



Down Syndrome (DS) or trisomy 21 is one of the most common congenital genetic conditions. Ireland is thought to have the highest incidence of DS in the world. While much is known about Down Syndrome there is much that we need to learn.

The National Register for Children with Down Syndrome was established in 2015 to increase our knowledge about Down Syndrome in Irish children with the ultimate aim of improving the quality of care and quality of life for children with DS and their families.

This prospective national Register will define the epidemiology of Down Syndrome in Ireland and provide data to guide healthcare service development and service provision. These data, including the number of children born with Down syndrome in Ireland each year, the area in which they live etc, will enable more informed decision making and optimise resource allocation leading to better clinical outcomes.

The Register will also expand our knowledge of DS by collecting data regarding health status, co-morbidities, illness severity, service utilisation and access to services etc. It will help ascertain if certain problems and illnesses are more prevalent or more severe in children with Down syndrome. It will provide more accurate evidence based information for counselling families and may enable screening programmes or early intervention to prevent avoidable secondary disability which has been so successful for those with DS who develop thyroid disease for example.

Through defining the epidemiology and systematically studying the issues faced by children with DS and their families the DS Register will enhance the health and well being of Children with Down syndrome in Ireland.

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