

PRE-BUDGET SUBMISSION OUT OF THE DARK



2022 - 2023
December 2021

ABOUT MIGRAINE AUSTRALIA

Migraine Australia is a patient advocacy and support body dedicated to improving the life and wellbeing of all Australians living with migraine. We represent the five million Australians living with migraine and their families.

Founded by a committee of people all significantly affected by migraine in July 2019, we are a very young organisation run mostly on the good will and effort of over 100 volunteers. However, we have already had a significant impact by raising awareness and uncovering several major and urgent problems that simply must be addressed effectively and quickly. Our strategic plan for the first five years is a holistic approach to bring migraine *out of the dark* – to enable people with migraine to be free of stigma, able to freely discuss their condition, and get the support and care they need, while simultaneously getting the broader community to see migraine as the complex, incurable, genetic condition it is, and ‘not just a headache’. The initiatives in this proposal are the cornerstones of that strategy.

The release of the first ever migraine attack prevention medicines specifically designed for migraine is a very significant part of our story. To put it simply, we would not exist as an organisation without the drug Aimovig (produced by Novartis) changing the lives of a number of our founding members. Physically well enough to advocate for ourselves for the first time in years, and for some, decades, we desperately want to lift the entire migraine community *out of the dark*, and back to productive and healthy lives. While the addition of Emgality and Ajoovy to the PBS is a major step forward, we need to broaden the access criteria, add the rest of the new medications coming through, and improve access to older medications, to bring migraine *out of the dark*.

Migraine Australia proposes to work with individuals, families, communities, the medical profession, employers, all levels of government and stakeholders to transform the way migraine is managed and perceived. Migraine is not a headache, and the effort required to change that perception, and ensure people with migraine are properly managed, is substantial. As an organisation led exclusively by people with a lived experience of migraine, with a unique understanding of the challenges involved, we are best placed to drive that change and deliver the migraine community *out of the dark*.

ABOUT MIGRAINE

Migraine is a genetic neurological disorder that causes a dysfunction of brain networks and sensory processing. The migraine brain works differently all the time, but as we currently lack a diagnostic test it is diagnosed symptomatically through the presentation of recurrent attacks involving a combination of symptoms, most commonly nausea, vomiting, photophobia (sensitivity to light), and phonophobia (sensitivity to sound), and a severe pulsating or throbbing headache.

Migraine is:

- complex
- incurable
- inherited
- a spectrum disorder
- an invisible disability.

It is never 'just a headache'.

While classified as a primary headache disorder, migraine is more accurately a complex neurological disorder with many presentations. For many people living with migraine headache is not a significant symptom, or indeed they may not experience headache at all. There are many subtypes of migraine, including hemiplegic migraine which causes stroke-like symptoms, vestibular migraine which significantly affects balance, or brainstem aura which causes decreased consciousness.

THE STIGMA PROBLEM

The perception of migraine as ‘just a headache’ is ubiquitous. The word ‘migraine’ is used synonymously with ‘bad headache’, and is still defined in some dictionaries as a headache. Migraine attacks are referred to as ‘migraines’, reinforcing the notion that it is a transient and minor health complaint. This perception is the main underlying cause of an entrenched stigma which prevents proper care and creates an enormous hidden burden on the community and the economy.

This stigma also prevents migraine researchers from getting funding¹ and contributes to significant under-reporting in prevalence studies and other health research². As a result migraine is not appropriately accounted for in policy decisions. The statistics available on migraine prevalence in Australia are limited, something we propose in this submission to fix. The National Health Survey conducted by the ABS puts ‘long term’ migraine at 6.2% of Australians³, well below the global prevalence rate of 14%. As a result of our advocacy, the ABS has conceded their number is flawed and have agreed to change the way they ask about migraine in the next National Health Survey. The Australian Institute of Health Welfare has also conceded the gap in information about migraine, and the HILDA study has also agreed to consider better accounting for migraine in their study. Analysis by Deloitte Access Economics based primarily on American research puts it at 20.55%⁴. Our own research has found that the rate of migraine in Australia may be one of the highest in the world at 28%⁵. This is 1 in 4 people; more prevalent than diabetes, epilepsy and asthma combined⁶.

Most importantly, the stigma prevents people from seeking care or taking their condition seriously. Research from ANU⁷ indicates that migraine literacy is very low, including among those who live with migraine, with up to a quarter of respondents unable to identify the difference between headache and migraine symptoms. Over half of those diagnosed with migraine only use over the counter medications, and an alarming proportion are unaware of the potential for medication overuse headache (MOH). We also find awareness among medical professionals is low, and despite guidelines being available, most clinicians do not follow them when treating migraine.⁸

We also know anecdotally and from overseas research that most people will not reveal their migraine diagnosis to employers. People with migraine are routinely passed over for promotion, demoted, and managed out of their roles because of migraine. Many change jobs rapidly, and it is very common for people with migraine to drop back to work beneath their ability, less than full time hours, or start their own businesses to find the flexibility they need to manage migraine. And because the largest demographic significantly affected by migraine attacks are working age women, this is a significant contribution to the gender pay gap.

