



2019 – 2020 Pre-Budget Submission

February 2019

“In the fullness of time, the mainstream handling of chronic Lyme disease will be viewed as one of the most shameful episodes in the history of medicine because elements of academic medicine, elements of government and virtually the entire insurance industry have colluded to deny a disease. This has resulted in needless suffering of many individuals who deteriorate and sometimes die for lack of timely application of treatment or denial of treatment beyond some arbitrary duration”.

Dr Kenneth B. Leigner

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About us

The Lyme Disease Association of Australia (LDAA) is a registered charity and Australia's peak patient body. It's run by a small number of volunteers who work to change how 'Lyme-like' illness is viewed and how patients are treated.

We represent patients and undertake activities in four key areas: information, support, education and awareness. Our mission is to:

- advocate for individuals and families living with Lyme-like illness;
- educate and seek support from governments, doctors and local communities;
- act as a conduit between international developments, treatments and other Lyme communities; and
- raise money to assist people living with Lyme disease and Lyme-like illness.

We are committed to lead collaboration towards a new model of scientific and medical excellence in Australia to facilitate world class standards in Lyme-like disease prevention, research, diagnostics, patient care and treatment protocols.

We educate people on awareness, prevention and diagnosis, inform government and medical associations on policy and best practice and empower patients to fully recover without experience of bias, denial, bureaucracy, distraction or burden of disease.

Introduction

An increasing number of Australians are becoming chronically ill after a tick bite. Around 20,000 people p.a. are infected with pathogens through the bite of a tick. Many find themselves in an uncertain medical situation, complicated by an unexpected lack of accurate diagnostics. They are routinely denied treatment or medical support when they report a tick bite which often sets them on a path to a debilitating and chronic illness, causing unnecessary economic burdens upon patients and their families.

Due to a lack of funding for research into tick-borne illness there remains a long-standing controversy about 'causative agents' and disease presence. Legacy thinking underpins widespread ambivalence in the medical community and reinforces the apathy of policy makers who fail to properly investigate the issue.

Patients are frequently told they have 'medically unexplained symptoms' or a psychiatric ailment, rather than an infection. There are no primary care pathways to identify and support these patients and many are left medically abandoned with declining health and permanent disability. In the absence of primary care support, they turn to the handful of voluntary patient organisations.

Through patient led action, there has been Government and Parliamentary focus on the issue of Lyme-like illness in Australia, or 'Debilitating Symptom Complexes Attributed to Ticks' (DSCATT), as contrived by the Department of Health. The Australian Government have conducted formal inquiries into Lyme disease and three parliamentary reports have been tabled¹. Each inquiry has highlighted significant gaps in our knowledge including the associated impact on public health. Despite each inquiry recommending Government's urgent action, adequate funding to address the agreed research priorities AND the needs of patients has not been prioritised.

The Senate's inquiry² into Lyme-like illness recommended the Government '*increase funding for research into tick-borne pathogens as a matter of urgency*' and '*allocate funding for research into medically-appropriate treatment of tick-borne disease*'. As a result, the National Health and Medical Research Council conducted a Targeted Call for Research³ and recently awarded \$3m to two research projects expected to complete in 2023.

In the meantime, thousands of patients become increasingly debilitated as our medical and scientific community cannot agree on a causative agent[s], or appropriate diagnostic tools, or case definitions, or treatment protocols. Patients are inexplicably burdened by this ambiguity.

According to the World Health Organisation, vector-borne disease is entirely preventable through the development of informed protective measures⁴. In Australia we have no such measures. Awareness and prevention education rely on patient organisations and their voluntary efforts to inform the general public about the dangers of tick bites.

There is an urgent need for state, territory and commonwealth health organisations to address this issue. The LDAA calls upon the Commonwealth Government to prioritise the funding set out in this submission.

