EUROPEAN
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GASTEIN

Isla, Julian
Foundation 29

Julian Isla is the founder of the European Dravet Syndrome Federation, an European organization of patients with Dravet Syndrome. Julian Isla founded Dravet Syndrome Foundation twelve years ago. Dravet Syndrome Foundation is committed to find new treatment for Dravet Syndrome, an epileptic encephalopathy having long lasting seizures refractory to treatment as severe developmental delay as main symptoms. Julian is the father of Sergio, a young boy fifteen years old who has Dravet Syndrome. Julian is software engineer by training and he works for Microsoft as full time employee. Despite of not having a neuroscience or medical background he gained the skills to be member of the Orphan Drug Committee at European Medicines Agency (EMA) as patient representative, he has been member of this committee the last 12 years. Julian is also part of the Therapeutic Advisory Group for Eurordis, the biggest organization of rare diseases in Europe. In Spain he member of Ciberer (Spanish Network for research on rare diseases) scientific advisory group and member of the committee at National Health Institute (Carlos III) making evaluation of funding for non-commercial clinical trials. He also serves as board member on three Spanish nonprofit organizations.