



CANADIAN PAEDIATRIC SOCIETY

# CPS news



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## Surveillance program: A 15-year success story

It began in 1996 with only a handful of conditions under study. Since then, it has had significant impact on Canadian children, youth and their families.

This year, the Canadian Paediatric Surveillance Program (CPSP) marks its fifteenth anniversary. The CPSP, which collects data on rare childhood conditions and emergent child and youth health issues, has seen its range and impact grow by leaps and bounds. It has become a timely, cost-effective tool that serves an important surveillance function within the Public Health Agency of Canada (PHAC).

“National surveillance of rare conditions is essential to obtain sufficient information,” said Dr. Danielle Grenier, CPS Medical Affairs Director. “Patients with rare conditions can often feel alone and isolated. Paradoxically, when grouped together, rare diseases affect six to ten percent of the population.”

One of the program’s strengths is the commitment of the paediatric community.

“A program like this could not function without the volunteer time of the physicians who participate,” Dr. Grenier said. “Without their dedication the CPSP would not be able to collect epidemiological data to improve the lives of affected patients.”

This year, the CPSP will introduce the option of web-based monthly reporting. While the



response rate is already high, web-based reporting ensures the program stays timely and cost-effective, and that it adds value for the volunteer participants.

Dr. Kim Dow, Professor of Paediatrics, Obstetrics and Gynaecology at Queen’s University and current chair of the CPSP Steering Committee, also emphasizes the strength and impact of program data. “There are important implications for public health policies, for educating families and providers, and for establishing or revising practice guidelines.”

### ‘Surveillance in action’ a key success factor

“You don’t just obtain information about the incidence rate,” she said. “You also collect very rich clinical data about risk factors and treatment. And because we’re prompting physicians to look for and report on cases every month, they have a visual reminder, and are participating in an active versus passive surveillance system.”

“The CPSP is surveillance in action,” Dr. Grenier agreed. “As soon as results are available, the program begins knowledge transfer by disseminating results through a variety of communication vehicles. Participants can see firsthand the impact of their contribution.”

The data gathered also helps the Canadian Paediatric Society develop initiatives that influence policy. For example, CPSP findings contributed to the 2004 ban on baby walkers, the identification of vitamin D deficiency in vulnerable populations and the legislation

*continued on page 2*

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### Surveillance... continued from page 1

requiring booster seats for children weighing between 18 and 36 kg. Since its inception, the program has also collected data on acute flaccid paralysis, which confirms Canada's non-polio status to the World Health Organization.

"Some studies also confirm the validity of current clinical practice guidelines, such as the recommendation to give intramuscular vitamin K to newborns to prevent hemorrhagic disease," Dr. Dow said.

Another reason for the program's success is the collaborative relationship between the CPS and PHAC.

"If an emergent health concern arises and needs to be examined promptly, the CPSP has the framework and infrastructure to quickly gather data to inform public health decisions," Dr. Grenier said. Recent one-time surveys have identified suspected serious adverse reactions of antiviral drugs during the H1N1 pandemic and documented potential hazards of baby products.

The program's impact also extends well beyond Canadian borders. Dr. Grenier co-chairs the International Network of Paediatric Surveillance Units, which encourages researchers to run studies simultaneously and publish comparative results.

### 'Diagnostic tool for public health'

"This program plays a major role in improving the health of children," said Dr. Gilles

### CPSP by the numbers

- Approximately 2,500 Canadian paediatricians and paediatric subspecialists participate.
- The program has carried out 45 studies and 20 one-time surveys.
- Included conditions must be rare (less than 1,000 cases a year) or lead to rare complications.
- Eight to 12 studies are usually ongoing at any one time.
- Return rates on studies are more than 80% for monthly reports and 90% for detailed questionnaires.

Delage, vice president of medical affairs in microbiology at Héma-Québec. Dr. Delage spent more than 10 years on the CPSP Steering Committee, including six as chair.

"Surveillance is your diagnostic tool for public health," he said. "Once you have a good handle on a condition, you can inform prevention strategies and prescribe appropriate treatments."

Even when a study does not get included in the program, the CPSP Steering Committee often helps investigators refine and improve their projects, and directs them to other potential supporters.

"For each project submitted, the steering committee needs to ensure that the CPSP is the best vehicle to carry out surveillance for that specific disease," Dr. Delage said. 🌟

### Planning to attend the Annual Conference?

Don't miss *CPS Today*, the 2011 Annual Conference newsletter included with this issue of *CPS News*. It has details on educational programming and keynote speaker Pierre Lavoie, Ironman World Champion in 2004. You'll also learn more about the Practice What You Preach event, social activities, tours and other networking activities — all you need to get the most from your visit to Quebec City in June.

For more information and to register, visit [www.cps.ca](http://www.cps.ca). Register by April 30 and save up to \$150.