When supported, people with migraine are great employees: we know from the higher rates of migraine in banking and finance, professions such as law and accounting, and academia, that many living with migraine are of above average intelligence and highly capable. Making workplaces migraine friendly will enable dramatic improvements in productivity, reducing absenteeism and presenteeism. And, by empowering more people with migraine to stay in work, these efforts reduce the impact of migraine on the welfare bill.

1 \$7.1m in NHMRC funding over the last decade directed to migraine studies. Personal communication with Greg Hunt, Federal Minister of Health,

2 Yeh, W. Z., Blizzard, L., & Taylor, B. V., 2018. What is the actual prevalence of migraine?. *Brain and behavior*, 8(6), e00950. doi:10.1002/brb3.950

3 ABS, 2018. National Health Survey: First Results, 2017-18, Table 3.3 ‘Long term health conditions, Proportion of persons. Accessed from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4364.0.55.0012017-18> 31 October 2019.

4 Deloitte Access Economics, 2018. *Migraine in Australia White Paper*. Accessed from <https://www2.deloitte.com/au/en/pages/economics/articles/migraine-australia-whitepaper.html> 13 October 2019.

5 All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD), 2010. *Headache Disorders - not respected, not resourced*, House of Commons, London. Accessed from http://www.migrainetrust.org/wp-content/uploads/2015/12/2010Mar-APPGPHD_REPORT_Headache_Disorders-NotRespNotReso.pdf 31 October 2019.

6 All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD), 2010. *Headache Disorders - not respected, not resourced*, House of Commons, London. Accessed from http://www.migrainetrust.org/wp-content/uploads/2015/12/2010Mar-APPGPHD_REPORT_Headache_Disorders-NotRespNotReso.pdf 31 October 2019.

7 Goodhew, S.C. 2019, *Migraine Literacy and Treatment in a University sample*, *SN Compr. Clin. Med.* 1: 749. <https://doi.org/10.1007/s42399-019-00124-y>, accessed 12 October 2019.

8 Gunasekera, L., Sun-Edelstein C., Heywood, J., Sanders, L., 2018. Management of migraine in the Australian emergency department, *Journal of Neurology, Neurosurgery & Psychiatry* 2018;89:A8-A9.

THE COMORBIDITY PROBLEM

Migraine is a gateway condition: having migraine puts you at a significantly higher risk of a long list of other conditions from heart disease, to cancer, to recurrent miscarriage. In many cases, we don't know why, because there is limited substantive research on migraine globally.

Of highest priority and concern is the growing evidence that migraine and COVID-19 are a poor combination. COVID-19 exacerbates migraine symptoms, in particular bringing on aura or more severe presentations of migraine that persist long after the infection has passed. People with migraine are also at a significantly greater risk of Long COVID or Post COVID Neurological Syndrome. To effectively deal with COVID-19 and Long COVID, we must effectively deal with migraine.

We know that there is a substantially higher risk of stroke, believed to be due to the strain migraine attacks put on blood vessels in the brain. Migrainous infarction is a type of ischaemic stroke that happens as a result of a migraine attack. Migraine with Aura has long been recognised as causing a risk of stroke 1.8 times higher than otherwise healthy people. To effectively deal with stroke we must effectively deal with migraine.

Mental health issues are proven to be linked with migraine disorders. It is estimated by the American Migraine Foundation that people with migraine are five times more likely to live with anxiety, affecting up to 60% of people with migraine, while 25% of people living with migraine also have depression⁹. Additionally, rates of bipolar disorder and PTSD are higher in people with migraine. The disease itself feeds mental ill-health: we worry about when the next attack will come, what will trigger it, and feel helpless and frustrated about the unpredictability of migraine and how it is affecting our lives. And, when we don't know when the next attack is coming, it can cause a great deal of migraine related anxiety. Then, when migraine has completely taken over your life, it is natural that people become depressed. To effectively deal with anxiety and depression, we must effectively deal with migraine.

There has been debate for a long time about the links between migraine and dementia, with similar symptoms – white matter hyperintensities particularly in the frontal lobe – visible on MRI scans in both dementia and migraine patients, and a lack of clarity about whether later life migraine diagnoses were early symptoms of dementia. This debate was largely resolved in 2020 with the publication of a very large national register study in Denmark of 1,657,890 people. This study found that people with migraine are 1.5 times more likely to develop dementia, and people with migraine with aura subtypes are more than twice as likely to develop dementia¹⁰. To effectively deal with dementia, we must effectively deal with migraine.

