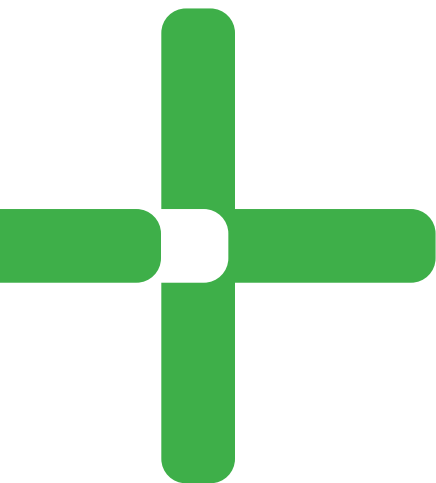




The Edwards Family

ANNUAL REVIEW

2017



amdf+

AUSTRALIAN
MITOCHONDRIAL
DISEASE FOUNDATION



Noah

AUSTRALIAN MITOCHONDRIAL DISEASE FOUNDATION (AMDF)

MISSION

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

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 AMDF 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 AMDF's work.

A MESSAGE FROM OUR FOUNDER AND OUR CEO

While this Annual Review is focused on the financial year 2016/17, it is immensely satisfying to look back over the last nine years and see how far the foundation has come in its efforts to support the mito community whilst seeking a cure.

Support, research, education and advocacy are AMDF's four key areas of focus, and to enable this work we implement a number of fundraising strategies.

Recently there have been significant advances in the understanding of mitochondria, as well as mito, its prevention and diagnosis. Progress is being made towards potential treatments and cures. Feedback from the mito community has led to greater emphasis on support and advocacy, with more services available than ever before. It is a challenge to educate the medical profession and this issue will be addressed next year.

The foundation has expanded from a handful of committed unpaid individuals to a dedicated team of five full time and six part time staff together with an amazing group of volunteers – all focused on serving the mito community. AMDF remains the peak body for mitochondrial disorders in Australia, and regularly collaborates with similar organisations both locally and around the world.

Our dedicated volunteers, board and advisory panel members have been instrumental in the progress that has been made. These people are the core of our organisation and their commitment has made AMDF's accomplishments possible.

The impact made by our donors, community fundraisers, Bloody Long Walkers, Stay in Bed Day participants, trusts, foundations and corporate supporters is substantial. Their financial contribution has given people affected by mito support today and hope for tomorrow.

We are fortunate to benefit from some very special individuals who for years have gone above and beyond. The reliability and effort of those who altruistically give their time to raise funds and awareness, and who provide specialist skills to further AMDF's work, cannot be undervalued. We have not identified them in this Annual Review, instead choosing to thank them personally and publically acknowledging their work through the AMDF Awards.

It is important for us, on behalf of AMDF, to thank everyone who has ultimately made a difference to the lives of those affected by this debilitating disease.

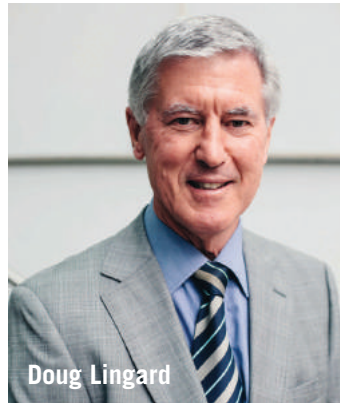
Thank you.

Doug

Doug Lingard
Founder and Chair

Sean

Sean Murray
CEO



Doug Lingard



Sean Murray

“The Australian Mitochondrial Disease Foundation supports those affected by mito, funds essential research into the prevention, diagnosis, treatment and cures of mitochondrial disorders, and increases awareness and education about this devastating disease.”

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 for 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 the disease on to their children.

Mitochondrial disease is highly complex and takes many forms.

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





The Beard Family

OUR SUCCESSES

SUPPORT

In response to mito community feedback, AMDF significantly expanded its support services in the financial year 2016/17. The newly developed 'Mito Connect' program introduced support teleconferences and specific support related emails. Existing services, such as the Facebook group, support group meetings, Information Days, Support Network and the Helpline were improved.

The last financial year marked the first full year of the Helpline being run in-house by AMDF staff. Previously, the mito community benefited from the significant experience and empathy of Dr Karen Crawley, who ran the service as a volunteer. AMDF extends its gratitude to Dr Crawley for her commitment to helping those with mito. The Helpline now incorporates an option for email communication in addition to the telephone. The Services Team responded to hundreds of calls and emails over the year.

The reality of living with mito or seeking a diagnosis is an expensive one. Many families face financial hardship, and travelling costs can be a major barrier to attending an Information Day. Financial assistance from AMDF enabled people to benefit from these invaluable information and support sessions.

More support group meetings were held with some taking place following Information Days, while community members organised others.

One of the biggest challenges faced by those affected by mito is finding doctors who are familiar with the condition and its many complications. To help overcome this, AMDF created the Mito Professionals Directory, which

has proved to be a valuable resource in pairing patients with clinicians.