¹ Communicable Disease Network Australia; Chief Medical Officer's Clinical Advisory Committee on Lyme Disease; Department of Health Scoping Study; Senate Inquiry on Lyme-like illness and the House of Representatives inquiry into Chronic Disease Prevention and Management in Primary Healthcare.

² *Journals of the Senate*, No. 126–12 November 2015, p. 3380.

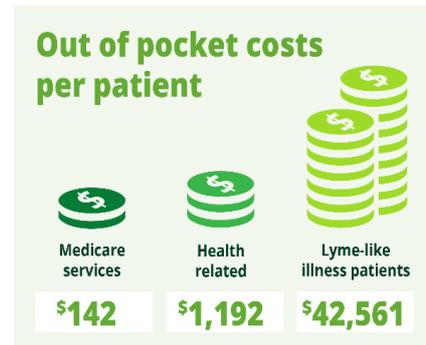
³ NHMRC <https://nhmrc.gov.au/funding/find-funding/targeted-call-research-debilitating-symptom-complexes-attributed-ticks>

⁴ WHO Vector-borne disease fact sheet: <https://www.who.int/news-room/fact-sheets/detail/vector-borne-diseases>

Economics of Lyme-like illness

In 2017 the LDAA analysed 349 patient submissions to the Senate Inquiry on Lyme-like illness. We found the reported out-of-pocket health-related costs for those patients totalled \$2.7m, equating to \$42,561 per person.

According to the Australian Institute of Health and Welfare's (AIHW) report on *Patients' out-of-pocket spending on Medicare services, 2016–17*, the Australia's total health-related expenses averaged \$1,192 per person. **The cost to patients with Lyme-like illness is 3570% higher than the general population**⁵.



If patients are appropriately diagnosed and promptly treated with prophylactic antibiotics, then the associated costs are covered largely under the Medicare rebate system. This still attracts a cost for a visit to a medical practitioner, pathology tests and antibiotics. However, treatment failure is common for a variety of reasons and researchers report that treatment fails between 35 – 50 percent of the time⁶.

The Australian patient submissions we analysed showed that the majority of patients were undiagnosed, or misdiagnosed and never treated, or inadequately treated; as such we classify them as cases of 'treatment failure'. Therefore, up to 50 percent of the Australians infected each year are likely to be misdiagnosed or undiagnosed, incurring more than \$425m in out-of-pocket medical expenses. Not to mention the gap in Medicare rebate costs, the non-medical costs or the considerable economic loss in the patient's productivity and the associated flow on effects.

A 2015 study conducted by Johns Hopkins Bloomberg School of Public Health⁷ in the U.S. looked at the costs of treating patients in the year following their Lyme disease diagnosis. The researchers found that, on average, people with Lyme disease cost the system \$2,968 more than their matched controls. Those patients had 87 percent more visits to the doctor and 71 percent more visits to the emergency room within the year following diagnosis. They were nearly five times more likely to have fatigue, nerve pain, joint pain, cognitive troubles, within that year and were five times more likely to have a diagnosis of debility due to excessive fatigue.

A more recent *Review of the economic burden of Lyme disease and the cost-effectiveness of Lyme disease interventions: A scoping review*⁸ across multiple countries, found a significant annual economic impact of \$735,550 USD for Scotland (0.14 USD per capita, population = 5.40m), \$ 142,562 USD in Sweden (0.014 USD per capita, 9.96m), \$ 40.88m USD in Germany (0.51 USD per capita, 80.59m), \$ 23.12m USD in the Netherlands (1.36 USD per capita, 17.08m), and up to \$ 786m USD in the US (2.41 USD per capita, 326.63m). The researchers concluded that "societal costs for Lyme disease can be equally impactful as healthcare costs but are not fully understood".

Our submission to the Senate Inquiry reported a cost of more than \$7.5m p.a. in 2015 for patients who were in receipt of sickness or disability benefit, and those that have spent time in a hospital due to their Lyme related illness. A health economics study for the cohort of patients with a Lyme-like illness is long overdue and should be considered as part of the 2019-2020 budget cycle.