According to the Global Burden of Disease Study, migraine is the seventh most disabling condition in the world. Services Australia has advised us there are 13,948 Australians currently on Disability Support Pension listing migraine among their top conditions¹¹, at an estimated cost of \$350m a year. From research derived from our members, we believe the number of people on JobSeeker with migraine who are unable to work (but have been refused DSP or believe they are ineligible) is considerably higher - around 100,000. We also know from our members that most who have applied for access to the NDIS, regardless of disability, have been declined. Providing adequate support to people living with migraine, including system-wide recognition of migraine as an invisible disability, is essential to empowering the community to come out of the dark.

9 American Migraine Foundation, 'Depression and Anxiety in Migraine Patients', accessed from <https://americanmigrainefoundation.org/resource-library/depression-and-anxiety-in-migraine-patients/>, 30 October 2019.

10 Islamoska, S., Hansen, Å.M., Wang, HX. et al. Mid- to late-life migraine diagnoses and risk of dementia: a national register-based follow-up study. *J Headache Pain* 21, 98 (2020). <https://doi.org/10.1186/s10194-020-01166-7>

11 Figure supplied by the Data and Analytics division of Services Australia, 22 November 2021

MANAGING MIGRAINE OUT OF THE DARK

Migraine is complex and incurable, but in most cases, it is manageable. In patients with well-managed migraine the co-morbidity rate is significantly less, mental health issues are considerably less, and they are less encumbered by our invisible disability and more able to fully participate in society. However, migraine is far from well-managed in the patient population, with a minority of patients using migraine abortive drugs (triptans), and a significant proportion of those misusing the medication. Migraine literacy is very low, even among those who live with migraine. Approximately half of those with migraine are self-diagnosed and have never sought proper medical care, spending hundreds and even thousands each year on over-the-counter medications and the array of ‘cures’, ‘diets’ or ‘protocols’ peddled wantonly to this vulnerable community.

The suite of measures outlined in this proposal are like parts of a puzzle; they all need to work together to deal with the complexity of the issues and bring about the transformative change we want to see in migraine management.

Nothing in migraine is small. We are always dealing with millions of patients, enormous obstacles, and many stakeholders. While the commitment asked for in this submission is substantial, we believe that the flow-on benefits in reduced burden on the health and welfare systems, reduced mismanagement of medications, and increased tax revenue, mean this transformative change program can be delivered in a way that improves the budget bottom line. Additionally, we believe that if the array of new migraine medications coming to market are supported on the PBS as soon as possible, the savings and increase to revenue will be greatly enhanced long term, more than covering the cost of those medications.

TABLE 1: PRIORITY FUNDING RECOMMENDATIONS - IDENTIFIED PROJECTS

Note: This is not inclusive of initiatives or projects not yet costed.

	INITIATIVE	ESTIMATED EXPENDITURE
Priority 1	Research First	\$12.2m
Priority 2	A National Strategy	TBD
Priority 3	Raise Awareness	\$47.7m
Priority 4	Migraine at Work	\$6.7m
Priority 5	Access to care	TBD
Priority 6	Supporting the community	\$7.4m
TOTAL		\$74m

PRIORITY 1: RESEARCH FIRST

One of the greatest challenges we have in figuring out how to deal with migraine is the stunning lack of data. The Australian Institute of Health and Welfare (AIHW) has never published a report on migraine, and they have advised Migraine Australia that they couldn't do one without undertaking substantial primary research, due to the lack of available data. The National Health Survey will include a migraine section for the first time in 2022, but it will only capture data on triptan usage. We have been in touch with the Department of Social Services and the University of Melbourne to better capture migraine in HILDA, but that will take some time to work through, and if it goes ahead, it will take many years to see results. We have also contacted the National Coronial Information Service about a report on deaths where migraine was an underlying cause, but the stigma of migraine as "just a headache" means it is almost never recorded as a cause of death, even though it is very clear from reading some case reports that migraine was their primary health issue and directly linked to their death.

Deloitte Access Economics was commissioned by Novartis to produce a white paper on migraine in 2018, after PBAC requested better economic modelling for the PBS submission for Aimovig. The Deloitte figures, and our own research (to be published in 2022), are the only available statistics on migraine prevalence in Australia. We must do better to accurately document the problem if we are to bring migraine out of the dark. The following proposals are what we would like to see as a minimum: there are many migraine researchers keen to do more, and we maintain that a targeted call for research would be ideal.

