

Irish Childhood National Diabetes Register

Abstract:

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Sir,

I read with great interest the letter by Professor Denis Gill, entitled "Counting and Caring for Chronically Ill Children: The Need for a Paediatric Registry" in the October issue of the Irish Medical Journal the establishment of a National database of children with chronic illness, including diabetes mellitus. The ability to accurately define the frequency of occurrence of chronic disease in our childhood population is important and is fundamental to inform decisions of appropriate resource allocation to meet the needs of these patient groups. Epidemiological based disease registries are an ideal and robust method of providing this information and monitoring epidemiological changes. In any management process the key to successful planning begins with reliable information. I would agree with Professor Gill that such information is limited in the Irish population.

¹ in which he calls for

In the area of childhood diabetes we noted a particular lack of epidemiological information in the Irish population. The limited information available had suggested that Ireland had a very low incidence of Type 1 diabetes in childhood, among the lowest in Europe at 6.8 per 100,000 per year. However, clinicians working in the area felt that this was an underestimate and we undertook a prospective study of the national incidence of type 1 diabetes in our population which found that Ireland had a high incidence of Type 1 diabetes of 16.3 per 100,000 per year, in the top 25% for Europe. The incidence of Type 1 diabetes is subject to huge international variation and most countries in Europe are experiencing increases in disease incidence, ranging from 0.6 -9.3% per annum. To monitor the epidemiological changes of this important disease in our population I am delighted to report that we established a National Register of Childhood Type 1 diabetes on the 1st January 2008. Developing a national disease register poses a significant number of challenges and much planning. The Irish Childhood Diabetes National Register (ICDNR) is now in its third year and has received tremendous national support from paediatric endocrinologists, paediatricians, endocrinologists, public health clinicians and the families of those with diabetes. It is generously funded by the National Children's Hospital Foundation.

The Register collaborates with the Eurodiab Network, a network of diabetes registries established by the World Health Organisation. The data from the initial years of the Register, now in the final stages of preparation to be published later this year, confirms the previously described high incidence of Type 1 diabetes in our population which is rising as elsewhere. The particular value of this Register is that it will provide accurate information which will inform decision making and provide robust denominator data vital for monitoring outcome measurement in this important disease.

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