



#bloodylongwalk



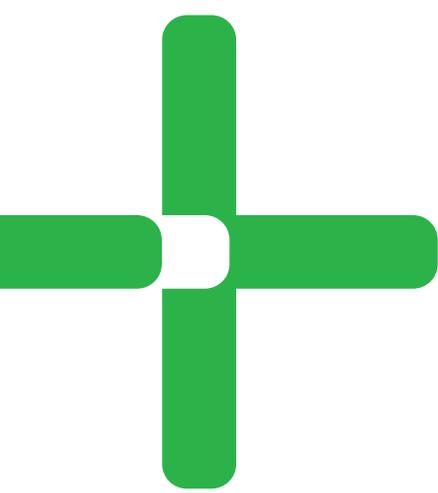
Like Comment Send

bloodylongwalk Made it!!!!!!! #bloodylongwalk #35km #finisher  
#walkingtocuremito #amdf  
30 SECONDS AGO

Sophia, Toni and Alana

# ANNUAL REVIEW

# 2018



**mito+**  
**FOUNDATION**  
Hope for mitochondrial disease

# THE MITO FOUNDATION

## MISSION

To support the mitochondrial disease (mito) community whilst seeking cures.

## VISION

To be the pre-eminent source of energy and hope for the mito community.

## VALUES

**Unrelenting:** We will work tirelessly and urgently to make a difference to those affected by mito.

**Caring:** We will show empathetic support for everyone impacted by mito.

**Professionalism:** We are a peak body whose team members communicate effectively, and operate in an ethical and transparent manner at all times.

**Gratitude:** We are accountable for the support we receive at all levels by appropriately acknowledging and expressing gratitude.

**Lean:** We optimise our resources to ensure that every dollar has maximum impact for the mito community.

## STRATEGIES

**Support:** Improve the experience of mito patients and families by offering a range of Mito Foundation and community generated activities that result in the mito community feeling cared for, heard, supported and empowered.

**Research:** Drive research into mito by identifying and funding strategic research initiatives that improve diagnosis and treatment, and translate into preventions and cures.

**Advocacy:** Transform outcomes for the mito community by advocating to achieve equitable access to high quality diagnosis, treatment and support for all patients.

**Education:** Increase awareness and understanding of mito by educating those affected, and key decision makers, to make mito mainstream.

**Fundraising:** Maintain and grow sustainable fundraising practices to enable and drive all of the Mito Foundation's work.



Fiona and Aidan

# A MESSAGE FROM OUR FOUNDER AND OUR CEO

**As Chairman and CEO, we spend our time searching for ways to improve the lives of those with mitochondrial disease (mito). Both of us have suffered the loss of loved family members from this devastating disease, and this gives us a commitment to drive the Mito Foundation forward. With the guidance of the Board, members of our expert advisory panels and small team of dedicated staff, we are heartened that so much progress has been made.**

The financial year 2017/18 has been one of significant growth across the Foundation's four key areas of support, research, education and advocacy. The Foundation continues to add support services for mito sufferers and education events for medical professionals as well as the mito community. It has actively advocated for legislative change to prevent mito being passed from mother to child, and it continues to fund research into better diagnostic techniques, more effective treatments and cures.

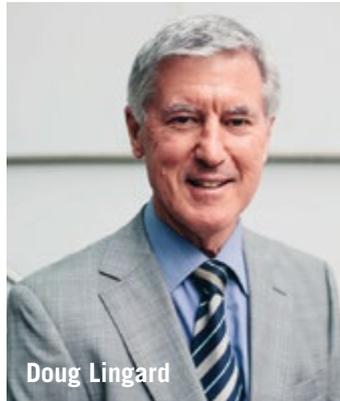
As the only not-for-profit, patient-oriented organisation in Australia focusing on mito the Foundation is committed to listening to its constituents – those people who are personally affected by this awful disease. Over the years, people in the mito community have begun referring to the 'Australian Mitochondrial Disease Foundation' as simply the 'Mito Foundation'. It's less of a mouthful and easier to remember. So we've taken on the feedback and from July 2018 embraced Mito Foundation as our operating name. We remain incorporated as the Australian Mitochondrial Disease Foundation. Throughout this report we will use our new name, however please be aware that during the financial year 2017/18 the organisation was publically known as AMDF.

