific Steering Committee expresses its sincere appreciation to Dr. **Joanne Embree**, who completed a six-year term on the Committee as the representative of Canada's Immunization Program ACTive (IMPACT). Her dedication and expertise on many complex issues, especially relating to immunizations during the COVID-19 pandemic, will be greatly missed by the Committee. We wish Dr. Embree the very best in her retirement.



The CPSP Scientific Steering Committee extends a special thank you to Dr. **Charlotte Moore Hepburn** for her unwavering commitment to child and youth health, her dedication, and her expertise while serving as the CPSP Medical Affairs Director for the past seven years. Dr. Moore Hepburn embraced many opportunities to bring the Program to new heights, working with new partners and innovating methods for near real-time data collection. From the start of the pandemic, her leadership enabled data on children and youth hospitalized with COVID-19 and MIS-C to be shared biweekly with stakeholders at all levels, ensuring the best decisions could be made for our youngest citizens, in the face of much public health uncertainty. We wish Dr. Moore Hepburn the very best in all her future endeavors and we thank her once again for her commitment to the CPSP.

# About the Canadian Paediatric Surveillance Program

## Overview

The Canadian Paediatric Surveillance Program (CPSP) is a joint project of the Public Health Agency of Canada and the Canadian Paediatric Society that contributes 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, and economic costs to society, despite their low frequency. The CPSP gathers data from approximately 2,800 paediatricians and paediatric subspecialists each month to monitor rare diseases and conditions in Canadian children.

## Objectives

- Maintain an active national surveillance system that monitors low-frequency, high-impact conditions and diseases in Canadian children and youth
- Involve paediatricians, paediatric subspecialists, and other medical professionals in related disciplines in the surveillance of rare conditions that are of public health and medical importance
- Generate new knowledge into rare childhood disorders to facilitate improvements in treatment, prevention, and health-care planning
- Respond rapidly to public health emergencies relevant to Canadian children and youth by initiating rapid one-time surveys and new studies
- Participate in international paediatric surveillance efforts through the International Network of Paediatric Surveillance Units (INOPSU)

## Surveillance

- The full surveillance process is summarized in Figure 1 and includes the 3Ds of surveillance: detection, deduction, and dissemination.
- Health surveillance can be defined as: the tracking of any health event or health determinant through the continuous collection of high-quality data (detection); the integration, analysis, and interpretation of the data (deduction) into surveillance products; and the dissemination of those surveillance products to those who need to know (dissemination).

## Process

- Study teams from across Canada are encouraged to submit proposals for new studies or one-time surveys that meet the “criteria for submission,” available on the CPSP website at [www.cpsp.cps.ca/apply-proposez/criteria-for-inclusion-of-studies](http://www.cpsp.cps.ca/apply-proposez/criteria-for-inclusion-of-studies).
- The CPSP Scientific Steering Committee then reviews the proposals on a biannual basis and selects those of highest medical and public health importance. Proposals are evaluated against set criteria and are subject to comprehensive feedback from the multidisciplinary Scientific Steering Committee, composed of representatives from the Public Health Agency of Canada, the Canadian Paediatric Society, former CPSP investigators, academic clinicians from diverse specialties, and community paediatricians.
- Each month, CPSP participants from across Canada receive a form listing the current conditions under study. Participants notify the Program if they have seen any cases that meet the case definitions or have “nothing to report.” Participants are encouraged to report all cases, including suspect or probable cases. This sometimes leads to duplicate reporting but avoids missed cases.
- Participants who have seen a case are sent a detailed clinical questionnaire to complete and return to the CPSP.
- Once the detailed questionnaire is returned to the CPSP, it is stripped of all unique identifiers and sent to the investigators for data analysis. All notifications of potential cases are assessed against the case definition. Duplicates or cases that don’t meet the case definition are excluded.

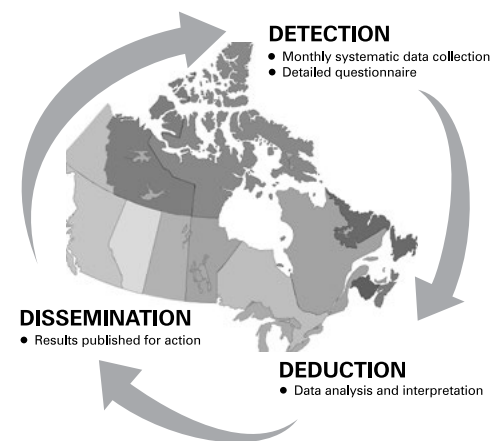
## CPSP Quick Facts

### Did you know?

- The CPSP celebrated its 26th anniversary in 2022.
- The CPSP is comprised of approximately 2,800 dedicated paediatricians and paediatric subspecialists.
- Since its inception, the CPSP has studied 85 rare conditions/diseases and initiated 59 one-time surveys.
- Over 85 peer-reviewed manuscripts on study/survey results have been published in high-impact journals.
- The average monthly response rate is 80%.
- The average detailed questionnaire response rate varies between 80 to 90%.
- By December 2022, 97% of participants had committed to receiving their monthly forms electronically.

Figure 1 – Surveillance process summary

### Pan-Canadian health surveillance



- It is important to note that CPSP studies use anonymized data from patient charts; the study investigators have no direct contact with individual patients.
- The study team is responsible for data analysis, and for ensuring that a solid knowledge translation plan is in place to disseminate the results in a timely and effective manner.
- Study results are published annually and acted upon to improve the health of children and youth in Canada. For example, CPSP study results help to warn of emergent public health issues, identify safety hazards, mobilize knowledge on rare conditions, and inform new policies and guidelines.

## Limitations of surveillance

As with any voluntary reporting surveillance system, the CPSP recognizes that its surveillance has some limitations, including the following:

- Reporting on minimum incidence rates can under-represent events in the population. For example, some cases may not be included in the surveillance totals because they presented to family doctors or other health care practitioners and not to paediatricians, while others may live in rural or remote areas and are less likely to receive timely specialist care.
- Some data elements (e.g., laboratory investigations, pre-existing medical conditions) may not be available in the patient chart at the time of reporting and therefore may be absent from the surveillance totals. Every effort is made to ensure complete data capture and to handle missing data appropriately in the data analysis (e.g., denominators vary according to the number of participants who completed specific data elements in the detailed questionnaire).
- The results presented in this annual report are provisional. At the time when investigators are asked to prepare study reports, some clinical questionnaires may still be pending. Once pending questionnaires are analyzed, study conclusions may change. Especially for preliminary study reports, the distribution of cases by province/territory may not be representative of the study's final results.
- Data from Quebec are incomplete. Due to Quebec legislation, cases reported from that province can only be included in the data analysis when reported from a centre with project-specific research ethics board approval.
- Since the start of the COVID-19 pandemic, with the unprecedented demands being placed on front-line health care providers, it is possible that some cases may have gone unreported.

Despite these limitations, surveillance serves an important purpose and provides rich clinical data that allows for a better understanding of the rare childhood conditions under study.

## Response rates

The CPSP's average national monthly response rate is 80% and the average detailed questionnaire completion rate varies between 80 to 90%.

**TABLE 1 – Initial response rates (%) and number of participants for 2022**

| Provinces/territories          | Reporting rates (%) <sup>*</sup> | Number of participants <sup>†</sup> |
|--------------------------------|----------------------------------|-------------------------------------|
| Alberta (AB)                   | 80                               | 365                                 |
| British Columbia (BC)          | 82                               | 317                                 |
| Manitoba (MB)                  | 80                               | 106                                 |
| New Brunswick (NB)             | 76                               | 36                                  |
| Newfoundland and Labrador (NL) | 76                               | 45                                  |
| Northwest Territories (NT)     | —                                | <5                                  |
| Nova Scotia (NS)               | 84                               | 88                                  |
| Nunavut (NU)                   | —                                | <5                                  |
| Ontario (ON)                   | 79                               | 1037                                |
| Prince Edward Island (PE)      | 89                               | 10                                  |
| Quebec (QC)                    | 77                               | 527                                 |
| Saskatchewan (SK)              | 83                               | 61                                  |
| Yukon (YT)                     | —                                | <5                                  |
| <b>Canada</b>                  | <b>80</b>                        | <b>2591</b>                         |

<sup>\*</sup> The CPSP national monthly reporting rate averages 80%. Every effort is made to maximize reporting, and annual response rates are subject to change due to delays in reporting.

<sup>†</sup> The total number of individual CPSP participants is approximately 2,800. However, in this table, the number of CPSP participants in Canada is calculated based on both individual and group reporting. When a group designate responds to the CPSP on behalf of group members, it is counted as one response.

**TABLE 2 – National initial response rates 2018–2022**

| Reporting year | Reporting rates (%) |
|----------------|---------------------|
| 2018           | 79                  |
| 2019           | 82                  |
| 2020           | 81                  |
| 2021           | 80                  |
| 2022           | 80                  |

**TABLE 3 – 2022 detailed questionnaire completion rates as of July 13, 2023\***

| Studies/conditions   | Notifications of potential cases | Pending   | % completion rate |
|--|----------------------------------|-----------|-------------------|
| Acute flaccid paralysis†   | 23                               | 0         | 100               |
| Adverse drug reactions – serious and life-threatening  | 21                               | 5         | 76                |
| Congenital syphilis  | 213                              | 31        | 85                |
| First-time hospitalizations for anorexia nervosa during the COVID-19 pandemic  | 206                              | 42        | 80                |
| Hypoglycemia during treatment of acute lymphoblastic leukemia  | <5                               | —         | —                 |
| Micronutrient deficiencies and autism spectrum disorder  | 18                               | 9         | 50                |
| Optic nerve hypoplasia and septo-optic dysplasia   | 38                               | 10        | 73                |
| Paediatric-onset leukodystrophies  | <5                               | —         | —                 |
| Paediatric pulmonary thromboembolism   | 19                               | 5         | 74                |
| Post-COVID-19 condition (long COVID)   | 17                               | 2         | 88                |
| Serious adverse events related to cannabis used for medical purposes   | <5                               | —         | —                 |
| Serious and life-threatening events associated with non-medical (recreational) cannabis use in Canadian children and youth | 53                               | 22        | 58                |
| Severe vaping-related illness and injury†  | <5                               | —         | —                 |
| <b>Total number of cases (all studies)</b>   | <b>610</b>                       | <b>84</b> | <b>78</b>         |

\* The numbers in this table were compiled later than those contained in the individual study reports and hence may differ because of delayed case reporting or case analysis.

† Includes case notifications from Quebec from centres with project-specific research ethics board approval. For all other studies, case notifications from Quebec were excluded.

## Glossary of terms in study results

**Reported:** Notifications of potential cases received by the CPSP

**Duplicates:** Cases reported by more than one participant

**Excluded:** Cases not meeting the case definition and cases reported from Quebec institutions without project-specific research ethics board approval

In mid-2018, the CPSP became aware of a change in Quebec legislation that affected the ability of the Program to collect detailed information from physicians who practise in that province. The ministère de la Santé et des Services sociaux approved the continued collection of CPSP case notifications (including date of birth and sex) from paediatricians and subspecialists in Quebec. More detailed case-level information for CPSP studies may also be collected in Quebec from institutions with project-specific research ethics board approval. Therefore, cases notified by Quebec participants after August 1, 2018 are included in the data analysis only if they are reported from an institution with CPSP project-specific research ethics board approval.

**Pending:** Detailed questionnaires not received or not yet verified as meeting the case definition

**Met case definition:** Cases verified as meeting the case definition, excluding duplicate case reports, cases failing to meet the case definition, cases pending verification, and cases reported from Quebec from institutions without project-specific research ethics board approval



# International Network of Paediatric Surveillance Units

The CPSP offers an opportunity for international collaboration with other paediatric surveillance units worldwide, through the International Network of Paediatric Surveillance Units (INOPSU). The network provides a successful and easily accessible platform for international surveillance. No other network enables international comparisons of demographics, diagnoses, treatments, and outcomes for rare childhood conditions.

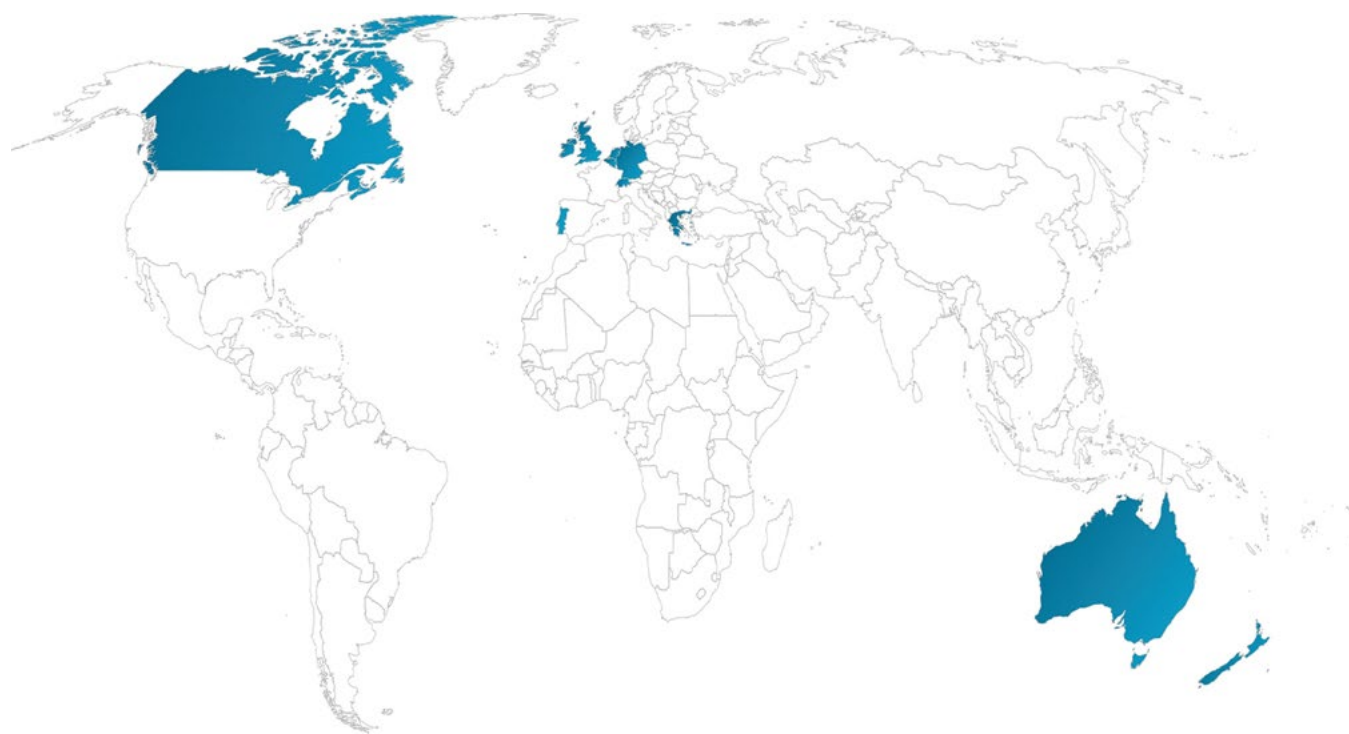
Established in 1998, INOPSU's membership includes many paediatric surveillance units from around the world, from Canada to New Zealand. Many of the paediatric surveillance units have been collecting data on rare childhood conditions for 20 years or more. Over 300 rare conditions have been studied to date, including rare infectious and vaccine-preventable diseases, mental health disorders, child injuries, and immunological conditions. The network encompasses approximately 10,000 child health care providers who voluntarily contribute data on these rare diseases every month.



Joint collaborative studies are seen as an important method of advancing the knowledge of uncommon childhood disorders around the world. For example, collaborative work is taking place to combine the data from the CPSP's congenital Zika syndrome and severe microcephaly studies with data from similar national surveillance projects conducted in the United Kingdom, Australia, and New Zealand.

During INOPSU meetings, member countries can highlight their surveillance program activities, explore innovative study ideas of interest to the network, discuss knowledge translation and joint publication opportunities, as well as strategize on how best to maintain active engagement of participants.

More information on INOPSU can be found at [www.inopsu.com](http://www.inopsu.com).



# Surveillance Studies in 2022

## Acute flaccid paralysis

Study duration: Ongoing study since January 1996



Marina Salvadori

### Principal investigator (interim)

Marina I. Salvadori, MD, FRCPC, Senior Medical Advisor, Infectious Diseases Program Branch, Public Health Agency of Canada; marina.salvadori@phac-aspc.gc.ca

### Co-investigator

Salem N

## ? Question

Did Canada maintain its polio-free status in 2022?

## ! Importance

- Poliomyelitis is targeted for eradication, with only two countries having ongoing wild poliovirus transmission. Acute flaccid paralysis (AFP) surveillance is the cornerstone of monitoring for polio and is critical for documenting the absence of poliovirus circulation required for countries to declare polio-free status.
- Canada conducts AFP surveillance in children under 15 years of age, in accordance with World Health Organization (WHO) recommendations and standards of practice.

