



CANADIAN PAEDIATRIC SOCIETY

CPS news



Spring 2014

CPS statement draws attention to need for improved child death review

Alberta Human Services Minister Manmeet Bhullar said in January that the province would change reporting rules and examine options for the review of all child deaths in Alberta. This announcement was made at the province's Roundtable on Death and Serious Injury in Children.

Dr. Jennifer MacPherson, a Calgary paediatrician, was presenting the CPS statement on child and youth death review during this event; she believes evidence cited in the statement may have had an impact on Alberta's decision to examine its death review system.

"The statement makes a compelling argument for ... a formal death review system," said Dr. MacPherson. "It cites other countries and explains that Canada should also be meeting a standard."

Dr. MacPherson sees Alberta's commitment as progress, but hopes other provinces and territories follow suit, and that Canada eventually has a nationwide standardized system.

Unintentional injuries are the leading cause of death in Canadian children and youth, but only a few provinces have formal child death review systems. Each is independent and operates differently, limiting how much regions can learn from one another. More importantly, lack of standardized data

“With a mandate and data easily available, systematic review is a tool for prevention.”

Dr. Jennifer MacPherson

makes it difficult to implement effective prevention and intervention strategies.

"With no systematic review, it's just a shot in the dark," said Dr. MacPherson. "With a mandate and data easily available, systematic review is a tool for prevention."

The CPS statement calls for a formal, standardized child death review system for every region in Canada to fill this information void. Recommendations include:

- Broad representation including: a regional chief medical examiner or coroner; representatives from law enforcement, child protective services, local public health; a crown attorney; a paediatrician, family physician and/or other health care provider.
- Structured processes for reporting trends.
- Linkable databases to allow meaningful data collection.

- A mechanism to report effectiveness of child death review follow-up and recommendations.
- Designated financial support by all levels of government.

Dr. Natalie Yanchar, co-author of the statement, envisions a nationwide system that would allow stakeholders from multiple disciplines and agencies to share information and learn from each other. This process would ideally lead to policies that prevent deaths and improve the overall health and safety of children and youth.

"We want to compare what's going on across the country, but more importantly, learn from each other to see what works—[and] we can't," said Dr. Yanchar. "[With a standardized, national system], you're going to be looking at the underlying causes. You can then identify the causes, ... determine the intervention and bring in the intervention that will reduce the risk." 🌱

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Long-time CPS member encourages physician advocacy: “Give that little bit extra for better care”

Dr. Barry Adams has been a CPS member for nearly 50 years. He has served on the board, including a term as president, and was instrumental in establishing the Canadian Paediatric Foundation, now known as Healthy Generations. Now at age 80, as he looks forward to retirement, Dr. Adams hopes to have more free time to dedicate to the CPS.

“The bringing together of people that dedicate their time for the benefit and the advocacy of children...these are things that you admire about the Society,” he said in a recent interview. “The feeling that you’ve been part of that is very rewarding.”

In addition to his CPS contributions, Dr. Adams has been a community paediatrician in Ottawa for 47 years.

“It’s a good career...Children are very versatile,” he said. “Though they get ill quite quickly, they get better quite quickly too. That’s a benefit of the practice: you see them improve overnight sometimes.”

Throughout his career, Dr. Adams has seen many changes to the field of medicine. The positives include the elimination or dramatic reduction of diseases, thanks to increased vaccination. The negatives include an

increase in patients struggling with behavioural or social issues—an advocacy issue he has become particularly concerned about over the years.

Being a father and grandfather has also been a great learning experience, said Dr. Adams.

He and his wife Betty Anne have seven children (three of whom work in the health care field), 19 grandchildren and one great granddaughter.

“When parents ask me about my family... I tell them I learned my paediatrics at home,” said Dr. Adams.

As paediatric medicine continues to change, Dr. Adams hopes to see more paediatricians become involved in the CPS and become advocates. It’s rewarding work, he said, and essential for health professionals to strive for better health care for all kids, not just their own patients.

