# **Batten Disease Support and Research Association Australia**

Batten Disease Support and Research Association Australia www.battens.org.au

BDSRA is dedicated to funding research, providing family support services, advancing education, raising awareness and advocating for legislative action.

Batten Disease is a group of rare genetic condition that manifests itself in childhood. Over time once healthy children lose their ability to walk, talk, eat and see. Children suffer worsening seizures and sadly eventually die.

The BDSRA believes that to effectively unravel the mysteries of Batten Disease, medical science, research and families must work together toward a common goal; develop treatments while assuring a better quality of life for those living with the disease.

# **Hunter Medical Research Institute (HMRI)**

The Hunter Medical Research Institute (HMRI) is one of NSW's largest medical research institutes with over 1700 affiliated researchers and staff.

One person, one family, one community at a time, HMRI fights the illnesses affecting lives throughout the world. Our translational research model aligns over 1700 researchers, students and support staff from Hunter New England Health and the University of Newcastle, inspiring new discoveries to deliver a healthier future.

### Mito Foundation

The Mito Foundation is Australia's only not-for-profit organisation focused on mitochondrial disease (mito). Mito is a debilitating genetic disorder that robs the body's cells of energy, causing multiple organ dysfunction or failure and potentially death. There is no cure and few effective treatments. One in 200 Australians are at risk.

The Mito Foundation supports patients and their families, fosters research into preventions, diagnosis, treatments and a cure, raises awareness about mito in the general public and medical profession, and advocates for equitable access to high quality diagnosis, treatment and support for those with this devastating disease.

### **Neuroscience Research Australia**

Neuroscience Research Australia (NeuRA) is an independent, not-for-profit research institute based in Sydney. As a leader in brain and nervous system research, their goal is to prevent, treat and cure brain and nervous system diseases, disorders and injuries through medical research.

NeuRA is changing the face of research into neurological diseases and is recognised for exceptional research in Parkinson's disease and Alzheimer's disease, other dementias, schizophrenia, bipolar disorder, depression, spinal and child injury, stroke, falls, autism, sleep apnoea and chronic pain.

### **Pain Foundation**

The Pain Foundation is an initiative of the University of Sydney and Royal North Shore Hospital. Pain Foundation is dedicated to discovering new treatments for persistent pain and is regarded as a world leader in its field. Their vision is to find more ways to enable people, children and adults suffering from acute or chronic pain live a better quality of life. Pain Foundation conducts basic and clinical research programs and operates a national and international educational program leading to a Masters qualification in Pain Management.

# The Pyjama Foundation

The Pyjama Foundation supports the dreams of kids living in foster care, helping them reach their potential by assisting them with reading, writing, and providing consistent love and support.

Volunteer mentors called 'Pyjama Angels' are screened, trained, recruited and then matched with a child in foster care. Pyjama Angels visit a child up to 1.5 hours a week to help with their homework, read books aloud and play educational games. In that time, they demonstrate that this child is valued and loved.

Children in care have the lowest education outcomes nationally. By improving their learning skills, The Pyjama Foundation is making a positive, life-long impact.

# Making Waves Foundation

Making Waves Foundation inspires optimism providing free life-skill programs that redefine what's possible for children and young people who experience disability and disadvantage and face an uncertain future.

The sea and sailing provide the perfect environment to achieve these outcomes. Children and young people take charge of a vessel and learn skills that enable them to navigate their way through life, building confidence, self-esteem, and

relationships for, and between, those who come on board.

In this way Making Waves Foundation changes lives and society's perception of those facing disability or disadvantage, creating the conditions for optimism to blossom in our community.

#### Rural Aid

Rural Aid is one of Australia's largest rural charities. Well known for the highly successful Buy a Bale campaign, the charity also provides financial assistance, water and counselling to farmers in times of drought, flood or fire. Other initiatives support its vision that farming and rural communities are safeguarded to ensure their sustainability both during and after these natural disasters.

### **Stand Tall-The Event**

Stand Tall is traditionally a one-day annual event in Sydney that brings together secondary students from across NSW, inspiring them to change the course of their lives and build hope for the future. Established to directly address the increasingly high incidence of mental health issues in young people, with one in four secondary students suffering from significant psychological problems, Stand Tall not only impacts those students who are known to be suffering, but most importantly the ones who slip under the radar.

In 2020, Stand Tall reached hundreds of schools across the nation due to live streaming the entire day from ICC Studios.

## Sunnyfield

Sunnyfield's mission is to enrich the lives of people with disability by creating choice, opportunities and skills for life. They support people with intellectual disability to increase their independence and live a meaningful life of their chosing. Sunnyfield provide services throughout NSW and in the ACT in the areas of accommodation, social and community participation, supported employment, skills development, support coordination and clinical services.

## Westpac Rescue Helicopter Service

The community's own Westpac Rescue Helicopter Service is a world-class aeromedical emergency service operating since 1975. No one has ever paid to be assisted by the rescue helicopters. That is because people in our community, along with the NSW Government, through NSW Health and NSW Ambulance, provide the funds to ensure the rescue helicopters are there when, and where, they are needed 24 hours a day every day of the year.

The unique sponsorship relationship with Westpac is recognised as one of the longest serving corporate partnerships in Australia's history. Every dollar raised

is valuable and helps to ensure the Service remains a vital link in the emergency care chain.