## ➡ Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/acute-flaccid-paralysis>.

### Case definition

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

### Unique to this study

Cases are captured through both the Canadian Paediatric Surveillance Program (CPSP) and Canada's Immunization Monitoring Program ACTive (IMPACT) based in 12 paediatric tertiary care centres. Of the cases reported from Quebec, only AFP cases reported by Quebec IMPACT centres are eligible for data analysis in this report.

## ✓ Results – January to December 2022

Note: This report represents a snapshot as of January 3, 2023. There may be uncaptured cases in this report due to reporting delays. The total AFP case counts for 2018 to 2022 have been updated with all the confirmed cases that have been reported and are presented in Table 2.

| TABLE 1 – AFP cases in 2022 |            |          |         |                      |
|-----------------------------|------------|----------|---------|----------------------|
| Reported                    | Duplicates | Excluded | Pending | Met case definition* |
| 13                          | 0          | 0        | 0       | 13                   |

\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis, unless reported from a centre with project-specific research ethics board approval. Cases reported through the following centres were included in the data analysis for this report: CHU Sainte-Justine, Montreal Children's Hospital, and Centre mère-enfant Soleil CHU de Québec-Université Laval.

| TABLE 2 – Annual comparison of AFP cases 2018–2022 |             |
|--|-------------|
| Year   | Total cases |
| 2022   | 13          |
| 2021   | 8           |
| 2020   | 30          |
| 2019   | 36          |
| 2018   | 73          |

### Cases that met the case definition

- In total, 13 reports of sudden onset muscle weakness in children younger than 15 years of age were provided to the Public Health Agency of Canada. Twelve of 13 cases (92%) were reported through an IMPACT centre.

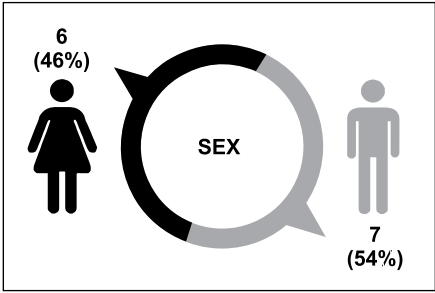
- At the time of analysis, all 13 cases (100%) were verified as meeting the AFP case definition in 2022; none were assessed as meeting the polio case definition.
- The median time from case onset of paralysis to reporting was 103.0 days and the mean was 87.5 days (range: 24–142).

### Demographics

- Seven cases were male (54%) and six cases were female (46%).
- Cases ranged in age from 1 month to 14 years, with a median of 4.0 years and a mean of 6.1 years.

### Presentation and diagnosis

- All 13 cases (100%) were hospitalized. Length of stay ranged from 5 to 27 days, with a median of 9.0 days and a mean of 13.1 days.
- Diagnoses reported for the cases include Guillain-Barré syndrome, transverse myelitis, and acute flaccid myelitis (AFM). The most frequent diagnosis was Guillain-Barré syndrome.
- Polio vaccination status was reported for 12 of 13 cases (92%). Where vaccination status was recorded, the majority of cases were reported to be up-to-date for their polio vaccinations.
- Fewer than five cases had stool sample submitted for viral testing. No stool samples were positive for polio.



### Treatment and outcomes

- Twelve of the 13 cases (92%) had outcomes documented at initial report, and all 12 of these cases had either fully recovered or partially recovered with residual weakness.
- Fewer than five cases had clinical outcomes reported at least 60 days after the onset of paralysis or weakness.

| TABLE 3 – Measure of Canada’s performance against WHO AFP surveillance performance indicators in 2022 <sup>1</sup> |                             |   |                                       |
|--|-----------------------------|---|---------------------------------------|
| Number of cases  | Incidence rate <sup>*</sup> | % with adequate stool sample <sup>2†§</sup> | % with 60-day follow-up <sup>‡§</sup> |
| 13   | 0.21                        | 77%   | 30.8%                                 |

<sup>\*</sup> Per 100,000 population in those less than 15 years of age - target is 1.0 AFP case per 100,000 population less than 15 years of age

<sup>†</sup> Target is at least 80% of cases have adequate stool sampling within 14 days of paralysis onset

<sup>‡</sup> Target is at least 80% have follow-up examination for residual paralysis at least 60 days after onset

<sup>§</sup> Percentage should be interpreted with caution due to the small number of cases

### Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- Stool samples in patients with AFP are sometimes difficult to obtain due to the nature of the patient’s symptoms, including constipation. Additionally, rapid availability of advanced diagnostic testing often identifies the diagnosis prior to the collection of the stool sample.

## Conclusions

- Although Canada did not meet the WHO performance indicators for national AFP surveillance in 2022, there was sufficient evidence to suggest that no paediatric polio cases occurred in Canada.
- The detection of vaccine-derived poliovirus type 2 (VDPV2) in Canada from wastewater sampling, reported December 23, 2022, is a critical reminder of the importance of maintaining a sensitive and active surveillance system that allows for prompt and appropriate investigation of AFP cases to detect polio. Polio is a reportable disease in every province and territory, and is nationally reportable.

## Anticipated study impact

Canada’s polio-free status remains intact, as assessed annually by Canada’s National Certification Committee for Polio Eradication.

## Publication and dissemination

Polio and acute flaccid paralysis (AFP). *Vaccine Preventable Disease: Surveillance Report to December 31, 2019*. Ottawa (ON): Public Health Agency of Canada; 2022 May 20. Available from: <https://www.canada.ca/en/public-health/services/publications/healthy-living/vaccine-preventable-disease-surveillance-report-2019.html#b8>

### Acknowledgements

The investigators would like to thank everyone who participated in collecting the data. They would also like to acknowledge the excellent work of Disha Bhagat, Y. Anita Li, and Kristyn Franklin from the Public Health Agency of Canada.

1. Detailed information on WHO surveillance performance indicators can be found at <https://polioeradication.org/polio-today/polio-now/surveillance-indicators/>
2. Adequate stool sample refers to one stool sample taken within 14 days of paralysis onset.

# Adverse drug reactions – serious and life-threatening

Study duration: Ongoing study since January 2004



Sally Pepper

## Principal investigator

Sally Pepper, BScPhm, RPh, Patient Safety Section, Marketed Health Products Directorate, Health Canada; sally.pepper@canada.gc.ca

## ? Question

What serious and life-threatening events suspected to be related to adverse drug reactions (ADRs) in children and youth were reported in 2022?

## ! Importance

- Only a minority of prescribed pharmaceuticals on the market in North America have been tested in paediatric patients, and many of them are used without the benefit of adequate and/or specific guidance on safety or efficacy in this population.
- Post-marketing surveillance is essential for detection of ADRs and contributes to the ongoing monitoring of the benefit-risk profile of health products used in children.

## ➡ Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/adverse-drug-reactions-serious-and-life-threatening>.

### Case definition

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

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

### Exclusion criteria

Reactions to medical devices, blood products (platelets, red cells and single-donor plasma), vaccines, poisonings or self-administered overdoses

### Unique to this study

Significant results for the ADR study contribute to the monthly ADR Tips distributed by the Canadian Paediatric Surveillance Program (CPSP).

## ✓ Results – January to December 2022

| TABLE 1 – ADR cases in 2022 |            |          |         |                      |
|-----------------------------|------------|----------|---------|----------------------|
| Reported                    | Duplicates | Excluded | Pending | Met case definition* |
| 14                          | 0          | 3        | 0       | 11                   |

\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the “Reported” column, but detailed case information was not collected and these cases were excluded from the data analysis.

### Cases that met the case definition

- At the time of analysis, 11 suspected serious and life-threatening paediatric ADR reports were verified as meeting the case definition in 2022.

- In a small number of cases, more than one product was suspected of causing the adverse reaction.
- The health product classes (using the Anatomical Therapeutic Chemical classification system) most frequently suspected of causing the adverse reactions in 2022 were antibacterials and immunosuppressants. Fewer than five cases were reported for each class. The third most frequently reported health product class was antiepileptics, with fewer than five cases.

| Year | Total cases |
|------|-------------|
| 2022 | 11          |
| 2021 | 5           |
| 2020 | 9           |
| 2019 | 13          |
| 2018 | 20          |

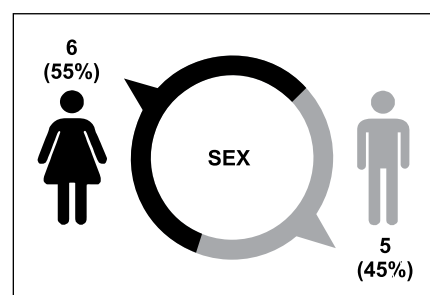
| Class of health product  | Name of health product     |
|--|----------------------------|
| Antibacterials for systemic use                                    | Amoxicillin, ceftriaxone   |
| Antiepileptics   | Carbamazepine, lamotrigine |
| Anti-inflammatory and antirheumatic products                       | Celecoxib                  |
| Hormones and related agents  | Leuprolide                 |
| Immunosuppressants   | Azathioprine, infliximab   |
| Antidiarrheals, intestinal anti-inflammatory/anti-infective agents | Sulfasalazine              |
| Other systemic drugs for obstructive airway disease                | Montelukast                |

### Demographics

- Patient sex was male in 5 (45%) cases and female in 6 (55%) cases.
- Cases were reported from all of the following age ranges: 0 to 5 years, 6 to 12 years, and 13 to 17 years.

### Presentation and diagnosis

- The 11 cases were classified as serious according to the following criteria (more than one cause for classification was provided in some of the reports): fewer than five cases were considered to be life-threatening; 6 (55%) cases required hospitalization; and 8 (73%) cases were considered to be medically important. Medically important is defined as a case that may not be immediately life-threatening or result in death/hospitalization but may jeopardize the patient or require intervention to prevent one of these other outcomes from occurring.
- The majority of the adverse reactions described skin and subcutaneous tissue disorders. This finding is consistent with the trend seen for all reports received through the CPSP since the study's initiation in 2004.
- Adverse reactions also described the following disorders, among others: blood and lymphatic system disorders; gastrointestinal disorders; immune system disorders; psychiatric disorders; and respiratory, thoracic, and mediastinal disorders.



### Treatment and outcomes

- The outcome was known in most of the 11 cases, with the majority of patients (82%) experiencing a full recovery.
- No deaths were reported.

### Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- All adverse reactions to health products are considered as “suspected,” as a definite causal association often cannot be determined. The true incidence of adverse reactions is unknown because they remain under-reported and total patient exposure is unknown.

## Conclusions

- Antibacterials and immunosuppressants were the classes of health products most frequently suspected of causing adverse reactions in 2022.
- Since the implementation of the CPSP surveillance for adverse reactions in 2004, the product classes most frequently associated with suspect products have been antibacterials for systemic use, antiepileptics, and psychoanaleptics. The most frequently reported suspect drugs in these classes are amoxicillin, carbamazepine, and methylphenidate respectively. No reports meeting the study criteria were received in 2022 for psychoanaleptics.
- The most frequently reported suspect drug for immunosuppressants since 2004 is infliximab.

## Anticipated study impact

- Health Canada recognizes the need to strengthen information related to paediatric health, as medication safety and efficacy may be significantly different for children than adults, and data on safety and efficacy in the paediatric population are limited.<sup>1,2</sup> The

1. Klassen TP, Hartling L, Craig JC, et al. Children are not just small adults: the urgent need for high-quality trial evidence in children. *PLoS Medicine* 2008;5(8):1180-2  
 2. Abi Khaled L, Ahmad F, Brogan T, et al. Prescription medicine use by one million Canadian children. *Paediatr Child Health* 2003;8(A):6A-56A

ongoing sharing of safety information through voluntary reporting of ADRs from various sources, such as the CPSP, is valuable to Health Canada as it contributes to ongoing monitoring of the benefit-risk profile of health products used in children and can thus result in the implementation of risk mitigation measures.

- In acknowledgement of the importance of safety information provided by ADR reporting, Health Canada has implemented Vanessa's Law, an amendment to the *Food & Drugs Act* that requires certain health care institutions to identify and report serious ADRs and medical device incidents to the federal regulator (for more information, visit: [www.canada.ca/en/health-canada/services/drugs-health-products/medeffect-canada/adverse-reaction-reporting/mandatory-hospital-reporting/education/module-1.html](http://www.canada.ca/en/health-canada/services/drugs-health-products/medeffect-canada/adverse-reaction-reporting/mandatory-hospital-reporting/education/module-1.html)). A key objective of mandatory reporting is to improve the quality and quantity of serious ADR reports, and to expand on the real-world data available to monitor the safety of health products used in children.

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#### **Acknowledgements**

The assistance of Stephanie Silva is greatly appreciated.



# Congenital syphilis

Study duration: June 2021 to May 2023



Jared Bullard

## Principal investigators

Carsten Krueger, MD, Division of Infectious Diseases, Immunology & Allergy, University of Ottawa; ckrueger@cheo.on.ca

Jared Bullard, MD, Section of Paediatric Infectious Diseases, University of Manitoba; jared.bullard@gov.mb.ca

## Co-investigators

Bitnun A, Brophy J, Comeau J, Embree J, Govindapillai S, Gravel G, Isaac M, Johnson D, Leis K, Purewal R, Robinson J, Roussin B, Sauvé L, Sheffield H, Talarico S, Tomas K, Wong S

## Collaborators

Guedes J, Sandhu J

## ? Questions

- What maternal/birthing parent sociobehavioural risk factors are associated with congenital syphilis (CS)?
- How are paediatricians recognizing, diagnosing, and managing infants with CS?

## ! Importance

- CS has become increasingly common and can have irreversible consequences if the diagnosis is missed.
- Understanding the barriers preventing pregnant people from engaging in prenatal care is crucial to preventing CS.
- Understanding the patterns of presentation, as well as current patterns in the diagnosis and management of CS, can inform education efforts for health care workers caring for infants and children.
- Data on the epidemiology of CS can be used to inform public health policy and guide population-level interventions.

## Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/congenital-syphilis>.

### Case definition

Any neonate, infant, or child <4 years old with a new diagnosis of confirmed or probable CS in the last month.

#### Confirmed congenital syphilis (requires one of the following)

1. Identification of *Treponema pallidum* in the infant/child's specimen by polymerase chain reaction or fluorescent antibody examination
2. Reactive serology from venous blood in an infant that is four-fold greater than the maternal serology collected near the time of birth
3. Reactive serology from venous blood in an infant that persists beyond their second birthday

#### Probable congenital syphilis

1. Infant born to a mother who had untreated or inadequately treated syphilis at delivery, regardless of findings in the infant
- OR BOTH OF THE FOLLOWING:
2. An infant or child with a reactive treponemal test result
  3. One of the following additional criteria:
    - a. Clinical signs of CS on physical examination
    - b. Evidence of CS on radiographs of long bones
    - c. Abnormal cerebrospinal fluid cell count or protein without other cause
    - d. Reactive treponemal immunoglobulin M (IgM) (19S-IgM antibody test or IgM enzyme-linked immunosorbent assay)

#### Unique to this study

This study was designed in conjunction with the Sexually Transmitted and Blood-Borne Infections (STBBI) Surveillance Division of the Public Health Agency of Canada.

## ✓ Results – January to December 2022

TABLE 1 – CS cases in 2022

| Reported | Duplicates | Excluded* | Pending | Met case definition* |
|----------|------------|-----------|---------|----------------------|
| 188      | 19         | 16        | 64      | 89                   |

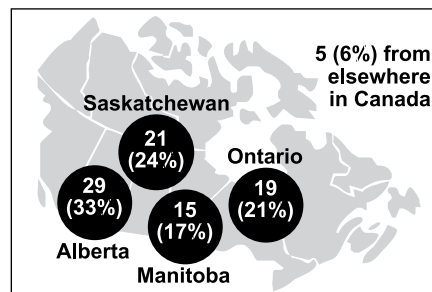
\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

### Cases that met the case definition

At the time of analysis, 89 cases of CS were verified as meeting the case definition from January 1 to December 31, 2022 and 64 cases were pending verification.

### Demographics

- The geographic distribution of cases was: 29/89 (33%) from Alberta, 21/89 (24%) from Saskatchewan, 19/89 (21%) from Ontario, 15/89 (17%) from Manitoba, and the remaining 5/89 (6%) from elsewhere in Canada. Over one third of the cases (32/89, 36%) were from rural areas.
- The median maternal/birthing parent age was 27 years (range 18–39).
- The most commonly reported sociobehavioural risk factors of mothers/birthing parents with affected children were substance use (59/70, 84%) and child protection involvement with another child (25/42, 60%). For other risk factors, “Unknown” was a common response. For example, for receipt of social assistance, “Unknown” was the response entered for 81% (72/89) of the mothers/birthing parents.
- Of mothers/birthing parents with reported substance use, 41% (24/59) used methamphetamines and 22% (13/59) used cocaine.
- Maternal/birthing parent co-infections were common, with 42% (36/85) of mothers/birthing parents having at least one other STBBI. Chlamydia was the most common (22/36, 61%) maternal/birthing parent co-infection, but importantly 17% (6/36) were diagnosed with hepatitis C.