“As well as doing your necessary clinical work, you also need to spend some time in advocacy for better child care across the country,” he said. “You can do that by being involved in different areas, in your community or provincially, but you have to give a little more than what you do in your everyday office or hospital practice and give that little bit extra for better care and better lives for children.” 🌱

POSITIONS AVAILABLE



EXECUTIVE DIRECTOR MEDICAL EDUCATION DIRECTOR

Friends Without A Border, the founder of Angkor Hospital for Children in Siem Reap, Cambodia, is in the process of founding Lao Friends Hospital for Children in Luang Prabang, Laos.

The ED will design programs for LFHC, hire and train medical personnel, and assist the procurement of medical needs. Once opened, the ED will be responsible for managing daily operations, oversight of educational programs, grant writing and management, and budget planning and monitoring.

A long-term commitment required.

The MED will primarily plan and implement the clinical and didactic education of the physicians and nurses, create curriculums for medical training, and coordinate teaching volunteers. Minimum 3 month commitment required.

This is an opportunity to be in on the creation of a pediatric teaching hospital that will significantly improve the quality of medical care throughout the country. Visit www.fwab.org for more information. Send CV with cover letter to hr@fwab.org.

CPS advocates bike helmets for all cyclists

Bicycle helmets reduce the risk of head injuries and should be legislated for all ages across Canada, said the Canadian Paediatric Society in a recent position statement. However, only 4 of 13 Canadian provinces and territories meet the CPS recommendations: British Columbia, Nova Scotia, New Brunswick and Prince Edward Island.

“Bicycle helmets reduce the risk of head and brain injuries significantly, and studies show that legislation increases the use of helmets,” said Dr. Brent Hagel, statement co-author and member of the Injury Prevention Committee.

Cycling is the leading cause of sport and recreational injury in children and adolescents, accounting for four per cent of all injuries seen in the emergency department and seven per cent of all hospital admissions for unintentional injury. Head injuries are among the most severe injuries, often with devastating consequences.

“Everyone is at risk for head injury, regardless of age group,” said Dr. Hagel, an injury prevention epidemiologist and associate professor at the University of Calgary. “Children see adults and often adopt similar behaviours, so if we can get helmets on adults then children and adolescents will be more likely to wear them too.”

In addition to helmet legislation, the CPS is calling for public education programs and bicycle-friendly city planning. Paediatricians should inform patients of the importance of bicycle helmets and advocate for their use.

For more information about the importance of bike helmets that you can print and share with families, visit www.caringforkids.cps.ca. 🌱

Dr. John Godel: Mentor, advocate and leader in Northern and International paediatrics

Dr. John Godel, a Professor Emeritus in the Department of Pediatrics at the University of Alberta, was a true CPS leader, having played pivotal roles in the International Child Health Section and the First Nations, Inuit, and Métis Health Committee. Dr. Godel passed away in March 2014 after a sudden illness.

Dr. Godel spent two years of his career teaching at the University of Lagos in Nigeria, five years as Chief of Pediatrics at a Tunisian hospital and was involved with several sub-Saharan Africa projects. One of these projects was Healthy Child Uganda, a partnership between the CPS and Ugandan and Canadian universities, which works to improve child health in rural southwestern Uganda.

“John’s own vision of better health for children in rural Uganda was the spark that initiated our Healthy Child Uganda partnership. His personal commitment inspired others to join the cause. John’s passion and love for children and their families was contagious and has been instrumental to our success,” said Dr. Jenn Brenner, a Calgary paediatrician and the Canadian Director for Healthy Child Uganda.

Even after he retired in 1997, Dr. Godel continued his international work with Healthy Child Uganda.

Other notable career achievements included Dr. Godel’s findings about vitamin D and his advocacy for it to be used as protection from a host of health conditions.



Dr. John Godel in Uganda.

He also contributed significantly to the CPS as a statement author and committee member, including 20 years as a member of the First Nations, Inuit and Métis Health Committee.