Every year we are impressed at the lengths some people go to help others affected by mito – either through their fundraising efforts, by raising awareness with their stories, using their contacts and influence, or by volunteering their time. To show our gratitude many were given a special AMDF Award during Global Mitochondrial Disease Awareness Week. The impact these individuals have made is substantial – so thank you.

We are fortunate to have a wealth of expertise on our Board and advisory panels. The contribution each member has made is immeasurable. The Foundation continues to be the peak body for mitochondrial disorders in Australia and regularly collaborates with similar organisations both locally and internationally.

The Foundation does not receive any sustained government funding and so relies on the generosity of its supporters, both those who donate directly and those who invite donations from friends and family through events in their local community. The Bloody Long Walk and Stay in Bed Day continue to be our major community events. We are also very grateful for the financial and in kind support we receive from companies, trusts and foundations.

On behalf of the Foundation, we thank everyone who has made a difference.



Doug Lingard



Sean Murray

*“The Foundation continues to add support services for mito sufferers and education events for medical professionals as well for as the mito community.”*

*Doug*

**Doug Lingard**  
Founder and Chair

*Sean*

**Sean Murray**  
CEO

## ABOUT MITO

One Australian child born each week will develop a severe or life-threatening form of mitochondrial disease.

Mitochondrial disease is terminal; there are no cures and few effective treatments.

Mitochondrial disease is a debilitating genetic disorder that robs the body's cells of energy, causing multiple organ dysfunction or failure and potentially death.

Mitochondrial disease affects 1 in 5,000 people, making it the second most commonly diagnosed, serious genetic disease after cystic fibrosis.

One in 200 people, or more than 120,000 Australians, may carry genetic changes that put them at risk of developing mitochondrial disease or other related symptoms including diabetes, deafness or seizures during their lifetimes. Many of these people are symptomatic but undiagnosed or misdiagnosed. Some are not yet symptomatic, and others are unknowingly at risk of passing on the disease to their children.

Mitochondrial disease is highly complex and takes many forms.

Mitochondrial disease can cause any symptom in any organ at any age.





## OUR SUCCESSES

### SUPPORT

The Mito Foundation's support services, which are some of its most important activities, continue to grow. The team offers practical information regarding medical specialists via the Mito Professionals Directory, updates on research at Information Days, puts those affected in contact with others through the Support Network and is always happy to offer an empathetic ear on the Helpline.

#### During the Financial Year 2017/18:

- 8 Mito Connect teleconference calls
- 7 Information Days
- 9 travel grants  
to enable people to attend Information Days
- 9 support group sessions
- 14 publications of new fact sheets
- 60 individuals have joined the Mitochondrial Disease Patient Registry (Mito Registry)
- 3,500 'interactions' in the mito community Facebook group

### RESEARCH

Thanks to the generosity of our donors, we approved funding for more research projects than ever before. Some projects continued from previous years; we have highlighted some of the key programs. Each project was chosen because of its expected impact on those affected by mito.

#### Project 1 – Booster Grant (\$75,000):

Aims to improve genetic testing and diagnosis of mito patients. Early diagnosis will avoid the ongoing pain and heartache of searching for answers. It will improve access to specialist care, clinical trials and allow patients to make informed reproductive decisions.

#### Project 2 – Booster Grant (\$75,000):

Will establish the first national clinical database for

adult patients. The project will help determine optimal standards of care and evaluate current standards. It will encourage future clinical trials in Australia and assist in family planning options.