1.1 CENTRE OF RESEARCH EXCELLENCE

Some of the world's best migraine researchers are Australian, including Brain Prize winner Professor Peter Goadsby and world leading migraine geneticist, Distinguished Professor Lyn Griffiths. They have applied on multiple occasions for a centre for research excellence and, despite a phenomenally good proposal, they have not been successful. This is consistent with the experiences of most migraine researchers, who believe the entrenched stigma against migraine is what prevents any of them from getting the desired funding from the NHMRC. We would ask that the Government seek to address this discrimination and right the wrong through directed funding for a CRE for migraine.

1.2 A MIGRAINE CENSUS

We do not have academic research on migraine prevalence in Australia. This makes it very difficult to plan, to know what is needed and where, and indeed makes it difficult for the PBAC to have confidence about the uptake of migraine medications. Our own research, performed by a market research company, found levels of migraine prevalence higher than that modelled by Deloitte Access Economics, and considerably higher than the world average. It also indicated there may be a considerably high level of Vestibular Migraine that is being largely undiagnosed. Further detailed research into the prevalence and presentation is required. We would like to see a Census-style large sample study that tries to capture as many different experiences of migraine as possible, in order that we can truly understand the size and complexity of the problem hiding in the dark.

Migraine Australia would like to run this study in-house, in partnership with the Migraine Centre for Research Excellence or other appropriate academic researchers, at an estimated cost of \$1.6m over three years. Ideally, this study would be repeated every three years so that we can get longitudinal data on the migraine experience. By running it internally we can manage the dataset long term, leverage our trusted brand, and if any respondents indicate they are not doing well we can direct them to our support services.

1.3 SOCIAL AND ECONOMIC IMPACT OF MIGRAINE

Following on from the migraine census study, the next thing to find out is how much it is really costing the economy. The Deloitte Access Economics white paper (2018) is a good first step, but it is no substitute for primary research that will provide solid numbers. The hidden nature of the condition and the related stigma, combined with the lack of data, makes economic modelling challenging. Specific issues to be investigated are:

- The burden and impact of migraine stigma,
- the costs of absenteeism and presenteeism of those at the lower end of the spectrum and the cost of that to workplace productivity,
- the burden on the health and welfare system,
- the economic cost of unapproved therapies and 'miracle cures', and
- the contribution migraine makes to the gender pay gap.

Migraine Australia has already been in contact with various health and social research centres about this work. We would like the Government to fund us to commission and coordinate these five important studies at an estimated cost of \$550,000.

1.4 A DIAGNOSTIC TEST

The single biggest thing that migraine needs is a diagnostic test. According to surveys of our members, most people are diagnosed early because their presentations are identical to their parents, or only after years of tests, fear and many visits to the doctor. Our members have reported it taking on average 10 years before they are finally referred to a neurologist and get certainty in their diagnosis (and much longer in regional areas). With a test, we can diagnose people much earlier and easier. It also removes doubt over who can benefit from what medication or therapy, makes things like insurance claims much more straightforward, and it would significantly contribute to ending the stigma of migraine as 'just a headache'.

Genetic testing is currently available through QUT for some severe forms of migraine, but it is cost-prohibitive and not comprehensive. Researchers at the University of Sydney expressed interest in working on a saliva test. Work is well underway at the University of Adelaide on a blood test for a biomarker, and they have indicated it would only require approximately \$100,000 to complete the project. Funding is required for these projects to be completed, and to make the tests available through Medicare.

1.5 BUILDING ON THE CGRP BREAKTHROUGH

The new CGRP medications are having a transformative effect on migraine management, the migraine community, and the broader community. Patients are coming out of the woodwork and going back to their doctors for the first time in many years; formerly completely debilitated people are getting their lives back and can suddenly go back to work or study they never thought they would do again. This is a big rock creating a lot of ripples, and we need to understand where and how the community is impacted so we can understand the potential benefit as more new medications come to market and restrictions for currently available medications are eased.

We support a proposed study using scenario modelling to understand the wide socioeconomic impact of the CGRP medications on our health and welfare systems and society more broadly. Additionally, a global consortium of researchers led by the University of Sydney are working on using imaging and other tests to find out why some people respond well to the new medications, and others don't respond at all; this research is critical to more effective targeting and restrictions based in science. There are many researchers that are keen to work on CGRP medications, these are the two studies outside of the ongoing clinical research that we feel are most important.

1.6 UNDERSTANDING THE MIGRAINE BRAIN

The CGRP breakthrough has been the result of a significant shift in the fundamental understanding of what migraine is. The medical world is still adapting to understanding migraine as a complex genetic sensory processing disorder, rather than a vascular headache, which means it is the perfect time to continue to push and challenge the many assumptions and unproven theories about migraine. For example, the theory that migraine aura is caused by cortical spreading depolarisation. But the biggest question is how the migraine brain works differently: we know from MRI studies that the migraine brain is structurally and functionally different from a neurotypical brain – but what does that mean?