Dr. Sam Wong, current First Nations, Inuit and Métis Health Committee chair, credits Dr. Godel for inspiring his career focus.

As a young trainee in 1997, he remembers watching Dr. Godel diagnose a case of Blount’s disease in Tuktoyaktuk, Nunavut, using only a stethoscope and X-ray machines from the 1950s—the only tools that were available in the community.

It was an experience that left a lasting impression on Dr. Wong, and encouraged him to pursue a career focused on Aboriginal health.

“He is the primary reason I’m doing what I’m doing now with Aboriginal and Northern health. [He was] truly an amazing man,” said Dr. Wong. 🌱

Welcome, new members

The Canadian Paediatric Society welcomes the following new members, who joined or rejoined in 2013. The CPS also welcomes all first-year paediatric residents in Canada, who receive complimentary membership.

American Academy Members

Lisa Gelman, Toronto, Ont.

Associate Health Professional

Elise Larouche, Terrebonne, Que.
Dallas Parsons, Toronto, Ont.
Karine Vallée-Pouliot, Montreal, Que.
Barbara Wheeler, Winnipeg, Man.

Associate Medical Students

Dara Abells, Toronto, Ont.
Amirah Aujnarain, Ottawa, Ont.
Nicholas Avdimiretz, Edmonton, Alta.
Erin Boschee, Edmonton, Alta.
Andrea Brown, Sturgeon County, Alta.
Sean Bryan, Thunder Bay, Ont.
Etienne Caron, Montreal, Que.
Matthew Carwana, Waterloo, Ont.
Sam Chippin, London, Ont.
Jo-Anna Clark, Mount Pearl, Nfld.
Paulo De Gouveia, Ottawa, Ont.
Karim El Mofly, Montreal, Que.
Renee Farrell, Kingston, Ont.
Gregor Forgeron, Calgary, Alta.
Rola Ghaddar, Ottawa, Ont.
Suzanne Girard, Thunder Bay, Ont.
Stevi Golden-Plotnik, Winnipeg, Ont.
Victoria Leung, Edmonton, Alta.
Carrie Lewis, St. Albert, Alta.
Ana Sofia Lopez, Kingston, Ont.
Melissa Lui, Edmonton, Alta.
Geneviève Michaud, Ottawa, Ont.

Ashley Pardoe, Toronto, Ont.
Dara Petel, Dollard-des-Ormeaux, Que.
Jody Platt, Calgary, Alta.
Michelle Ruhl, Edmonton, Alta.
Sarah O'Connor, London, Ont.
Ori Scott, Edmonton, Alta.
Joel Semeniuk, Edmonton, Alta.
Neel Shoh, Mississauga, Ont.
Henry Stringer, Vancouver, B.C.

Associate Nurses

Julia Bokhaut, Orleans, Ont.
Erin Chard, Regina, Sask.
Julie de Salaberry, Vancouver, B.C.
Ronda Manning, Woodstock, Ont.
Amanda Squire, Stephenville, Nfld.

Associate Physicians, Surgeons and Dentists

Alice Charach, Toronto, Ont.
Marie-Pascale Ethier, Montreal, Que.
Hélène Gagnon, Montreal, Que.
Michael Harlos, Winnipeg, Man.
Zahra Kurji, Edmonton, Alta.
Sarah Olson, Vancouver, B.C.
Earl Rubin, Montreal, Que.
Azita Zereghar, Saskatoon, Sask.

Corresponding Fellows

Mohammad Jaber, Montreal, Que.
Ravi Malik, New Delhi, Delhi
Seyedyasser Qorashi, Toronto, Ont.