#### Project 3 – Clinical Trial Support Grant (\$225,000):

This project will play an important role in attracting more clinical trials to Australia, giving access to potentially lifesaving drugs trials to Australian mito patients. It will support the set up of an Australian Clinical Trials Network for Mitochondrial Disease (ACTN-MD). The model will then be tested by running a clinical trial using a drug, idebenone, to reduce visual loss.

#### Project 4 – Partnership Grants (\$200,000):

The Mito Foundation, in partnership with the Australian Genomics Health Alliance, continues to fund research into next generation sequencing. This project compares genomic testing methods with current diagnostic methods to assess its cost effectiveness and efficacy. The project will form the evidence base for nationwide implementation of genomic testing.

#### Project 5 – Partnership Grants (\$100,000):

The Mito Foundation and the Lily Foundation (UK) are funding a pioneering project to develop nucleoside therapy as a treatment for mitochondrial depletion syndromes. This research project, which hopes to be a precursor to future drug trials, will study treatment formulations on skin cells taken from patients with mitochondrial depletion syndrome RRM2B.

#### Project 6 – Partnership Grant (\$90,000):

Progress continues to be made on this longitudinal study which aims to develop a less invasive, faster and more accurate diagnostic technique. The study first received funding from us in 2015 and will determine the use of FGF21 and GDF15 in diagnosis and predictions and disease progression in paediatric mitochondrial respiratory chain disorders.

#### Project 7 – Translational Research Grant (\$287,000):

Australian children with suspected mito will have the best possible opportunity to achieve a diagnosis, thanks to this project. It will underpin the ongoing sustainable provision of genomic and functional genomic testing.

### **Project 8 – Project Grant (\$40,000):**

The Mito Foundation is working with the International Centre for Community-Driven Research to understand the experience of people diagnosed with mito and what they want to see from future treatment, care and support. This PEEK (Patient Experience Expectations Knowledge) study into mito is the largest of its kind and will provide valuable insights to drive change.

### **Project 9 – Project Grant (\$145,500):**

Planning for an innovative new telehealth project progressed. It will enable more patients to be seen by specialists and will avoid patients having to undergo the challenges of travelling to the clinic for each appointment.

### **Project 10 - Research Fellowship (\$200,000):**

Effective treatments for mito are incredibly limited. Research into understanding the basic biology and physiology of mitochondria is a vital step in the development of medical treatments. This project will investigate how mitochondrial protein import dysfunction leads to mito.

### **Project 11 – Translational Research Grant (\$75,000):**

Will evaluate the economic benefit of using whole genome sequencing (WGS) to diagnose mito. It will compare the cost of using non-invasive WGS to the current diagnostic approach of clinical testing and muscle biopsy.

## **ADVOCACY**

Australian families are now closer to accessing mitochondrial donation, a potentially lifesaving IVF technique. It can prevent certain types of mito being passed on from mother to child. A Senate Report released in June 2018, recommended a pathway to legislative change. The actions of the mito community were instrumental in this decision. Thank you to everyone who spoke to their MP, provided submissions to the Senate Inquiry, spoke at the Senate Hearing and shared their stories through the media.

The Services Team worked with parents and schools to provide the best outcome for school children with mito. They also advocated to get the greatest benefit for individuals from the National Disability Insurance Scheme and in many other ways.

## **EDUCATION**

One of the major challenges faced by people with mito is finding a GP who understands the disease – to recognise its many and varied symptoms, to know how to manage them and to refer the patient to appropriate specialists. During the FY2017/18, 'Maybe it's Mito', an exciting new education program for GPs was developed. GPs will be able to earn Continuing Professional Development Points by completing a module through Australian Doctor from September 2018.

The Mito Foundation has developed a school education kit called 'Mito 4 Kids'. It contains information and activities for children from kindergarten to year 6 and can be downloaded from [mito.org.au](http://mito.org.au). School age mito patients and their siblings can find it challenging when

their teachers and classmates don't understand what it means to have mito, and this program is designed to improve their knowledge.

