

Australian Mitochondrial Disease Foundation 2015 Services Survey Report

The Australian Mitochondrial Disease Foundation (AMDF) 2015 Services Survey gathered information from AMDF supporters in regards of their use and opinions of the patient services currently offered by the foundation.

The survey was sent to 326 AMDF contacts via email. They were chosen due to their personal connection with mitochondrial disease, or the fact that they had joined the Mitochondrial Disease Patient Registry. It was also advertised via social media and the AMDF website. A total of 75 people completed the survey.

The areas examined by the survey were:

- Website
- Online resources
- School pack
- Helpline
- Information days
- Social media
- eNewsletter
- Mitochondrial Disease Patient Registry
- Advocacy
- Support Groups

The key areas of feedback were:

- There was an overwhelmingly positive response about the AMDF Helpline. The work of Dr Karen Crawley was lauded and there was a consensus that this is the most useful of the services AMDF currently offers.
- Most responses on online resources were positive, with the majority of people happy with the amount of communications they receive from the eNewsletter and social media.
- In regards to the Mitochondrial Disease Patient Registry, the majority of people have found the process of signing up simple and they are happy with the AMDF privacy policy. However there was a distinct majority of respondents who had not signed up, due to being unaware of the registry.
- The majority of feedback involved a need for personal contact with other patients or carers. Suggestions for contact included support groups, online forums and newsletters.
- In regards to the support groups, while there was a desire for them, there is a distinct lack of responses from people willing to assist in organisation of groups.
- Information days are currently the only service AMDF offers which are face-to-face and while these are well received, there is the desire for these to run in areas besides capital cities.

Recommendations

In response to the survey and furthering its commitment to supporting people affected by mito, AMDF has developed the following initiatives.

Support groups

- Maintain AMDF Facebook group as a virtual support group.
- Incorporate support sessions into existing Mito Information Days.
- Establish support groups in conjunction with guest speakers via teleconference.
- Establish face-to-face support groups around Australia connecting community members who live in close proximity.
- Extend the AMDF Support Network to enable more people to connect. (Support Network established October 2015)

Advocacy

- Advocate for members of the mito community to ensure they receive the support they are eligible for.
- Collaborate with other rare disease not-for-profit organisations to gain greater recognition with the government.
- Stimulate government funding for medical research through support of the Medical Research Future Fund Action Group.
- Develop an advocacy program to educate politicians about the challenges faced by mito patients and gain their commitment to help make changes.
- Campaign for changes in Australian legislation to legalise mitochondrial donation enabling women who carry the genetic mutation to have children free of mito. (Two symposia held in September started the conversation about the technique in Australia.)

Education

- Provide a Parent and Teacher Resource Kit to parents of children affected by mito to share with their child's school. (Pack created November 2015)
- Commence a mito education project in primary schools.

Research

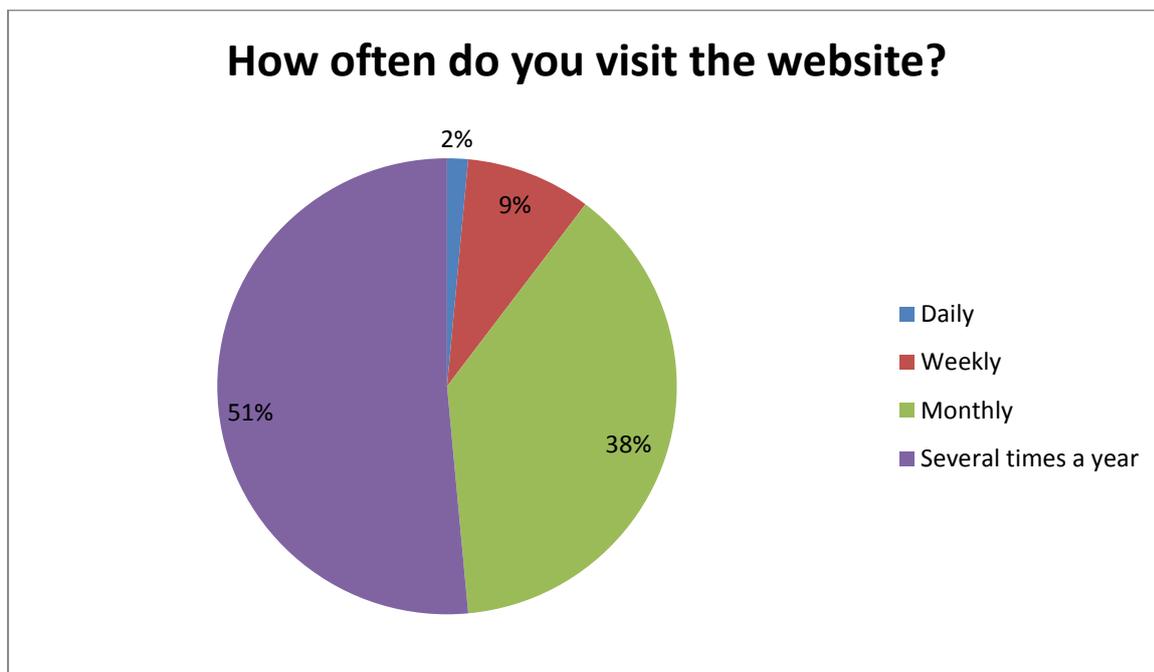
- Fund research designed to assist patients and carers on a daily basis, for example investigating out of pocket expenses for people and families affected by mito.
- Collaborate with prominent research institutes around Australia to attract and retain leading scientists and researchers into the field of mitochondrial disease research.
- Position Australia as a prime location for clinical drug trials and inform those on the AMDF Mitochondrial Disease Patient Registry of relevant studies. (Permanent Mito Registry article added to the eNewsletter to increase awareness within mito community)

Resources

- Create Living with Mito section on the website. (Article on exercise published October 2015)
- Provide information about the National Disability Insurance Scheme. (Web page created December 2015)
- Provide information regarding government payments and support services through agencies such as Centerlink.

AMDF Website

The AMDF website is the first port of call for many Australians looking for information on mitochondrial disease. The website contains information on the disease itself, as well as resources for patients, research and medical news, upcoming events and media attention.



The AMDF website has been visited by 90% of survey respondents. Of those who have not visited the site there was an even split in responses, with 50% not being aware of the website, and 50% not needing to visit (*I find websites less than perfect. The AMDF doesn't offer useful services to me so the newsletter gives me enough information*).