Fellows

Mahammad Ansari, Winnipeg, Man.
Johann Baard, Nipawin, Sask.
Suzanne Beno, Toronto, Ont.
Sylvie Bergeron, Toronto, Ont.
Margaret Bertoldi, St. Thomas, Ont.
Alan Berzen, Thornhill, Ont.
Roderick Canning, Moncton, N.B.
Tahir Chaudhry, Prince George, B.C.
France de Villers, St-Jérôme, Que.
Branda D'Souza Singh, St. Albert, Alta.
Julie Emberley, St. John's, Nfld.
Meghan Garner, Saskatoon, Sask.
Brenda-Louise Giles, Winnipeg, Man.
Ram Gobburu, Stratford, Ont.
Kristan Goulet, Stittsville, Ont.
Janet Greenman, Wheaton, IL
Joachim Kapalanga, Owen Sound, Ont.
Elene Khalil, Montreal, Que.
Olaf Kraus de Camargo, Hamilton, Ont.
Ramneek Kumar, Edmonton, Alta.
Thomas Lacroix, Sarnia, Ont.
Kevin Lee, Markham, Ont.
David Mack, Ottawa, Ont.
Muhaned Marah, Dauphin, Man.
Leopold Medou Nytame, Val d'Or, Que.
Adel Mohamed, Toronto, Ont.
Fateh Mohammed, Edmonton, Alta.
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Sunit Nanda, London, Ont.
Angela Noble, Kingston, Ont.
Stephen Noseworthy, Ottawa, Ont.
Halah Obaid, Airdrie, Alta.

Andrea Perello, Gatineau, Que.
Riffat-Ur Rahman, Windsor, Ont.
Rashid Rajah, Oshawa, Ont.
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Mary Sherlock, Hamilton, Ont.
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Judy Van Stralen, Ottawa, Ont.
Joseph Vayalumkal, Calgary, Alta.
Nabeela Waja, Chilliwack, B.C.
Brandy Wicklow, Winnipeg, Man.
Mahmoud Zalam, Winnipeg, Man.
Amini Zarlashat, Ottawa, Ont.

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Daniel Au-Yeung, Saskatoon, Sask.
Lauren Badalato, Ottawa, Ont.
Marta Bejuk, Kingston, Ont.
Lindsey Craw, Oakville, Ont.
Jennifer Davis Das, Toronto, Ont.
Claudia Garcia Gelvez, Toronto, Ont.
Magdalena Grzyb, Kingston, Ont.
Marie-Eve Blanchet, Quebec, Que.
Hasan Merali, Toronto, Ont.
Luie Murguia-Favela, Toronto, Ont.
Luise Neuendorff-el Helou, Hamilton, Ont.
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Kirstin Weerdenburg, Toronto, Ont.

6th International Meeting on Indigenous Child Health Resilience: Our ancestors' legacy, our children's strength



Join the Canadian Paediatric Society and the American Academy of Pediatrics for the 6th International Meeting on Indigenous Child Health. Child health providers and researchers dedicated to working with American Indian, Alaska Native, First Nations, Inuit, and Métis children and families are encouraged to attend, share model programs and research, and develop practical skills that can be utilized in community settings.

SAVE THE DATE!

March 20-22, 2015 / Ottawa, Ontario

For updated conference information, visit www.cps.ca or www.aap.org/nach.

Deadline for workshop proposal submission: **May 12, 2014.**

Deadline for abstract submission: **November 3, 2014.**

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CPS Vice President honoured as a leader in early childhood development

There are many ways to describe Dr. Robin Williams: Vice-President of the Canadian Paediatric Society, public health physician, tireless advocate for the early years. Now there is one more: Member of the Order of Canada.

Dr. Williams began her career as a community paediatrician in Niagara Falls, Ont., with an academic appointment at McMaster University. In the mid-1990s, she became Medical Officer of Health for the Region of Niagara, while maintaining a focus and interest on children and families. She is currently the Associate Chief Medical Officer of Health for Ontario.



Dr. Robin Williams

Her colleague, Dr. Andrea Feller, said Dr. Williams is highly deserving of this honour for her role in developing crucial health programs, services and interventions for children and families, and for her advocacy for maternal and child health.

