

Migraine Australia Pre-Budget Submission 2021-2022



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Introduction

Migraine is a genetic, incurable, serious neurological condition that affects an estimated 4.9 million Australians¹.

As a result of COVID-19, we think that number is going to increase. The COVID-19 pandemic and lockdowns in Australia have significantly affected the migraine community by exacerbating migraine triggers such as stress and increasing the impact from comorbidities such as anxiety and depression. Anecdotally, there has been an explosion in migraine diagnoses and increasing severity of migraine attacks for those already diagnosed².

Our major concern is those reporting long term neurological symptoms after infection with COVID-19. More research is required to determine if there is a link, but the symptoms being reported are identical to a typical presentation of significant migraine: headache, fatigue, impaired consciousness, brain fog, nausea, dizziness, sensitivity to light, taste and smell dysfunctions³. If it were not for a previous COVID-19 diagnosis, these patients would most likely have been diagnosed with migraine with aura. We believe it is possible these people have had their underlying migraine disorder triggered by the COVID-19 virus. This is concerning on multiple fronts and must be researched urgently - if the COVID-19 virus can activate migraine, then we may be looking at a migraine pandemic that will have far reaching impacts on the economy and our society long after global vaccination has resolved the COVID-19 pandemic.

Many people with migraine will live relatively unencumbered lives and are able to manage their infrequent attacks. But migraine is a spiralling condition, and at some point, those who dismiss their migraine – whether triggered by COVID-19 or not - as ‘just a headache’ will find their attacks becoming more frequent and more severe. And the more they try to drown them with painkillers, or will them away by ignoring them, the more frequent and severe those migraine attacks become, until they are completely debilitated.

Migraine disproportionately affects working age women⁴ and as a result has a substantial impact on the economy and significantly contributes to the gender pay gap. It has a huge impact on families, with many anecdotes of children being forced to care for their mum, or taught how to call an ambulance for their mum at a very young age, as well as evidence of higher rates of domestic violence and family breakdown^{5,6}.

Migraine can be managed. The most effective way to manage it is ‘hard and fast’: getting on top of attacks quickly with effective medication, developing healthy routines and diets uniquely tailored for each patient, and having appropriate and effective preventative medication ready to deploy once the frequency of attacks is above a level that can be managed acutely.

To do that, however, a patient first needs to be aware and informed about their condition: most are not. They need to work with medical professionals who understand the complexity and severity of migraine: most do not. And they need their employers, Government, and the community at large to understand and respect their condition, recognising it as a disability and not some failure of their own behaviour, weakness of character, or ‘just a headache’. None of this happens currently.



Brenda Moore
Chair, Migraine Australia Ltd

Coupled to this has been the failure to have the new, highly effective CGRP migraine medications listed on the PBS, even though PBAC has recommended them multiple times for people living with chronic migraine. Emgality was first recommended over a year and a half ago. The Government is well aware of our ongoing frustration on this issue, as are the many members of parliament who have been contacted by thousands of Australians living with migraine begging for action. We need the new migraine treatments recommended by PBAC to be listed on the PBS urgently.

Migraine Australia is the only patient body for people living with migraine. We are run by patients, for patients, and all of our people are volunteers. This is a particularly challenging time to be a new charity, without an established donor base and with donations diminishing thanks to COVID-19 job losses. Additionally, many of our volunteers have been getting too sick or too busy with the extra burdens of the new 'COVID-normal' world to continue volunteering at the same level, while simultaneously the demand for our support has increased.

Migraine Australia believes that we have a significant and urgent role to play to advocate for people living with migraine. Between migraine stigma, an apparent worsening of the disease burden in the community, and an endemic lethargy in Government to subsidise life-changing medications, the migraine community - made up of nearly 20% of the Australian population - needs an active voice to advocate on their behalf. COVID-19 has stretched our resources as the problem of migraine has become larger and more intense. In order to have an effective, permanent voice, and provide Australians and our community with the support needed to effectively manage migraine, we will need to hire paid staff.