The opinions of the layout were generally positive (*Fairly easy to navigate. Looks good and not too clustered. Pleasant colours. / Nice set-out, great information*) There was some criticism on how the website is laid out (*The moving images are annoying/ Couldn't find what I was looking for*)

Following on from the previous question, there were quite a few suggestions for improvements for the site (*[It needs] new updated information, similar to the American site/ Slow down the front page banner so you can read it/ Let other parents know that there are other families around that they can talk to/Make it easier to find the helpline number/ Make it faster/ Maybe the date when future mito is on the media?*)

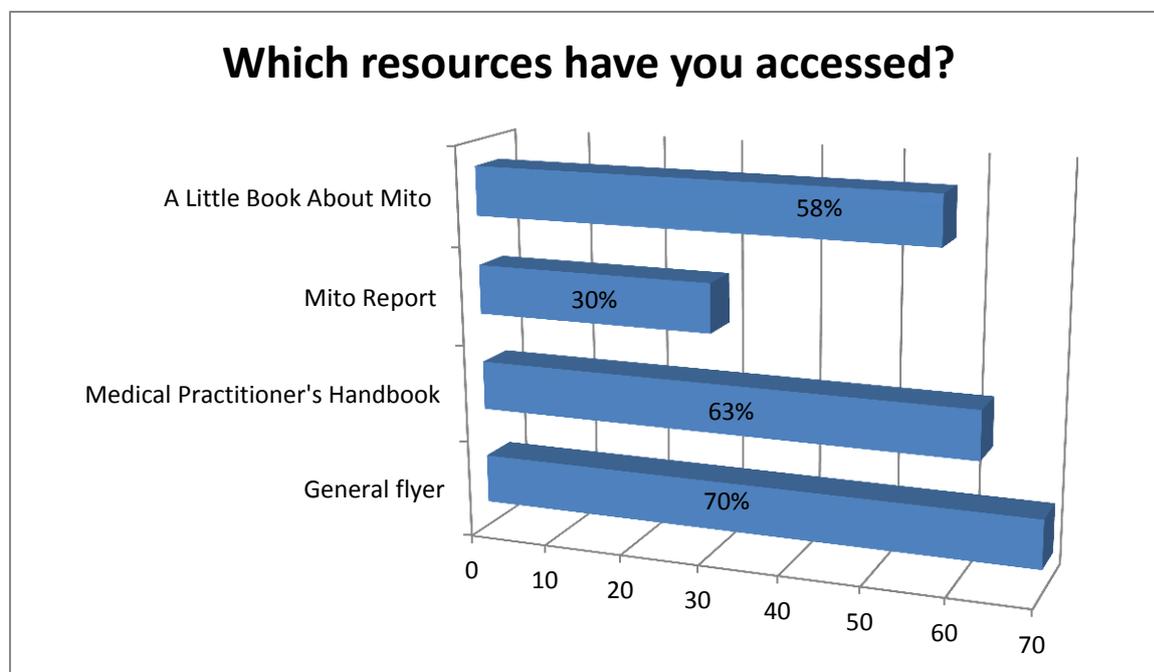
Respondents were asked if they believed that the site was missing any crucial aspects. Some of the responses received included: *List of doctors specialising in mito and treatments/ Current research taking place around the world/ Information on new drugs and patients trials/ [I'm]looking for more information on management of mito... Diet, exercise especially in over 40s [with] onset of MELAS symptoms.*

Some general feedback on the website:

- “I feel there should be a 'suggestion' page included in the website. Perhaps also include a 'bulletin board' so that parents who would like to advertise a wheelchair or other equipment that they want to sell or give away to other parents in need can put their details and a photo on the site to enable other parents to get in touch with them.”
- “It's easy to navigate and find everything. An obvious FB link to the group page. I only stumbled onto the FB page by chance, and went from there to the website. All of my previous searches ended up on overseas mito websites.”
- “Do something to bring your technology up to date and make it user friendly with practical interesting patient and carer information in it. Don't be afraid try it.”
- “We find it very informative and well laid out. The stories of mitochondrial sufferers are interesting and it really brings it home how hard some of their lives must be. But you keep news and reports up beat and positive and very up to date. Your Facebook entries are also a constant reminder of how much people are doing to help raise money and to keep the disease in the news.”
- “Maybe a list of where/how families/patients can get support”

Resources

Currently AMDF offer a range of resources to patients, including flyers, medical practitioner handbooks, fact sheets and The Mitochondrial Disease Report. There is also a list of patient services on the website.



Feedback included: *Haven't looked at these because haven't found them. Not obvious. Would be interested/Karen Crawley: she is the best resource the AMDF has. "Living well with Mitochondrial Disease" was a really good book also.*

Some suggestions for further resources include *information on exercise/ group email lists for people suffering the same disease/ How to cope - emotional resources - for parents with dying children /more information on clinical trials or research happening overseas/ Specialised section for doctors/ A whole lot more on help and management/ Key symptoms of the various forms of mito/ Something for schools with kids with mito*

Some general feedback on the resources:

- “A little mito book is excellent”
- “Could have them in doctors waiting rooms and hospitals”
- “They were really good. I gave the General Practitioner the handbook which she appreciated as she has little understanding of mito disease and she then has been better able to understand some of the issues that I have to deal with and how to help me.”
- “With the exception of a little book about mito which is good for kids, the rest give you a degree of information. But as a sufferer you are always going to search and research your disease more and more with your neurologist and on the internet”
- “More about adult disease would be good.”

School Pack

The school pack is a proposed information pack that will be sent to schools to educate teachers and students on mitochondrial disease. They will primarily be used in schools where children suffering from mitochondrial disease attend.

24% of respondents answered that they have trouble conveying information about mito to their child’s school.

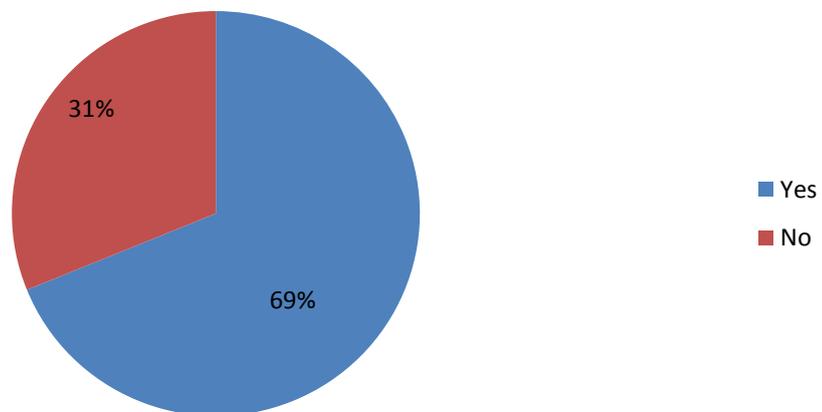
Some struggles that have been encountered include *Just getting them to understand that some days they function just like every other boy and girl and other days they struggle to walk and talk. That they are not making it up/ Teachers not communicating with home/ Ensuring school and community are aware of the serious and complex nature of mito disease. Keeping them informed of changes that can and do occur on a daily basis for patients with mito. Helping support them so they feel comfortable and confident to cater to your child’s needs in an educational setting whilst being aware of, and having enough information to be able to support, monitor and intervene if necessary to keep your child safe whilst helping them learn and develop.*

To assist with these struggles, respondents have suggested that the school pack could contain *Information for parents for when problems arise with school / procedures protocol/ maybe an easy DVD with someone explaining it very simply/ A template documenting any modifications child needs to help them learn (teaching aids, physical aids, physical modifications to school classroom and/or access to school), a medical checklist Health Care Plan including list of scheduled medications and/or seizure action plan, a template outlining special considerations as a result of their mito diagnosis to be documented as part of individuals IEP in an educational setting (e.g. rules of attendance, best time of day for energy intensive activities, guidelines for rest periods for downtime, variable schedule for high/low activities etc)*

