

Anne Lawlor

Anne is a co-founder of the 22q11 Ireland Support Group. From just 3 families in 2007 to 160 in 2018 this parent-led voluntary organisation supports Irish families affected by 22q deletion syndrome, their vision is for integrated coordinated life-span care for 22q11.2 deletion syndrome across medical, educational and social domains.

Anne was prompted to help set up an Irish organisation to help parents of children born with 22q after her she and her daughter Áine (diagnosed at aged 15 in 1998) attended their first international conference in 2006.

Having first-hand knowledge of the profound effect of not knowing about the diagnosis for those first 15 years Anne then became acutely aware of the negative impact that lack of knowledge of 22q and how the lack of integrated care impacts on families and vowed to change how health and social care for 22q11.2 deletion syndrome is delivered in Ireland.

Anne was a 2017 Global Genes Rare Champion of Hope awardee and 22q11 Ireland also picked up two other separate awards last year, including a GSK Health Impact Award. Recognising that parents are experts in their own right Anne is a passionate believer in the promotion of co-production and co-design of services and advocates for collaboration at all levels of development of services for families affected by 22q11.2 deletion syndrome. She uses social media extensively to share information, research and knowledge of 22q and works closely with academic institutions, clinicians and researchers to bring about needed change in services.

Anne works for 22q11 Ireland in a voluntary capacity and lives in Dublin with her daughter Áine, now 34.