The proposals outlined in this pre-budget submission are designed to maximise our large volunteer workforce to the best of our ability and to make the greatest possible change in the fastest possible time. They include coordinating a COVID-19 research program; conducting some basic, cornerstone research on migraine in Australia; training and support for our volunteers who work to support patients and clinicians, while also raising awareness of migraine in their local communities; developing resources for clinicians; and support for conducting our major national awareness event, Migraine Awareness Month.

These proposals will help us to support the increasing number of people living with migraine, improve their health and welfare, and address the two most significant areas of need we have identified: lack of understanding of migraine, and lack of research about migraine.

Migraine Australia acknowledges the \$600,000 in funding allocated in the 2020-2021 federal budget for migraine awareness, but our understanding is that none of this funding has been expended as at January 2021.

Migraine Australia is ready and able to lead the way in taking urgent action to achieve better migraine management. Migraine matters: to the people who live with it, to business, to our families and communities, and it has to matter to our governments too. We cannot afford to continue ignoring and dismissing this serious neurological condition; we must act now.

Brenda Moore
Chair
Migraine Australia Ltd

About Migraine Australia

Migraine Australia is a national patient advocacy organisation working to support all Australians living with migraine and their families. Migraine Australia Ltd was registered as a charity with the ACNC in June 2020. All our leadership team and most of our volunteers live with significant migraine.

We want all Australians living with migraine, whether they have a migraine attack every day, barely one a year, or anything in between, to feel supported and able to live a full and productive life. And to not feel like they need to hide their condition.

Through advocacy, information and support, and led by people living with migraine, our mission is to actively and demonstrably improve the quality of life and wellbeing of all Australians living with migraine and their families, and reduce the burden of migraine, through the prevention of migraine attacks, medication overuse headache, and other migraine related conditions.

Our goals are to:

- Advocate for people living with migraine through lobbying, making submissions, and other actions to ensure people living with migraine are heard in any decision-making processes.
- Support the migraine community by achieving practical changes that make our lives easier, improve our quality of care and life, and providing opportunities for people living with migraine to connect and share.
- Raise awareness of migraine in Australia, from what it is, to how to manage it and how others can support people living with migraine.
- Coordinate and encourage migraine research that benefits the health and wellbeing of people living with migraine.

Our organisation grew out of advocacy around getting the new CGRP medications for prevention of migraine attack listed on the PBS, so this will always be one of our highest objectives. However, we quickly realised that migraine simply does not have the awareness, resources and support that other conditions do, and we needed to work on the much larger problem of how we manage migraine. Our long-term goal is to implement a system of migraine management plans and support systems that will upskill migraine patients from first diagnosis so they can effectively manage their migraine.



Previous funding requests/grants in progress but not yet awarded

As noted in the introduction, \$600,000 in funding for migraine awareness was allocated in the 2020-2021 federal budget, but to date none of this funding has been expended and we have not as yet been contacted by the Department of Health about this funding.

Migraine Australia submitted two grants to the Information, Linkages and Capacity Building (ILC) programs in December 2020. The first of these was for the Economic and Community Participation Stream for a value of \$1,199,400, for our proposed *Work Ready, Work Safe, Work Smart* program to support people living with migraine, and their employers, to return to work. The second was for the Social and Community Participation Stream for a value of \$348,650, to roll-out our *Migraine Warrior Support Network* across the country and fill the vacant niche of migraine support services. We will not be notified of the outcome of these grant submissions until April 2021.

The estimated cost of listing the new CGRP monoclonal antibody medications (Aimovig, Emgality and Ajovy) on the PBS is around \$70m-\$100m a year. There are a number of other new migraine preventative medications in the pipeline as well, all of which will be essential to list on the PBS and should be accounted for.