### Presentation and diagnosis

- Almost a third of mothers/birthing parents of affected children (19/60, 32%) had no documented prenatal care.
- Almost a quarter of mothers/birthing parents (20/87, 23%) did not have syphilis screening in pregnancy.
- Of the 58 mothers/birthing parents who had positive serology in pregnancy, treatment information was provided in 49 cases and, of these, 22% (11/49) did not receive treatment.
- Substance use was associated with increased odds of inadequate prenatal care (univariate logistic regression OR 8.2,  $p < 0.01$  95% CI [2.56–26.2]), and lack of maternal treatment (OR 3.5,  $p = 0.03$  95% CI [1.10–11.5]), but not diagnosed STBBI co-infection (OR 1.75,  $p = 0.26$  95% CI [0.64–4.7]).
- Most neonates with CS (54/88, 61%) had normal physical exams, and 25% (22/88) were born prematurely. The most common physical exam finding was hepatomegaly (10/88, 11%).

### Treatment and outcomes

- Most neonates (76/87, 87%) with confirmed or probable CS started treatment within their first week of life.
- All 82 infants for whom antibiotic type and duration of treatment were known received at least 10 days of aqueous penicillin G, the treatment of choice for CS.
- In 69% (61/89) of cases, there were no complications of CS documented at the time of reporting.

### Study limitations

- Limitations common to all Canadian Paediatric Surveillance Program studies are listed on page 11.
- Many potential maternal/birthing parent sociobehavioural risk factors were unknown to reporting physicians.

## Conclusions

- Maternal/birthing parent substance use was identified as a risk for inadequate prenatal care and lack of syphilis treatment during pregnancy. However, because the presence of other potential sociobehavioural risk factors (e.g., housing insecurity, income inadequacy) was often not known by reporting paediatricians, the sociostructural risk context predisposing to substance use remains unknown.
- Most affected infants identified by this study were diagnosed and treated early.

## Anticipated study impact

- The data gathered may help inform public health strategies for preventing CS.
- Study results may inform an upcoming Canadian Paediatric Society position statement on CS, as well as Public Health Agency of Canada discussions on the revision of the national case definition for CS.
- Next steps include exploring perceived barriers to engaging in prenatal care by interviewing mothers/birthing parents of affected infants.

## Publication and dissemination

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Presentation to the Public Health Agency of Canada's Syphilis Knowledge Exchange Webinar, in December 2022

Presentation to the Syphilis Outbreak Investigation Coordination Committee, a federal/provincial/territorial group focusing on the enhanced surveillance of syphilis within Canada, in November 2022

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### **Acknowledgements**

A special thanks to João Guedes and Jaskiran Sandhu from the STBBI Surveillance Division of the Public Health Agency of Canada for their data entry, processing, analysis, and general expertise.

# First-time hospitalizations for anorexia nervosa during the COVID-19 pandemic

Study duration: September 2021 to August 2023



Debra Katzman

## Principal investigators

Debra K. Katzman, MD, FRCPC, The Hospital for Sick Children and University of Toronto; [debra.katzman@sickkids.ca](mailto:debra.katzman@sickkids.ca)

Ellie Vyver, MD, FRCPC, Alberta Children's Hospital and University of Calgary; [ellie.vyver@ahs.ca](mailto:ellie.vyver@ahs.ca)

## Co-investigators

Agostino H, Chan H, Coelho JS, Cooney M, Couturier J, Devoe DJ, Dimitropoulos G, Dominic A, Findlay S, Iynkkaran I, Johnson N, Kurji A, Lam PY, Lane M, Lebeuf S, Norris M, Patten S, Pesant C, Spettigue W, Steinegger C, Taddeo D, Thompson W, Veilleux-Lemieux M

## ? Questions

- What is the minimum incidence rate of first-time hospitalizations for anorexia nervosa (AN) among children and adolescents during the COVID-19 pandemic, as compared to the three years prior to the pandemic?
- What are the clinical features and COVID-19 pandemic risk factors associated with hospital admissions for a first presentation of a primary diagnosis of AN during the COVID-19 pandemic?

## ! Importance

- AN is a serious mental illness with significant, life-threatening medical and psychiatric co-morbidity and mortality.
- Since the beginning of the COVID-19 pandemic, paediatricians across Canada have been seeing increased numbers of children and adolescents with AN presenting to their practices. The exact cause of this increase is unknown.
- This study will address an important and timely paediatric health issue with significant scientific and public health importance by providing valuable data on the incidence, clinical characteristics, severity, and key individual, family system, and other pandemic-related factors thought to drive the observed increase in the number and severity of children and adolescents with AN presenting to hospital for care.

## 🔄 Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/first-time-hospitalizations-for-anorexia-nervosa-during-the-covid-19-pandemic>.

### Case definition

Any patient 11 to 18 years of age (up to their 18<sup>th</sup> birthday) hospitalized with a primary admitting diagnosis of AN for the first time.

As defined in the *Diagnostic and Statistical Manual for Mental Disorders*, Fifth Edition (DSM-5), a diagnosis of AN requires all three of the following criteria:

1. Restriction of energy intake relative to requirements leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.
2. Intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.
3. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

### Exclusion criteria

1. Patients hospitalized for weight loss and/or malnutrition, however the:
  - a) patient has another DMS-5 diagnosis of an eating disorder (e.g., avoidant restrictive food intake disorder, bulimia nervosa, binge eating disorder)

- b) patient's presentation is explained by another medical condition or mental disorder
- c) cause of weight loss is indeterminate/uncertain
- d) patient has had previous admission(s) to hospital for anorexia nervosa

2. Patients admitted to a partial hospital or day treatment program

3. Patients admitted for a primary reason other than AN

### Unique to this study

To compare the rate of first-time hospitalizations for AN among children and adolescents prior to and after the beginning of the pandemic, this study will use health administrative data sources including, but not limited to, the Canadian Institute for Health Information, employing the ICD 10 codes for AN (F50.0, F50.01, and F50.02).

## ✓ Results – January to December 2022

**TABLE 1 – Cases of first-time hospitalizations for AN during COVID-19 pandemic in 2022**

| Reported | Duplicates | Excluded | Pending* | Met case definition* |
|----------|------------|----------|----------|----------------------|
| 196      | 0          | 10       | 100      | 86                   |

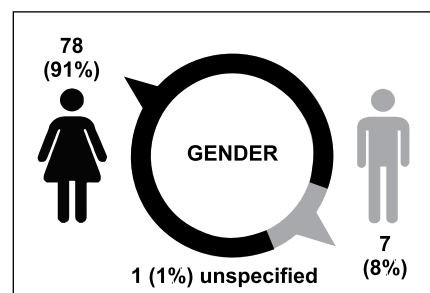
\* Due to Quebec legislation, site-specific research ethics board approvals are required for cases notified by Quebec participants to be included in the data analysis. These approvals are pending, so cases notified by Quebec participants were counted in the "Reported" and "Pending" columns, but detailed case information was neither collected nor included in the data analysis.

### Cases that met the case definition

At the time of analysis (February 17, 2023), 86 cases were verified as meeting the case definition from January 1 to December 31, 2022. Pending cases include notifications from Quebec (n=33) and cases that still need information from reporting physicians (n=67). Clinical data from cases reported from physicians in Quebec must be excluded from the analysis until necessary centre-specific research ethics board approvals are in place.

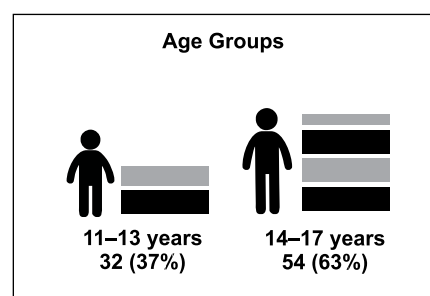
### Demographics

- The vast majority of cases identified as female (78/86, 91%). In the remaining cases, gender was male (7/86, 8%) or unspecified (1/86, 1%).
- Cases ranged in age between 11 and 17 years. The majority of cases were aged 14 to 17 years (54/86, 63%) and the remaining cases were aged 11 to 13 years (32/86, 37%).
- The most common patient-reported population group was White (48/86, 56%), followed by unknown (26/86, 30%).
- Over half of the cases were admitted to a general paediatric ward (48/86, 56%), while more than a third were admitted to a specialized paediatric eating disorders unit (30/86, 35%).
- Cases were most frequently admitted to hospital in the month of January (16/86, 19%), followed by August (13/86, 15%). March (11/86, 13%) and June (12/86, 14%) were also common months for admission.



### Presentation and diagnosis

- The COVID-19 pandemic was identified by the reporting physician as a precipitating factor in the development of AN in 27/86 (31%) cases in 2022 compared to 20/41 (49%) cases in the first reporting period for this study, from September to December 2021.
- The COVID-19 pandemic was identified by the reporting physician as having precipitated the hospitalization in 14/86 (16%) cases in 2022 compared to 15/41 (37%) cases in the first reporting period for this study, from September to December 2021.
- The reporting physician identified that 51/86 (59%) cases had one or more comorbid psychiatric condition(s), of which 44/51 (86%) had a comorbid anxiety disorder. In 13/86 (15%) cases, the patient had a comorbid medical condition.
- Leading up to admission, in 65/86 (76%) cases, the patients were attending school in-person, while in 11/86 (13%) cases the patients were either attending school virtually or attending through a hybrid of in-person and virtual school. In 7/86 (8%) cases, the patient was not attending school at all and, in the remainder of cases (3/86, 3%), information on school attendance was not reported.
- Changes in, or disruptions to, peer contact and friendships due to the COVID-19 pandemic were rated by the reporting physician as contributing to the admission "moderately" to "very/extremely" in 18/86 (21%) cases and "slightly" or "not at all" in 11/86 (13%) cases. In the remainder of cases (57/86, 66%), this information was not known or left blank.
- Exposure to dieting, nutrition, exercise, and eating disorder and fat-phobic content was reported to have contributed "moderately" to "very/extremely" to the admission in 14/86 (16%) cases and "slightly" or "not at all" in 11/86 (13%) cases. In the remainder of cases (61/86, 71%), this information was not known or left blank.



- Disruption of daily structure and routine contributed “moderately” to “very” to the admission in 21/86 (24%) cases and “slightly” to “not at all” in 13/86 (15%) cases. In the remainder of cases (52/86, 60%), this information was not known or left blank.
- Other potential COVID-19-related factors such as following public health directives, cancellation of important events, not seeking health care due to fear of exposure to COVID-19, changes in eating disorder health care service delivery, increased family conflict, increased parental/caregiver(s) mental health concerns, and patient-expressed loss of control or helplessness were not identified as potential contributors in 2022 to a first-time hospitalization for AN.
- The top three reasons for admission to hospital were: low weight (79/86, 92%), defined as either less than 75% of median body mass index (BMI) (46/86, 53%) or less than 80% of target weight (33/86, 38%); rapid and/or significant weight loss (63/86, 73%); and severe bradycardia, defined as a heart rate <50 beats/minute at daytime and/or <45 beats/minute at night (56/86, 65%).

### Study limitations

- Limitations common to all Canadian Paediatric Surveillance Program (CPSP) studies are listed on page 11.
- This is a preliminary analysis as some centres may not yet have reported all of their cases.
- The methodology is reliant on children and their families accessing paediatric medical care and the diagnosis being made accurately and appropriately in this setting.
- Recognizing that this study is cross sectional, it will not provide information about the medical and psychiatric treatment responses, long-term health service usage, and prognosis.
- Once the required centre-specific research ethics board approvals from Quebec are obtained, cases reported from physicians in Quebec can be included in the data analysis and study conclusions may change.

## Conclusions

- The COVID-19 pandemic was identified to be a precipitating factor in the development of AN in almost a third of cases of children and adolescents reported to the study in 2022. This is a decrease when compared to the initial reporting period of September to December 2021.
- The percentage of cases where the COVID-19 pandemic was identified as having precipitated the hospitalization decreased by more than half in 2022 compared to the first reporting period of September to December 2021.
- Similar to the first reporting period, in 2022 the majority of hospitalized patients with a first-time diagnosis of AN were female, 14 to 17 years old, and admitted to a general paediatric unit. It is concerning that 11 to 13 year olds comprised more than a third of cases.
- In over half of cases there was one or more comorbid psychiatric conditions.
- Based on the case history, reporting physicians identified that disruptions to peer contact and friendships due to the COVID-19 pandemic, exposure to dieting, nutrition, exercise, eating disorder and fat-phobic content, and disruption of daily structure and routine were potential COVID-19-related factors that contributed to a first-time hospitalization for AN.
- Other potential COVID-19-related factors surveyed were not identified as potential contributors in 2022 to a first-time hospitalization for AN.

## Anticipated study impact

- This study will establish a minimum incidence of first-time hospitalizations for AN in children and adolescents in Canada during the pandemic.
- This study will provide needed information on the clinical presentation and potential precipitating factors of first-time hospitalizations for AN in children and adolescents during the pandemic.
- Study results will provide important data that will facilitate the implementation of prevention strategies and best ways to adapt, modify, and deliver needed services to support children and adolescents with AN and their families during this pandemic and in the case of future public health emergencies.

## Publication and dissemination

The surge in eating disorders: What does the hospital paediatrician need to know? Vyver E, Grisé M. Canadian Paediatric Society Annual Conference, Montreal, in May 2022 (oral presentation)

### Acknowledgements

Thank you to all the collaborating Canadian paediatric eating disorder programs, the CPSP, and CPSP participants. We gratefully acknowledge funding for this study from the CPSP. We also thank the Public Health Agency of Canada for their contributions and support of this work, with a special thanks to Ithayavani Iynkkaran for her support with data analysis.



# Hypoglycemia during treatment of acute lymphoblastic leukemia

Study duration: October 2022 to September 2024



Mary Jiang

## Principal investigators

Mary Jiang, MD, FRCPC, Paediatric Endocrinology Fellow, Children's Hospital of Eastern Ontario, University of Ottawa; MJiang@cheo.on.ca

Alexandra Ahmet, MD, FRCPC, Paediatric Endocrinologist, Children's Hospital of Eastern Ontario, Associate Professor of Paediatrics, University of Ottawa; AA Ahmet@cheo.on.ca

Scott Somerville, MD, FRCPC, Paediatric Endocrinologist, Children's Hospital of Eastern Ontario; SSomerville@cheo.on.ca

## Co-investigators

Bassal M, Ens A, Geddie H, Gibson P, Goulet G, Harvey M, Healey A, Luca P, Marks SD, Mitchell J, Mokashi A, Panagiotopoulos C, Punnett A, Rousseau-Nepton I, Saleh D, Simoneau-Roy J, Speckert M, Waldner R

## ? Questions

- What is the minimum incidence of a first episode of biochemically proven hypoglycemia while being treated for acute lymphoblastic leukemia (ALL)?
- What is the frequency of a first episode of symptomatic hypoglycemia while being treated for ALL?
- What is the timing of onset and duration of hypoglycemia associated with treatment for ALL?
- What are the management strategies for hypoglycemia associated with treatment for ALL?

## ! Importance

- Likely under-appreciated, a recently recognized adverse event associated with standard ALL treatment is hypoglycemia. Two medications that have been found to be associated with hypoglycemia are asparaginase (most commonly in the form of L- and peg-asparaginase) and 6-mercaptopurine (6-MP).
- Hypoglycemia places children at risk of decreased level of consciousness, seizures, and possibly negative neurocognitive sequelae, especially in younger children.

## ➡ Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/hypoglycemia-and-all>.

### Case definition

Any patient less than 18 years of age (up to the 18th birthday) with a first known episode of biochemically proven hypoglycemia via laboratory serum glucose sample (if not available, then point-of-care) with blood glucose level below 3.0 mmol/L during chemotherapy for acute lymphoblastic leukemia (ALL) (all agents and protocols).

### Exclusion criteria

Patients who have had a previous documented episode of biochemical hypoglycemia during chemotherapy for ALL (blood glucose <3.0 mmol/L)

### Unique to this study

The study team will be collaborating with the Cancer in Young People in Canada program (CYP-C) to clearly identify the denominator of patients with ALL who were treated with the various forms of asparaginase during the study period.

## ✓ Results – October to December 2022

TABLE 1 – Hypoglycemia during treatment of ALL cases from October 1 to December 31, 2022

| Reported | Duplicates | Excluded | Pending | Met case definition* |
|----------|------------|----------|---------|----------------------|
| <5       | 0          | 0        | 0       | <5                   |

\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

### Cases that met the case definition

Fewer than five cases were verified as meeting the case definition in Canada from October 1 to December 31, 2022.

### Demographics

As per Canadian Paediatric Surveillance Program (CPSP) policy, case numbers and data for fewer than five cases cannot be presented.

### Presentation, diagnosis, treatment, and outcomes

Specific information on this study cannot be presented at this time due to the small number of cases.

### Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- This study is limited to gathering data from patients who have biochemically proven hypoglycemia. Therefore, the study will not be able to capture the true incidence of hypoglycemia — including symptomatic or asymptomatic patients for whom a blood glucose was never drawn.
- In hospitalized patients, hypoglycemia may be masked by the use of glucose containing intravenous fluids in young children.



## Conclusions

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- Fewer than five cases were reported during the first three months of the study.
- More time is required before conclusions can be drawn. Data collection will continue for a total of 24 months.