Medical research is often focused on deficits and the bad things of any condition, but we believe there are many good things about a migraine brain that should be identified and explored with a targeted call for research. Do we have higher IQs as was believed for a long time? Or do we just have brains that adapt and learn faster? By understanding how the migraine brain works differently we can develop early intervention therapies, or modify environments, to better manage migraine across society. By identifying what is good about a migraine brain we can really shatter the stigma and shame and bring migraine out of the dark.

TABLE 2: PRIORITY 1 FUNDING RECOMMENDATIONS - IDENTIFIED PROJECTS

PRORITY 1	PROJECT	ESTIMATED BUDGET ('000'S)
1.1	Migraine Centre of Research Excellence	2500
1.2	Migraine Census	1600
1.3	Social and Economic impact of migraine	550
1.4	A diagnostic test – University of Adelaide Biomarker	100
1.5	Building on the CGRP breakthrough	2450
1.6	Understanding the migraine brain – Targeted call for research	5000
TOTAL		\$12.2m

PRIORITY 2: A NATIONAL STRATEGY

In the history of chronic disease management in Australia, the only disease areas that are successfully managed are those with a national strategy. More than just funding, a national strategy is about getting all the stakeholders on to the same page, developing a roadmap, and focusing the attention of all stakeholders on the goal: getting migraine out of the dark.

In the case of migraine, a national strategy will also be the strongest thing we can do to really combat migraine stigma. Something that is 'just a headache' doesn't get a national strategy. All migraine organisations in Australia including the Australia New Zealand Headache Society have been calling for a national strategy in recent years. We are united on this, and we all understand there is a great deal of work to do in developing the strategy.

We expect the national strategy will address:

- Choke points in accessing migraine care such as lack of access to specialists and lack of training for GPs.
- Strategies for early diagnosis and intervention, including early intervention therapies for very young children.
- Changing the focus for the management of migraine from acute treatment to preventative management.
- A more holistic approach to primary care for migraine patients that unites general practitioners, specialists, allied health and pharmacists into a care team.
- Strategies for medication management and reducing medication overuse headache.
- Better accommodation of migraine in workplaces and educational institutions.
- Addressing the extra challenges faced by at risk groups and rural patients in accessing migraine care.
- Better care for migraine crisis, including migraine crisis centres adjacent to major emergency departments.
- Better training for doctors and other medical staff, including:
 - a specialist accreditation program for neurologists and pain specialists,
 - migraine nurse educator and migraine nurse practitioner programs, and
 - migraine specialist programs for pharmacists.

PRIORITY 3: RAISE AWARENESS

The perception of migraine as 'just a headache' is a global problem, and the most significant obstacle to getting people with migraine the help they need to adequately manage their migraine. Migraine is, unfortunately, interpreted as 'a sickie', and used interchangeably with 'bad headache'. We hear stories every day of relatives or employers cruelly attacking people with migraine for making up or exaggerating the facts of their reality, bullying them into pushing through, and damaging their health. People with migraine feel isolated because the people around them don't understand, and they are constantly having to advocate for themselves and battle this stigma.

Changing such entrenched misinformation and stigma can only be done with a significant effort over an extended period. Migraine Australia is best placed to do this work given our unique understanding of migraine and our passion for our disorder and community to be seen differently. We have also demonstrated we are able to support skilled people with migraine who have been pushed out of traditional workplaces to do this vital work in a way that enables them to manage their condition and reduce the burden of migraine on the welfare system.

3.1 RESOURCE DEVELOPMENT

The first task is to develop tools and resources to accurately and effectively communicate the truth about migraine.

This will include:

- Creation of a wizard-like tool to help GPs and other medical practitioners diagnose or exclude migraine, and multiple resources for people living with migraine and their families.
- A new patient info pack for GPs or neurologists to distribute to people diagnosed with migraine, including basic information about the condition, treatment options and support available, as well as how to connect with the Migraine Australia community.
- General information materials about migraine for the broader community and public events, signage, and other resources that support the goals of the organisation.

3.2 MIGRAINE IN THE MEDIA

How migraine is represented and spoken about in both news and entertainment media is critical to bringing migraine out of the dark. Our media relations staff will work on liaising with all kinds of media agencies and producers to change the language being used to be consistent with the language guide, and promote a positive vision of migraine well managed. Training and information sessions will also be made available for media professionals.

MIGRAINE STIGMA IN TV PROGRAMS

Recently 'Home and Away' on the Seven Network had a classic depiction as part of its story line. Beginning on 21 September, 2021, the show depicted new character Theo as unreliable and untrustworthy. One of the ways they did this was to have him go home with 'a migraine' one hour after starting work in a new job. The scene, and multiple following scenes making reference to it, was replete with many migraine tropes, including being offered Panadol, and several discussions that he was faking it and migraine is not real. Migraine Australia has been in contact with the show who have apologised and agreed to work with us on any migraine storylines in the future.