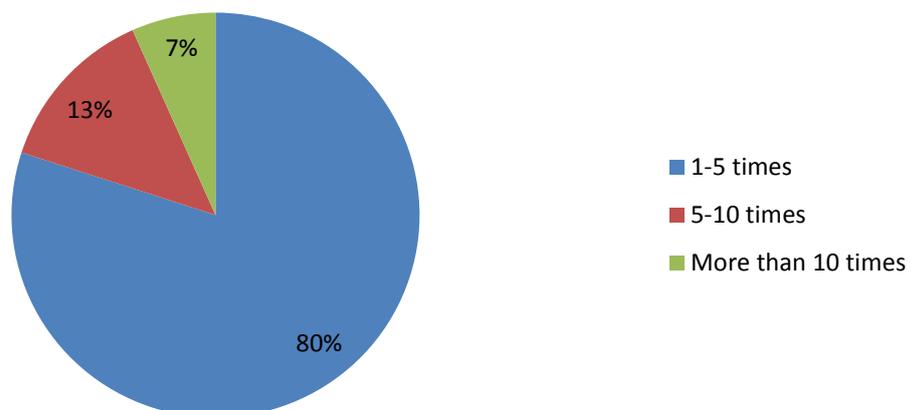
Helpline

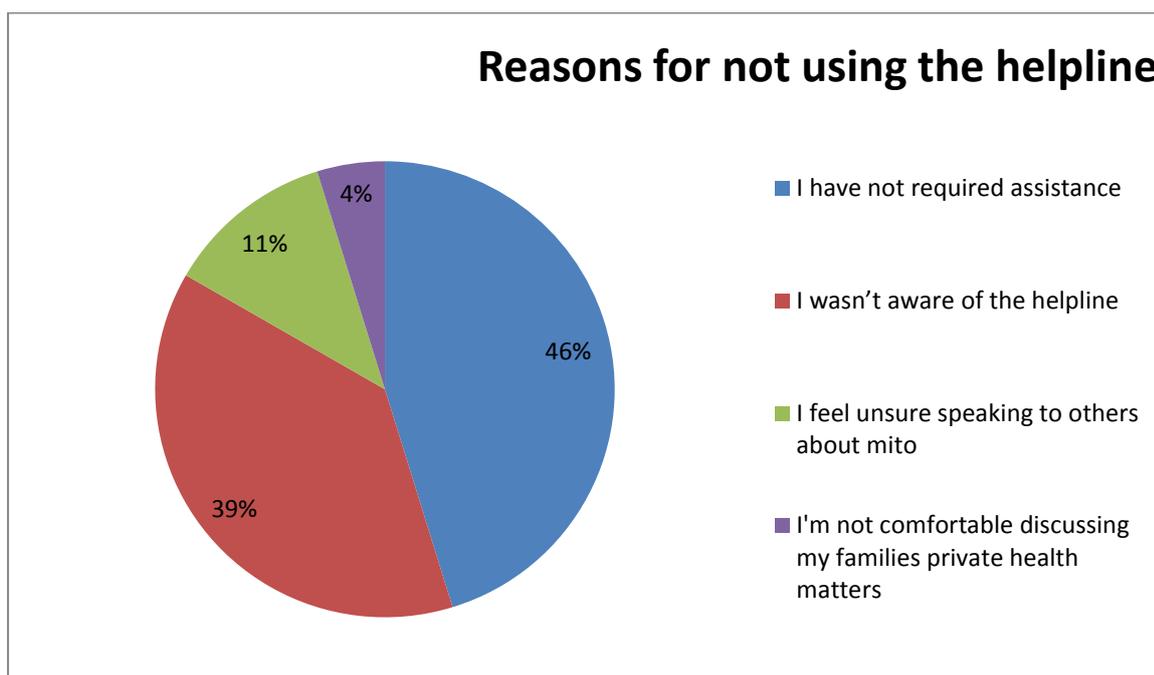
The AMDF runs a helpline, coordinated by Dr Karen Crawley. The helpline is designed to support patients looking for information on mitochondrial disease and medical professionals. It also offers a place for people who are looking for emotional support.

Were you aware the AMDF provided a helpline?



How many times have you called the helpline?





Feedback included: *Already know a lot. Live non-NSW rural area so wouldn't expect more knowledge of local resources than I already have either / I didn't feel a part of the mito community enough to use it / I haven't used the helpline but I have emailed Karen. I'm hesitant to ring as I imagine she is extremely busy & feel my questions are comparatively minor compared to others. Karen has been very helpful though. 75% of all respondents answered that they would use the helpline in the future.*

When asked if the respondent had received the information they were looking for by calling the helpline, some responses included *Yes, Karen is a wealth of information! / yes exactly, I wanted to know the best way for me in Melbourne to get a diagnosis. / Karen is the most amazing woman who provides realistic information that is really helpful, even if it is not what you want to hear*

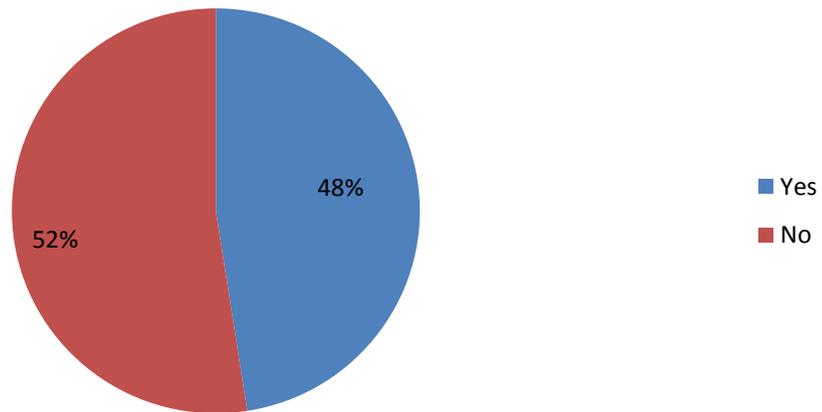
Some general feedback on the helpline:

- “Personal and helpful advice given”
- “This is a wonderful service provided by an extremely knowledgeable doctor with an intimate understanding of mitochondrial conditions, available services, and how best to access them. Dr Crawley is amazing and an invaluable asset to the AMDF.”
- ‘Dr Karen was great but she needs other doctors to help.’
- “It's an amazing service”
- “I have not used the helpline but it’s good to know that it's there if I would ever need it.”

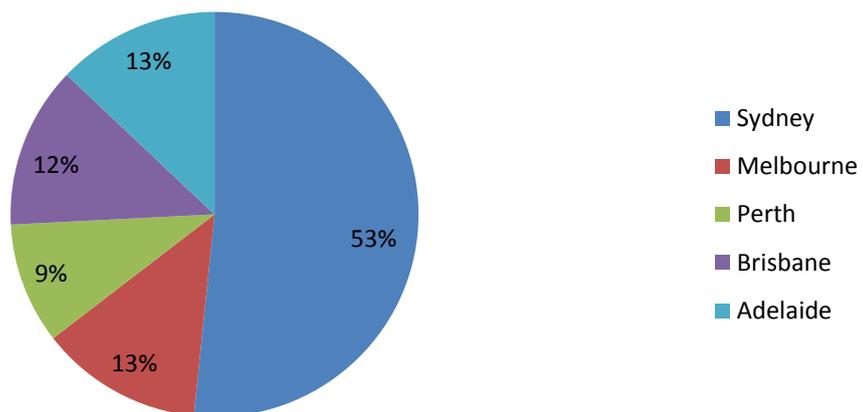
Information Days

Currently AMDF hosts Information Days in Sydney, Melbourne, Adelaide and Brisbane at least once a year. These sessions include presentations from clinicians, researchers and patients. They also provide an area for networking amongst patients and carers.

