

**Developing integrated care in the context of rare chromosomal conditions: 22q11 Deletion Syndrome; A parent/clinician collaboration. The Irish Story – An overview of a 10 yr journey.**

22q11 Ireland is a parent-led organisation set up in 2007 to connect Irish families affected by 22q11.2 deletion syndrome. The organisation promotes awareness of the condition among health-care providers and provides accurate information and support to parents and individuals with 22q11.2 DS in Ireland.

A primary objective of the Irish group is to develop life-span integrated, coordinated care for individuals with the condition. Despite the fact that international guidelines have been developed for the treatment/management of 22q11.2 deletion syndrome and a multi-disciplinary approach to the condition is recommended, Ireland like many jurisdictions lacks a fully-funded 22q11 clinical care centre to treat individuals over their lifespan.

In 2015 the organisation took its first steps to officially redress this situation beginning with a decision to employ an independent mental health researcher to help the group obtain this objective. A series of parent/clinicians meetings began and CARA (Clinicians And Research Advocates) was born. (CARA translates from the Gaelic to mean ‘friend’)

These meetings included a masterclass with Donna McDonald-McGinn from CHOP who shared her knowledge and expertise of 22q11DS with a number of Irish doctors.

Our journey is far from over but in September 2017 a one-day-a-month 22q clinic began operating in one of the largest children’s hospitals in Dublin.

This is our story about how a small committed group of people helped make this happen.

*A journey of a thousand miles begins with one step. Lao Tzu*

[mailto:https://www.researchgate.net/publication/320497688\\_Developing\\_integrated\\_care\\_in\\_the\\_context\\_of\\_rare\\_chromosomal\\_conditions\\_22q11\\_Deletion\\_Syndrome\\_A\\_parentclinician\\_collaboration](mailto:https://www.researchgate.net/publication/320497688_Developing_integrated_care_in_the_context_of_rare_chromosomal_conditions_22q11_Deletion_Syndrome_A_parentclinician_collaboration)

Anne Lawlor, co-founder and chairperson of 22q11 Ireland.

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