
Acquired demyelinating syndromes of the central nervous system

February 2004

The incidence of acquired demyelination of the central nervous system in Canadian children is unknown. Children experiencing acquired demyelination face an uncertain future, as a small proportion will go on to experience recurrent demyelinating attacks that characterize Multiple Sclerosis (MS).

The Paediatric Demyelinating Disease Network initiated a survey to determine the number of children in Canada experiencing acquired demyelination and to determine the proportion of those children who were subsequently diagnosed with MS. The study also inquired whether MS was considered by the treating physician.

The survey was sent out to 2,320 paediatricians and paediatric subspecialists across Canada. Results of the 611 responses (26%) indicated that 130 (21%) had cared for a child with acquired demyelination within the last two years. A total of 285 patients were reported. Each paediatrician had seen from one to 60 patients, with an average of 2.3 per paediatrician. Six of the 130 respondents did not indicate the number of patients they had assessed. Forty-six of the 285 patients with demyelination (16.14%) experienced recurrent demyelinating episodes and were subsequently diagnosed with MS.

Paediatricians were asked whether the possibility of recurrent demyelination was entertained, as many health-care professionals may not consider MS as a possible diagnosis of an initial demyelinating event. Eighty-four of the 130 paediatricians (65%) who have seen a case indicated that they considered MS as a possible outcome of acute demyelination in children.

The CPSP Steering Committee has since approved a full two-year study on acquired demyelinating syndromes of the CNS that began in April 2004. To date, 52 patients with acute demyelination have been reported. Study results are found on page 15. A follow-up survey will be sent out at study completion to assess whether a greater proportion of paediatricians are considering MS as a potential outcome in patients experiencing a first demyelinating episode.

Demyelination in Canada may not be as rare as previously thought. It is hoped that the study will successfully assess the incidence and clinical features of paediatric demyelination in Canada as well as increase awareness among paediatricians of paediatric MS as an outcome of demyelination. The advent of disease-modifying therapies for MS and the recent evidence of improved long-term outcome associated with early therapy initiation emphasize the need for prompt diagnosis and coordinated care for children affected with MS.

Principal investigator

Brenda Banwell*, MD, Paediatric Multiple Sclerosis Clinic, The Hospital for Sick Children,
555 University Ave., Toronto ON M5G 1X8; tel.: 416-813-7857; fax: 416-813-6334;
brenda.banwell@sickkids.ca

* Representing the Paediatric Demyelinating Disease Network (22 paediatric care facilities across Canada)