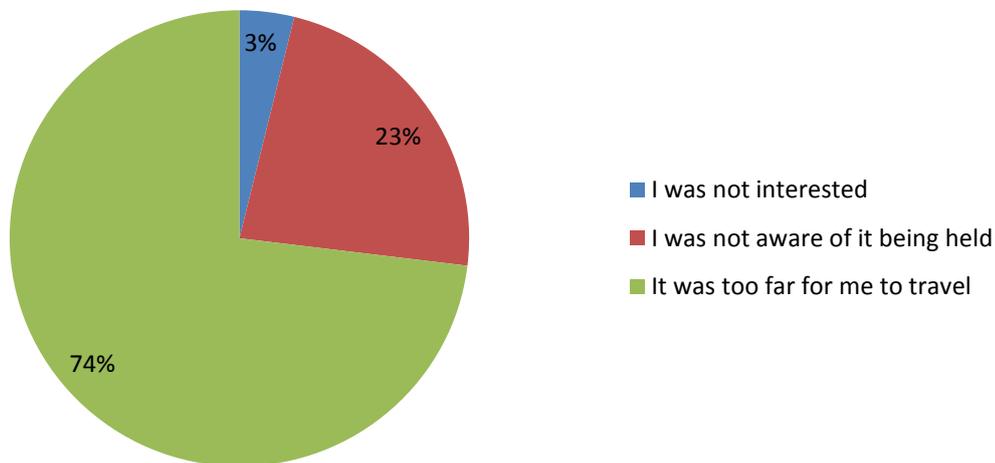
Have you ever attended a mito information day?



In which city have you attended a mito info day?

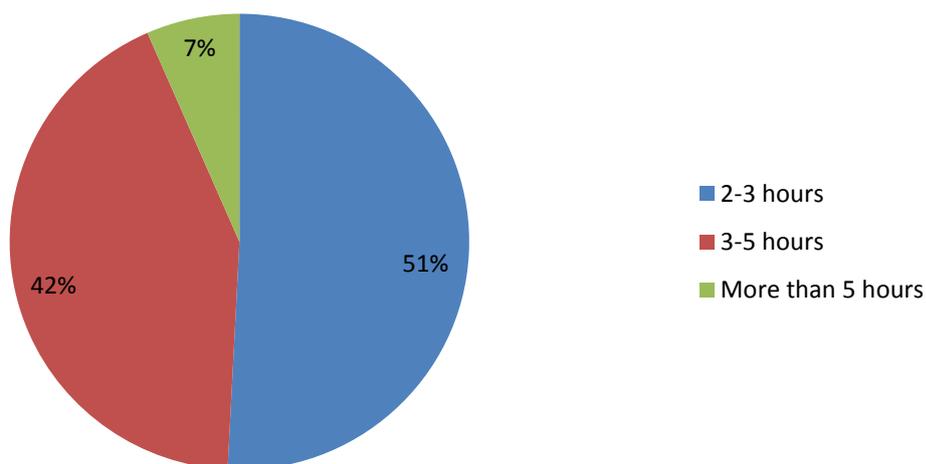


Reasons for not attending an info day

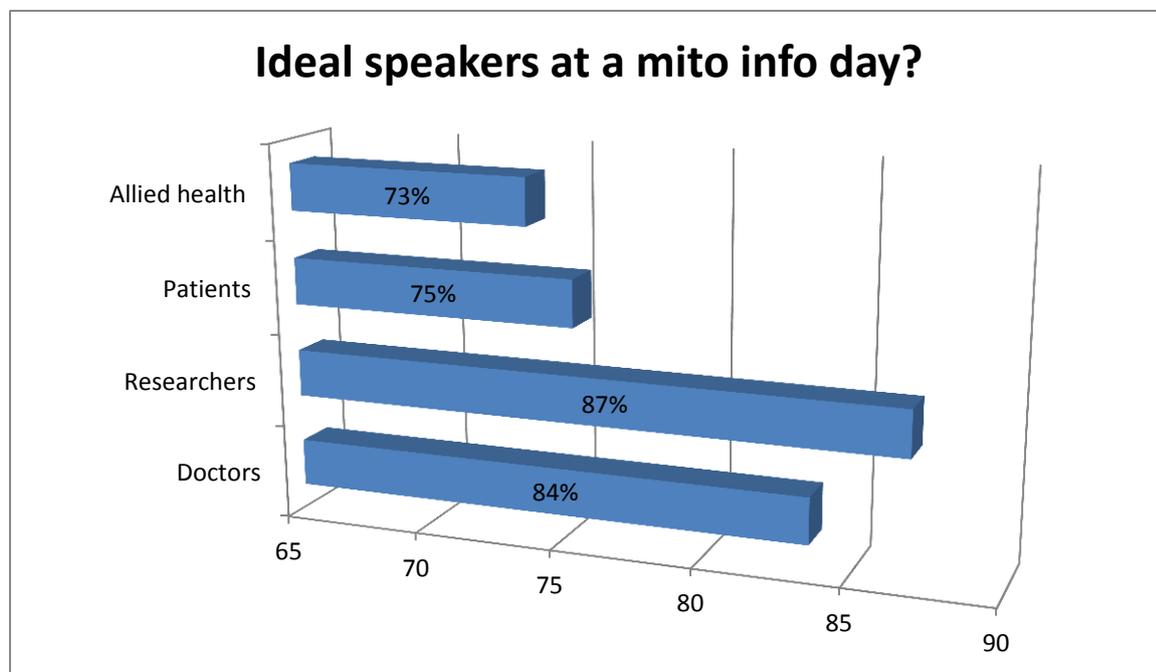


Feedback included: *Only attended one of the many held because of distance, time and need for accommodation etc. / I live in the ACT / I live in Tasmania. My child had Leigh's so I felt no information could be gained to help him to justify the expense of attending. / was not feeling well on the day/ We missed last year due to not knowing it was on/ I have either been sick or in hospital when they were being held / I am in New Zealand, we do not have anything like this in Auckland / My daughter is an adult and the Information Days in Brisbane are geared towards children*

Ideal length for a mito info day?

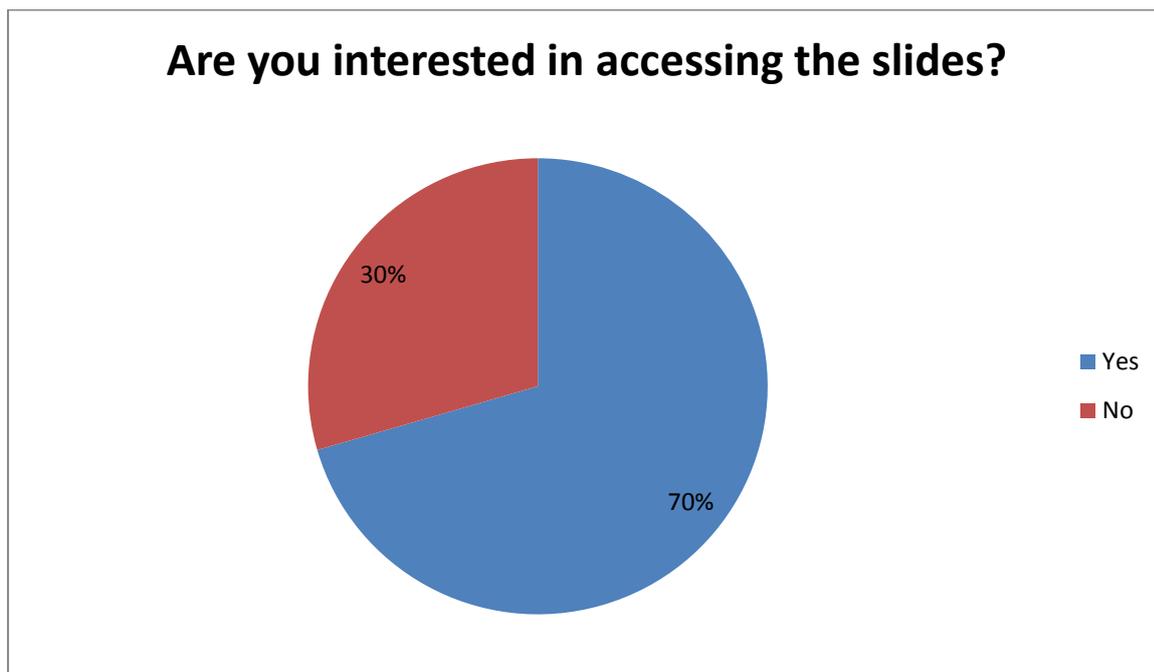


79% believed the information days should remain at a centralised location, however there were some other suggestions (*I don't call the royal north shore hospital central. They should be held in the city centre/ It would be nice if we had one in the main centres in New Zealand/ an easy place to access e.g. conference rooms or hotels somewhere more relaxed*)