Global Mitochondrial Disease Awareness Week proved successful with many activities taking place. More than 100 monuments lit up green around the world, including 34 in Australia, as part of the 'Light Up for Mito' campaign.

The Foundation hosted a symposium for researchers, clinicians, and members of the mito community on mitochondrial donation. We took the opportunity to recognise some of our outstanding supporters, as well as the important contribution four GPs made to their patients.

Since 2010, the Foundation held a stand at NSW Parliament House during Awareness Week. Staff spoke to MPs about mito and invited them to wear green awareness ribbons.

Stay in Bed Day concluded Awareness Week with schools holding pyjama days, members of the mito community getting sponsored to stay in bed and others organising PJ themed morning teas. More than 58 articles were published in the media (print, online and radio) raising awareness with hundreds of thousands of people.

## **FUNDRAISING**

The Bloody Long Walk National Series 2017 raised \$1.6 million. More than 11,400 registered for the seven 35km walks in Adelaide, Brisbane, Canberra, Melbourne, Perth, Sydney East and Sydney North. The events increased awareness of mito with participants, those who sponsored them, and the many people who saw each event.

In February a fundraising appeal featured a beautiful little girl called Steph (pictured on page 5) who bravely battles mito. A further appeal at the end of the financial year featured the inspiring words of Fiona, the mum of young Adian (pictured on page 3). This appeal included an offer by an anonymous donor to match donations up to \$12,000. The two appeals raised \$39,355.

Community fundraising continued to be a valuable fundraising stream, and we are grateful for those who organised fundraising events. Events included the Ray White Long Lunch, Indie Train, City2Summit, Mito Masters, and many more. Members of the community also fundraised and raised awareness as part of Stay in Bed Day.

The Mito Foundation is fortunate to have a number of ongoing meaningful partnerships with trusts, foundations, and corporations, that together donated \$155,794. The Thyne Reid Foundation played an important role in our advocacy initiative towards changing legislation to allow mitochondrial donation.

Overall the fundraising income in financial year 2017/18 was a 19% increase on the previous financial year.

# YOUR DONATIONS AT WORK

Over the last year your donations have made a **HUGE** difference to people affected by mitochondrial disease – thank you!

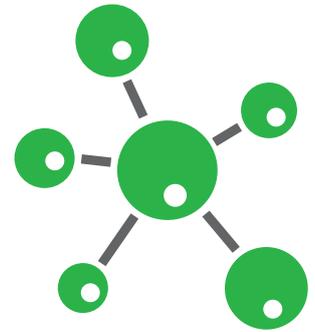


One new school education program, Mito 4 Kids, was launched.



**\$2.5 million**

in additional funding by the Mito Foundation has been made available for vital medical and research projects.



One study into mutations in a tiny molecular component to uncover if and how its functions cause Sengers syndrome, a type of mito.



One Senate Report has recommended a pathway to legislative change to allow Australian families to access mitochondrial donation.



One National Clinical Database is in development and will help improve and standardise patient care.



**6 million**

people heard about mito during Global Mitochondrial Disease Awareness Week.



**70**

children and adults are currently undergoing genomic testing through the Australian Genomics Flagship program. Most will get a conclusive diagnosis avoiding months of painful and invasive tests.



One study evaluating the economic benefit of diagnosing mito using non-invasive whole genome sequencing verses current painful and often inconclusive methods.



One study aiming to improve genetic testing to enable the diagnosis of most patients with mito, enabling them to access specialist care sooner.

