

Canadian Paediatric Surveillance Program

Studying Neural Tube Defects: Lessons Learned

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Editorial published in CPSP 1998 Results Neural tube defects (NTD) occur in one in every 1,000 live births. For the Canadian Paediatric Surveillance Program and other national paediatric surveillance units which monitor rare diseases and conditions¹, this is a relatively common occurrence. In 1997, the CPSP added neural tube defects to its list of studies, and the surveillance of NTDs provided valuable insight into our surveillance strategies.

The final results of the study, which concluded this year, show that NTDs were being under reported. Understanding why this happened will help us improve future surveillance studies.

When studying the occurrence of NTDs and other conditions that involve a number of health care professionals, it is critical to establish a network of collaborators. Only by involving all the professionals who may come in contact with women carrying babies with the condition, or children born with the condition, can we ensure complete ascertainment. In the case of NTDs, some women may terminate pregnancies when they learn the fetus has an NTD, or the baby may die shortly after birth. Neither of these scenarios would be reported to the surveillance program, since they would never have been seen by a paediatrician.

If, in the course of a study, we notice irregularities and discrepancies in the number of cases being reported, we need to be able to employ alternative strategies, such as personal contact with people working in the field. Maintaining strong liaisons with other ascertainment groups through exchanging relevant data, while always respecting patient confidentiality, should enhance the program's ability to capture the widest possible sample of available information.

In this study, CPSP participants provided valuable data on the cases of NTDs they did report, and 93% of those who reported seeing babies or children with NTDs completed detailed reports. This not only indicates tremendous dedication but has also allowed us to collect vital health information:

- 50 of 62 (80.6%) of women with a pregnancy affected by an NTD, for whom information was available, had not taken folic acid during the first four weeks of their pregnancies ([Table 1](#)), even though current medical literature attests that periconceptual use of folic acid decreases the incidence of NTDs.^{2 3}
- Two of 95 (2.1%) of women had a previous pregnancy affected by an NTD, and 14 of 74 (19.0%) had a relative with NTD ([Table 2](#)).

This information highlights the need for more education emphasizing targeted prevention: Women in high-risk groups need increased supplementation of folic acid—up to 4 mg daily instead of the recommended 0.4 mg for women without risk factors. [Table 3](#) shows the significant morbidity suffered by children with NTDs. Many have

ongoing health care needs in areas such as neurosurgery, orthopaedics and urology, as well as lifelong medical and rehabilitation care. Prevention at a population level is critical.

In the absence of a staple food supplemented with adequate levels of folic acid, women in reproductive years must be vigilant about supplementing their diet with folic acid—0.4 mg daily from conception to at least 5 weeks after conception. Women in higher risk groups should be prescribed up to 4 mg daily. Health care professionals have a responsibility to educate women in their childbearing years about the need for folic acid supplementation, informing them that folic acid supplementation can help reduce the risk of a potentially devastating birth defect.

Thanks in part to the surveillance of neural tube defects, we have the necessary knowledge to set in motion the appropriate measures so that fewer babies are born with these terrible conditions. What we need now is action. As Dr. Deborah Davis wrote in 1997, “Is it not time Canada led the way towards prevention of this chronic disease?”

1. Hall SM, Nicoll A. The British Paediatric Surveillance Unit: A pioneering method for investigating less common disorders of childhood. *Child: Care, Health and Development*, 1998;24(2):129-143.
2. Davis DJ. [Periconceptual folic acid and the prevention of NTD: Some food for thought for Canadian paediatricians](#). *Paediatr Child Health* 1997;2(2):114-9.
3. Canadian Paediatric Society. [Periconceptual use of folic acid for reduction of the risk of neural tube defects](#). *Paediatr Child Health* 1997;2(2):152-4

Table 1. Folic acid taken during first four weeks of pregnancy

	Number of women	Percent of reported
Yes	12	19.4
No	50	80.6
Total	62 (45 not reported)	

Table 2. Previous NTD-affected pregnancy/relative with NTD

	Previous NTD-affected pregnancy (%)	Relative with NTD (%)
Yes	2 (2.1)	14 (19.0)
No	93 (97.9)	60 (81.0)
Total	95 (100.0)	74 (100.0)

Table 3. Reported surgery and assessments of live born infants (excluding infants with anencephaly)

Type of surgery	Number of infants reported to have had surgery
Closure of lesion	43
Hydrocephalus shunting	20
Shunt revision due to blockage	2
Vesicostomy	2
Other surgery	8
Assessment	Number of infants reported having positive result
Seizure disorder	2
Spasticity	4
Club feet	12
Congenital hip dislocation	8
Refluxing	4
Hypospadias	3
Problems with wound healing	4
Special seating requirement	3
Other assessment	4