

Mito Foundation
Project Report for Society for the Study of Inborn Errors of
the Metabolism
June 2019

Project Title:	Brisbane Mito Information Day
Project Aim:	To empower and inform the Mito Community in Queensland
Grant:	AUD\$3,774 (€2,500)
Project Date:	25/05/2019

Mitochondrial Disease and the Mito Foundation

Mitochondrial disease (mito) is a debilitating genetic disorder that robs the body's cells of energy, causing multiple organ dysfunction or failure. It's terminal, there is no cure and few effective treatments.

One Australian child born each week will develop a severe or life-threatening form of mito. Although you may not have heard of it, it's the second most commonly diagnosed, serious genetic disease after cystic fibrosis, affecting 1 in 5000 people.

The Australian Mitochondrial Disease Foundation funds essential research into the diagnosis, treatment and cure of mitochondrial disorders, and supports sufferers and their families.

Project Update

The Brisbane information day, supported by SSIEM, took place on 25th May at the Queensland Children's Hospital.

42 people attended the event from all over Queensland, including Sunshine Coast, Gold Coast, and Mackay. There were also patients from northern NSW. This turnout is three times higher than at information days in other cities earlier in the year.



The presentations at the Information Day focussed on managing the symptoms of mito:

- Accredited Exercise Physiologist Brent Nichol spoke about the benefits of exercise for Mito.
- Psychologists Andi Alperin and Anna Hickling discussed the relationship between mental health and mito.
- Fiona Davis from allied health services provider Therapy Pro spoke about accessing the NDIS and how the different types of allied health practitioners can improve an individual's quality of life.
- Patient speakers David Collyer and Rebecca Patterson also gave very moving presentations about caring for and living with mito and how it has affected them.

The attendees varied greatly in all aspects, there were whole families, couples and both young and old. People came from rural towns and cities. There were patients that have confirmed mito who were helping those who suspected they had it and were looking for information on being diagnosed.

"Thank you so much for the amount of effort you put into the Brisbane info Day. Please pass onto the team that not only myself but my family and a few other people commented to me on how well you ran the day and the manner and engagement you had with everyone was impeccable. So thank you from QLD."
Rebecca Patterson, mito patient.

Thank you to the Society for the Study of Inborn Errors of the Metabolism for enabling this Information Day to go ahead. Thanks to you 42 people affected by mito feel more informed and empowered.

Caroline Christensen
Development Manager
Caroline.christensen@mito.org.au
02 8033 4113