⁵ LDAA Blog - <http://www.lymedisease.org.au/latest/out-of-pocket-medical-costs-out-of-control-for-lyme-patients/>

⁶ Aucott, J.N., et al., Post-treatment Lyme disease syndrome symptomatology and the impact on life functioning: is there something here? *Qual Life Res*, 2013. 22(1): p. 75-84.

⁷ Adrion ER, Aucott J, Lemke KW, Weiner JP (2015) Health Care Costs, Utilization and Patterns of Care following Lyme Disease. *PLoS ONE* 10(2): e0116767. doi: 10.1371/journal.pone.0116767

⁸ Mac S, da Silva SR, Sander B (2019) The economic burden of Lyme disease and the cost-effectiveness of Lyme disease interventions: A scoping review. *PLoS ONE* 14(1): e0210280. <https://doi.org/10.1371/journal.pone.0210280>

Recommendations

For the 2019-20 Budget we call on the Government to join in our mission to improve the lives of Lyme patients now and into the future; collaborating towards a new model of scientific and medical excellence in Australia, by investing in world class strategies for Lyme-like disease prevention, research, diagnostics, treatment protocols and patient care.

We can achieve this through:

1. Increasing research funding and investing invest in an integrated platform for early diagnosis and personalised treatment of vector-borne illness for Australians
2. Funding a series of educational programs across Primary Health Networks and hosting an international Lyme summit so Australian practitioners can increase their knowledge of vector-borne disease
3. Investing in patient support services, education and assistance
4. Investing in awareness and prevention programs

Costing of initiatives

Summary of action	Forward Estimates Cost
Invest in an integrated platform for early diagnosis and personalised treatment of vector-borne illness	\$2.8m phased over 5 years to be funded from the Medical Research Future Fund
Invest in professional education and international summit to enhance practitioner knowledge of vector-borne illness	\$.92m
Invest in patient support services, education and assistance	\$.642m
Invest in prevention and awareness initiatives	\$.712m
TOTAL COST	\$5.074m

Recommendation 1 – Invest in an integrated platform for early diagnosis and personalised treatment of vector-borne illness

Research into micro-organisms as a causal link to neuro inflammatory diseases is an exciting area of international and Australian focus. Australian research projects investigating central nervous system diseases, the brain/biome axis, chronic diseases, rheumatoid arthritis and infectious diseases are poised to take advantage of this shift in research.

The introduction of Lyme-like illness into the research priorities of the NHMRC enable Australian researchers more opportunities to collaborate, publish and become front line adapters to innovative approaches in scientific breakthroughs and diagnostic technologies focused on micro-organisms as a causal link to disease. However, a \$3m research budget is inadequate in terms of the scope of the problem when it comes to tick borne diseases.

Australian scientists will be able to identify native strains and match biomarkers, enabling therapeutics to be re-purposed for clinically diagnosed patients to access effective treatments, safeguarding the Australia's population from growing environmental threats derived from vectors. This is the vector equivalent of ensuring the Australian population has access to antivenin when bitten by a venomous snake.

The Medical Research Future Fund⁹ validates the need for precision and personalised medicine and revolutionary ways to treat serious and chronic illness. Personalised medicine models involving genomics, biobanking and integrated platforms that allow for early diagnosis and personalised treatment are **urgently** needed to address a better quality of life for people with Lyme-like illness.

A consortium of researchers¹⁰ led by Macquarie University Professor Gilles Guillemin, propose a unique platform that will collect, test and store an integrated and comprehensive biobank of samples from patients with Lyme-like illness a critical resource missing for all researchers working in this area.

Using longitudinal samples, the team will identify new biomarkers for diagnostic and prognostic purposes as well as measure a patient's response to treatment. A registry and database will house all clinical and biological information collected from patients.