Summary of priorities

Priority Objective	Proposal	Cost
Priority Objective 1: Research the effect of COVID-19 on migraine.	Proposal 1: Call for research investigating the relationship and comorbidity of COVID-19, migraine, and other neurological impacts	\$2,500,000
	Proposal 2: Fund a research project into the impact of COVID-19 and related social measures on people living with migraine	\$280,000
Priority Objective 2: Provide cornerstone data on migraine in Australia	Proposal 3: Migraine Prevalence and Awareness survey	\$105,000
	Proposal 4: Surveys of the migraine community	\$4,000
	Proposal 5: Directed PhD scholarships on migraine	\$320,000
Priority Objective 3: Support & empower patients through awareness and promotion.	Proposal 6: Support the Migraine Warrior Support Network and other volunteers	\$240,000
	Proposal 7: Develop the MiMAP program and app	\$250,000
Priority Objective 4: Increase the understanding of migraine within the community.	Proposal 8: Develop and distribute materials and training to increase awareness and support GPs and other clinicians in managing migraine patients	\$580,000
	Proposal 9: Migraine Awareness Month	\$150,000
Total:		\$4,429,000

Priority objective 1: Research the effect of COVID-19 on migraine

Proposal 1: Call for research investigating the relationship and comorbidity of COVID-19, migraine, and other neurological impacts

Emerging research into COVID-19 has highlighted that headache with migraine-like features can be a symptom⁷. As noted in the introduction, we have a considerable worry that COVID-19 is triggering underlying migraine and potentially exploding the number of people who will be debilitated by migraine attacks over the next few years. While less than 30,000 Australians have been diagnosed with COVID-19 to date, we need to know urgently if the virus is activating migraine, as asymptomatic and undiagnosed infections may still result in the neurological symptoms being described. We may be facing a migraine pandemic to follow the COVID-19 pandemic.

Given the substantial impact of migraine on society and the economy, we believe that any factor which increases this impact requires investigation. We suggest an MRFF or NHMRC call for research into this question and propose funding a three-month study into the effect of COVID-19 on migraine, both as a causative factor and an aggravating factor, seeking answers to these three critical questions and related issues:

1. Is migraine (particularly atypical sub-types of migraine) activated or triggered by COVID-19?
2. Does COVID-19 increase the frequency of attacks or severity of symptoms in people with existing migraine diagnoses?
3. Do people experiencing long term neurological symptoms after a COVID-19 infection share genetic markers with people who live with migraine?

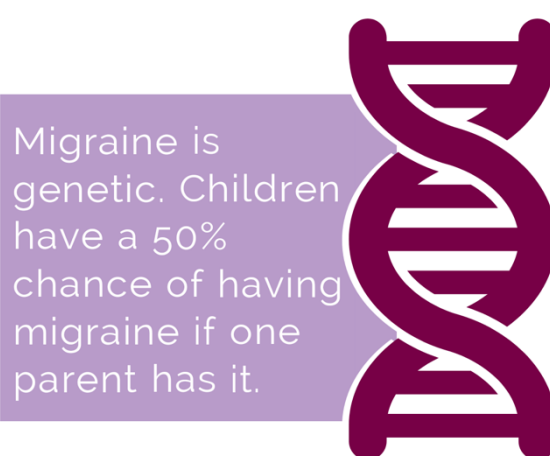
We have spoken to Professor Lyn Griffiths at Queensland University of Technology (QUT), one of the leading migraine genetics researchers in the world, about this research and they are happy to consider it if there is appropriate funding available. Genetics research is expensive, thus we would expect the largest portion of the requested funding to go to this effort.

There are other world-leading migraine researchers in Australia and a number have indicated they are looking at the neurological symptoms of COVID-19. Thus, we believe a call for research through either the MRFF or the NHMRC is the best way to both encourage rapid advancement into this urgent area of research and the best return for expenditure.

We have previously called for funding to research migraine more generally, and would still be delighted for that to occur, but this is the most urgent work and will be more resource intensive than non-genetic based research into migraine.

