

CPSP contributes to research: Call for new studies

Low-frequency, high-impact diseases or conditions are often labelled 'orphan diseases'.

Underlying difficulties pertaining to these conditions are twofold:

- Scientific data on national incidence, prevalence and morbidity are sparse or nonexistent.
- Substantial research investments are difficult to secure even though these are high-impact diseases which cause a heavy emotional and financial burden on families and communities of affected children.

What can the Canadian Paediatric Surveillance Program (CPSP) offer?

- A national collaborative surveillance network.
- A prospective epidemiological tool.
- A robust infrastructure.
- A timely and flexible program.
- An educational component pertinent to practice.

The Canadian Paediatric Surveillance Program (CPSP) is a joint project of the Canadian Paediatric Society and Health Canada's Centre for Infectious Disease Prevention and Control that undertakes the surveillance of rare diseases and conditions in children. For more information visit our Web site at <www.cps.ca/english/cpsp> or <www.cps.ca/francais/pcsp>.

What impact have CPSP studies had?

- Provided survey data to support Health Canada's total ban on baby walkers in April 2004.
- Documented burden of necrotizing fasciitis and its link to varicella complication, reinforcing Health Canada's National Advisory Committee on Immunization recommendation of universal varicella immunization in February 2004.
- Established national incidence estimates.
- Increased awareness for specific uncommon diseases within the paediatric community.
- Allowed for earlier age of diagnosis and management to improve outcome.

Interested in proposing a new study? Call us

The CPSP is currently seeking new studies and would welcome your proposal. For more information, contact Andrea Medaglia, CPSP Senior Coordinator, at 613-526-9397 ext 239 or by e-mail at cpsp@cps.ca.