Feedback included: *Good to have the mix, but would like most emphasis on the medical stuff with the widest relevance eg breaking results of the genetic research etc. / [I would like to hear] what the AMDF is doing / The more the better, though patients and parents who have already lost a child would be great. It puts a face to a story, makes it more real.)*

Some impressions of the information days include *I find them very interesting and informative. / Well organised and informative/ Confusing, informative, not a lot of hope in the near future / The first one was excellent, but subsequent ones became less informative as they tended to be a little repetitive; as they needed to be as most were aimed towards first timers*



71% of respondents were aware that AMDF upload the slide shows that presenters use to the AMDF website.

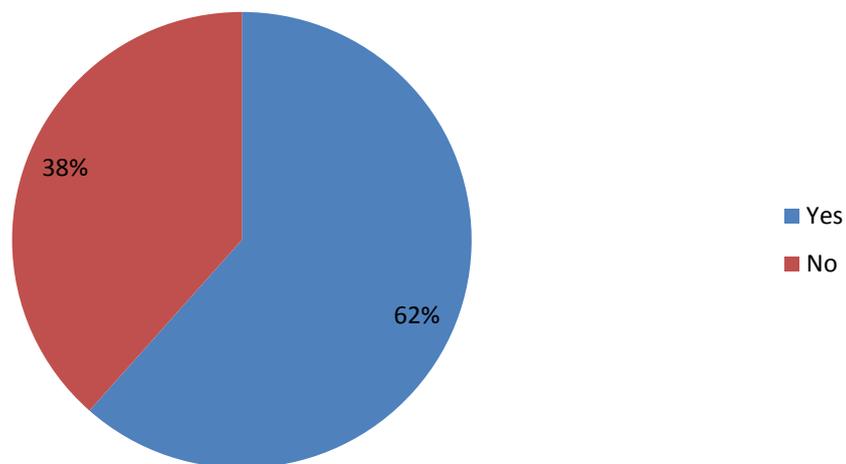
Some general feedback on the information days:

- “Allow more time and opportunity for a formal introduction for families and patients that are newly diagnosed to other families who have been on the journey for awhile to promote a sense of inclusiveness and connect people so they can establish support within the mito community.”
- “Please try to stick to the same time of year so that those interested in attending can plan ahead. Some people travel from the country or other places and like to book flights and accommodation well in advance, enabling cheaper costs for the trip.”
- “These are information days not social days for those attending and should not be seen by the AMDF as such and therefore a reason not to attempt getting patients and or carers to meet up separately in support groups or for coffee mornings. Stop focusing on the clinical and think of helping those living with the disease”

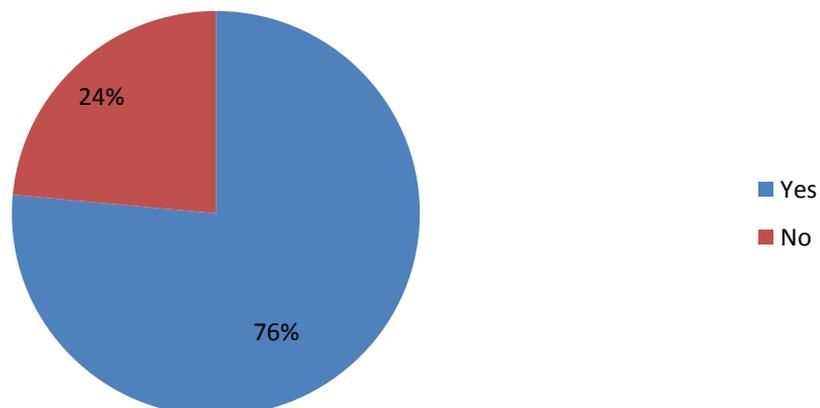
Facebook

54% of all survey respondents have a Facebook account. Currently AMDF run a Facebook page, which lets followers know what is happening within the organisation, as well as keep them up to date with upcoming events and breaking news. The AMDF also runs a Facebook group, where users are only permitted to join if they have a connection to mitochondrial disease. The group acts as an online forum and support group for patients and carers.

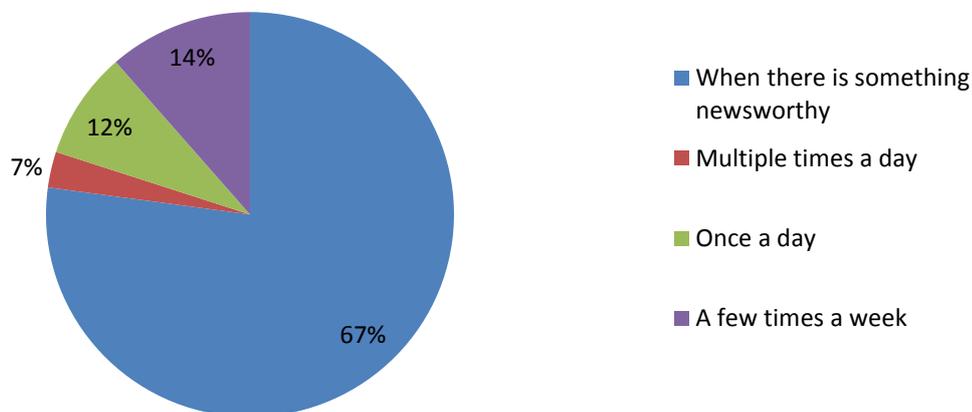
Have you liked the Facebook page?



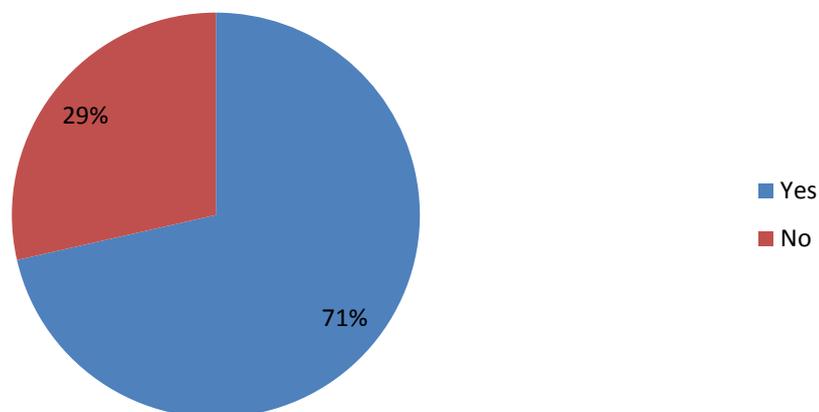
Are you happy with the amount of posts on the Facebook page?



How often would you like AMDF to post on the Facebook page?