Cost: \$2,500,000 (suggested call for research pool)

Priority: Critical



Proposal 2: Fund a research project into the impact of COVID-19 and related social measures on people living with migraine

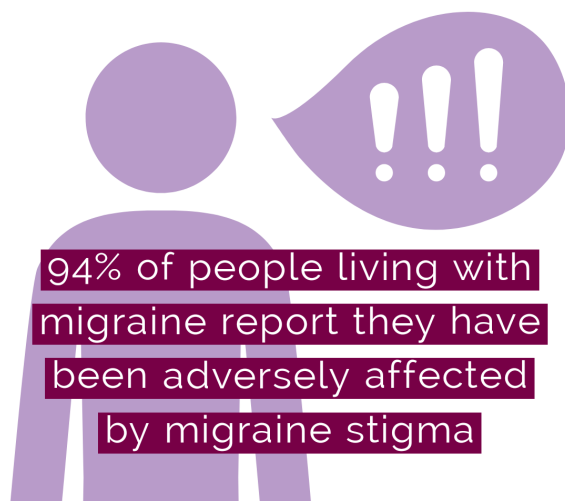
We have strong evidence from surveys and anecdotal submissions to Migraine Australia that the entire COVID-19 experience, particularly lockdowns and the changes to the way we go about our lives, has had significant impact on people who live with migraine.

However, the detail of what has changed, how severe the worsening of migraine symptoms has been, and how changes to the way we work may be beneficial for people living with migraine, are not clear and require investigation.

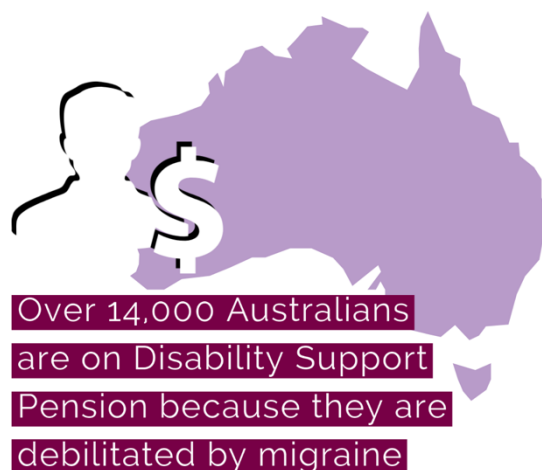
We would like to partner with a university centre that specialises in the social impact of health to conduct a three-month study on the impact of the COVID-19 pandemic to Australians living with migraine, with a view to greatly informing what we can do to assist people living with migraine, and to assist the Government to make decisions that will help people adjust to COVID-normal.

Cost: \$280,000

Priority: Moderate



94% of people living with migraine report they have been adversely affected by migraine stigma



Over 14,000 Australians are on Disability Support Pension because they are debilitated by migraine

Proposal	Detail	Cost
Proposal 1: Call for research investigating the relationship and comorbidity of COVID-19, migraine, and other neurological impacts	MRFF or NHMRC call for research into COVID-19 related migraine research, with the largest proportion of funds flagged for genetic research	\$2,500,000
Proposal 2: Fund a research project investigating the comorbidity of COVID-19 with migraine, and other neurological impacts	Three-month study at a recognised migraine research centre	\$280,000
Total:		\$2,780,000

“My migraine attacks start by feeling like I’m going blind. Then one side of my body goes all numb my face and tongue included. Then the worst pain in my head starts, like if I smashed my head against a brick wall it would make it feel better. Then the vomiting starts, and then I want to drill a hole in my head to relieve the pressure.”

- Bree

Priority Objective 2: Provide cornerstone data on migraine in Australia



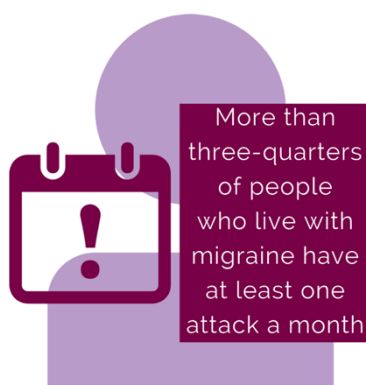
The most significant barrier to improving the management of migraine in Australia and effectively supporting people who live with migraine and their families is the astounding lack of data on migraine in Australia.