A new range of downloadable fact sheets on topics including diagnosis, accessing healthcare in rural areas, nutrition and exercise, gave easy access to the latest information.

RESEARCH

AMDF funds research into prevention, diagnosis, treatments and cures for mito.

AMDF has committed \$200,000 over two years to facilitate the genomic testing of people with a strong suspicion of having mito, avoiding months, if not years, of invasive, painful and risky tests. This project, co-funded with the Australian Genomics Health Alliance, will determine the efficacy and cost effectiveness of genomic screening and assist in convincing the government to standardise national testing. The project aims to increase diagnosis rates and shorten the diagnostic journey.

Incubator grants facilitate preliminary investigation which enables researchers to apply for further, external funding to complete their research. One project that received funding hopes to identify compounds that repair the cells' mitochondria. Researchers have developed a method to rapidly test thousands of therapeutic compounds in a cell model. The aim is for these compounds to undergo further testing before being developed into drug formulation, and taken to clinical trials - hopefully leading to a treatment.

AMDF's PhD funding program includes research that will lay the groundwork for drug design and therapeutic intervention bringing viable treatments closer. One such project uses cutting edge techniques to investigate mitochondrial gene expression and energy production to understand how impaired function causes symptoms of mito. PhD grants support future experts, encouraging them to focus their careers in mitochondrial research.

ADVOCACY

AMDF's efforts to change legislation to allow mitochondrial donation in Australia transitioned from planning to implementation. This ground-breaking IVF technique aims to enable affected parents to have biologically related children free from mito. The successful change depends on members of the mito community taking action, and we are grateful to those who have discussed the issue with their local MP. There were meetings with more than 40 MPs and other key decision makers in FY2016/17. An important strategy in educating the general public, as well as key decision makers, was to secure traditional and social media coverage.

AMDF also advocated for individuals in specific situations, such as helping to navigate the National Disability Insurance Scheme.

EDUCATION

Mito affects one in 5,000 people, and yet is still relatively unknown. Education of both the medical profession and general public is vital. In November 2016, AMDF sponsored AussieMit, Australia's premier mitochondrial research conference which highlighted advances in research and acted as a forum for educating clinicians and researchers.

The Schools Mito Education Program was developed in response to calls from parents of affected children. They identified a need for teachers and pupils at their children's schools to learn about mito. Results of a pilot study have been successful, and the program will be rolled out in schools that have a connection to mito.

A number of events marked Global Mitochondrial Disease Awareness Week. AMDF held a symposium focused on the role of mitochondria in major disease. Monuments around Australia were illuminated green as

part of the Light Up for Mito campaign. Stay in Bed Day concluded the week with participants raising awareness through events and on social media.

While The Bloody Long Walk is primarily a fundraising campaign, it provides a unique opportunity to educate participants, most of whom have not heard of mito before. They received targeted emails and phone calls, and engaged in social media. The event had a multiplier effect with participants sharing information among their networks, and allowing AMDF to communicate with their 26,000 donors.

FUNDRAISING

AMDF's flagship fundraising event is The Bloody Long Walk National Series, which raised \$1.6 million in FY2016/17. The most successful fundraisers usually had a mito connection, but it was exciting to see the 95 per cent of participants who had no connection to the disease also raising significant funds.

AMDF ran Christmas and Tax Appeals and raised funds through Stay in Bed Day and other events. AMDF is grateful for the support of its community fundraisers, who not only raise vital funds, but also awareness.

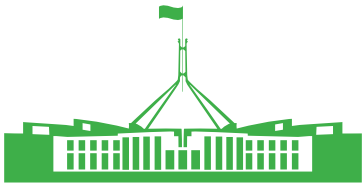
Strategic fundraising, including trusts and foundations, major donors, and corporations, contributed just under \$350,000. AMDF is working to establish and strengthen relationships with philanthropic funders across Australia to grow this area of fundraising.

AMDF's diverse fundraising streams ensure it is a sustainable entity. Each year fundraising offerings are reviewed to maximise efficiency and effectiveness, and to optimise opportunities to increase income.

AMDF's strategic plan calls for a 10 per cent growth of fundraising year on year for five years. The increase from FY2016 to FY2017 was 47 per cent, due largely to significant growth in The Bloody Long Walk and strategic fundraising. This rapid growth gives AMDF significantly more capacity to deliver its mission.

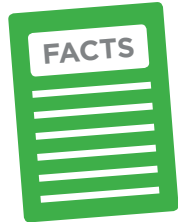
YOUR DONATIONS AT WORK

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



40

MPs and other officials received personal briefings on mitochondrial donation. This initiative seeks to change legislation to enable parents to have disease-free children.



18

information packs, fact sheets and other new resources for people with mito and medical professionals were produced.



