

Rare Disease Patient Organisation

22q11.2 deletion syndrome



Website

<https://www.22q11ireland.org/>

Addison's Disease



<https://www.addisons.org.uk/articles.html/addisons-ireland/>

Alpha 1 Foundation



<https://www.alpha1.ie/>

Alternating Hemiplegia



<http://www.ahci.ie/>

Angelman Syndrome Ireland



<http://www.angelman.ie/>



## Rare Disease Patient Organisation

Arthrogryposis Association of Ireland



## Website

<http://www.arthrogryposis.ie/>

Debra Ireland



<https://debraireland.org/>

Muscular Dystrophy Ireland



<http://www.mdi.ie/>

Fighting Blindness



<https://www.fightingblindness.ie/>

**Rare Disease Patient Organisation**

Irish Heart Foundation



**Website**

<https://irishheart.ie/>

Irish Society for Colitis and  
Crohn's Disease



<https://www.iscc.ie/>

Cystic Fibrosis Ireland



<https://www.cfireland.ie/>

Cystinosis Ireland



<https://www.cystinosis.ie/>

Irish Fragile X society



<http://fragilexireland.org/>

Rare Disease Patient Organisation

Ataxia Ireland



Website

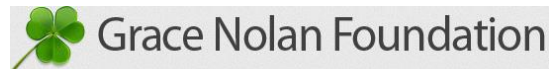
<http://ataxia.ie/>

Irish Haemophilia Society



<https://haemophilia.ie>

The Grace Nolan Foundation



<http://www.gracenolan.com/index.php>

Huntington's Disease



<http://www.huntingtons.ie/>

CRY



<https://www.cry.ie/>



## Rare Disease Patient Organisation

Marfan Syndrome Support Group  
Ireland



## Website

<http://www.marfan.ie/>

Irish Motor Neuron Disease  
Association



<https://imnda.ie/>

Irish Mucopolysaccharide Society



<http://www.mpssociety.ie/wordpress/>

Myasthenia



<https://www.myaware.org/>

Sound Ireland



<https://soundireland.ie/>

**Rare Disease Patient Organisation**

**Website**

Neurofibromatosis Association of  
Ireland



<http://www.nfaireland.ie/>

Polio Survivors Ireland



<http://polio.ie/>

Prader Willi Syndrome  
Association Ireland



<https://pwsai.ie/>

Irish Lung Fibrosis Association



<http://www.ilfa.ie/>

Pulmonary Hypertension  
Association



<https://www.pulmonaryhypertension.ie/>

**Rare Disease Patient Organisation**

**Website**

Retts Syndrome Association of  
Ireland



<http://rettsyndrome.ie/>

Raynaud's and Scleroderma



<http://www.irishraynauds.com/>

SCTI Sickle Cell and  
Thalassaemia Ireland



<http://sicklecellireland.ie/>

Spina Bifida Hydrocephalus  
Ireland



<http://www.sbhi.ie/>

Sudden Adult Death Syndrome



<https://irishheart.ie/get-support/support-groups/sads-support-group/>

Syringomyelia Ireland



<http://www.syringomyelia.ie/>



Rare Diseases  
Ireland

### Rare Disease Patient Organisation

Support Organisation for Trisomy  
13/18 (Patau's/Edward's  
Syndrome)  
SOFT Ireland



### Website

<http://www.softireland.com/>

Turner Contact Group Ireland



<http://www.tcgi.ie/>

Vasculitis Ireland Awareness



<http://vasculitis-ia.org/>

The Saoirse Foundation



<https://www.saoirsefoundation.com/what-we-do/bee-for-battens/>

Williams Syndrome



<http://www.williamssyndrome.ie/>