This issue has been discussed at length with Services Australia Minister Stuart Robert, and the staff of Health Minister Greg Hunt and Assistant Treasurer Michael Sukkar, who all acknowledge the problem and agree that it should be an easy one to fix. Our initial suggestion of having migraine included in the Census in a new section on chronic illness was rejected as consultations had closed; the alternative suggested by Minister Hunt's staff of having migraine included in the National Health Survey appears to have been diminished to a suggestion to include a single migraine question in a section on pain conditions, thus failing to deliver any meaningful insight of migraine.



The Australian Bureau of Statistics has admitted that survey design issues mean past published figures on migraine are not a measure of migraine prevalence. Additionally, the Australian Institute of Health and Welfare has never done a report on migraine. World Health Organisation reports on migraine state that no data is available for Australia.

In 2018, Deloitte Access Economics produced a white paper for the pharmaceutical company Novartis on Migraine in Australia. These numbers are useful, and they are what we currently use, but are based on US prevalence information so may be significantly off the mark. Government, health care providers, and Migraine Australia as the only organisation supporting migraine patients, desperately need reliable numbers on migraine in Australia.



There is no basic prevalence data to tell us how many Australians live with migraine. We do not know when and how people are getting diagnosed, what their comorbidities are, or what impact migraine is having on their lives. Before we can make good decisions on what to do about the increasing burden of migraine, we must have the data.

Proposal 3: Migraine Prevalence and Awareness survey

We propose to resolve the lack of data problem in the short term by conducting a basic prevalence and awareness online survey through a commercial polling provider (Ipsos). By doing this survey through a commercial polling firm, we can generate the desperately needed numbers quickly and relatively affordably, and with a much larger sample. The intended study will survey approximately 15,000 people to give a high accuracy rate and a lower margin of error than most surveys. The turnaround time will also be much faster than an academic study, enabling us, others in the sector, and Government to get to work on planning and developing strategies for better management of migraine in a matter of weeks.

It is not a substitute for an academic study of prevalence, as it will be limited to people over 18 and thus paediatric prevalence will not be captured, however as migraine attacks are more common in working

age people it will give us a solid baseline from which to work. National prevalence and awareness data must be collected nationally and from a very large sample, and it is beyond the capacity of our volunteers to do this cornerstone work.

Cost: \$105,000

Priority: Critical – must happen as soon as possible

Proposal 4: Surveys of the migraine community

Using the cornerstone figures, our volunteer team of researchers will then conduct a series of further surveys into:

- quality of life;
- quality of medical care;
- use and effectiveness of migraine treatments; impact on work performance and ability to stay in work;
- need for welfare and disability supports;
- impact on families, including domestic violence and marital breakdown;
- the financial cost of migraine on individuals and their households; and
- further study into stigma of migraine.

We can undertake these additional studies using our volunteer team of researchers (mostly current PhD students or employed in academic research) at minimal cost, but we cannot do them effectively without the cornerstone prevalence and awareness data, and appropriate survey software.

Cost: \$4,000

Priority: High

Proposal 5: Directed PhD Scholarships on Migraine

Migraine Australia has had in its long-term plans since we began the goal of offering directed PhD scholarships to encourage researchers to look at the social issues around migraine. This includes subjects such as the contribution of migraine to the gender pay gap, issues with retaining work, the contribution of migraine to mental health issues, links between migraine and higher rates of domestic violence, and the impact of migraine stigma.

COVID-19 and the documented increase in both prevalence and severity of migraine creates a strong need for this initiative to be brought forward. However, the current difficulties in fundraising makes it impossible for us to begin this initiative without assistance. With the requested funding we



will initiate two PhD scholarships, and once we are sure the fundraising pipelines are secure, expand to three new scholars per year.