Are you happy for members of the public to view the discussion on the Facebook group?



35% of respondents have joined the AMDF Facebook group. Of these, 76% are happy with the experience of the group. 73% are content with the privacy of the Facebook group.

Some general feedback on AMDF on Facebook:

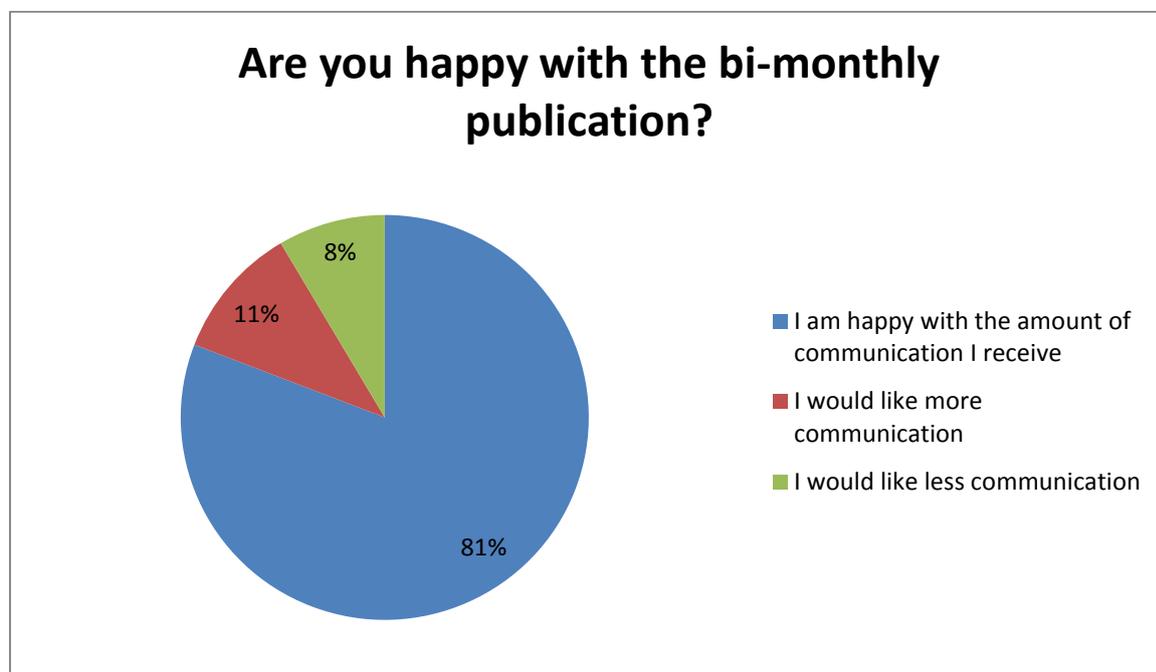
- “There should be two sites, a public one we see research news etc and a closed one. I don't use the page for medical issues - or respond to others who raise them - because it's public so shows in my feed and I don't share medical stuff with my wider Facebook community. I used other closed mito sites for that but they are all foreign. It would be great to have a closed Aussie site for patients or patient's carers.”

- “More interaction means more traffic. Rather than just mito or research etc, what about just general health & wellness eg simple tips on food choices, gentle exercise etc. Things that motivate and support are more likely to be read and shared by the general public.”

eNewsletter

AMDF provides an electronic newsletter (eNewsletter) to members of the mailing list every two months. The eNewsletter contains information on events, research and mitochondrial news.

80% of all respondents have signed up to receive the AMDF eNewsletter. All of these respondents answered that they were happy with the length of the eNewsletter and 93% are happy with the overall content. 81% of respondents are happy with the amount of communication they receive from AMDF.

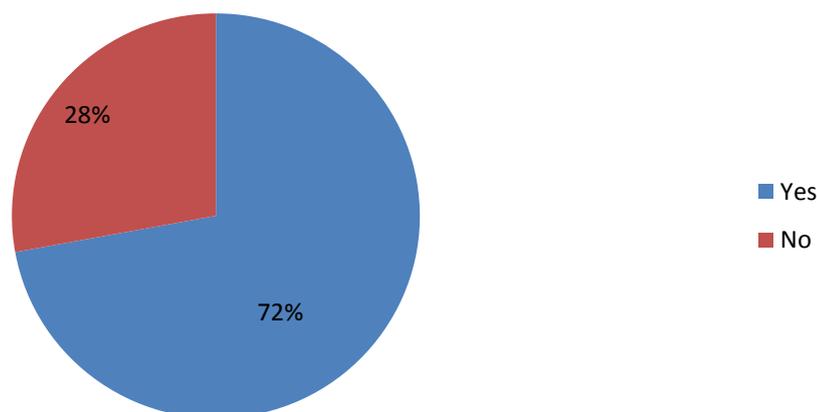


When asked what they would like to see included in the eNewsletter, some responses included *information about new findings on mito, things that may affect mito condition, research reports / Less clinical information especially how much money donated is given to scholarships and research and how little is spent on sufferers. More information on living with the disease, helpful hints, things going on, patients, what services the AMDF offer, second hand goods for sale, an ideas section for fundraising.*

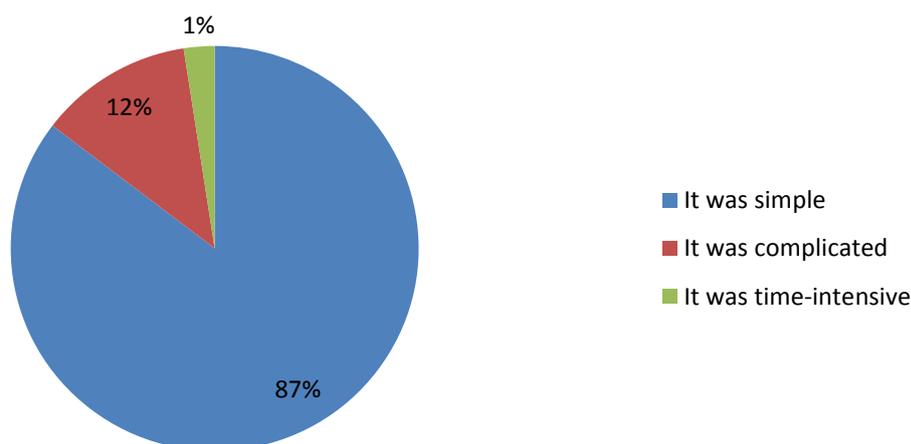
The Mitochondrial Disease Patient Registry

The AMDF facilitates a patient registry. This registry acts as a contact list of people who have mitochondrial disease (diagnosed or suspected). This list can then be utilised in the event of a clinical trial occurring in Australia.

Have you signed up to the Mitochondrial Disease Patient Registry?

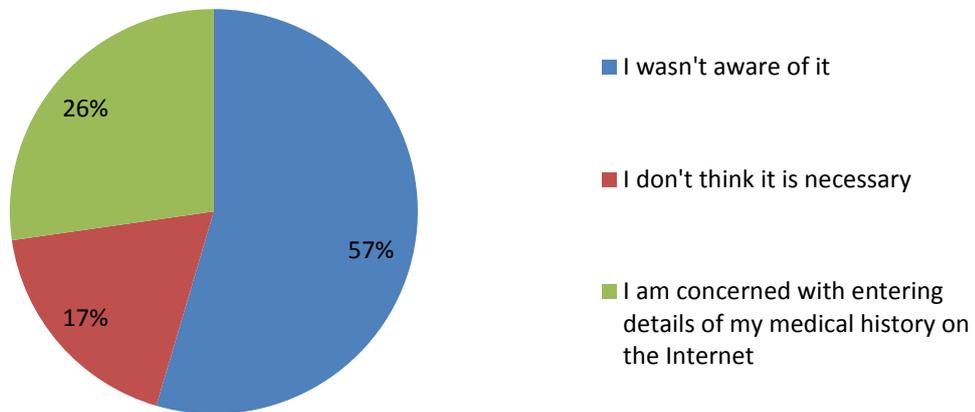


How did you find signing up to the Mitochondrial Disease Patient Registry?