3.3 MASS MEDIA CAMPAIGN

A broad public awareness campaign is a critical part of bringing migraine out of the dark. We need to start conversations and reach people living with migraine so they know we are here to help them and that they can manage their migraine better. Social media is both our most important and most dangerous space; full time social media curation and community management staff are required to control our message, reduce the level of misinformation, reach as many Australians living with migraine as possible and invite them into our safe spaces, and ensure we are the authoritative voice on migraine in Australia. Advertising on social, broadcast and other media and at the all-important point-of-care will draw more people into our network so we can help them manage their migraine better, and raise awareness with the broader population. A targeted and strategic public relations effort will ensure that positive and constructive stories about migraine remain in the headlines.

3.4 MIGRAINE AWARENESS MONTH

The introduction of Migraine Awareness Month in June of each year aligns with most of the world and importantly, the United States, who create much of the online chatter about migraine. Migraine Australia plays a key role in leading Migraine Awareness Month activities globally, working closely with partners in the US, Canada, New Zealand, Israel and other parts of the world.

We have taken on this leadership role with the hard work and dedication of our volunteers, but there has been a significant cost in the worsening of their migraine that renders most of them out of action for all of July. With funding for this important initiative we can have key staff do most of the work, and better utilise volunteers in a more sustainable way.

3.5 KEY GROUP TARGETING

There are four key target areas we have determined require specific messaging and support. These are:

- men with migraine, whom are often left out of the conversation given the dominance of women with migraine;
- mums with migraine, targeting new mums who are often dealing with significant changes to their migraine due to the hormonal shifts;
- university and TAFE students, particularly school-leavers who are adjusting to the new environment and life without parents, many having only just been diagnosed with migraine in their teenage years; and,
- younger children, who need to understand their condition and learn to manage it at a very young age and need age-appropriate materials, and their families and schools who need to support them.

3.6 CLINICIAN AWARENESS CAMPAIGN

Much has changed about migraine in recent years, but not a great deal of attention is given to migraine in medical degrees. Most clinicians need training on the latest understanding of migraine, the preferred language, and the support services Migraine Australia offers to their patients.

This campaign will involve materials and training for doctors, nurses, paramedics and allied health professionals or medical support staff, working closely with the Australia New Zealand Headache Society (ANZHS), other professional bodies and medical schools.

TABLE 3: PRIORITY 3 FUNDING RECOMMENDATIONS - IDENTIFIED PROJECTS

PRORITY 3	PROJECT	ESTIMATED BUDGET ('000'S)
3.1	Resource Development	1700
3.2	Migraine in the media	1350
3.3	Mass Media Campaign	4600
3.4	Migraine Awareness Month	850
3.5	Key group targeting	1620
3.6	Clinician Awareness Campaign	2300
TOTAL		\$47.7m

PRIORITY 4: MIGRAINE FRIENDLY WORKPLACES

Helping people living with migraine to get into, and more importantly stay in, meaningful work is a critical part of bringing migraine out of the dark.

Almost everyone living with significant migraine has a story to tell about a boss that didn't understand, or their efforts to hide migraine from colleagues. Many have experienced a spiral down from full time, to part time, to casual, to having to give up work. Many of these people are well trained and want to work, they just need help managing their migraine, and supportive employers.

Unmanaged migraine in the workplace is a significant problem for employers, driving a high level of absenteeism, presenteeism, and staff turnover. It's also a significant problem for the nation, with such a large proportion of working age women forced to step down or out of the workforce due to migraine; contributing to the gender pay gap.

Working in partnership with employer groups and unions, we plan to help workplaces reduce triggers in the work environment, support employees living with migraine, and become familiar with the kinds of reasonable adjustments that can make a substantive difference in the lives of their employees with migraine. The goal will be to demonstrate that through small, practical things and a little bit of understanding, they can significantly reduce absenteeism and presentism, keep their staff and increase productivity.

The bulk of this activity will be done through training and assessment, and the development of a Migraine Friendly Workplace accreditation program similar to what has recently been introduced in Europe¹¹. We will have people work inside and alongside business, identify what they can change or do to help reduce migraine triggers in their workplace, and run training sessions with management and human resources staff on how to adequately support their staff living with migraine.

We will also liaise with unions and employer groups to help them help their members; provide direct support on workplace matters to our members to help them stay in work wherever possible, and get back to work when they get their migraine managed.