“The vision she has always had is to ensure that every parent and child has a level playing field and the chance to reach their full potential. Dr. Williams has been known to describe her decision as a desire to ‘catch kids before they go over the falls’ rather than trying to fish them out of the turbulent waters,” said Dr. Feller. “She has accomplished her goals by paying attention, and seemingly always accepting her responsibility to make the world better for families and children.”

Dr. Williams has long had a special interest in the social determinants of health, especially as they affect early child development. She worked closely alongside pioneers like the late Dr. Fraser Mustard and Dr. Clyde Hertzman, who died in 2013.

She’s also left an indelible mark on the early childhood development system in Ontario: She founded the Niagara Early Years Planning Council, was a driving force behind the

establishment of Ontario’s Early Years Centres and the Niagara Children’s Charter and co-authored the report that led to the enhanced 18-month well-baby visit. Her influence has not been limited to the provincial level: Dr. Williams was a founding member of the Council for Early Childhood Development, and chairs the CPS Early Years Task Force.

She’s also been a role model and mentor for many people in her profession, including Dr. Feller.

“She has taught me how to balance analysis with action, to trust my instincts and understanding gained from listening to parents and families, has reinforced the importance of respecting all people, and above all has shown me that service and learning is a lifelong process and commitment,” she said. “While it is not uncommon to emerge from medical school with a somewhat idealistic view of medicine and its practitioners, it is rare to find the sort of physician mentor who lives up to every single principle, standard, and value day in and day out. Dr. Williams is that physician, and I have learned from her that it is possible to have a balanced life, a well-lived and fulfilling life, that includes having an enormous impact that changes the world for the better.”

CPS President Dr. Andrew Lynk also describes Dr. Williams as a leader in the field and as a valued member of the Board of Directors and Executive Committee.

“She is a wise and clear headed leader, who is passionate about securing a better future for all of Canada’s children.” 🌟

Member News

Nominating Committee membership & Annual General Meeting notice

The CPS Nominating Committee is responsible for choosing candidates for the Board of Directors elections. Every year, two members-at-large are selected to serve on the committee. Members will be approved at the CPS Annual General Meeting.

The CPS 91st Annual General Meeting will be held on Friday, June 27, from 7:00-10:30 a.m. in Room 511AD at the Palais des Congrès de Montréal.

Contact Jill Greenwell at 613-526-9397 ext 242 or jillg@cps.ca with questions about Nominating Committee membership, or to submit a motion for the Annual General Meeting.

Online registration for CPS Annual Conference now available

Register for the CPS Annual Conference by April 30 to receive the early bird rate. Visit www.annualconference.cps.ca to register, or for more information.

Breakfast with the CPS Board of Directors

Meet with your provincial/territorial board representative over breakfast on Friday June 27 starting at 7 a.m., and find out what the CPS is doing on your behalf. The breakfast is a great opportunity to raise regional or national issues that are important to you, and to explore how the CPS can help.



During breakfast, delegates can also be part of the inaugural CPS Leadership Forum, an ongoing series at annual conferences focusing on various leadership skills. This session will focus on advocacy.

Keynote speaker: Samantha Nutt, founding member of 'War Child'



Keynote speaker at this year's CPS annual conference is Dr. Samantha Nutt—humanitarian, author and child advocate.

As a medical doctor and a founding member of the international 'War Child' organization, Dr. Nutt has worked with children and families on

front lines around the world: in Iraq, Afghanistan, Somalia, the Democratic Republic of Congo, Sierra Leone and the Sudan.

Such experiences have yielded unique insights into modern conflict, including why they happen, the children they affect, and how to prevent them. A leading authority on current affairs, war, international aid and foreign policy, Dr. Nutt is an intrepid and recognized voice in humanitarian work in North America and abroad.

Dr. Nutt was recently called a 'transformational' Canadian by *The Globe and Mail*. She has also been recognized as a 'young global leader' by the World Economic Forum and as a leading activist by Time magazine. Dr. Nutt received the Order of Canada in 2011, for her work to improve the lives of young people in the world's worst conflict zones.