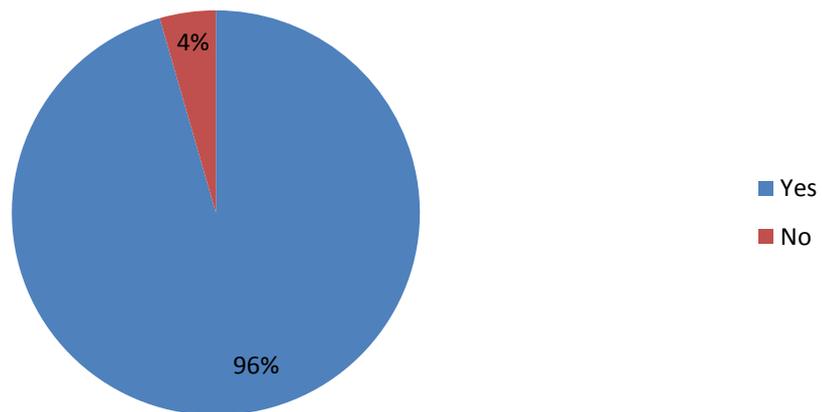
86% of respondents were aware that AMDF ran a mitochondrial disease patient registry (mito registry). 87% of respondents who have signed up reported that the registration process was relatively simple, though there were a few issues (*problematic as many of the boxes not known / couldn't enter a child who had died a few years ago*)

Reasons for not signing up to the Mitochondrial Disease Patient Registry



Feedback included: *I have no indicators for the disease / no definitive diagnosis so not considered for trials / I am concerned especially regarding the impact this may have on obtaining life and travel insurance)*

Are you satisfied with the privacy policy AMDF has in place?



77% of respondents reported that they were aware of the privacy policy that AMDF has in place to protect their information.

Advocacy

While the AMDF does not promote itself as an advocate for patients with mitochondrial disease, it is keen to assist patients and their carers with issues that they face.

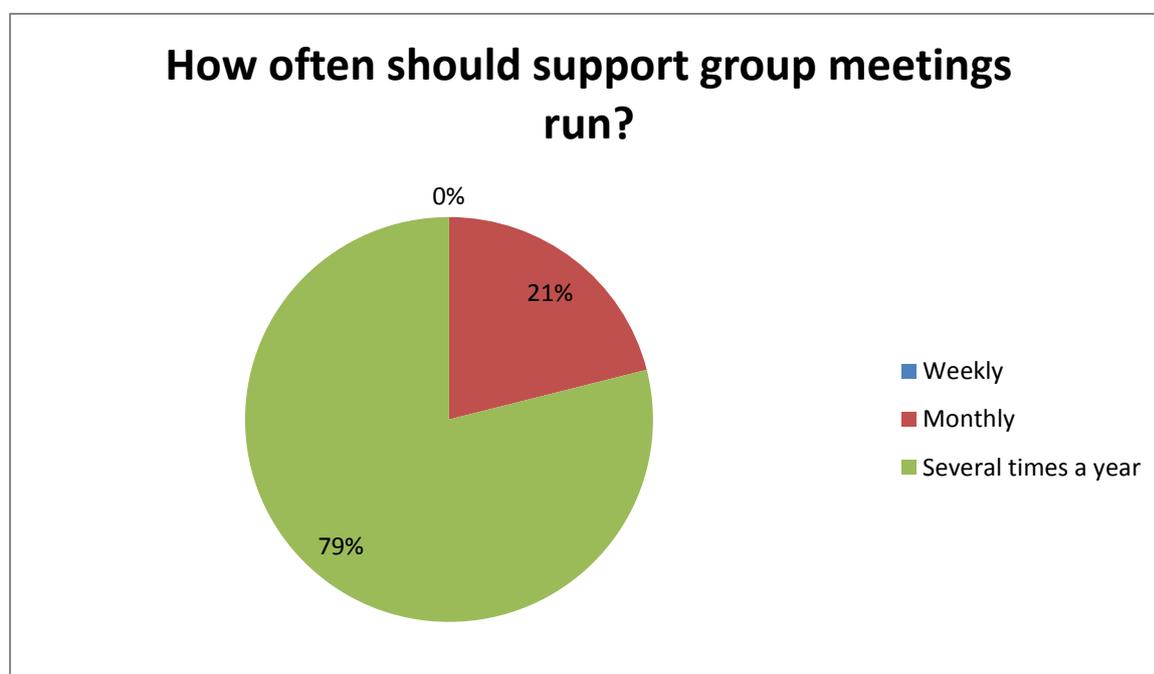
The survey asked respondents for any ideas of where the AMDF could take its advocacy role. Some responses included *Lobby government to include mito on the NDIS. Helping patients contact other mito patients with the same type of mitochondrial disease. Put together list of allied health services and GPs who are Mito aware / my daughters need advice for when they have children / Better education of medical staff.*