## Anticipated study impact

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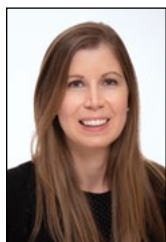
- This study will provide insight into the scope of this iatrogenic side effect in children undergoing ALL therapy.
- Study results may inform clinical guidance, screening, and strategies to prevent hypoglycemia during ALL therapy, as well as help to promote increased recognition of this adverse drug reaction.

### Acknowledgements

The investigators would like to thank the physicians who reported cases for this study.

# Micronutrient deficiencies and autism spectrum disorder

Study duration: January 2020 to December 2022 – Final report



Laura Kinlin

## Principal investigator

Laura Kinlin, MD, MPH, FRCPC, Division of Paediatric Medicine, The Hospital for Sick Children;  
laura.kinlin@sickkids.ca

## Co-investigators

Birken C, Conway M, Critch J, Erdle S, Holland J, Jetty R, Lagacé C, Shouldice M, Weinstein M, Zwaigenbaum L

## Questions

- Among children and youth with autism spectrum disorder (ASD) in Canada, what is the minimum incidence of specific micronutrient deficiencies (vitamin A deficiency/xerophthalmia; scurvy; severe, symptomatic vitamin D deficiency; and severe iron deficiency anemia)?
- What clinical characteristics, use of health care services, and health complications are associated with micronutrient deficiencies in children and youth with ASD in Canada?

## Importance

- The incidence of micronutrient deficiencies in children and youth with ASD in Canada is unknown. The paediatric population with ASD may be at risk of nutritional problems due to food refusal, limited dietary repertoire, and high-frequency single food intake.
- Better understanding the burden of serious micronutrient deficiencies in children and youth with ASD will inform anticipatory guidance, screening, and prevention strategies in this population.

## Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/micronutrient-deficiencies-and-autism-spectrum-disorder>.

### Case definition

All children and youth less than 18 years of age (up to their 18th birthday) with autism spectrum disorder **AND** a new diagnosis of one or more of the following micronutrient deficiencies:

- Vitamin A deficiency/xerophthalmia
- Scurvy
- Severe, symptomatic vitamin D deficiency
- Severe iron-deficiency anemia

The patient's autism spectrum disorder must have been diagnosed by a general paediatrician, developmental paediatrician, psychiatrist, or psychologist. Definitions for the micronutrient deficiencies and laboratory reference ranges can be found in Appendix 1 of the study protocol.

## Results – January 2020 to December 2022

TABLE 1 – Micronutrient deficiency and ASD cases from January 1, 2020 to December 31, 2022

| Year         | Reported  | Duplicates | Excluded  | Pending   | Met case definition* |
|--------------|-----------|------------|-----------|-----------|----------------------|
| 2020         | 33        | 1          | 14        | 7         | 11                   |
| 2021         | 30        | 2          | 12        | 6         | 10                   |
| 2022         | 16        | 0          | 3         | 7         | 6                    |
| <b>Total</b> | <b>79</b> | <b>3</b>   | <b>29</b> | <b>20</b> | <b>27</b>            |

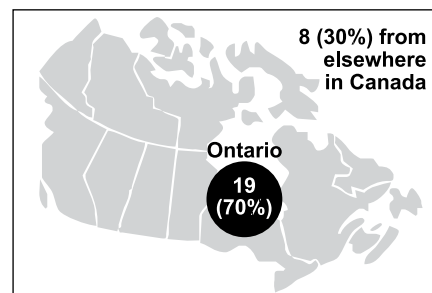
\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

### Cases that met the case definition

- At the time of analysis, 27 children and youth with micronutrient deficiency and ASD were verified as meeting the case definition from January 1, 2020 to December 31, 2022. With an additional 20 cases pending verification, these results are provisional and may be subject to change in the final study analysis.
- The majority of patients (18/27, 67%) met the case definition for only one of the four micronutrient deficiencies under surveillance; however, one-third of the patients had more than one of the deficiencies (9/27, 33%).
- Among the 27 patients, there were  $\geq 35$  diagnoses of micronutrient deficiency.
- Scurvy was the most commonly reported micronutrient deficiency (17 diagnoses), followed by severe iron deficiency anemia (10 diagnoses), severe, symptomatic vitamin D deficiency (7 diagnoses), and vitamin A deficiency/xerophthalmia (<5 diagnoses).

### Demographics

- The vast majority of patients were male, which may reflect that ASD is more common in males than females.
- The median age of patients was 7.7 years (range 1.8–14.9 years).
- Most patients (19/27, 70%) resided in Ontario, with the remainder residing in other provinces.



### Presentation and diagnosis

- Signs and symptoms of micronutrient deficiency were identified in the vast majority of cases (24/26, 92%).
- In patients with scurvy, arthralgia/limp/abnormal gait/inability to bear weight was the most common presenting symptom (12/17, 71%).
- All patients (27/27, 100%) were deemed to have a restricted diet/limited food repertoire. In all cases (27/27, 100%), the reporting physician attributed the restricted diet/limited food repertoire to the patient himself/herself (e.g., picky eater, unwilling to try new foods).
- The total number of different foods in the patient's diet was less than 10 for the majority of patients (20/23, 87%).
- Most patients (19/27, 70%) were reported as being non-verbal (i.e., using no spoken language or only a few spoken words).
- A minority of patients (8/26, 31%) had medical conditions other than ASD, and very few ( $n < 5$ ) had food allergies/intolerances diagnosed by a medical professional.
- Height and weight were not always measured at the time of micronutrient deficiency diagnosis (height and weight measured in 16/27, 59%). Based on the reporting physician's classification of weight status or growth measurements at diagnosis, most patients (18/26, 69%) were of normal/healthy weight, with the remainder classified as either underweight or overweight.
- The majority of patients (22/27, 81%), had their micronutrient deficiency first diagnosed by a general paediatrician.
- One-third of patients (9/27, 33%) underwent an invasive procedure as part of their diagnostic workup (e.g., bone marrow aspiration, general anesthetic for imaging).

### Treatment and outcomes

- Two-thirds of the patients (18/27, 67%) were admitted to hospital either for investigations leading to diagnosis of their micronutrient deficiency, or for management. The median duration of admission was eight days ( $n=17$ , range 3–32 days).
- All patients (27/27, 100%) were treated via administration of enteral vitamins. Other additional treatments were sometimes used.
- Prolonged immobilization secondary to micronutrient deficiency was reported infrequently ( $n < 5$ ). No other serious sequelae were reported, although the timing of reporting may limit respondents' ability to comment on long-term effects of micronutrient deficiencies.

### Study limitations

- Limitations common to all Canadian Paediatric Surveillance Program (CPSP) studies are listed on page 11.

## Conclusions

- Over the three-year period from January 2020 to December 2022, 27 children and youth with ASD were verified as meeting the case definition for one or more of the micronutrient deficiencies under surveillance. Scurvy was the most commonly reported of the four micronutrient deficiencies. Follow-up of pending cases is ongoing.
- The 27 cases identified in this study suggest that:
  - Very restricted diet/limited food repertoire is common in cases of micronutrient deficiency, and this dietary restriction is imposed by the child or youth themselves.
  - Weight status and micronutrient status are not synonymous; a child or youth with a micronutrient deficiency may not be underweight.
  - Hospital admission and invasive investigations are not uncommon in children and youth with ASD and micronutrient deficiency.
  - Serious sequelae of micronutrient deficiencies in children and youth with ASD appear to be rare.



## Anticipated study impact

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- This study is the first to evaluate the minimum incidence, clinical characteristics, associated use of health care services, and health complications of micronutrient deficiencies in children and youth with ASD in Canada.
- Results will inform anticipatory guidance, screening, and prevention strategies in this population.



## Publication and dissemination

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Micronutrient deficiencies in autism spectrum disorder: A macro problem? Kinlin LM, Birken CS. *Paediatr Child Health* 2021 Jun 5;26(7):436-7. doi: 10.1093/pch/pxab032. eCollection 2021 Nov

Food intake as a vital sign for autistic children. Smile S, Kinlin LM. Canadian Paediatric Society Annual Conference, Montreal, in May 2022 (seminar)

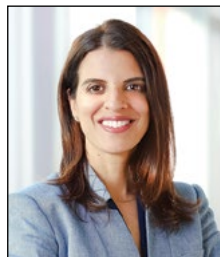
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### Acknowledgements

We are grateful to Melanie Laffin Thibodeau and the CPSP staff for their assistance with study coordination and management. We thank the physicians who reported cases for their time and effort.

# Optic nerve hypoplasia and septo-optic dysplasia

Study duration: November 2021 to October 2022 – Final report



Shazhan Amed

## Principal investigators

Shazhan Amed, MD, FRCPC, MSc.PH, Clinical Professor, University of British Columbia, Paediatric Endocrinologist, BC Children's Hospital; samed@cw.bc.ca

Brandy Wicklow, MD, FRCPC, MSc Epi, Associate Professor, University of Manitoba, Paediatric Endocrinologist, The Children's Hospital of Winnipeg; bwicklow@hsc.mb.ca

## Co-investigators

Alfattouh R, Bassilious E, Clark I, Hozjan I, Mitchell J, Nour M, Perry R, Pinto T, Rafay M, Rengan S, Rosolowsky E, Scott R, Stein R, Zuijdwijk C

## ? Questions

- What is the minimum incidence of optic nerve hypoplasia (ONH) and septo-optic dysplasia (SOD) in children from 0–17 years of age in Canada?
- What are the prenatal risk factors for developing ONH?
- What is the incidence of pituitary hormone dysfunction (PHD) at diagnosis in patients with ONH/SOD and what is the specific pattern of hormone deficiency?
- What risk factors are associated with the presence of PHD at diagnosis of ONH/SOD?

## ! Importance

- A better understanding of the incidence and risk factors associated with ONH and SOD in children, as well as the presence of PHD, will inform clinical guidance, screening, and prevention strategies.
- PHD is a common finding in children with SOD and can be associated with significant morbidity if not detected early.

## ↻ Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/optic-nerve-hypoplasia-and-septo-optic-dysplasia>.

## Case definition

Optic nerve hypoplasia (ONH) and septo-optic dysplasia (SOD) diagnoses are along a continuum. Patients are classified as having ONH when hypoplasia of the optic nerves is an isolated finding and as SOD when there are two or more of the following findings: hypoplasia of the optic nerves, pituitary hormone dysfunction (PHD), and/or midline abnormalities of the brain. A case of ONH can progress into a case of SOD, or clinical evidence of PHD can lead to a diagnosis of SOD, if ONH is present on ophthalmologic examination or magnetic resonance imaging (MRI).

All patients less than 18 years of age (up to their 18<sup>th</sup> birthday) with a new diagnosis of any one of the following:

1. Isolated ONH\*
2. SOD, defined as two or more of the following findings:
  - a) ONH
  - b) PHD<sup>†</sup>
  - c) Midline abnormalities of the brain (including agenesis of the septum pellucidum and/or corpus callosum on brain imaging)
3. PHD<sup>†</sup> in a patient known to have ONH
4. ONH reported as a component of a complex genetic syndrome

\* ONH is defined as hypoplasia of the optic nerves confirmed by an ophthalmologist's evaluation indicating the presence of the double ring sign on direct ophthalmoscopy and/or nerve diameter <1.5 mm and/or MRI findings reported by a paediatric radiologist.

† PHD is defined as one or more of the following hormone deficiencies, based on laboratory testing supported by clinical symptoms and physical examination:

- Growth hormone (GH)
- Adrenocorticotrophic hormone (ACTH)
- Thyroid stimulating hormone (TSH)
- Antidiuretic hormone (ADH)
- Luteinizing hormone (LH)
- Follicular stimulating hormone (FSH)

## Exclusion criteria

ONH thought to be associated with other postnatal events such as retinopathy of prematurity



## ✓ Results – November 2021 to October 2022

**TABLE 1 – ONH and SOD cases from November 1, 2021 to October 31, 2022**

| Reported | Duplicates | Excluded* | Pending | Met case definition* |
|----------|------------|-----------|---------|----------------------|
| 42       | 0          | 9         | 18      | 15                   |

\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the “Reported” column, but detailed case information was not collected and these cases were excluded from the data analysis.

### Cases that met the case definition

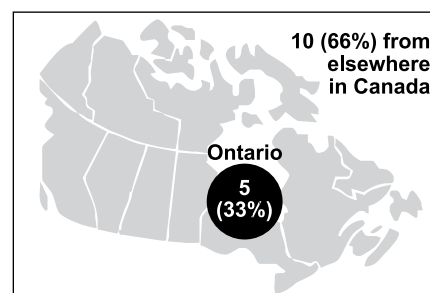
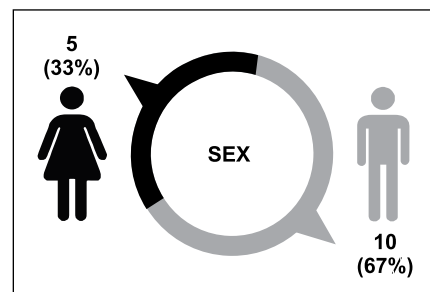
- At the time of analysis, 15 cases met case definition criteria from November 2021 to October 2022.
- With an additional 18 cases still pending verification, these results are preliminary and may be subject to change during the final study analysis.

### Demographics

- Patient sex was female in 5 (33%) cases and male in 10 (67%) cases.
- Of the confirmed cases, 5 (33%) were from Ontario and the other 10 cases were from elsewhere in Canada.

### Presentation and diagnosis

- The median gestational age of the patients was 39 weeks and the median birth weight was 3.3 kg.
- The median maternal age was 28 years old.
- The most common diagnoses were SOD (7/15, 47%) and isolated ONH (5/15, 33%).
- Of the 15 patients reported, 6 (40%) had nystagmus. The following clinical findings were less frequently documented: hypoglycemia, cleft lip/palate, cardiac defects, and micropenis.
- A complex genetic syndrome was suspected in fewer than five cases.



### Treatment and outcomes

- Of the confirmed cases, 12 (80%) patients had an ophthalmology exam. Of those patients, 8 (67%) had bilateral ONH.
- Magnetic resonance imaging (MRI) findings were reported for 10 (67%) patients. The most common findings included: 10 (100%) cases of ONH and 5 (50%) cases with absent septum pellucidum. Other less common MRI findings included: optic chiasm hypoplasia, ectopic posterior pituitary, hypoplastic pituitary stalk, hypoplastic anterior pituitary gland, corpus callosum hypoplasia, and thinning of the corpus callosum.
- Hormone deficiencies reported included growth hormone deficiency, adrenocorticotrophic hormone deficiency, thyroid stimulating hormone deficiency, antidiuretic hormone deficiency, and luteinizing hormone/follicle stimulating hormone deficiency.

### Study limitations

- Limitations common to all Canadian Paediatric Surveillance Program studies are listed on page 11.
- All new cases of paediatric ONH and SOD in Canada may not have been captured.
- Given the relatively small number of reported cases, these results should be interpreted with caution.

## 🔍 Conclusions

- Although 18 case notifications are still pending verification, at the time of writing this report, only 15 cases were confirmed as meeting the case definition for ONH or SOD.
- Based on previous research, the study team anticipated that 150 cases would be detected within Canada in a one-year period and suspects the number of confirmed cases in this study is a gross underestimation of the true minimum incidence of cases in Canada. A possible contributing factor is that research ethics board approvals/data transfer agreements were not in place to collect detailed case information from the province of Quebec.

## + Anticipated study impact

- The study will provide Canadian-specific data regarding the minimum incidence rates of ONH and SOD in children and will identify risk factors associated with PHD.
- Study results may inform clinical guidance, screening, and prevention strategies.

### Acknowledgements

We would like to thank the reporting physicians for their participation in this study.

# Paediatric-onset leukodystrophies

Study duration: December 2019 to November 2022 – Final report



Sunita Venkateswaran

## Principal investigators

Geneviève Bernard, MD, MSc, FRCPC, Associate Professor, Departments of Neurology and Neurosurgery, McGill University, Paediatrics and Human Genetics, McGill University Health Centre; genevieve.bernard@mcgill.ca

Roberta La Piana, MD, PhD, Assistant Professor, Department of Neurology and Neurosurgery, McGill University, Associate Member, Department of Diagnostic Radiology, Montreal Neurological Institute-Hospital; roberta.lapiana@mcgill.ca

Sunita Venkateswaran, MD, FRCPC, Associate Professor, Division of Paediatric Neurology, University of Ottawa, Department of Paediatrics, Children's Hospital of Eastern Ontario; svenkateswaran@cheo.on.ca

## Co-investigators

Blaser S, Brna P, Chakraborty P, Constantin E, Demos M, Geraghty M, Goetz H, Li P, Mah J, Mahmutoglu S, Major N, Meaney B, Miller E, Prasad C, Prasad N, Riou E, Rossignol E, Rupar T, Srour M, Vadeboncoeur C

## Questions

- What is the minimum incidence of paediatric-onset leukodystrophies (LD) in Canada?
- What are the patterns of presentation, clinical features, comorbidities, and diagnostic journeys of children and youth with different types of LD?