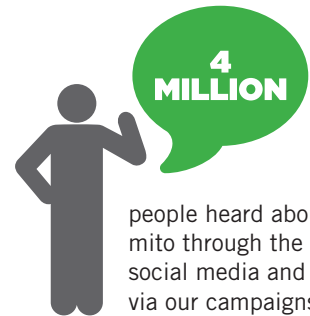
331

patients and carers benefited from Information Days, support group meetings and Mito Connect calls.



200

people suspected of having mito will have access to free genetic testing. This revolutionary genomics study, co-funded by the Australian Genomics Health Alliance, aims to diagnose every Australian with mito and to facilitate faster access to specialist care.



4 MILLION people heard about mito through the media, social media and emails via our campaigns.



160

researchers, clinicians and patients shared the latest developments in research at Australia's premier mito conference, AussieMit.



97 information packs were provided to GPs to assist them in delivering the best care to their patients.

93



93 medical professionals joined the new Mito Professionals Directory, making it easier for those affected to find doctors who understand mito.



100 children participated in a pilot Schools Education Program about mito.



5 PhD scientists continued vital research into mito thanks to AMDF grants.



300 patients joined the Mito Patient Registry since establishment. They will hear about upcoming clinical trials first and will help identify areas of low diagnosis across Australia.



298

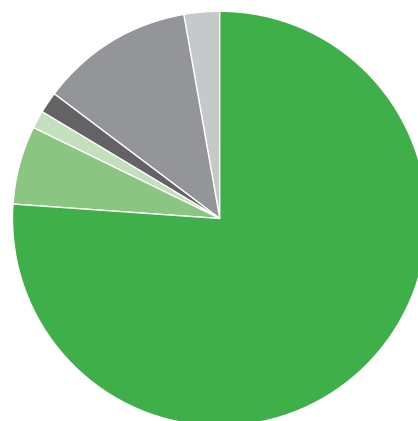
298 people contacted the Helpline for assistance with identifying specialist doctors, managing symptoms, accessing disability benefits and simply an empathetic ear.

FINANCIALS

Income	30 June 2017
Direct Fundraising	
AMDF Events and Appeals	\$1,637,696
Community Fundraising	\$127,871
General Donations	\$34,609
Total Direct Fundraising	\$1,800,177
Strategic Fundraising	
Corporate Partners	\$35,196
Trusts and Foundations	\$253,178
Major Gifts	\$58,015
Total Strategic Fundraising	\$346,390
Event Income (non-fundraising)	
Event Income	\$791,752
Total Event Income	\$791,752
Other Income	
Investments	\$16,824
Total Other Income	\$16,824
Total Income (Gross Profit)	\$2,955,142
Operating Expenses	
Event Expenses	\$798,877
Fundraising	\$134,163
General and Admin	\$44,453
Rent	\$22,490
Remuneration Packages (Operational)	\$274,670
Total Operating Expenses	\$1,274,654
Operating Profit	\$1,680,489
Program Expenses	
Remuneration Packages (Programs)	\$274,670
Support	\$20,241
Research	\$79,393
Advocacy	\$76,125
Education	\$100,020
Total Program Expenses	\$550,450
Net Profit	\$1,130,039*

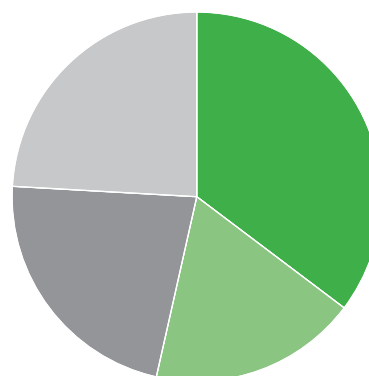
* Targeted for future investments in programs

Fundraising sources



- AMDF 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!

AMDF is grateful for the significant support of the following, as well as to those who wish to remain anonymous:

TRUSTS, FOUNDATIONS AND CORPORATIONS:

Andrews Foundation
ASX Thomson Reuters Charity Foundation
Bennelong Foundation
Coopers Brewery Foundation Inc
Courtney-O'Connor Foundation
Coxswain Alliance
Dick Smith Foods Foundation
Gandel Philanthropy
ITS PipeTech
James N. Kirby Foundation
Jenour Foundation
Milton Corporation Foundation
QBE Foundation
Thyne Reid Foundation
UBS Australia

IN KIND SUPPORTERS:

Acumen Insurance Proprietary Limited
AMP Capital
Brown Wright Stein Lawyers
Grant Samuel

AMDF acknowledges the mutual support and respect between many of the organisations within the rare disease community.



AMDF 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
Human Genetics Society of Australasia
Metabolic Dietary Disorders Australia
Rare Voices
Research Australia

Mito Organisations:

International Mito Patients
The Lily Foundation
MitoCanada
MitoAction
United Mitochondrial Disease Foundation



To learn more about AMDF's work and the read the stories of those who have generously allowed us to feature their photos in this report, please visit: amdf.org.au

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Follow AMDF on:





Will and Tom

LIVING TODAY WITH HOPE FOR TOMORROW

For anyone affected by mito, or by
any of the diseases it can cause

We're here.