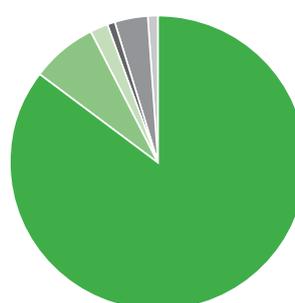
# FINANCIALS\*

Income	30 June 2018
<b>Direct Fundraising</b>	
Mito Foundation Events and Appeals	\$2,184,451
Community Fundraising	\$185,604
General Donations	\$49,277
<b>Total Direct Fundraising</b>	<b>\$2,419,332</b>
<b>Strategic Fundraising</b>	
Corporate Partners	\$23,669
Trusts and Foundations	\$90,706
Major Gifts	\$24,500
<b>Total Strategic Fundraising</b>	<b>\$138,875</b>
<b>Event Income (non-fundraising)</b>	
Event Income	\$1,668,360
<b>Total Event Income</b>	<b>\$1,668,360</b>
<b>Other Income</b>	
Investments	\$26,588
<b>Total Other Income</b>	<b>\$26,588</b>
<b>Total Income (Gross Profit)</b>	<b>\$4,253,155</b>
<b>Operating Expenses</b>	
Event Expenses	\$1,317,171
Fundraising	\$150,346
General and Admin	\$51,273
Rent	\$60,686
Remuneration Packages (Operational)	\$290,368
<b>Total Operating Expenses</b>	<b>\$1,869,844</b>
<b>Operating Profit</b>	<b>\$2,383,310</b>
<b>Program Expenses</b>	
Remuneration Packages (Programs)	\$327,436
Support	\$92,053
Research	\$402,800
Advocacy	\$55,263
Education	\$128,221
<b>Total Program Expenses</b>	<b>\$1,005,773</b>
<b>Net Profit</b>	<b>\$1,377,537**</b>

\* Unaudited financials. Audited financials will be available in 2019.

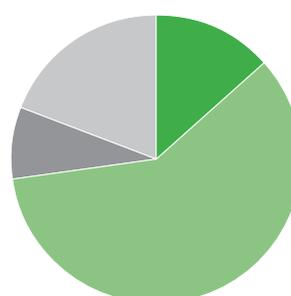
\*\* Targeted for future investments in programs

## Fundraising sources



- Mito Foundation Events and Appeals
- Community Fundraising
- General Donations
- Corporate Partners
- Trusts and Foundations
- Major Gifts

## Your donations at work



- Support Services
- Research
- Advocacy
- Education

# THANK YOU!

**The Mito Foundation is grateful for the significant support of the following, as well as to those who wish to remain anonymous:**

## TRUSTS, FOUNDATIONS AND CORPORATIONS:

ASX Thomson Reuters Charity Foundation  
James N Kirby Foundation  
Jenour Foundation  
Milton Corporation Foundation  
Marian and E H Flack Trust

## IN KIND SUPPORTERS:

Acumen Insurance Proprietary Limited  
Brown Wright Stein Lawyers  
Grant Samuel

## THE MITO FOUNDATION IS PROUD TO COLLABORATE AND BE ASSOCIATED WITH THE FOLLOWING ORGANISATIONS:

Australian Genomics Health Alliance  
Genetic Alliance Australia  
Genetic and Rare Disease Network  
Genetic Services Network Victoria  
Rare Voices  
Research Australia



## Mito Organisations:

International Mito Patients  
The Lily Foundation  
MitoCanada  
MitoAction  
United Mitochondrial Disease Foundation  
Mitocon  
Mitochondrial Medicine Society

**The Mito Foundation acknowledges the mutual support and respect among many of the organisations within the rare disease community.**



To learn more about the Mito Foundation's work and read the stories of those who have generously allowed us to feature their photos in this report, please visit: [mito.org.au](http://mito.org.au)

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02 8033 4113 / [info@mito.org.au](mailto:info@mito.org.au) / ABN: 84 135 324 39

Follow the Mito Foundation on:   



Aidan

# ***LIVING TODAY WITH HOPE FOR TOMORROW***

For anyone affected by mito, or by  
any of the diseases it can cause  
**We're here.**