## Importance

- Determining the minimum incidence of paediatric-onset LD in Canada will provide information that will help with more effective planning of services to children and youth with this condition, and help families and health care practitioners more effectively advocate for this vulnerable group of patients.
- By determining the proportion of children with each specific LD, diagnostic protocols and educational programming can be developed to enhance clinical care.
- This study will be foundational for the development of national and international collaborative studies on the natural history and pathobiology of LD, which will serve as a step towards future therapeutic developments.

## Methodology

The complete protocol can be accessed at [www.cpsp.cps.ca/surveillance/study-etude/paediatric-onset-leukodystrophies](http://www.cpsp.cps.ca/surveillance/study-etude/paediatric-onset-leukodystrophies).

### Case definition

All children and youth less than 18 years of age (up to their 18th birthday) with a new diagnosis of a leukodystrophy, defined as a genetically determined disorder characterized by primary involvement of the white matter. Disorders characterized as leukodystrophies include, but are not limited to, the following (non-exhaustive list):

- Pol-III related disorders (4H syndrome (hypomyelination, hypodontia, and hypogonadotropic hypogonadism))
- 18q minus syndrome
- X-linked adrenoleukodystrophy (X-ALD)
- Adult-onset leukodystrophy with neuroaxonal spheroids and pigmented glia (including hereditary diffuse leukoencephalopathy with spheroids, HDLS, and pigmentary type of orthochromatic leukodystrophy with pigmented glia, POLD)
- Aicardi-Goutières syndrome (AGS)
- Alexander disease (AxD)
- Autosomal dominant leukodystrophy with autonomic disease (ADLD)
- Canavan disease
- Cerebrotendinous xanthomatosis (CTX)
- Chloride ion channel 2 (ClC-2) related leukoencephalopathy with intramyelinic oedema
- eIF2B related disorder (vanishing white matter disease or childhood ataxia with central nervous system hypomyelination (CACH))
- Fucosidosis
- Globoid cell leukodystrophy (Krabbe disease)
- Hypomyelination with atrophy of the basal ganglia and cerebellum (H-ABC)
- Hypomyelination with brainstem and spinal cord involvement and leg spasticity (HBSL)
- Hypomyelination with congenital cataract (HCC)

- Leukoencephalopathy with brainstem and spinal cord involvement and lactate elevation (LBSL)
- Leukoencephalopathy with thalamus and brainstem involvement and high lactate (LTBL)
- Megalencephalic leukoencephalopathy with subcortical cysts (MLC)
- Metachromatic leukodystrophy (MLD) and its biochemical variants
- Oculodentodigital dysplasia
- Pelizaeus-Merzbacher disease (PMD)
- Pelizaeus-Merzbacher-like disease (PMLD)
- Peroxisomal biogenesis disorders (including Zellweger, neonatal adrenoleukodystrophy, and infantile Refsum)
- Polyglucosan body disease (PGBD)
- RNase T2 deficient leukoencephalopathy
- Sialic acid storage disorders (Salla disease, infantile sialic acid storage disease and intermediate form)
- Single enzyme deficiencies of peroxisomal fatty acid beta oxidation (including only D-bifunctional protein deficiency; sterol carrier protein X (SCPx) deficiency; peroxisomal acyl-CoA-oxidase deficiency)
- Sjögren-Larsson syndrome
- SOX10-associated PCWH: peripheral demyelinating neuropathy, central dysmyelinating leukodystrophy, Waardenburg syndrome, and Hirschsprung disease

\* For information on the availability of and access to genetic testing in your region, refer to the list of study principal investigators/co-investigators at the beginning of the study protocol and contact the one who is located closest to your practice.

## Results – December 2019 to November 2022

**TABLE 1 – Paediatric-onset LD cases from December 1, 2019 to November 30, 2022**

| Years        | Reported  | Duplicates | Excluded | Pending*  | Met case definition* |
|--------------|-----------|------------|----------|-----------|----------------------|
| 2019-2020†   | 29        | 0          | 4        | 7         | 18                   |
| 2021-2022‡   | 41        | 0          | 5        | 16        | 20                   |
| <b>Total</b> | <b>70</b> | <b>0</b>   | <b>9</b> | <b>23</b> | <b>38</b>            |

\* Due to Quebec legislation, site-specific research ethics board approvals are required for any cases notified by Quebec participants to be included in the data analysis. These approvals are pending, so cases notified by Quebec participants were counted in the "Reported" and "Pending" columns, but detailed case information was neither collected nor included in the data analysis.

† December 1, 2019 to December 31, 2020

‡ January 2021 to November 30, 2022

### Cases that met the case definition

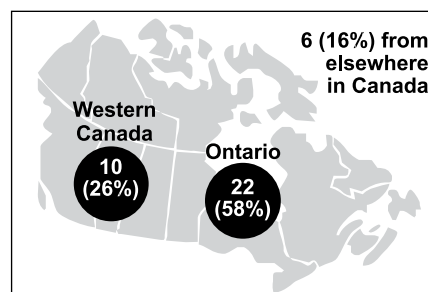
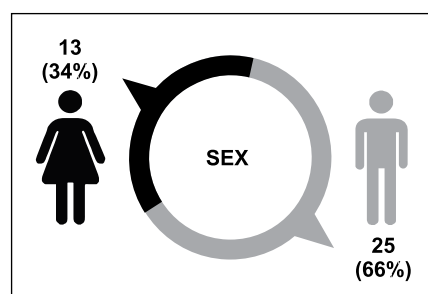
- A total of 38 cases of paediatric-onset LD were verified as meeting the case definition from December 1, 2019 to November 30, 2022.
- With an additional 23 cases pending verification, these results are provisional and may be subject to change in the final study analysis. Clinical data from cases reported from physicians in Quebec must be excluded from the analysis until necessary centre-specific research ethics board approvals are in place.

### Demographics

- Patient sex was reported as 25/38 (66%) males and 13/38 (34%) females.
- The average age at presentation was 25 months (SD 27.2).
- The geographic distribution of cases was 22/38 (58%) from Ontario, 10/38 (26%) from Western Canada, and the remaining cases from other parts of Canada.

### Presentation and diagnosis

- Multiple signs/symptoms were seen in the majority of patients at the time of presentation to medical care.
- Global developmental delay was the most common sign/symptom at presentation (26/38, 68%), and among these patients, 10/26 (38%) presented with subsequent regression. Five out of 38 patients (13%) presented with developmental regression alone.
- The next most frequently reported signs/symptoms at presentation included the following: abnormal muscle tone (16/38, 42%), feeding issues (15/38, 39%), vision impairment (14/38, 37%), seizures (13/38, 34%), and gait issues, including ataxia and falls (9/38, 24%).
- The most commonly reported LD diagnoses were globoid cell leukodystrophy (Krabbe disease) (6/38, 16%), metachromatic leukodystrophy (5/38, 13%), Pelizaeus-Merzbacher disease (5/38, 13%), and X-linked adrenoleukodystrophy (5/38, 13%).
- LD diagnoses were made most often via whole exome sequencing, next generation sequencing, or single gene testing in equal proportions. The remaining cases were diagnosed using chromosomal microarray, single gene testing, and family history.



- On average, it took 18.5 months (SD 27.3) after symptom onset for patients to have a confirmed diagnosis.
- After presentation to medical attention, patients obtained an LD genetic diagnosis in 6.5 months (SD 19.6), on average.

### Treatment and outcomes

- Patients required an average of six different services (SD 2.5) for their ongoing care. Allied health, rehabilitation, and dietician/feeding team were each counted as one service even though multiple services fall under each of their umbrellas.
- Interestingly, most reporting physicians did not indicate that making the diagnosis was one of the most important challenges to caring for children with LD (7/37, 19%). The most important challenges followed the diagnosis and were associated with the patient's medical complexity (22/37, 59%), the patient's psychosocial complexity (19/37, 51%), the lack of multidisciplinary care teams (15/37, 41%), and the physician's lack of experience caring for patients with these rare conditions (10/37, 27%). Multiple challenges could be listed for each patient.

### Study limitations

- Limitations common to all Canadian Paediatric Surveillance Program (CPSP) studies are listed on page 11.
- Due to COVID-19 restrictions, in-person patient visits and access to diagnostic tests, including neuroimaging and genetic testing, may have been limited. Neuroimaging is a key part of the clinical pathway prior to genetic testing for patients with LD and, starting in March 2020, access to both imaging and anaesthesia services required by this population was limited across the country.
- There is variable access to genetic testing across the country.
- The conditions diagnosed are among the more commonly identified conditions via magnetic resonance imaging (MRI) pattern recognition. There may be several other undiagnosed LD that have been suspected based on neuroimaging but not yet diagnosed during the study time period.
- Once the required centre-specific research ethics board approvals from Quebec are obtained, cases reported from physicians in Quebec can be included in this analysis and study conclusions may change.

## Conclusions

- Over the three-year period from December 2019 to November 2022, 38 children and youth were verified as meeting the case definition for paediatric-onset LD. Follow-up of pending cases is ongoing.
- The diagnosis of the more common paediatric-onset LD took an average of 6.5 months after the patient presented to medical attention.
- Interestingly, the majority of confirmed cases were reported in Ontario where there is more than one centre with expertise in diagnosing LD. Early diagnosis allows for optimal management. Disease-specific treatments (e.g., bone marrow transplant, gene therapy), where available, can be provided once a genetic diagnosis is obtained. In order to make an early diagnosis, the patient must be able to access care from a provider with expertise in childhood neurological conditions.
- Paediatric-onset LD continue to be challenging to manage, both for the patient and the health care provider, due to the patient's medical and psychosocial complexity, the need for multiple subspecialists and multidisciplinary care, and a lack of physician experience caring for patients with these rare conditions.

## Anticipated study impact

- Study results will assist with developing knowledge translation activities to educate child health care providers about the types of LD, the various presentations, and the needs of children with LD. Increasing awareness about the current diagnostic journey of children and youth with LD, may lead to improvements in timely diagnosis and the early implementation of potential therapies as well as the establishment of multidisciplinary clinics which are required to provide the best care for these children.
- The collaboration of interested paediatricians and subspecialists from across the country in this study may set the foundation for expanding the Canadian Paediatric Genetically-determined White Matter Diseases Network and creating LD centres of excellence across Canada, in collaboration with health care decision makers. Ultimately, this work may lead to the development of a prospective Canadian LD registry to study longitudinal cohorts and determine natural history, morbidity, and mortality rates of LD.
- Study results could contribute to the development of standardized clinical diagnostic algorithms and management guidelines for LD relevant to the Canadian population.

# Paediatric pulmonary thromboembolism

Study duration: January 2020 to December 2022 – Final report



Kristina R. Krmpotic

## Principal investigators

Kristina R. Krmpotic, MD, MSc, FRCPC, Associate Professor, Department of Critical Care Medicine, Dalhousie University and Department of Paediatric Intensive Care, IWK Health Centre; kristina.krmpotic@iwk.nshealth.ca

Paul C. Moorehead, MD, MS, MSc, FRCPC, Paediatric Hematology/Oncology, Memorial University and Janeway Children's Health and Rehabilitation Centre; paul.moorehead@easternhealth.ca

## Co-investigators

Chan AKC, Plint AC

## Site champions

Amid A, Bishop J, Bhatt M, Brandao L, Bruce A, Charlebois J, Gibson P, Halparin J, Herrington K, Kulkarni K, Larson C, Le D, Lee A, MacGregor Steele J, MacLean G, Pelland-Marcotte MC, Sabapathy C, Silva M, Sinha R, Stoffman J, Terry J, Tole S, Trottier E, Winikoff R

## Questions

- What is the minimum incidence of pulmonary thromboembolism in the Canadian paediatric population, and what are the associated demographics?
- What is the clinical presentation of paediatric pulmonary thromboembolism, and what are the risk factors and short-term outcomes?
- What diagnostic modalities and therapeutic interventions are chosen by clinicians?

## Importance

- Pulmonary thromboembolism is a rare but life-threatening event, with very little known about the epidemiology and presenting characteristics in the paediatric population.
- Variability exists in diagnosis and management.
- Improved knowledge of the incidence, presentation, and risk factors can help to promote early detection and diagnosis, and improve management and outcomes.

## Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/paediatric-pulmonary-thromboembolism>.

### Case definition

Any patient up to their 18<sup>th</sup> birthday with a new diagnosis of confirmed or suspected pulmonary thromboembolism. Pulmonary thromboembolism is defined as in situ thrombus or embolism, including fragments and fat embolism, situated anywhere in the pulmonary arterial circulation from the right ventricle (RV), through the outflow tract, to the peripheral and subsegmental regions of the pulmonary arteries. Report patients including, but not limited to, asymptomatic patients, post-operative patients, pregnant or recently pregnant patients, and deceased patients.

Confirmed pulmonary thromboembolism – patient fulfills one of four criteria:

1. Pulmonary thromboembolism diagnosed on computerized tomography (CT) pulmonary angiography **OR** conventional pulmonary angiography **OR** magnetic resonance imaging/magnetic resonance pulmonary angiography
2. Ventilation-perfusion (V/Q) scan reporting high probability of pulmonary thromboembolism
3. Echocardiogram demonstrating thrombus in the RV **OR** outflow tract **OR** main pulmonary artery/branch pulmonary arteries **OR** in transit
4. Pulmonary thromboembolism identified on autopsy

Suspected pulmonary embolism – patient fulfills one of two criteria:

1. Clinical suspicion of pulmonary thromboembolism **AND** V/Q scan reporting intermediate probability of pulmonary thromboembolism
2. Clinical suspicion of pulmonary thromboembolism **AND** echocardiogram demonstrating RV dysfunction with no other explanation

### Unique to this study

Initially this study was limited to patients up to their 16<sup>th</sup> birthday. An amendment was accepted by the research ethics board to allow for broadening the case definition to include patients up to their 18<sup>th</sup> birthday, with retrospective reporting allowed for cases identified since study onset.



## Results – January 2020 to December 2022

**TABLE 1 – Paediatric pulmonary thromboembolism cases from January 1, 2020 to December 31, 2022**

| Year         | Reported  | Duplicates | Excluded* | Pending   | Met case definition* |
|--------------|-----------|------------|-----------|-----------|----------------------|
| 2020         | 17        | 0          | 5         | 3         | 9                    |
| 2021         | 18        | 0          | 3         | 6         | 9                    |
| 2022         | 23        | 0          | 4         | 6         | 13                   |
| <b>Total</b> | <b>58</b> | <b>0</b>   | <b>12</b> | <b>15</b> | <b>31</b>            |

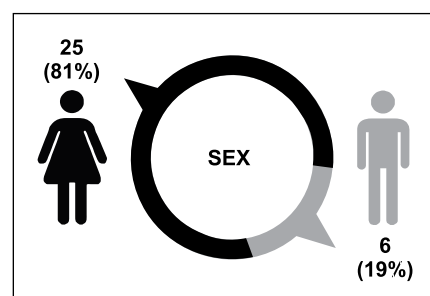
\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the “Reported” column, but detailed case information was not collected and these cases were excluded from the data analysis.

### Cases that met the case definition

- At the time of analysis, 31 cases of paediatric pulmonary thromboembolism were verified as meeting the case definition from January 1, 2020 to December 31, 2022.
- With an additional 15 cases pending verification, these results are provisional and may be subject to change in the final study analysis.

### Demographics

- Cases were predominantly female (25/31, 81%) and between the ages of 11 to 18 years (26/31, 84%).
- At least one risk factor was present in 28/31 (80%) patients, most commonly exogenous hormone therapy (10/31, 32%), obesity (9/31, 29%), and infection (8/31, 26%); 6/31 (19%) patients had a deep vein thrombosis on presentation.



### Presentation and diagnosis

- Almost all cases were symptomatic (27/31, 87%), most commonly presenting with chest pain (18/31, 58%), tachycardia (13/31, 42%), and/or shortness of breath (13/31, 42%).
- Most symptomatic patients presented with more than one symptom (24/27, 89%).
- The most common diagnostic modality used was CT pulmonary angiogram (25/31, 81%).

### Treatment and outcomes

- Almost all patients were admitted to hospital (28/31, 90%) and almost one-third required intensive care (10/31, 32%).
- The majority of cases (25/31, 81%) were treated exclusively medically. The most frequently reported treatments were low molecular weight heparin (21/31, 68%), oral anticoagulants (9/31, 29%), and unfractionated heparin (6/31, 19%).
- Treatment complications were reported in 8/31 (26%) patients with 5/31 (16%) experiencing significant bleeding or cardiac arrest.
- Fewer than five deaths were reported and none were attributed to treatment complications.

### Study limitations

Limitations common to all Canadian Paediatric Surveillance Program (CPSP) studies are listed on page 11.



## Conclusions

- From January 2020 to December 2022, 31 paediatric patients were verified as meeting the case definition for confirmed or suspected pulmonary thromboembolism. Follow-up of pending cases is ongoing. Adolescents, particularly females, appear to be at highest risk of disease.
- Though variable, most patients presented with at least one symptom and had at least one risk factor.
- Most cases were admitted to hospital and treated with systemic anticoagulation; many required intensive care unit admission.



