Irish Childhood Diabetes National Register

Diabetes Registries allow the monitoring of the frequency of diabetes in populations worldwide. This epidemiological monitoring is important to increase our understanding of the condition and ultimately shed light on what causes type 1 diabetes (T1D). Despite much research internationally the cause of T1D remains elusive. Monitoring has shown that T1D is becoming more common in children and adolescents in most countries but with wide geographical fluctuations in incidence. At a population level monitoring the incidence of T1D (considered a basic health indicator by WHO) allows improved healthcare planning and appropriate resource allocation which ultimately results in enhanced patient care. Most countries have established registers of Type 1 diabetes for these reasons.

The Irish Childhood Diabetes National Register (ICDNR) was established in 2008 to monitor this important condition in the Irish population. Prior to this no robust national data were available regarding T1D epidemiology, apart from the baseline pilot studies from our group. Previous data had suggested that Ireland had one of the lowest rates of diabetes in childhood and adolescence in Europe when in fact our incidence of Type 1 diabetes is among the highest in Europe and remains in the top 25% worldwide. The ICDNR monitors the epidemiology of this important disease and provides robust data to support clinical care and audit. It provides anonymised data and prevalence forecasts to the HSE to support its service planning for diabetes care in children and young people.

The ICDNR undertakes additional projects in diabetes care, such as, national monitoring of the incidence of the serious metabolic decompensation of diabetes ketoacidosis (DKA) at diagnosis which is potentially fatal and leads to a path of poor metabolic control with increased risk of diabetes complications into adulthood. Preventing DKA is the most important therapeutic target in T1D second only to preventing the disease itself. In addition to monitoring DKA rates the ICDNR has developed an intervention campaign in collaboration with TUD and Diabetes Ireland to increase diabetes awareness at a population level to prevent DKA.

The ICDNR was established by researchers researchers from the University of Dublin, Trinity College Dublin, supported and hosted by Tallaght University Hospital and generously funded by the National Children’s Hospital Foundation.

We are deeply grateful to all Parents and Children diagnosed with Type 1 diabetes since 2008 who have registered with the ICDNR and to all Health care providers who support the Register.

For further information contact diabetes.register@tcd.ie

(*EURODIAB is an international collaboration of 26 European approved diabetes registers)