¹¹ The Migraine Friendly Workplace Stamp program was launched by the European Migraine and Headache Alliance in September 2021, acknowledging those employers who made efforts to people with migraine on an equal footing with other employees. See more at <https://www.emhalliance.org/for-workplaces/>

TABLE 4: PRIORITY 4 FUNDING RECOMMENDATIONS - IDENTIFIED PROJECTS

PRORITY 4	PROJECT	ESTIMATED BUDGET ('000'S)
4.1	Migraine Friendly Workplace accreditation program	3200
4.2	Migraine in the workplace training	1350
4.3	Union and Employer Group Liaison	800
4.4	Worker support and advisory service	850
TOTAL		\$6.7m

PRIORITY 5: ACCESS TO CARE

Getting people the medications, doctors, and support they need to manage their migraine is essential to getting migraine out of the dark.

MEDICATIONS

Getting Emgality on the PBS in the last budget, followed by Ajovy a month later, was a significant win for our community. However, we are dismayed at the continued underestimation of the demand for new and better migraine treatments, and the challenging restrictions. The PBS listing for Emgality and Ajovy was capped at 10,000 patients; according to PBS statistics, that number was exceeded early in October 2021, barely three months into the listing. As at the end of December 2021, 16,766 people had been initiated on PBS subsidised CGRP therapy. The number of patients accessing BOTOX treatment has also increased approximately 60% to over 12,000 patients since the CGRPs came to market. This is consistent with the experience elsewhere in the world, as people who have not bothered going back to the doctor for years or even decades have come forward to seek out this glimmer of hope.

Migraine Australia holds a significant fear that the excessive restrictions and wholly inadequate cap on CGRP therapies and BOTOX for migraine may lead to drug companies withdrawing them from the market. We would like much greater certainty around supply and assurances that all the new migraine medications will be made available on the PBS for all suitable patients. We would also like to secure access to many older medications, but due to the nature of the relationship between the Government and the pharmaceutical industry, the way that migraine drugs have been previously treated by PBAC, and other administrative hurdles, we can't get drug companies to bring their products to market. This is a significant system failure that needs to be addressed.

As we increasingly understand the tricky challenges of how the migraine brain interacts with medication, there is also an increasing supply and demand for non-drug therapies such as nerve stimulator devices. However, the current system does not support their use and they are prohibitively expensive. Of the three devices currently available, two, Cefaly and the new Nerivio device, are available without a prescription but are not reimbursed through any public program and few private insurers provide any rebates. The third, GammaCore, does require a prescription, but as it is a device prescribed like a drug there is no path to reimbursement through either PBAC or MSAC. Physical therapy and psychology, both clinically proven to be of benefit in migraine management, are also difficult to obtain in an affordable way.

While we hold out some hope that the National Medicines Policy review and associated Health Technology Assessment review process may yield some improvements, we believe the scale of the problem, and the size of the migraine market, warrants a specific and targeted response. There are few conditions that threaten to collapse entire programs like the PBS just through sheer weight of patient numbers and the lifelong nature of the condition. We believe in a program or unit within the Department of Health to specifically manage the supply of migraine therapies, and would ask that the government consider a migraine therapy funding guarantee to give confidence to migraine patients, their doctors, and the pharmaceutical industry.

DOCTORS

Migraine patients face extraordinary obstacles to accessing doctors who can help manage their migraine. General Practitioners are often the only doctor a migraine patient sees, but they are undertrained and usually lack the necessary understanding of migraine - through no fault of their own. If they do get referred to a neurologist, the wait is long and the cost high.

At medical school, most medical practitioners were taught that migraine is a vascular headache and, on average, only received four hours of training for all headache disorders combined. We would like to see significant investment in professional development programs for migraine as well as three specialisation programs for neurologists, GPs, and nurse practitioners.

We believe that the development of a migraine nurse program, training both migraine nurse educators and migraine nurse practitioners, is key to addressing the many challenges people with migraine have in accessing care, and the best way we can help reduce the burden on the health system. It would also provide a good career option for the many thousands of nurses unable to stay on the ward because of their own migraine. These initiatives we believe are best addressed as part of the national strategy

One idea that offers a significant opportunity to make a great difference is a migraine bus and telehealth service, providing access to specialist migraine neurologists for rural and remote patients. The waiting time for a regional patient to be referred to a neurologist is years longer than patients in capital cities and the costs to travel to a neurologist are extremely prohibitive. The few neurologists who currently have visiting clinics in rural centres cannot keep up with demand. As one of our rural neurologists said to us, “most people in the regions would never have access to a neurologist, not even to confirm their diagnosis, and certainly not to an MRI machine.” It is also possible to put an MRI machine on a bus or truck (it was done for the first time in the UK in 1991) bringing this important imaging technology to areas that will never have the population to support one being installed. Alternatively, there may be opportunities to utilise the bedside MRI system being developed at the University of Queensland. The exact details and costs would need to be worked out in conjunction with neurologists and other stakeholders, but we believe this initiative can be achieved with an ongoing budget similar to the Heart of Australia bus.

