

# The Irish childhood national diabetes register

Childhood Type 1 diabetes is potentially fatal. Poor disease control can cause life-limiting complications in childhood and adult life, including blindness, kidney failure and amputations. These are largely preventable through good metabolic (blood sugar) control. Diabetes control requires quality data to achieve more effective health service planning, resource allocation and targeted measures. Diabetes registers allow the monitoring of diabetes in populations. This helps us understand the condition and its causes. Until recently, Ireland had no such register.

In 2008 the Irish Childhood Diabetes National Register (ICDNR) was established to provide data on Type 1 diabetes in children and young people. Now in its 14<sup>th</sup> year, the ICDNR is unique internationally due to its scope and level of detail. It makes robust and accurate data available to support clinical care and audit. It provides anonymised data and prevalence forecasts to the Health

Service Executive (HSE) to inform its resource allocation and planning of services for diabetes care in children and young people. Its data also support targeted measures, quality clinical care, high-quality research and audit.

*“Our monitoring has shown that we have an unacceptably high rate of life-threatening DKA at diagnosis that needs to be addressed.”*

## **Professor Edna Roche**

*Consultant Paediatrician and Professor in Paediatrics*

Research based on this register includes national monitoring of the incidence of diabetic ketoacidosis (DKA) at diagnosis. DKA is a serious and potentially fatal consequence of Type 1 diabetes associated with delayed diagnosis, which can increase the risk of complications in adulthood. The ICDNR

also leads a campaign in collaboration with Diabetes Ireland, supported by Novo Nordisk, to increase national awareness of childhood diabetes, promote early diagnosis and prevent DKA. The campaign materials were developed with students of the Technological University of Dublin at Tallaght.

Funded by the National Children’s Hospital Foundation and hosted at Tallaght University Hospital, the ICDNR is led by principal investigator Professor Edna Roche and governed by a steering group with expertise in medicine, nursing, IT, statistics and health informatics.