#CPS2014: Join the conversation

Have something to say about the 91st CPS Annual Conference? For the second year, the CPS is encouraging annual conference delegates to share their thoughts on Twitter. Join the conversation by using the hashtag #CPS2014 in tweets and follow @CanPaedSociety for regular conference updates.

By joining fellow delegates online, participants can create unique networking opportunities, receive conference updates as they happen, share experiences and insights, and learn information from sessions they couldn't attend.

Tribute to Dr. Mervyn Fox

Dr. Mervyn Fox, a Professor Emeritus in the Department of Paediatrics at Western University, passed away in November 2013. He was deeply committed to the field of developmental paediatrics and a tireless advocate on behalf of children.

"His understanding and compassion for little children with developmental problems, especially the 'hidden heroes' with learning disabilities was always inspiring," said Dr. Emmett Francoeur, a developmental paediatrician in Montreal.

Dr. Fox qualified in medicine in 1960 at London University's Wolfson Centre, Institute of Child Health. In England, he worked as principal physician for the Inner London Educational Authority, then the largest organization of elementary and secondary schools.

He formally retired as the Medical Director of Thames Valley Children's Centre in London, Ontario in 2003 but continued to provide consultation services until 2011.

Dr. Fox also took an active role as a CPS member. He was a founder and past president of the CPS Developmental Paediatrics Section and a past chair of the CPS Psychosocial Paediatrics Committee.

Dr. Fox co-edited the first edition of *Children with School Problems: A Physician's Manual*, published in 1998, and contributed to the second edition, published in 2012.

"Even after he retired, Mervyn would ask if there were some way in which he could help with projects in the Section, and when we needed one more writer to revise the second edition of *Children with School Problems*, he pitched in and substantially revised the chapter on learning problems in adulthood," said Dr. Debbi Andrews, co-editor of the second edition. "We appreciated his wisdom and experience, which informed every paragraph, and his careful writing." ✨

Halifax paediatricians honoured for developing health information system for Belize

Dr. Michael Graven and Dr. Noni MacDonald of Dalhousie University/IWK Health Centre were recently named Professionals of Distinction by Nova Scotia's Discovery Centre. They received this award for developing a fully integrated health information system that has dramatically improved health care in Belize—all for the annual cost of just four dollars per citizen.

Dr. Graven was chief architect and Dr. MacDonald, editor-in-chief of *Paediatrics & Child Health*, was in charge of protocol development for this tool, called the Belize Health Information System (BHIS).

Launched in 2007, the BHIS was adopted by 90% of the country's health care facilities within nine months. Almost immediately, there was a marked decrease in the rate of hospital admissions. The BHIS also helped to reduce the maternal mortality rate to zero by 2011; not even Canada can boast of such a low rate.

The reason for its success is simple: The BHIS was developed by health care professionals, for health care professionals.

"When you do something that is complex like this, there are three things you can get out of it: glory, money or satisfaction that it works [properly]," said Dr. Graven.

In this case, he and Dr. MacDonald volunteered their time with the sole mission of improving health care. Health outcomes, not technology, were the focus of this tool.

For example, the system helps health professionals catch and treat illnesses early by prompting them to check patients for common or potentially serious health issues. This early intervention approach keeps patients healthier, and in many cases, helps to reduce the need for hospital admission.

"Aggregate stimulus healthcare related expense in Belize has fallen three years in a row—one of only three countries in the world where that's true," said Dr. Graven.

Health care professionals nationwide can access the tool, which allows doctors and nurses to provide more personalized and appropriate care to each patient.

“We knew that scientific evidence-based guidelines work, but we had no idea how well they would work when everybody used them.”

Dr. Noni MacDonald

"It's countrywide," said Dr. MacDonald. "No matter how you come into the healthcare system, whether it's a clinic or the public health nurse or a crash on the side of the road, and the ambulance guys are there for you, they have access to all of your patient information."