SUPPORTS

To date, people disabled by migraine, even the more debilitating subtypes, have had significant difficulty accessing disability supports. Most are rejected from the NDIS. We need to completely rethink the way we support people with migraine.

While the vast majority of people living with migraine are able to get by without formal assistance, the delay and obstacles to getting the necessary support for those with significant, difficult-to-manage migraine are immense. However, like medications, the sheer weight of patient numbers threatens to overwhelm programs like the NDIS. While we are buoyed by an increasing number of NDIS applications being approved as a result of our advocacy in the last two years, we need to think strategically about how to manage increasing demand.

PRIORITY 6: COMMUNITY SUPPORT

Migraine Australia takes this challenge, of how to support such a large number of people with differing needs in a sustainable way, very seriously. It is simply not viable to assign social workers to manage a caseload of five million people – there aren't that many social workers. And, for many living with migraine, that kind of intensive support is not appropriate.

For the last year, we have been developing the Migraine Warrior Support Network, borrowing ideas from organised farming, unions, service clubs and Alcoholics Anonymous to encourage locally led group support. This program provides a peer support system run by volunteer group hosts in 32 regions. While this is a significant improvement, compared to the complete lack of any prior services, it is far too apparent that we are asking too much from our volunteer leaders. We employed a former nurse to provide direct assistance for crisis cases, but demand continues to outstrip our resources. We need to have appropriately qualified social workers to support our volunteer ambassadors and provide the intense social and emotional support that so many people with migraine need; expand the advocacy team; and facilitate more local support groups in cooperation with local health services.

We would like the Government to fund the core staff necessary for our support services. Social workers will act as regional organisers who provide training and assistance to our local volunteer ambassadors, and direct support and referrals for members in crisis. Within the groups, we will encourage each member to find a peer support person at the same stage of their migraine journey, and someone further along on their journey who can act as a mentor.

We believe this three-cornered approach – ambassador, mentor, peer – can provide a stable anchor for everyone living with migraine. For those who are travelling well and just want the social support of people who get it, the group can be light and enjoyable. For those struggling with a rapidly deteriorating condition, or finding their medication is not working, or are at risk of losing their job because of migraine, their mentor will be their primary support. For those in need of greater help, they can reach out to their Ambassador, who can refer people to the social worker team of Regional Coordinators as required. This trilogy also ensures there are always others to catch someone in need if their first go-to is too significantly affected by migraine to be able to assist them.

Best of all, this structure, based largely on local volunteer support, is far more affordable and effective than other options such as local social workers. The only expenses are the regional and national coordinators, training, and resources. And the best part of this program is that assistance structures are in place with contact established before any crisis, enabling a much more effective and efficient response.

When a crisis does strike our participants, the advocacy team will then directly assist to ensure people get the help and support they need. We expect the advocacy team will be predominantly nurses or others with a good knowledge of the system, comfortable talking to doctors and hospitals, and experienced in advocating for patients. Examples of advocacy work undertaken by this program so far include getting cancelled appointments rescheduled, getting patients connected with more appropriate care, resolving disputes when care has been refused, and connecting patients with the medical specialists they need.

We envisage that all the social workers and nurses employed for this program will live with migraine, ensuring they are best qualified for the job, as well as this initiative helping more trained people affected by migraine to stay in the workforce.

TABLE 5: PRIORITY 6 FUNDING RECOMMENDATIONS - IDENTIFIED PROJECTS

PRORITY 6	PROJECT	ESTIMATED BUDGET ('000'S)
6.1	Regional Support Coordinators	6200
6.2	Expanding the advocacy service	1200
TOTAL		\$7.4m

BRINGING MIGRAINE OUT OF THE DARK AT NO NET COST TO THE GOVERNMENT

The proposals outlined here are substantial, but necessary. Migraine has been so significantly neglected that it is considered the worst-managed condition in the country. There is no existing support structure which we can build on – we are starting from scratch.

However, because we are starting from such a low base, we believe the gains will be substantial, and quick. So much so, that the gain to the Government in both reduced welfare costs and increased tax revenue will cover the expenditure.

We estimate, if the Government can list all the new migraine medications on the PBS, combined with the awareness and management support we propose, the direct net savings to the Government (through reduce welfare costs, health system savings, and increased tax revenue) will conservatively be in the order of \$300m per year. Additionally, approximately \$10b in lost productivity returned to the economy each year, from year three onwards.

Nothing about managing migraine is small, including the potential benefit to the country and the economy. So let's work together to bring migraine out of the dark.



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