# Local and International Links

If epilepsy-related syndromes or rare diseases affect you or your family you may also want to explore information available through local or a number of international organisations and networks.

## International League Against Epilepsy (ILAE)

The ILAE have developed a website which outlines epilepsy syndromes. This website provides clinical features, seizure types, EEG, imaging, genetics and differential diagnosis information.

## Epilepsy Research Group

The Epilepsy Research Group aim to understand the spectrum of epilepsy syndromes and their underlying genetic causes. They hope this will improve the quality of life for children with epilepsy and their families. There are more than 2,000 New Zealanders affected by epilepsy, who are participating in their research. The research includes people with all forms of epilepsy – from the milder syndromes with a better prognosis to the more severe end – and all age groups from new-born to adulthood.

## Genetic Epilepsy Team Australia (GETA)

GETA is a group of parents whose children have rare genetic epilepsy. Genetic Epilepsy Team Australia's mission is to help world-leading Australian researchers cure genetic epilepsy. As part of this mission Genetic Epilepsy Team Australia aims to: raise awareness of the many forms of genetic epilepsy; promote Australia's world-leading research position in the discovery and treatment of genetic epilepsy; and, raise funds for research into cures and therapies for genetic epilepsy through the foundation of a precision medicine centre in Melbourne.

## Intractable Childhood Epilepsy Alliance

The Intractable Childhood Epilepsy Alliance is an organisation dedicated to improving lives of children affected by intractable epilepsy through evidence-based information, advocacy for appropriate medical treatment including compassionate use and Orphan drug products, promotion of drug development, data collection through patient registries, and funding of research.

## Rare Voice

Rare Voices Australia (RVA) is a national, not-for-profit organisation established in 2012 with a vision to be the unified voice for ALL Australians living with a rare disease. RVA is Australia's national alliance advocating for those who live with a rare disease. RVA provides a strong common voice to promote health policy and a healthcare system that works for those with rare diseases.

## Genetic Alliance Australia

Genetic Alliance Australia (GA) is a peak umbrella group for rare genetic conditions and diseases. GA endeavours to facilitate contact between families/individuals affected by the same, or similar condition, and provide information about relevant support groups both nationally and internationally.

## EURODIS Rare Diseases Europe

EURORDIS is a non-governmental patient-driven alliance of patient organisations representing 812 rare disease patient organisations in 70 countries. EURORDIS is the voice of 30 million people affected by rare diseases throughout Europe.

## Rare Diseases International (RDI)

RDI global alliance of people living with a rare disease of all nationalities across all rare diseases. RDI brings together national and regional rare disease patient alliances from around the world as well as international rare disease-specific federations to create a global alliance of rare disease patients and families.

## RareShare

RareShare is part of the Rare Genomics Institute founded in 2008 to give people and their loved ones a sense of community; a place to sympathize, celebrate, and share their experiences and expertise.

## Orphanet

Orphanet is a unique resource, gathering and improving knowledge on rare diseases so as to improve the diagnosis, care and treatment of patients with rare diseases. Orphanet aims to provide high-quality information on rare diseases, and ensure equal access to knowledge for all stakeholders. Orphanet was established in France by the INSERM (French National Institute for Health and Medical Research) in 1997, with ongoing support through the European Commission.