Investigating ways to protect the health of newborns

After Dr. Michael Sgro, of St. Michael’s Hospital, saw several children with severe neonatal hyperbilirubinemia, he became motivated to improve treatment of this disorder to possibly prevent complications. He therefore conducted a study through the Canadian Paediatric Surveillance Program (CPSP).

“The epidemiological data generated through the CPSP is used as a catalyst for providing information to physicians to raise awareness and improve treatment of rare diseases and conditions affecting children and youth,” explains Dr. Danielle Grenier, CPSP Medical Advisor.

Dr. Sgro submitted a proposal to the CPSP, which was accepted. In 2002, he began a two-year study to gather surveillance data on severe neonatal hyperbilirubinemia. Unlike hyperbilirubinemia—which is very common and usually benign—severe neonatal hyperbilirubinemia can cause long-term neurological impairment.

Advancing knowledge through national data

“I chose to look at this problem through national surveillance because the complications are rare,” he explains. “Just doing it in one hospital or doing it in the Toronto area would not have a large enough scope.”

“When the data is collected on a national basis capturing a whole population, people respect the information and take it quite seriously,” he adds. The study, for which Dr. Sgro served as the principal investigator, revealed that there were 259 confirmed cases of severe hyperbilirubinemia in neonates. Results were published September 12, 2006 in the Canadian Medical Association Journal (CMAJ).

Increasing awareness and influencing practice guidelines

According to Dr. Sgro, the data had a significant impact on three fronts: It attracted international attention, had an impact on guidelines for care and raised Canadian paediatricians’ awareness of severe neonatal hyperbilirubinemia.

“Our data was well-respected. The CMAJ article has often been quoted internationally,” says Dr. Sgro. “In addition, we had an impact on care. National survey data was taken into account when the CPS position statement, Guidelines for detection, management and prevention of hyperbilirubinemia in term and late preterm newborn infants (35 or more weeks’ gestation) was revised in 2007.

“There is a built-in educational component for paediatricians with the CPSP,” explains Dr. Sgro. “When you initially start the surveillance, there is a backgrounder sent that provides information on the disease and why you are concerned about it.” The CPSP reaches a national network of more than 2,500 actively practicing professionals.

A well-established program

Dr. Sgro is currently leading another CPSP study on kernicterus. “My experience has been great with the surveillance program and that is why I was interested in conducting a second study,” he says. “I have already submitted abstracts of preliminary data and have been receiving phone calls about the study from leading experts around the world.”

Dr. Sgro is primarily a clinician, but he devotes about 20 to 25 per cent of his time to research. He likes working with the CPSP because the program, which has been operating since 1996, offers established infrastructure and administrative support. CPSP studies also typically attract high response rates, with an average response rate of 93 per cent to detailed questionnaires.

“Logistically, the CPSP is nice for a researcher. As far as getting grants and getting good response rates, when you go with a well-established program, people tend to pay more attention. Physicians take the results seriously as well.”

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