

Laura Egan



Laura Egan is a rare disease parent and co-founder of Rare Ireland Family Support Network which is a charity organisation supporting families of children and young adults with rare conditions.

Laura's daughter is 22 and was diagnosed with Koolen de Vries Syndrome, a deletion on chromosome 17, a number of years ago. Following her diagnosis Laura was very surprised to learn there was no support network in Ireland to support families through a rare diagnosis. After meeting her fellow co-founder, another mother Louise, and hearing her similar story they decided to provide a network of support.

Rare Ireland Family Support Network represents almost 1600 rare disease families. They offer subsidised therapies, subsidised counselling, gift boxes for rare children in hospital and any other

supports their families require. They advocate on behalf of families to have their voices heard. RIFSN recently held their first rare disease conference which was attended by 130 rare disease families, experts and advocates.

Laura believes in extensive networking and working in partnership with other rare disease organisations, groups, advocates & allies. Laura has a passion for awareness, advocacy & acceptance of the rare disease community in Ireland.