## Anticipated study impact

This study provides Canadian-specific data on the epidemiology, presentation, and outcomes of paediatric pulmonary thromboembolism, and how clinicians diagnose and manage this condition.

### Acknowledgements

Thank you to the paediatricians and paediatric subspecialists across Canada who reported cases for this study, and to the site champions for their support in promoting this study and assisting with reporting.



# Post-COVID-19 condition (long COVID)

Study duration: September 2022 to August 2024



Anu Wadhwa

## Principal investigators

Anu Wadhwa, MD, MEd, FRCPC, University of Toronto, The Hospital for Sick Children;  
anupma.wadhwa@sickkids.ca

Shaun Morris, MD, MPH, FRCPC, FAAP, University of Toronto, The Hospital for Sick Children;  
shaun.morris@sickkids.ca

Sanjay Mahant, MD, FRCPC, University of Toronto, The Hospital for Sick Children;  
sanjay.mahant@sickkids.ca

## Co-investigators

Barmherzig R, Barton M, Bergeron MJD, Bullard J, Dave M, De Souza C, Ethier L, Hudson J, Hui C, Karatzios C, Leifso K, Moore Hepburn C, Mullaithilaga N, Nashid N, Purewal R, Read S, Ricci C, Saleh S, Sinopoli K, Tse A, Tse SM, Vanderkooi O, Virji M, Watson D, Wong J, Wong P, Yeung R

## ? Questions

- What is the minimum incidence of long COVID in children and youth in Canada?
- What are the demographics and characteristics of children and youth who present with long COVID?
- What are the clinical characteristics of this condition at presentation? Specifically, what are the symptoms at presentation (including duration) and the impact on the child's participation in daily activities?

## ! Importance

- The incidence and clinical characteristics of long COVID in children and youth in Canada are unknown and the burden of this illness in children in Canada has not been described.
- Based on early reports and clinical experiences managing children with long COVID, the resource utilization for each patient can be significant.
- A better understanding of the extent and nature of this new condition in children is required so that health care systems may best support their recovery.

## ➡ Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/post-covid-19-condition>.

### Case definition

Any patient less than 18 years of age (up to the 18<sup>th</sup> birthday) who meets both of the following criteria:

- 1) Experiencing one or more new or persistent symptoms after recovery from acute COVID-19 (proven by laboratory testing and/or highly suspected based on clinical history)

AND

- 2) Symptom(s) have persisted for at least eight weeks

## ✓ Results – September to December 2022

TABLE 1 – Post-COVID-19 condition cases from September 1 to December 31, 2022

| Reported | Duplicates | Excluded* | Pending | Met case definition* |
|----------|------------|-----------|---------|----------------------|
| 17       | 0          | 2         | 4       | 11                   |

\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

### Cases that met the case definition

At the time of analysis, of the 17 cases reported during the first four months of the study, 11 met the case definition for long COVID and four were pending verification.



### Demographics

- Long COVID cases were reported from four provinces representing Western, Central, and Atlantic Canada.
- Cases ranged in age from 3 to 17 years, with a median of 15 years.
- The majority of cases were female.

### Presentation and diagnosis

- All 11 cases (100%) had a co-morbid condition. Common co-morbidities included: obesity, allergies, mental health conditions, and neurodevelopmental conditions.
- None of the confirmed cases experienced multisystem inflammatory syndrome in children (MIS-C).
- The number of persisting symptoms at presentation to paediatric care ranged from 2 to 13 (median 4). The most common persisting symptoms were fatigue, myalgia, headache, and sleep disturbance.
- Of the 10 cases (91%) reporting fatigue, 8 (80%) endorsed post-exertional fatigue.
- On average, long COVID cases presented to paediatric care 3.5 months after the onset of symptoms.
- The majority of cases experienced a mild acute COVID-19 illness, while a minority of cases were hospitalized during their acute illness.

### Treatment and outcomes

The management of these 11 long COVID patients included rehabilitation strategies (e.g., physiotherapy, occupational therapy), sleep hygiene measures, psychological/mental health support, and referral to additional specialists.

### Study limitations

Limitations common to all Canadian Paediatric Surveillance Program studies are listed on page 11.

## Conclusions

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- These findings represent the preliminary results from the first four months of a planned two-year surveillance study.
- Children are presenting to paediatricians across Canada with multiple persistent symptoms after acute COVID-19. The majority of long COVID cases reported to date experienced a mild acute COVID-19 illness.
- The management of patients with long COVID included multiple strategies addressing physical and mental health.

## Anticipated study impact

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- The study results will increase our understanding of the incidence and clinical characteristics of this new condition in children and youth in Canada.
- A better understanding of the extent and nature of long COVID in children and youth is required so that health care systems may better support their recovery.

# Serious adverse events related to cannabis used for medical purposes

Study duration: December 2019 to November 2022 – Final report



Lauren E. Kelly

## Principal investigators

Lauren E. Kelly, PhD, Department of Paediatrics and Child Health, Department of Community Health Sciences, George and Fay Yee Centre for Healthcare Innovation, University of Manitoba; lauren.kelly@umanitoba.ca

Geert 't Jong, MD, PhD, Department of Paediatrics and Child Health, Children's Hospital Research Institute of Manitoba; geert.tjong@umanitoba.ca

## Co-investigators

Bélanger RE, Finkelstein Y, Grant C, Moore Hepburn C, Rassekh R, Richer L, Rieder M, Siden H

## Collaborators

Abramovici H, Jack S

## ? Questions

- What are the clinical characteristics of serious adverse events (SAEs) related to cannabis used for medical purposes in children, including indications for use and concomitant medications?
- How were SAEs associated with intentional cannabis exposure identified and managed?
- What are the outcomes following SAEs related to cannabis or cannabis products used for medical purposes (with or without a medical authorization) in children and adolescents in Canada?

## ! Importance

- While Health Canada has not approved any product containing cannabinoids for use by children or youth, cannabis for medical purposes is currently used for a variety of conditions, including nausea and vomiting in children with cancer, drug-resistant seizure disorders, and refractory spasticity.
- There is little real-world Canadian data on SAEs in children using cannabis or cannabis products for medical purposes and limited knowledge about associated products, indications, and adverse events.
- There is also limited scientific evidence on the clinical characteristics, management, and outcomes following SAEs in children and youth exposed to cannabis or cannabis products used for medical purposes.

## Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/serious-adverse-events-related-to-cannabis-used-for-medical-purposes>.

### Case definition

Any serious or life-threatening adverse event\* in a child up to 18 years of age related to the intentional use of cannabis for medical purposes.† Report an adverse event even if there is not certainty it is related to the use of cannabis. Include any cannabis product from a licensed producer or private producer (home grown) such as dried cannabis to be smoked or vaporized, oils to be ingested or applied topically, and cannabis products taken by any other route of administration.

\* A serious or life-threatening adverse event is defined as a noxious and unintended severe response to a drug which occurs at any dose and results in emergency observation, hospitalization, persistent or significant disability, or death.

† Cannabinoids or cannabis used for medical purposes is defined as intentional cannabis use for any self-reported (or parent reported) health reasons, with or without physician authorization.

### Exclusion criteria

- Adverse events resulting from non-medical cannabinoid/cannabis use
- Adverse events resulting from accidental/unintentional cannabinoid/cannabis exposure (even if being used for medical purposes by another individual in the home)



## Results – December 2019 to November 2022

**TABLE 1 – SAEs related to cannabis used for medical purposes cases from December 1, 2019 to November 30, 2022**

| Reported | Duplicates | Excluded* | Pending | Met case definition* |
|----------|------------|-----------|---------|----------------------|
| <5       | 0          | 0         | 0       | <5                   |

\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the “Reported” column, but detailed case information was not collected and these cases were excluded from the data analysis.

### Cases that met the case definition

Fewer than five cases were verified as meeting the case definition in Canada from December 1, 2019 to November 30, 2022.

### Demographics

As per Canadian Paediatric Surveillance Program (CPSP) policy, case numbers and data for fewer than five cases cannot be presented.

### Presentation, diagnosis, treatment, and outcomes

Specific information on this study cannot be presented due to the small number of cases.

### Study limitations

Limitations common to all CPSP studies are listed on page 11.



## Conclusions

- Fewer than five cases were reported and verified as meeting the case definition for this study from December 2019 to November 2022.
- Case reporting was encouraged and promoted on social media via the Canadian Paediatric Society and the Canadian Childhood Cannabinoids Clinical Trials (C4T) and no new cases were reported.



## Anticipated study impact

- This study aimed to provide Canadian-specific paediatric data on the clinical characteristics, management, and outcomes of patients following SAEs related to the use of cannabis and cannabis products for medical purposes.
- The information from this study is shared directly with Health Canada and may be adapted for professional and public education materials.



## Publication and dissemination

High-potency cannabis products: How to address them with ease in paediatric clinical practice. Chadi N, Bélanger R. Canadian Paediatric Society Annual Conference, Montreal, in May 2022 (oral presentation)

### Acknowledgements

The investigators would like to thank the physicians who reported cases for this study.

# Serious and life-threatening events associated with non-medical (recreational) cannabis use in Canadian children and youth

Study duration: Ongoing since September 2018



Richard Bélanger

## Principal investigators

Richard E. Bélanger, MD, Department of Paediatrics, Centre mère-enfant Soleil — CHU de Québec — Université Laval; richard.belanger.med@ssss.gouv.qc.ca

Christina Grant, MD, Division of Adolescent Medicine, Department of Paediatrics, McMaster University; chgrant@mcmaster.ca

## Co-investigators

Abramovici H, Acker A, Ammerman SD, Gingras N, Jack S, Moore Hepburn C, Plebon-Huff S, Yates R

## Collaborator

Dirk Huyer, MD, Chief Coroner for Ontario

## ? Questions

- What is the minimum incidence of serious and life-threatening events associated with non-medical use of cannabis in children and youth in Canada?
- What are the clinical presentations and associated medical needs of children and youth presenting with serious and life-threatening events related to non-medical cannabis exposure?
- Are there changes in the incidence of serious and life-threatening events during the four-year period following cannabis legalization?

## ! Importance

- There are currently limited scientific data quantifying the impact of cannabis legalization and regulation on the health of children and youth in Canada.
- Data provided by this study will be used to assess the health impacts of cannabis legalization and regulation in the paediatric population and to inform policy, legislation and regulations, as well as public education and awareness communications.

## ➡ Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/serious-and-life-threatening-events-associated-with-non-medical-recreational-cannabis-use-in-canadian-children-and-youth>.

## Case definition

Any child or adolescent less than 18 years of age (up to the 18th birthday) presenting with a new health condition or a deteriorating chronic/previously diagnosed condition resulting in either hospitalization (inpatient, intensive care unit, psychiatric), permanent disability, or death, which was likely primarily caused by the use of cannabis for non-medical (recreational) purposes.

This includes either intentional or unintentional exposure to cannabis in a child or adolescent, or a condition resulting from use by another individual, such as a friend or a parent/caregiver, who is under the influence of cannabis.

## Exclusion criteria

- A condition resulting from cannabis use for non-medical purposes during pregnancy/breastfeeding
- A condition resulting from cannabis use for medical purposes

## ✓ Results – January to December 2022

TABLE 1 – Cases of serious and life-threatening events associated with non-medical use of cannabis in 2022

| Reported | Duplicates | Excluded* | Pending | Met case definition* |
|----------|------------|-----------|---------|----------------------|
| 52       | 0          | 1         | 23      | 28                   |

\* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

### Cases that met the case definition

- In total, 52 cases of serious and life-threatening events associated with non-medical use of cannabis among children and youth were reported through the Canadian Paediatric Surveillance Program (CPSP) in 2022.
- At the time of analysis, 28 of these cases were verified as meeting the case definition in 2022. In comparison, 10 cases met the case definition from September to December 2018, 38 cases in 2019, growing to 50 cases in 2020 and then decreasing to 34 cases in 2021.

| TABLE 2 – Annual comparison of cases of serious and life-threatening events associated with non-medical use of cannabis 2018–2022 |             |
|---|-------------|
| Year  | Total cases |
| 2022  | 28          |
| 2021  | 34          |
| 2020  | 50          |
| 2019  | 38          |
| 2018*   | 10          |

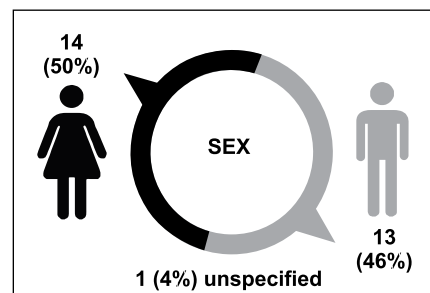
\* September to December

### Demographics

- Patient sex was female in 14/28 cases (50%, 95 CI 32–68), male in 13/28 cases (46%, 95 CI 28–65), and unspecified in 1/28 case (4%, 95 CI 0.5–23).
- The mean age was 7.7 years with a median age of 5.2 years. Most cases were among children 12 years of age and younger (19/28, 68%, 95 CI 48–83).

### Presentation and diagnosis

- Like in previous years, the most common primary presentation was poisoning/intoxication (10/28, 36%, 95 CI 20–56). Poisoning/intoxication cases exclusively involved children aged 12 years and younger, and 8/10 cases (80%, 95 CI 40–96) involved ingestion of cannabis in edible form.
- Other case presentations included psychosis, including drug-induced psychosis, (6/28, 21%, 95 CI 10–41) and neurological problems (6/28, 21%, 95 CI 10–41). In some cases, more than one primary presenting condition was reported.
- In more than half of all cases (16/28, 57%, 95 CI 38–74) cannabis was ingested in edible form and all of these cases involved children 12 years of age and younger.
- All nine cases involving children and youth aged 13 and older involved inhaled cannabis, primarily smoking as a route of administration (6/9, 67%, 95 CI 28–91).
- Consistent with data from previous years, many cases involved cannabis from unknown (19/28, 68%, 95 CI 48–83) or illegal (5/28, 18%, 95 CI 7–37) sources, as reported by the reporting physician. The reported source of cannabis was not verified.



### Treatment and outcomes

- All cases resulted in hospitalization (28/28, 100%): 21/28 cases (75%, 95 CI 55–88) were admitted as inpatients and 7/28 cases (25%, 95 CI 12–45) were admitted to a psychiatric bed.
- Physical treatment, such as intravenous fluids and patient monitoring, was received by 17/28 cases (61%, 95 CI 41–77). Fourteen cases (50%, 95 CI 32–68) received mental health treatment (e.g., psychiatry consultation, referral to a social, addiction or youth worker), either exclusively or in addition to physical treatment.

### Study limitations

Limitations common to all CPSP studies are listed on page 11.

## Conclusions

- Serious and life-threatening events associated with non-medical use of cannabis are occurring among children and youth in Canada, with 28 cases meeting the case definition in 2022. More than half of these cases involved ingestion of cannabis in edible form.
- The most common primary case presentation was poisoning/intoxication, exclusively in children 12 years and younger, and mostly involving cannabis in edible form. This trend continues to be monitored.
- The number of cases of psychosis in 2022 has increased from the previous year (fewer than five cases in 2021) and is now reportable at six cases. Twelve cases of psychosis have been reported since the study began. This trend continues to be monitored.
- More time is required to determine the impact of cannabis legalization and regulation on child and adolescent health. While most cases of serious and life-threatening events associated with non-medical use of cannabis were reported to have involved cannabis from unknown or illegal sources, legal edible cannabis products only became available for purchase in late December 2019, and awareness continues to be raised surrounding the distinction between legal and illegal cannabis.

## Anticipated study impact

- This study will provide Canadian-specific data on the impact of cannabis legalization and regulation on the health of children and youth. These data may be used to inform policies, legislation, and regulations related to cannabis used for non-medical purposes. To date, study results have contributed to the Canadian Paediatric Society's submission to the legislative review of the *Cannabis Act*.
- The information from this study may also be adapted to develop public education and awareness communication materials.

## Publication and dissemination

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High-potency cannabis products: How to address them with ease in paediatric clinical practice. Chadi N, Bélanger R. Canadian Paediatric Society Annual Conference, Montreal, in May 2022 (oral presentation)

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### **Acknowledgements**

Thank you to Sieara Plebon-Huff, Health Canada, for her involvement in the analysis of the data relating to this project and the writing of this preliminary report.

# Severe vaping-related illness and injury

Study duration: February 2021 to January 2022 – Final report



Nicholas Chadi

## Principal investigator

Nicholas Chadi, MD, MPH, Assistant Professor of Paediatrics, Division of Adolescent Medicine, Department of Paediatrics, CHU Sainte-Justine; [nicholas.chadi@umontreal.ca](mailto:nicholas.chadi@umontreal.ca)

## Co-investigators

Baker M, Bélanger R, Beno S, Brody D, Do MT, Fournier C, Grant C, Leslie K, Moore Hepburn C, Pike I, Richmond S, Tse SM, Tulloch T, Vyver E, Zysman-Colman Z

## Collaborators

Barrett G, Belzak L, Hardy J, Mischki T, Venugopal J

## ? Questions

- What is the minimum incidence of severe vaping-related illness or injury among children and youth?
- What are the clinical characteristics, product-level and substance-specific risk factors, comorbidities, and treatment outcomes of children and youth with severe vaping-related illness or injury?