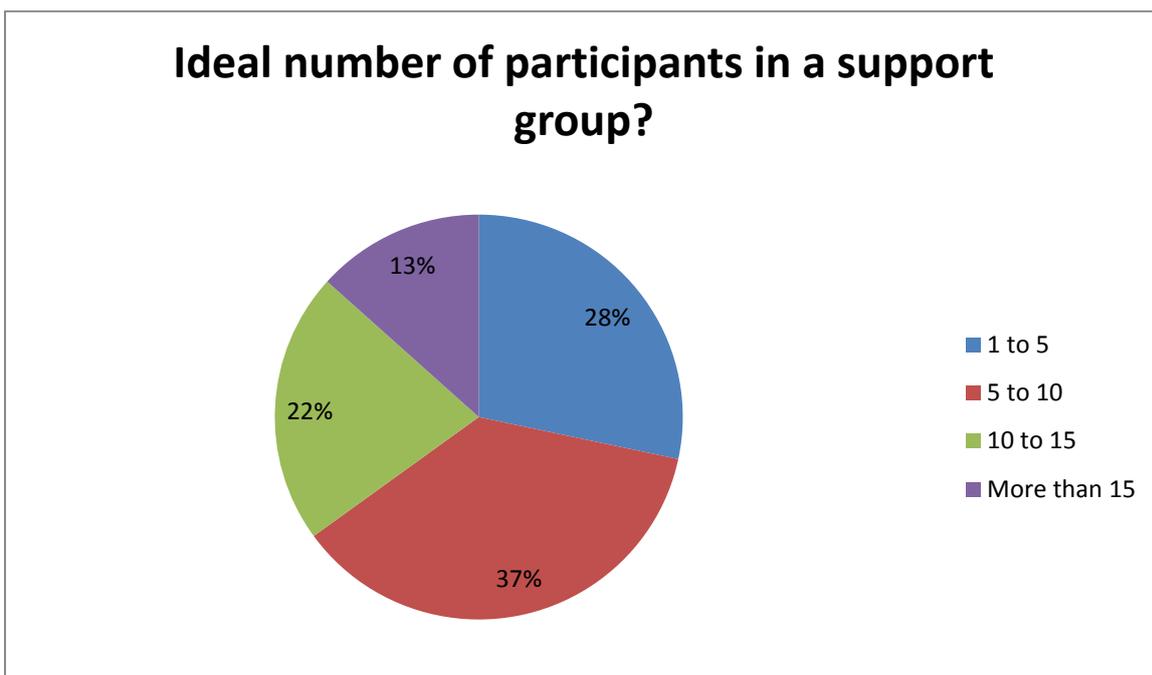
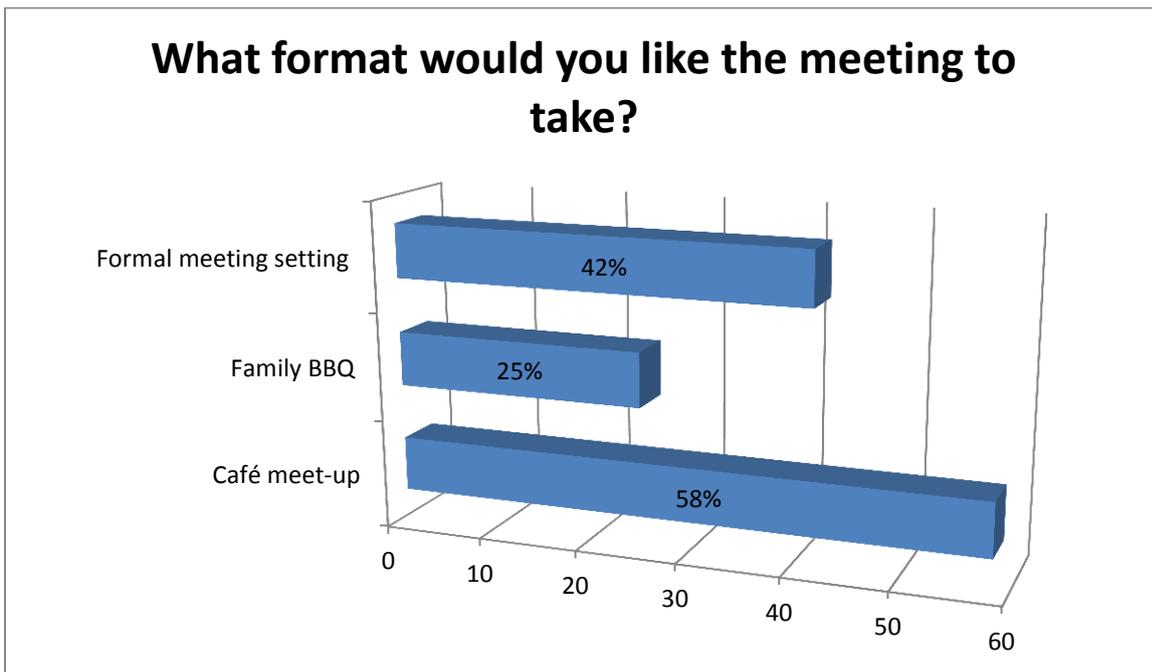
Some general feedback on advocacy:

- “Someone needs to lobby for changes to super laws so that it may be accessed when you have a terminally ill child.”
- “Anything that can increase the profile of Mitochondrial Disease.”
- “[Assistance with] Centrelink applications for Disability Support Pensions.”
- “Advocate within the major tertiary hospitals e.g. speak and Grand Rounds or at least provide information to the Geneticists. Grand Rounds is a great opportunity to reach all the different medical specialties and allied health professionals too.”

Support Groups

AMDF are currently not running any support groups but are keen to initiate sessions. It is the aim of the organisation to empower patients and carers to organise their own support group meetings.





66% of respondents indicated that they would be interested in attending a support group meeting. 19% of respondents would be happy to help coordinate a support group meeting.

General feedback on support groups:

- “Support groups rely on people feeling comfortable and safe so they can be open and honest in their communication in the spirit of sharing and helping others.”
- “Having 15+ will make it more worthwhile for guest speakers to address the attendees. Having an easy reach location. People are more likely to attend if it is a relaxed atmosphere with professional speakers who are interesting to listen to and will answer all questions.

Maybe questions can be requested ahead of time & returned with RSVP acceptance either by email or phone call”

- “Distance would be an enemy, might need to use video link up”
- “I was desperate to connect with people, although I don't know if there are enough people in Tasmania for it.”
- “I appreciate it can be challenging for families to attend, but if we could work through those challenges it can also be very rewarding”
- “Can't access one except for Facebook. Which is ok except sometimes you need a person to talk too.”
- “With so few people knowing anything about mitochondrial disease a support group could be very helpful in not feeling so 'alone' with mito. I'm interested in coordinating a support group but a bit hesitant to commit myself at the moment.”
- “Good for some but not my thing. Found previously groups have a negative complainy vibe (eg. the mothers group that complain they haven't slept) and would rather focus on the positives.. (the joy of a baby in home) if you get what I mean”
- “Yes they are the life blood of a disease based charity. Need sorting by area and it only takes two people to get one group off the ground just try it”
- “I think they would be very beneficial for the community aspect of mitochondrial disease”
- “Sometimes it gets a bit overwhelming to be asked to come to support groups as my child has already passed. I don't want to offer my support to an adult who is just going to complain about not being able to walk up stairs.... sorry if that sounds bitter”

General feedback on services not covered by the survey

- ‘Like UMDF, the possibility of having a 'ask the mito doctor' for general (not personal) questions to be answered”
- “Donations are very important & very necessary as we are all very aware of. Has it been considered offering books to clients patients that offer discounts at restaurants, cinema, bowling alleys etc to raise more funds? It is sad to say, but lots of people ask what’s in it for me!”
- “Providing more options of support to parents. Recognizing those who have passed from the disease is important for the family healing process as well I think. My little boy was 19 months. He didn't qualify for make a wish or anything like that. At the time it felt like he was diagnosed and then died at no one noticed... It didn't matter. It probably seems silly, but I think it is important at the time.”
- “I would like to see a protocol letter developed which patients could modify, perhaps in conjunction with their GP or specialist, to be used if hospitalised. This protocol could include things such as - No fasting, if necessary due to surgery etc... a dextrose IV is required before, during and after. A list of mito toxic antibiotics, anesthesia and other drugs. There are a few other things but the neuro doctors at RNSH, Westmead or Dr Crawley.”
- “AMDF is a great organisation but difficult to find. I found it by accident. Need to have a lot more liaison with mito clinics in public hospitals.”
- “Would it be feasible to have a weekend or couple of days conference for people throughout Australia to attend? Providing input from professionals and opportunities for discussion & networking.”
- “I need more help with setting up my daughters NDIS plan and what will be beneficial in the future.”
- “Yes. I am very interested in starting "Mito Quilts of hope" which I have spoken to Karen and Margie (and Sean) about. I have ideas but need to follow up on this and am not too good with web pages. It would have meant a lot to me when David was first diagnosed if someone had sent me a quilt to show I was not in this alone; and that's what I want to do for others”
- “This charity has lost its way. It is too focused on clinical work to the detriment of the current sufferers and carers. There is no transparency on where all the money goes other than on scholarships. The board appears to no longer be interested in providing help to the living just in finding a cure and this is not the fundamentals on what the charity was formed for nor why people donate.”
- “Please look at your registry and see who has lost their mito member as its sometimes hard to read the emails about me funding and giving at Christmas time. Those who have lost should not be asked to continually give. We try all we can so other families don't go through this pain...”