We would like assistance to begin this program immediately, with the intention that it will become an ongoing program funded by donors in the future. If we do not begin immediately, we will miss the opportunity of the current intense funding in the rapidly changing areas of our lives and health more generally: a directed PhD scholarship is a very cost-effective way of adding a scholar to look at the migraine aspects of larger issues, such as COVID-19, the way we work, or mental health. For example, we would be very keen to see a migraine aspect added to recently funded research on dementia and stroke, both of which are linked to unmanaged migraine.

Cost: \$320,000

Priority: High

Proposal	Detail	Cost
Proposal 3: Migraine Prevalence and Awareness survey	Conduct large survey through a commercial provider	\$105,000
Proposal 4: Surveys of the migraine community	Licence for survey software and supportive infrastructure	\$4,000
Proposal 5: Directed PhD Scholarships on Migraine	Coordination of a PhD scholarship program to encourage and support new scholars to research migraine	\$320,000
Total:		\$429,000



Priority Objective 3: Support and empower people living with migraine through awareness and promotion

Awareness of migraine is very low, even among those who live with the condition. It is estimated that 50% of people living with migraine have never spoken to a doctor about their symptoms, and most who have been diagnosed have very low awareness of how to manage and treat their condition. Additionally, there are no support services available other than our social media channels and volunteer led local support groups.

Proposal 6: Training and support for the Migraine Warrior Support Network and other volunteers

In October 2020 we began a migraine ambassador program, recruiting around 40 volunteers to cover 10 regions including most major centres. Our intention is to expand this to 150 ambassadors and 50 regions covering the whole country. Our ambassadors perform three essential tasks:

- Be instrumental in raising awareness in their area through establishing relationships with local doctors and other support services who can connect people living with migraine with Migraine Australia.
- Host local support groups of people living with migraine.
- Raise awareness online and through their local media.

To enable this program to be successful, we propose to train our ambassadors in migraine literacy, legal issues in the provision of support and management of health information, and effective use of media. This will enable our army of ambassadors to confidently engage in the urgent and important work of raising migraine awareness, supporting others living with migraine, and empowering them and those they connect with to better manage their migraine.

We have also requested funds under the Information, Linkages and Capacity Building (ILC) program to support the Migraine Warrior Support Network with appropriately qualified social workers and promotion to boost our reach.

In addition to our Ambassadors, we have over 70 volunteers who perform the essential work necessary for Migraine Australia to do all that it does. There will always be an important place for our volunteers in achieving everything we want to achieve, but the increased burden of COVID-19 and the deterioration of the health of many volunteers means we are now experiencing an unsustainable level of turnover. We require a paid staff member to coordinate and support our volunteers, reducing our downtime and providing stability to our organisation. The requested funding would cover the essential staff to facilitate and train our volunteers, as well as the necessary training and resources.

Cost: \$240,000

Priority: Critical

So many people in the community have no idea just how debilitating and unrelenting migraine attacks can be. I am 50 and have suffered hormonally triggered migraines for the last 10 years or so. They seem to be getting worse, and I have had a number of recent attacks where I have been unable to keep even water down.

- Emma

Proposal 7: Develop the MiMAP program and mobile app

One of the highest priorities of Migraine Australia is to empower patients to manage their own migraine journey. There are many commercial products that are marketed at us all the time, such as apps, diaries, protocols and systems: but none of them are very good, largely because they were designed by doctors rather than patients.

We have begun work on what we call the MiMAP – the Migraine Management and Action Plan. This involves three modules: prevention, mental health, and an action plan for how to manage attacks, and is informed by research both from academia and of our own members.

To take this program to the next level we need to put it in to a format that can be accessed online and via a mobile app by clinicians and patients. There are commercial partners willing to work with us on this project who have indicated it will cost around \$150,000 to get it to proof of concept, and a further \$100,000 to test with our membership. From that point it should be commercially viable and self-supporting.

We expect the MiMAP will be a significant tool, along with the new CGRP medications, to dramatically change the way migraine is managed and considerably reduce the burden of migraine on the community.

