

# Commitment to patient confidentiality

Collecting data on rare paediatric disorders appears to be a conundrum: how can one hope, when numbers are so few, to find enough cases of a rare disorder to produce sufficient data for meaningful analysis without identifying individual patients and compromising their inherent right to patient confidentiality? Yet, in accordance with the United Nations *Convention on the Rights of the Child*, which first specified the rights to individual privacy and professional secrecy more than 12 years ago, the Canadian Paediatric Surveillance Program (CPSP) achieves the above goal. Because patient confidentiality is of tantamount importance to the success of the program, all new CPSP studies must receive ethical approval from a certified research ethics board before commencing, and then the studies can only collect non-nominal data that are related to the condition under surveillance. Only the reporting physician is aware of the patient's identity; on the initial reporting form, the paediatrician provides the date of birth and the sex of the child to allow the program coordinator to identify and eliminate duplicate cases. The CPSP ensures that only aggregate pan-Canadian data are published and presented. The commitment to patient confidentiality is capitalized on by providing study investigators with invaluable, anonymous research material on which to build knowledge that will ultimately help children and youth afflicted by rare diseases and conditions. Even though the reporting physician does not have to inform the family or obtain consent because no identifying information is revealed, he or she may wish to introduce the CPSP and the importance of its research to families who would welcome additional insight into these rare conditions. However, a principal investigator may wish to follow-up a cohort of patients over time. In such a case, the principal investigator must secure the consent of the patient or the patient's parents before conducting any follow-up.

*The Canadian Paediatric Surveillance Program 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 <<http://www.cps.ca/english/proadv/cpsp/cpsp.htm>> or <<http://www.cps.ca/francais/proadv/pcsp/pcsp.htm>>*

### REFERENCES

1. United Nations. Convention on the Rights of the Child. <<http://www.unicef.org/crc/crc.htm>> (Version current at October 11, 2001)