## ! Importance

- According to the 2021 Canadian Tobacco and Nicotine Survey, 13% of adolescents 15 to 19 years of age reported vaping in the past 30 days, similar to the proportion reported in the 2019 and 2020 surveys.
- Gaining a better understanding of the specific risk factors and patterns of illness and injury related to vaping products is essential for the development of effective preventive and regulatory measures.

## ➔ Methodology

The complete protocol can be accessed at <https://cpsp.cps.ca/surveillance/study-etude/severe-vaping-related-illness-and-injury>.

### Case definition

Any patient less than 18 years of age (up to 18th birthday) requiring emergency department care, hospitalization, or admission to an intensive care unit (ICU) due to an illness or injury associated with any of the following:

1. Inhalation of aerosol from a vaping device (e.g., acute pulmonary injury, serious gastrointestinal symptoms, central nervous system activation/depression, acute nicotine toxicity or withdrawal)
2. Malfunction of a vaping device (e.g., burn, trauma to the eye, hand, and/or face)
3. Ingestion of a vaping substance (e.g., e-liquid with or without nicotine and/or flavours, tetrahydrocannabinol [THC] oil, hash oil)

Exposure to vaping devices/products/substances may be either **intentional** or **unintentional** and includes both primary (i.e., direct use/inhalation) and/or secondary exposures (i.e., exposure to another person's vaping aerosol or injury caused by another person using a vaping device).

Vaping devices include any type of electronic cigarette or similar device that aerosolizes a solid or liquid substance (vaping substance) which may contain some or all of the following: nicotine, cannabis, flavouring agents, and other chemicals.

### Unique to this study

- This study follows two previous Canadian Paediatric Surveillance Program (CPSP) one-time surveys on vaping-related illness and injury conducted in 2015 and 2019.
- Study investigators will cross-validate study findings with hospital discharge data obtained from the Canadian Institute for Health Information.





## Results – February 2021 to January 2022

**TABLE 1 – Severe vaping-related illness and injury cases from February 1, 2021 to January 31, 2022**

| Year              | Reported     | Duplicates | Excluded | Pending  | Met case definition <sup>‡</sup> |
|-------------------|--------------|------------|----------|----------|----------------------------------|
| 2021*             | <5           | 0          | 0        | 0        | <5                               |
| 2022 <sup>†</sup> | 0            | 0          | 0        | 0        | 0                                |
| <b>Total</b>      | <b>&lt;5</b> | <b>0</b>   | <b>0</b> | <b>0</b> | <b>&lt;5</b>                     |

\* February 1 to December 31, 2021

† January 1 to 31, 2022

‡ Due to Quebec legislation, any cases notified by Quebec participants were counted in the “Reported” column, but detailed case information was not collected and these cases were excluded from the data analysis, unless reported from a centre with project-specific research ethics board approval. Cases reported through the following centres were included in the data analysis for this report: CHU Sainte-Justine, Montreal Children’s Hospital, CHU de Sherbrooke.

### Cases that met the case definition

Fewer than five cases were verified as meeting the case definition in Canada from February 1, 2021, to January 31, 2022.

### Demographics

As per CPSP policy, case numbers and data for fewer than five cases cannot be presented.

### Presentation, diagnosis, treatment, and outcomes

Specific information on this study cannot be presented due to the small number of cases.

### Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- Cases of severe vaping-related illness or injury that might have presented to outpatient clinics or other non-hospital settings may not have been captured by this study. Similarly, vaping-related illnesses or injuries that did not meet the CPSP case definition of “severe” would also not be captured.



## Conclusions

- Very few cases of severe vaping-related injury or illness were reported during the one-year study period, contrasting with the 2015 and 2019 one-time CPSP surveys on vaping-related illness or injuries for which 35 and 88 cases were reported, respectively. Of note, these two previous surveys had slightly different case definitions and also included a small proportion of cases seen in outpatient settings.
- Initially planned for a two-year period, this CPSP study was closed at the end of January 2022 due to the very low number of reported cases after the first 12 months.
- Potential explanations for the lower-than-expected case numbers in this study may include an actual decrease in the incidence of vaping-related illness or injury, changes in provincial and federal vaping policies and regulations, increased monitoring and control of vaping products by resellers and manufacturers, and changes in access and use of vaping products by children and youth in the context of the COVID-19 pandemic.



## Anticipated study impact

- Given the rapidly evolving landscape of vaping products across the country and high rates of youth vaping, further research is needed to measure the acute and long-term impacts of vaping-related illness and injury among children and youth.
- Ongoing surveillance and research work by the study team, using other data sources, such as hospital discharge data and consumer safety reports, will allow for the continued collection of useful details on individual cases, including product-level and substance-related information, which even in low numbers, may help to inform ongoing changes in vaping-related policies and public health preventive measures.



## Publication and dissemination

Opportunities and challenges in capturing severe vaping-related injuries among children and youth. Chadi N, Richmond SA, Tulloch T, Grant CN, Venugopal J, Moore Hepburn C. *Prev Med Rep* 2023. doi: 10.1016/j.pmedr.2023.102186

# One-Time Surveys

## Button battery ingestions

August 2022



Alexandra Hudson

### Principal investigators

Matthew Carroll, MHSc, BSc, BMed, FRACP, Paediatric Gastroenterologist, Division of GI & Nutrition, Stollery Children's Hospital, Associate Professor, Department of Paediatrics, Faculty of Medicine & Dentistry, University of Alberta; mcarroll@ualberta.ca

Alexandra Hudson, MD, FRCPC, PGY5 Paediatric Gastroenterology Subspecialty Resident, University of Alberta; ashudson@ualberta.ca

### ? Question

What type of button battery ingestions have paediatricians and paediatric subspecialists in Canada observed, what treatment strategies did they employ, and what were the resulting complications?

### ! Importance

- Button battery ingestions pose a serious threat to child and youth health, and have been increasing over time.
- The size and power of button batteries have also increased, which has led to increased morbidity and mortality. Tissue damage has been shown to occur in as little as 15 minutes.
- In the United States, the rate of button battery ingestions has increased 60-fold from 1995 to 2015, with a corresponding 10-fold increase in complications.<sup>1</sup> Little is known about button battery ingestions in Canada.

### ↪ Methodology

A one-time survey was sent to paediatricians and paediatric subspecialists through the Canadian Paediatric Surveillance Program (CPSP). The survey tool can be accessed at [https://cpsp.cps.ca/uploads/surveys/Button\\_battery\\_ingestions\\_survey\\_Aug\\_29\\_2022\\_Final.pdf](https://cpsp.cps.ca/uploads/surveys/Button_battery_ingestions_survey_Aug_29_2022_Final.pdf).

### ✓ Results

The survey response rate was 39% (1067/2716). Of the 1067 survey respondents, 299 (28%) reported having observed or been involved in one or more cases of children ingesting button batteries in the previous 12 months.

#### Respondent demographics

Of the physicians who reported having seen one or more button battery ingestions, 145/299 (48%) indicated their area of practice, with 32% (46/145) being general paediatricians and 68% (99/145) being paediatric subspecialists.

#### Button battery guideline knowledge

- Of all the respondents who replied about their awareness of specific guidelines directing the care of children and youth following button battery ingestions, few were aware of guidelines for the administration of honey (189/721, 26%) or sucralfate (118/721, 16%).
- Just over two-thirds of the respondents knew about button battery removal recommendations (493/721, 68%).

1. Litovitz T, Whitaker N, Clark L, White NC, Marsolek M. Emerging battery-ingestion hazard: clinical implications. *Pediatrics* 2010;125:1168–77

### Button battery ingestion cases

- Of the 299 respondents who reported having observed or being involved in a button battery ingestion case in the previous 12 months, 815 cases of ingestions were reported. Patient case details were provided for 133 of these 815 cases.
- The most affected age group was children between 1 to 2 years of age (60/128, 47%).
- The most common presenting symptoms were dysphagia (23/133, 17%), coughing (13/133, 10%), and pain (13/133, 10%).
- Just over half of the button battery ingestions were witnessed (73/133, 55%).
- Over half of the time (73/131, 56%), it was unknown how the child got the button battery. If known, the battery was most often found on the ground or laying around (34/131, 26%), or obtained from inside a household product such as a car key fob (13/131, 10%).

### Complications

- Endoscopic removal of the button battery was required in 77 patients (77/131, 59%).
- Esophageal burns (32/133, 24%) and gastric burns (6/133, 5%) were the most common injuries.
- The most common long-term complication was an esophageal stricture (11/111, 10%).

### Survey limitations

- Limitations common to all CPSP surveys are listed on page 11.
- The survey asked about button battery ingestions seen in the previous 12 months, so there is a potential for recall bias.
- Multiple specialists are likely involved in the management of button battery ingestion cases and the reporting of duplicate cases cannot be ruled out (i.e., more than one responding physician may have reported the same case).
- This survey did not capture the experience of all physicians (e.g., otolaryngologists, general surgeons, and others who are not included in the CPSP).



## Conclusions

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- Nearly half of the button battery ingestions reported in this survey were not witnessed, highlighting the importance of a high degree of suspicion, even in the absence of a positive history.
- There should be a low threshold to obtain x-ray imaging in young children with airway or chest/abdominal symptoms, given that in almost half of the cases, there was no indication that a foreign body had been swallowed (e.g., caregivers did not witness an ingestion, the patient didn't tell their caregiver about the ingestion).
- Prevention efforts should continue to be aimed at safe battery storage and disposal, given that finding a loose battery was the most commonly reported way in which the children accessed the button battery, and most of the time the source of the battery was unknown.
- There is a need for increased dissemination of available button battery ingestion guidelines, since modifiable patient factors, such as honey and/or sucralose administration while awaiting definitive treatment, can improve patient outcomes.



## Anticipated survey impact

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- This survey can help inform advocacy efforts for improved button battery packaging, storage, and disposal safety.
- This survey can inform paediatric training programs and continuing medical education programs about the need to distribute existing button battery ingestion guidelines among paediatricians.

# Home-based phototherapy

November 2022



Karissa Holyer

## Principal investigators

Karissa Holyer, MD, Department of Paediatrics, Western University; karissa.holyer@lhsc.on.ca

Farah Abdulsatar, MD, FRCPC, FAAP, Department of Paediatrics, Western University;  
farah.abdulsatar@lhsc.on.ca

## Co-investigators

Millar D, Miller MR, Sgro M, Taheri S

## ? Questions

- In the past 12 months, have paediatricians and paediatric subspecialists in Canada seen patients with adverse events associated with home-based phototherapy?
- What are the risk factors associated with these adverse events?

## ! Importance

- Home phototherapy for the treatment of neonatal unconjugated hyperbilirubinemia is gaining popularity, with new studies reporting its feasibility and effectiveness.
- Studies have not identified significant adverse safety outcomes; however, sample sizes have been small in these studies.
- Home phototherapy provision is varied across Canada with no overarching guidelines for administration and monitoring.

## ↻ Methodology

A one-time survey was sent to paediatricians and paediatric subspecialists through the Canadian Paediatric Surveillance Program (CPSP). The survey tool can be accessed at [https://cpsp.cps.ca/uploads/surveys/Home\\_Phototherapy\\_Survey\\_FINAL.pdf](https://cpsp.cps.ca/uploads/surveys/Home_Phototherapy_Survey_FINAL.pdf).

## ✓ Results

The survey response rate was 31% (844/2741). Of these respondents, 62% (495/800) said they provided care for neonates with unconjugated hyperbilirubinemia and these surveys were included in the data analysis. The remaining 44 respondents did not indicate if they provided care for neonates with unconjugated hyperbilirubinemia.

### Adverse events associated with home phototherapy

- Twenty-eight cases of adverse events associated with home phototherapy were reported by 15 respondents, with a mean of 2.13 cases (SD 1.96) per respondent.
- The type of adverse event was reported in 20/28 (71%) cases, with the vast majority (19/20, 95%) being admissions/readmissions to hospital for inpatient phototherapy.
- There were no cases of serious adverse events including acute bilirubin encephalopathy, or of neonates requiring intravenous immunoglobulin (IVIg) or exchange transfusion.
- In the 15 cases with a reported outcome, there were no anticipated permanent sequelae due to the adverse event.
- Of the 12% (57/493) of respondents who said home phototherapy was offered at their centres, 18% (10/57) reported one or more cases of adverse events.

### Risk factors for adverse events

- Risk factors were identified in 67% (14/21) of cases of adverse events associated with home phototherapy. In seven cases, the respondent indicated that there were no risk factors for the adverse events.
- The majority of the risk factors identified were infant-related (e.g., significant weight loss over 15% of birth weight, direct antibody test positivity) (8/14, 57%).
- Provider/system factors (e.g., lack of, or incomplete, risk factor screening, inappropriately delayed scheduled follow up) and family factors (e.g., poor treatment compliance, parent delayed follow up) were each identified in fewer than five cases.

### Status of home phototherapy in Canada

- Home-based phototherapy was offered at the centres of 12% (57/493) of respondents who provide care for newborns with unconjugated hyperbilirubinemia. The practice settings in those communities were reported as 60% (34/57) urban, 16% (9/57) suburban, and 14% (8/57) rural/remote, with the remainder reporting more than one practice setting.
- Among respondents who had home phototherapy available at their centres, 63% (35/56) said they had formalized protocols to assess patient appropriateness for home-based phototherapy and 86% (48/56) had a formal process or protocol to ensure appropriate patient follow up.
- Respondents said that their home phototherapy programs offered the following types of on-call support for parents/caregivers: 43% (24/56) of respondents said there was 24/7 support, 21% (12/56) said there was part-time support (e.g., during regular business hours Monday to Friday), and 16% (9/56) said there was no on-call support available. The remainder of respondents did not know if on-call support was available.

### Survey limitations

- Limitations common to all CPSP surveys are listed on page 11.
- Risk factors associated with these adverse events were based on the respondent's evaluation of the case.
- Further analysis of data is ongoing and, as such, some results may change.
- The reporting of duplicate cases cannot be ruled out (i.e., more than one respondent may have reported the same case).



## Conclusions

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- Fifteen paediatricians and paediatric subspecialists from across Canada reported 28 patients with adverse events associated with home phototherapy for unconjugated hyperbilirubinemia in the previous 12 months.
- Almost all of the adverse events reported were admission/readmission for inpatient phototherapy and there were no cases of severe adverse events.
- None of the cases of adverse events associated with home phototherapy were predicted to have permanent sequelae.
- The most common risk factors for adverse events were infant-related.
- Home phototherapy is available across Canada with variable implementation of features that may promote patient safety including on-call support for parents/caregivers and formalized protocols to ensure appropriate patient selection and follow-up.



## Anticipated survey impact

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- The results of this survey indicate that home phototherapy administration varies greatly as does on-call support for parents indicating the need to develop national standardized guidelines.
- Survey results may support home phototherapy as a safe alternative to inpatient phototherapy for low-risk infants with neonatal unconjugated hyperbilirubinemia.

### Acknowledgements

We wish to acknowledge the CPSP for providing survey funding through the Resident Surveillance Grant.

# Potential adverse events among breastfeeding infants exposed to maternal cannabis use

January 2022



Shamini Selvakumar

## Principal investigators

Shamini Selvakumar, MD, Department of Paediatrics, McMaster University; [selvaks@mcmaster.ca](mailto:selvaks@mcmaster.ca)

Lucia Giglia, MD, Department of Paediatrics, McMaster University; [gigliam@mcmaster.ca](mailto:gigliam@mcmaster.ca)

## Co-investigators

Dann M, Fang L, Grant C, Lowe AM, Moore Hepburn C, Raha S, Shea A, Thabane L, Walker O, Williams C

## Questions

- What adverse events are paediatricians in Canada seeing in neonates or infants exposed to cannabis through breastmilk, and what are the associated investigations and outcomes?
- Are paediatricians screening for maternal cannabis use in breastfeeding mothers and are they aware of institutional policies on the use of breastmilk when the mother is known to use cannabis?

## Importance

- The impact of cannabis exposure through maternal breastmilk on infants and neonates is unclear due to limited research and conflicting results.
- Given the paucity of data, this survey was designed to assesses if adverse events have been observed by paediatricians in Canada.

## Methodology

A one-time survey was sent to paediatricians and paediatric subspecialists through the Canadian Paediatric Surveillance Program (CPSP). The survey tool can be accessed at <https://cpsp.cps.ca/uploads/surveys/Survey-Cannabis-and-breastfeeding.pdf>.

## Results

The survey was sent to 2779 paediatricians and paediatric subspecialists and 1008 responded, for a 36% response rate. Paediatricians who reported that they do not provide care to breastfeeding infants were excluded (n=207), and the remaining responses from paediatricians who provide care to infants (n=801) were included in the data analysis.

### Respondent demographics

- Of the respondents who provide care to infants, general paediatricians comprised 60% (484/801) of respondents, while 34% (275/801) were subspecialists, and 5% (42/801) did not identify their specialty.
- The top three subspecialties that participated in the survey were neonatologists, paediatric emergency medicine physicians, and paediatric endocrinologists.