Cost: \$250,000

Priority: High

Proposal	Detail	Cost
Proposal 6: Training and support for the Migraine Warrior Support Network and other volunteers	Volunteer training and support, volunteer coordination	\$240,000
Proposal 7: Develop the MiMAP program and app	Develop program to proof of concept	\$150,000
	Test the MiMAP with our members	\$100,000
Total:		\$430,000

Priority Objective 4: Increase the understanding of migraine within the community

The stigma of migraine is pervasive and entrenched. A recent survey of Migraine Australia members found that only 6% of people living with migraine do not feel affected by the ‘just a headache’ myth and other stigma of migraine. Surprisingly, medical professionals were revealed as the most significant source of stigma⁸.

The broad lack of understanding of what migraine is and how it can affect people is not something that will be fixed easily or quickly. This priority is to start working on the stigma problem with the two groups that matter most: doctors who treat us; and people who live with migraine, particularly those with low severity or infrequent migraine attacks who may have never seen a doctor, or do not understand the very basics of their condition.

Proposal 5: Develop and distribute materials to support GPs and other clinicians in managing migraine patients.

Information around migraine, specifically migraine management, is scarce. Few readily available resources exist, and this prevent patients and their carers understanding the complexity of migraine. Additionally, as the understanding of what migraine is and how to manage it is changing so rapidly that most clinicians need training to bring them up to date. GPs, specialists, and other allied professionals including physiotherapists and psychologists, have asked us to provide them with material that they distribute to patients and their carers.

This initiative will include:

1. Development of migraine fact sheets, including different sub-types of migraine and effective strategies for migraine management, which clinicians or patients can download.
2. Working with other patient bodies for conditions that are more common in people with migraine (for example, allergies, endometriosis, stroke and heart disease) to develop fact sheets on how the two conditions affect each other, and make them available to download from both Migraine Australia's and our fellow organisations' websites.
3. Distribution of small migraine pamphlets and printed factsheets to GPs, specialists, and other allied professionals around the country to distribute to patients or have available in waiting rooms.
4. Training videos and information sessions for clinicians to learn more about migraine, and when it is available, the MiMAP program.

This proposal was included in the 2020-2021 Migraine Australia pre-budget submission to cover materials only, with volunteers developing the factsheets, and without the training element suggested in point 4. As COVID-19 has exacerbated the demand for this information, we must accelerate factsheet development, to be done urgently by paid staff and be more comprehensive than originally envisioned.

Cost: \$580,000

Priority: Critical

Proposal 6: Migraine Awareness Month 2021

Migraine Awareness Month falls in the month of June each year. There are some 40 other countries that participate in Migraine Awareness Month each year, including global campaign efforts such as Shades for Migraine, which Migraine Australia is proud to have brought to Australia in 2020. This initiative aims to bring the migraine community together, continue to empower and educate patients and their carers about migraine, and continue to raise awareness about migraine in the broader community.

Our theme for Migraine Awareness Month 2021 is 'Your Migraine, Your Way' focusing on our priority to empower people living with migraine to take control of their migraine journey, get educated about their condition, and get the tools they need to effectively manage their migraine.



In addition to a great deal of online activity, we propose to have in-person events around the country (COVID-19 restrictions permitting) and a national virtual summit.

The requested funds would partially support this activity by enabling the appointment of an event manager, pre-ordering of materials, signage, and a small online advertising budget to promote Migraine Awareness Month and events such as Shades for Migraine.

Cost: \$150,000

Priority: Moderate

Proposal	Detail	Cost
Proposal 5: Develop and distribute materials to support clinicians in managing migraine patients	Pamphlet and factsheet development and distribution	\$285,000
	Training videos and materials	\$75,000
	Clinician liaison and training staff	\$220,000
Proposal 6: Migraine Awareness Month	Event materials and signage	\$20,000
	Event management	\$95,000
	Advertising	\$35,000
Total:		\$430,000

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My migraine attacks feel like the worst brain freeze imaginable on one side, with a watering eye that’s so painful want to scoop it out with a spoon. Plus I get a running nose on the same side, nausea, vomiting, and severe light sensitivity.

- Lisa

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Migraine
Australia 