Dr. Graven and Dr. MacDonald are thrilled to have received recognition for their work, but are even more excited about the positive results their information system has achieved.

"It has really helped change acute care in Belize because less people are now coming to the hospital with acute care problems; they're being prevented upstream because of immunization, better pre-natal care. [People] are now being better managed so they don't need to end up in hospital," said Dr. MacDonald.

The biggest lesson, said Dr. MacDonald, is that a health care tool such as the BHIS can be extraordinarily powerful, especially when embraced so enthusiastically.

In fact, the BHIS is actually the number two lifesaver in Belize, beating out immunization and antibiotics combined.

"We knew that scientific evidence-based guidelines work, but we had no idea how well they would work when everybody used them," said Dr. MacDonald. "Hypertension was the number one cause of death in 2003 in Belize, and it's barely in the top ten now. Who knew these guidelines could be so powerful? They're only that powerful because everybody's doing it."

Visit the Discovery Centre's website to watch the video about all 2013 Professionals of Distinction award recipients : www.discoverycentre.ns.ca/support/discovery-awards 📺

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CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

Study examines sudden unexpected death in epilepsy

Sudden unexpected death in epilepsy, or SUDEP, is a potentially avoidable cause of death in children that has not been adequately explored through research. A new Canadian Paediatric Surveillance Program (CPSP) study aims to better understand children at risk of SUDEP so that they can be better identified and protected.

Many of these deaths may be a result of seizures or co-morbid conditions, but some deaths in children with epilepsy remain unexplained.

For this study, SUDEP is defined as the sudden, unexpected death in someone younger than 18 years of age: with epilepsy (defined as >1 unprovoked seizure); with or without evidence of a recent seizure; without documented status epilepticus; and without trauma.

Ideally to meet strict criteria for SUDEP, a post mortem examination must be completed and demonstrate no anatomical or toxicological cause of death. However, given the low rates of autopsy, researchers use the term 'probable SUDEP' when all criteria are met but when an autopsy has not been performed.

In adults, the annual incidence of SUDEP is estimated to be 1 per 1,000 people with epilepsy; for children, limited literature suggests 0.2-0.4 per 1,000 cases per year

but researchers worry this may be an underestimate.

"Recognition of SUDEP is a significant barrier to accurate statistics. Not infrequently, a child with epilepsy will die and an autopsy will not be performed resulting in the death being attributed to

“It is important that these front-line physicians know about SUDEP and understand how to reduce the risk.”

Dr. Elizabeth Donner

another cause without sufficient supporting evidence. These cases may meet criteria for SUDEP, but are not recognized as such," said principal investigator Dr. Elizabeth Donner, Associate Professor of Paediatrics (Neurology), at the Hospital for Sick Children.

Lack of research on childhood SUDEP has contributed to a lack of understanding in the medical community, and may even keep at risk patients from accessing appropriate care.

For example, said Dr. Donner, her research group conducted a previous one-time survey of all CPSP participants in August 2011, to evaluate knowledge of SUDEP. Among paediatricians who reported caring for children with epilepsy, only 56% had prior knowledge that children with epilepsy are at increased risk of sudden unexplained death; only 33% were aware of the term SUDEP.

"We know that many children receive their epilepsy care from paediatricians. It is important that these front-line physicians know about SUDEP and understand how to reduce the risk," said Dr. Donner.

Through this study, investigators hope to establish an updated estimate of the number of Canadian cases as well as the number of autopsies conducted in deaths of children with epilepsy. They also hope their research will help to identify characteristics of children who are most at risk for SUDEP.

"We are so grateful to the CPSP for the opportunity to identify SUDEP deaths in children. SUDEP is a potentially avoidable cause of death in children. By learning more, I believe we will be able to develop targeted preventative strategies aimed at saving lives." said Dr. Donner.

This study runs from January 2014 to December 2015. For more information on this or other CPSP studies, visit www.cpsp.cps.ca. 🌟