### Institutional policies and screening frequency

- Only 8% (62/801) of respondents reported that their institution has a policy on the use of breastmilk when the mother is known to use cannabis, while 44% (349/801) reported that their institution does not have a policy. The remaining respondents were uncertain 48% (387/801) or did not provide a response (n=3).
- Just 13% (105/801) of respondents reported always screening for cannabis use among mothers who are breastfeeding or providing breastmilk. More than half of respondents (481/801, 60%) reported never or rarely screening breastfeeding mothers for cannabis use. Over a quarter of the respondents reported that they sometimes screen (210/801, 26%). The remaining respondents did not provide a response (n=5).

### Adverse events

- Adverse events were uncommon, with 2% (18/801) of respondents reporting having cared for a breastfed infant with an adverse event that was, or may have been, associated with exposure to cannabis through breastmilk in the previous 12 months.

- From these 18 respondents, 23 infants were reported with confirmed or suspected adverse events associated with exposure to cannabis through breastmilk.
- The most frequently reported types of adverse events were poor feeding (n=12), irritability (n=11), tremors (n=11), somnolence (n=7), and poor weight gain (n=6), with apnea, bradycardia, and accidental trauma being less frequently observed. Some infants had more than one type of adverse event.
- Of the reported cases, 10 infants were also exposed to one or more of the following substances in addition to cannabis: selective serotonin reuptake inhibitors, alcohol, opioids, or stimulants.
- In 13 of the reported cases, there was a history of maternal cannabis use during pregnancy as well.

#### **Investigations and outcomes**

- Glucose (n=9), electrolytes (n=6), newborn urine toxicology (n=6), and head ultrasound (n=5) were the most frequently completed investigations to exclude other possible explanations for newborn symptoms.
- For most of the cases of adverse events, symptoms resolved without intervention. Some cases required cessation of maternal cannabis use or changing to formula/donor milk.

#### **Survey limitations**

- Limitations common to all CPSP surveys are listed on page 11.
- Adverse events secondary to the use of cannabis and other substances reported in this survey are considered to be “suspected,” as a definite causal association often cannot be determined.
- As this survey examined adverse events that occurred in the previous year, the results are susceptible to recall bias.
- The reporting of duplicate cases cannot be ruled out (i.e., more than one respondent may have reported the same case).

## **Conclusions**

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- Eighteen paediatricians and paediatric subspecialists from across Canada reported a total of 23 infants with confirmed or suspected adverse events associated with exposure to cannabis through breastmilk in the previous 12 months.
- The most common adverse events reported were poor feeding, irritability, and tremors.
- Most symptoms resolved without intervention.
- More than half of respondents who care for breastfed infants, never or rarely screen for cannabis use among mothers who are breastfeeding.
- Less than 10% of respondents reported that there was an institutional policy at their place of practice regarding the use of breastmilk when the mother is known to use cannabis.

## **Anticipated survey impact**

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- This study describes suspected adverse events among infants exposed to cannabis through breastmilk that have been observed by paediatricians in Canada.
- Data from this survey may be used to encourage the development and implementation of practice guidelines and hospital policies, and inform future research regarding the screening and management of infants exposed to the breastmilk of mothers who use cannabis.



# Severe/life-threatening opioid, stimulant, or sedative use

March 2022



Matthew Carwana

## Principal investigators

Matthew Carwana, MD, MPH, Clinical Assistant Professor, University of British Columbia Department of Paediatrics, Paediatrician, BC Children's Hospital; matthew.carwana@cw.bc.ca

Nicholas Chadi, MD, MPH, Clinical Assistant Professor of Paediatrics, Université de Montréal, Division of Adolescent Medicine, Department of Paediatrics, CHU Sainte-Justine; nicholas.chadi@umontreal.ca

Eva Moore, MD, MSPH, Associate Professor of Paediatrics, Division of Adolescent Health and Medicine, Department of Paediatrics, University of British Columbia; eva.moore@cw.bc.ca

## Co-investigators

Bélanger RE, Citron S, Grant C, Samji H, Shariati H

## ? Questions

- What is the minimum incidence of children and youth with severe/life-threatening opioid, stimulant, or sedative exposure presenting to paediatricians and paediatric subspecialists in Canada?
- What are the treatment and services available for youth presenting with substance use to paediatric care in Canada?

## ! Importance

- Illicit drug overdose is a public health emergency in Canada. An increasing number of children and youth in Canada suffer from severe, life-threatening overdose; it is now the leading cause of death in children and youth 10 to 18 years of age in Western Canada.<sup>1</sup>
- Data from the Public Health Agency of Canada suggests that approximately 2% of overdose deaths and 5% of overdose hospitalizations in Canada occur in children and youth 19 years of age and under.<sup>2</sup>
- Epidemiologic data related to this population, including treatment availability for children and youth with severe substance use disorders, remains limited.

## ↪ Methodology

A one-time survey was sent to paediatricians and paediatric subspecialists through the Canadian Paediatric Surveillance Program (CPSP). The survey tool can be accessed at <https://cpsp.cps.ca/uploads/surveys/Survey-Severe-life-threatening-opioid-stimulant-or-sedative-use.pdf>.

## ✓ Results

A total of 1027/2791 respondents completed the survey, for a response rate of 37%. A large majority of survey respondents 934/1027 (91%) reported providing care to children and youth 12 years of age and older.

### Availability of overdose-related services

- Among respondents caring for children and youth 12 years of age and above, 296/934 (32%) answered questions about overdose-related service availability in their communities.
- The majority of respondents reported that their communities had overdose-related services for outpatient mental health for patients 12 to 15 years of age (251/296, 85%) and for 16- to 18-year-olds (248/296, 84%).

1. Federal, Provincial, and Territorial Special Advisory Committee on the Epidemic of Opioid Overdoses. *Opioid- and Stimulant-related Harms in Canada*. Ottawa: Public Health Agency of Canada; December 2022. Chapter: Apparent Opioid and Stimulant Toxicity Deaths January 2016 to June 2020. Available from: <https://health-infobase.canada.ca/substance-related-harms/opioids-stimulants/>
2. Federal, Provincial, and Territorial Special Advisory Committee on the Epidemic of Opioid Overdoses. *Opioid- and Stimulant-related Harms in Canada*. Ottawa: Public Health Agency of Canada; December 2022. Chapter: Opioid and Stimulant Poisoning Hospitalizations January 2016 to June 2020. Available from: <https://health-infobase.canada.ca/substance-related-harms/opioids-stimulants/>

- For all other surveyed overdose-related services, including inpatient stabilization and intensive outpatient management programs, respondent awareness of service availability was low to moderate (25–53%).

### Respondent demographics

- Fourteen percent (128/934) of responding paediatricians who provide care to patients 12 years of age and older reported having cared for at least one child or youth with severe or life-threatening overdose in the previous 24 months.
- Of these paediatric providers, most practised in urban settings (108/128, 84%), but there were cases reported in suburban (12/128, 9%) and rural/remote (7/128, 6%) environments as well. In the remaining case, no response was provided (1/128, 1%).
- The majority (93/128, 73%) of respondents who cared for a case worked in academic settings, while a quarter worked in community/non-academic settings (33/128, 26%). In the remaining cases, no response was provided (2/128, 2%).

### Severe or life-threatening opioid, stimulant, or sedative use cases

- The 128 respondents who cared for cases of severe/life-threatening substance use in the previous 24 months, reported having seen at least 636 cases.
- Stimulant overdose was the most commonly reported type with 187 cases, followed by sedative overdose (n=180), opioid overdose (n=171), and opioid use requiring pharmacotherapy (n=98).
- Of the respondents who had seen a case, the majority (76/128, 59%) reported providing care to patients with sedative overdose in the past 24 months. Of those, 46/76 (61%) saw 1 to 2 cases, 18/76 (24%) saw 3 to 5 cases, 10/76 (13%) saw 6 to 9 cases, 2/76 (3%) saw 10 to 19 cases, and none (0/76, 0%) saw 20 or more cases.
- A similar number of respondents (74/128, 58%) reported providing care to patients with stimulant overdose in the past 24 months. Of those, 43/74 (58%) saw 1 to 2 cases, 26/74 (35%) saw 3 to 5 cases, 1/74 (1%) saw 6 to 9 cases, 2/74 (3%) saw 10 to 19 cases, and 2/74 (3%) saw 20 or more cases.
- Half of respondents (65/128, 51%) reported providing care to patients with opioid overdose in the past 24 months. Of those, 36/65 (55%) saw 1 to 2 cases, 19/65 (29%) saw 3 to 5 cases, 8/65 (12%) saw 6 to 9 cases, 1/65 (2%) saw 10 to 19 cases, and 1/65 (2%) saw 20 or more cases.
- Over one-third of respondents (48/128, 38%) reported providing care to patients requiring medication assisted treatment for opioid use in the past 24 months. Of those, 31/48 (65%) saw 1 to 2 cases, 13/48 (27%) saw 3 to 5 cases, 3/48 (6%) saw 6 to 9 cases, 1/48 (2%) saw 10 to 19 cases, and none (0/48, 0%) saw 20 or more cases.

### Survey limitations

- Limitations common to all CPSP surveys are listed on page 11.
- Children and youth who did not seek paediatric care after an overdose, and youth who received care from adult health services, were not captured in this survey.
- The reporting of duplicate cases cannot be ruled out (i.e., more than one respondent may have reported the same case).

## Conclusions

- Paediatricians and paediatric subspecialists interface significantly with children and youth with severe/life-threatening substance use and overdose.
- The number of cases of severe/life-threatening substance use and overdose reported among children and youth 12 to 18 years of age is significant and concerning at the population level, particularly because this data does not include children and youth who did not seek paediatric care after an overdose, and those who received care from a non-paediatric provider.
- Apart from mental health services, paediatric providers have limited awareness of service availability for children and youth who use substances.

## Anticipated survey impact

- This survey provides the first evidence of the number of paediatric providers in Canada who are seeing cases of severe/life-threatening substance use in their practices.
- Given the high number of severe substance use-related presentations revealed in this survey, a multi-year CPSP study on this topic will take place in the upcoming years to better characterize this issue.
- Data from this survey may help to inform the development of preventive and treatment interventions for children and youth with severe substance use disorders.
- This survey highlights the need to increase paediatricians' training and level of comfort in the identification and management of severe substance use presentations.

### Acknowledgements

The investigators thank the BC Children's Hospital Research Institute Clinical Research Support Unit for funding that supported a research assistant for data cleaning and analysis.

# Publications 2019–2022

## Peer-reviewed papers related to studies and one-time surveys

(For a complete list with hyperlinks, see [www.cpsp.cps.ca/publications/published-papers-related-to-studies-and-one-time-surveys](http://www.cpsp.cps.ca/publications/published-papers-related-to-studies-and-one-time-surveys).)

### Acute flaccid paralysis

Acute flaccid myelitis in Canada, 2018 to 2019. Dickson C, Ho Mi Fane B, Squires SG. *Can Commun Dis Rep* 2020 Oct 1;46(10):349–53. doi: 10.14745/ccdr.v46i10a07

### Adrenal suppression

Screening practices for paediatric asymptomatic adrenal suppression in Canada: Are we addressing this important risk? Goldbloom EB, Ahmet A. *Paediatr Child Health* 2020 Oct;25(6):389–93. doi: 10.1093/pch/pxy174. Epub 2019 Mar 30

### All-terrain vehicle safety

All-terrain vehicle serious injuries and death in children and youth: A national survey of Canadian paediatricians. Gill PJ, McLaughlin T, Rosenfield D, Moore Hepburn C, Yanchar NL, Beno S. *Paediatr Child Health* 2019 Feb;24(1):e13–8. doi: 10.1093/pch/pxy059. Epub 2018 Jun 18

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## **CPSP Highlights published in *Paediatrics & Child Health***

(For a complete list with hyperlinks, see [www.cpsp.cps.ca/publications/cpsp-highlights](http://www.cpsp.cps.ca/publications/cpsp-highlights).)

### **Anorexia nervosa and COVID-19**

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### **Micronutrient deficiencies and autism spectrum disorder**

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### **Self-harm**

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# Presentations in 2022

((For a complete list with hyperlinks, see [www.cpsp.cps.ca/publications/presentations](http://www.cpsp.cps.ca/publications/presentations).)

## **5q spinal muscular atrophy**

5q spinal muscular atrophy Canadian Paediatric Surveillance Program 2020–2021 results. Price T, Hodgkinson V, Innes M, Korngut L, Parboosingh J, Mah JK. Canadian Neurological Sciences Federation's Congress, Montreal, in June (poster)

## **Cannabis use**

High-potency cannabis products: How to address them with ease in paediatric clinical practice. Chadi N, Bélanger R. Canadian Paediatric Society Annual Conference, Montreal, in May (oral)

## **COVID-19**

Clinical manifestations and disease severity of SARS-CoV-2 infection among infants in Canada. Piché-Renaud PP. Canadian Paediatric Society Annual Conference, Montreal, in May (poster)

Risk factors for severe COVID-19 in hospitalized Canadian children: A national prospective study. Farrar DS. 40th Annual Meeting of the European Society of Paediatric Infectious Diseases meeting, virtually and in Athens, Greece, in May (oral)

Risk factors for severe COVID-19 in hospitalized children in Canada: A national prospective study from March 2020–May 2021. Farrar DS. Canadian Paediatric Society Annual Conference, Montreal, in May (poster)

## **First-time hospitalizations for anorexia nervosa during the COVID-19 pandemic**

The surge in eating disorders: What does the hospital paediatrician need to know? Vyver E, Grisé M. Canadian Paediatric Society Annual Conference, Montreal, in May (oral)

## **Identifying child maltreatment in virtual medical appointments**

Identifying child maltreatment in virtual medical appointments – What are we missing? Lim-Reinders S. Canadian Paediatric Society Annual Conference, Montreal, in May (poster)

## **Micronutrient deficiencies and autism spectrum disorder**

Food intake as a vital sign for autistic children. Smile S, Kinlin LM. Canadian Paediatric Society Annual Conference, Montreal, in May (seminar)





# Canadian Paediatric Surveillance Program

## New Study and One-Time Survey Opportunities

### The opportunity

- Benefit from the CPSP's well-established, timely, cost-effective, and internationally recognized surveillance platform.
- The CPSP is effective at monitoring low-frequency, high-impact diseases and conditions encountered by general paediatricians and paediatric subspecialists.

### Track record

- The average monthly response rate from approximately 2,800 paediatricians is 80%.
- The average detailed questionnaire response rate varies between 80% to 90%.

### Themes of interest

Including examples of successful CPSP studies

- Rare diseases (including genetic, metabolic, or rare acquired conditions)
  - Congenital myotonic dystrophy
  - Medium-chain acyl-coenzyme A dehydrogenase deficiency
- Rare complications of more common diseases
  - Adrenal suppression with glucocorticoid therapy
  - Serious adverse events associated with complementary and alternative medicine
- Emerging infections
  - COVID-19
  - Lyme disease
- Threats to public health and safety
  - Vaping
  - Neonatal abstinence syndrome
  - Serious/life-threatening use of opioids, stimulants, and sedatives

### Study success factors

- A disease or condition with an incidence of less than 500 cases per year
- A multidisciplinary study team, with national representation
- Local champions who encourage study reporting at their institutions

### Study impact

**Knowledge translation:** Studies have been published in high-impact, peer-reviewed journals; the CPSP is well known and recognized by prominent editorial boards.

**Public health policies and legislation:** Results have informed the total ban on baby walkers and the promotion of booster seats to prevent lap-belt syndrome.

**Professional medical guidelines:** Results have informed guidelines such as the Canadian Paediatric Society position statements on neonatal hyperbilirubinemia and medical assistance in dying.

**Public health promotion and education:** Results have informed efforts to prevent vitamin D deficiency rickets and the use of e-cigarettes in those under the legal age to use conventional tobacco products.

*“As the Paediatric Chairs of Canada representative to the CPSP Scientific Steering Committee, I have witnessed the extraordinary ability of the CPSP to bring together study investigators from across paediatric disciplines and across Canada in the study of rare paediatric diseases. For conditions that are high in disability, morbidity, mortality, and economic costs to society, despite their low frequency, national surveillance to capture case-level data is essential. On behalf of the Scientific Steering Committee, I would like to extend a sincere thank you to the thousands of CPSP participants who contribute to the Program. We are truly fortunate to have such a robust paediatric surveillance program in Canada.”*

Ciarán M. Duffy, MB, BCh, MSc, FRCP, FRCP; Professor, Department of Paediatrics, Faculty of Medicine, University of Ottawa; Past CPSP Steering Committee representative, Paediatric Chairs of Canada



For more information, please call us at 613-526-9397 ext. 239, email [cpssp@cps.ca](mailto:cpssp@cps.ca), or visit [www.cpssp.cps.ca](http://www.cpssp.cps.ca)







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

**Canadian Paediatric Society**

Manager, Surveillance  
2305 St. Laurent Blvd., Suite 100  
Ottawa ON K1G 4J8

Tel.: 613-526-9397, ext. 239

Fax: 613-526-3332

[cpssp@cps.ca](mailto:cpssp@cps.ca)

[www.cpssp.cps.ca](http://www.cpssp.cps.ca)

