

Condition	Name of Organisation	Website
22q11 deletion	22q11 Ireland	www.22q11ireland.org
Addison's disease	Addison's Ireland - Irish Branch of Addison's Disease Self-Help Group (ADSHG)	www.addisons.org.uk/comms/adshg/ireland
Alpha 1 antitrypsin deficiency	Alpha One Foundation	www.alpha1.ie
Alternating hemiplegia	AHCI Alternating Hemiplegia of Childhood, Ireland	www.ahci.ie
Angelman syndrome	Angelman Syndrome Ireland	www.angelman.ie
Arthrogryphosis	Athrogryphosis Association of Ireland	www.arthrogryphosis.morsolutions.ie
Batten's disease (NCF)	Bee for Batten's	www.beeforbattens.org/contact-us.php
Blindness	Fighting Blindness	www.fightingblindness.ie
Cardiomyopathy	Cardiomyopathy Support Group	www.irishheart.ie/iopen24/cardiomyopathy-support-group-t-11_35_218.html
Chron's disease	The Irish Society for Colitis and Crohn's Disease	www.iscc.ie
Cystic Fibrosis	Cystic Fibrosis Ireland	www.cfireland.ie
Cystinosis	Cystinosis, Ireland	www.cystinosis.ie
Duchenne and Becker Muscular Dystrophy	Duchenne Ireland	www.duchenne.ie
Epidermolysis Bullosa	DEBRA Ireland	www.debraireland.org
Fragile X	IFXS Irish Fragile X Society	www.fragilexireland.org
Friedreich's Ataxia	Ataxia Ireland	www.ataxia.ie
Haemophilia	Irish Haemophilia Society	www.haemophilia.ie
Hereditary Haemorrhagic Telangiectasia	The Grace Nolan Foundation	www.gracenolan.com
Huntington's Disease	Huntington's Disease Association of Ireland	www.huntingtons.ie
Long QT and cardiomyopathy - Tallaght hospital	CRY Cardiac Risk in the Young	www.cry.ie
Long QT syndrome	Long QT Syndrome Support Group	www.irishheart.ie/iopen24/long-syndrome-support-group-t-11_35_221.html
Marfan Syndrome	Marfan Syndrome Support Group of Ireland	www.marfan.ie
Motor neurone Disease	Irish Motor Neurone Disease Association	imnda.ie
Mucopolysaccharidosis	The Irish MPS Society	www.mpssociety.ie/wordpress
Muscular Dystrophy	Muscular Dystrophy Ireland	www.mdi.ie
Myasthenia Gravis	Myaware - Fighting Myasthenia Together	www.mga-charity.ie
Narcolepsy (post vaccine)	SOUND Sufferers of Unique Narcolepsy Disorder	www.soundireland.ie

Neurofibromatosis	Neurofibromatosis Association of Ireland	www.nfaireland.ie
Post-polio syndrome	Post Polio Support Group	www.ppsg.ie
Prader Willi Syndrome	Prader Willi Syndrome Association Ireland	www.pwsai.ie
Pulmonary Fibrosis	Irish Lung Fibrosis Association	www.ilfa.ie
Pulmonary Hypertension	Pulmonary Hypertension Association	www.pulmonaryhypertension.ie
Rett syndrome	Rett Syndrome Association of Ireland	www.rettsyndrome.ie
Rare Chromosome UNIQUE		
www.rarechromo.org		
Scleroderma	Raynaud's and Scleroderma, Ireland	www.irishraynauds.com
Sickle cell and Thalassemia	SCTI Sickle Cell and Thalassaemia, Ireland	www.sicklecellireland.ie
Spina Bifida	SBHI Spina Bifida Hydrocephalus Ireland	www.sbhi.ie
Sudden Adult Death syndrome	SADS Support Group	www.irishheart.ie
Syringomyelia	Irish Ants - Syringomyelia Ireland	www.syringomyelia.ie
Trisomy 13 and 18	SOFT Ireland	www.softireland.com
Turner syndrome	Turner Contact Group Ireland	www.tcgi.ie
Vasculitis	Vasculitis Ireland Awareness	www.vasculitis-ia.org
Williams syndrome	WSAI William's Association Ireland	www.williamssyndrome.ie
Worster-Drought syndrome	The Worster-Drought Syndrome Foundation Ireland / Elizabeth's Little Friends	www.wdsfoundation.ie