The integrated platform will provide a faster and more accurate diagnostic tool and will ultimately allow personalised treatment for patients with Lyme-like illness and help inform government agencies on evidenced-based awareness and prevention strategies.

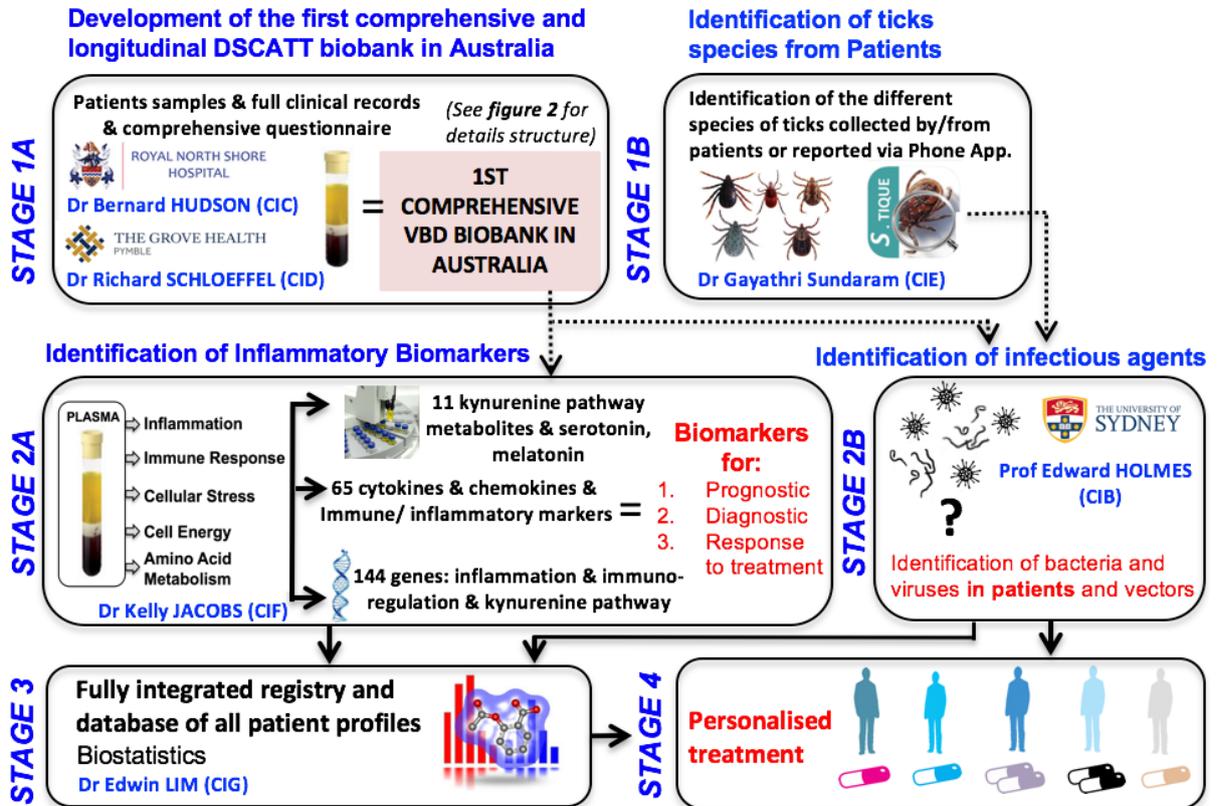
The proposed research will:

- Establish the first large-scale and longitudinal biobank for Lyme-like illness (DSCATT), initially with NSW-based patients, and once established, extended to other states and territories and made accessible to international collaborators;
- Use longitudinal samples to identify biomarkers for diagnostic and prognostic purposes as well as monitoring response to treatment;
- Use all the databases in the registry (immuno- and proinflammatory profiles) together with the causative pathogens identified (viruses, bacteria, parasites) to deliver a personalised treatment regimen adapted to each patient with Lyme-like illness / DSCATT within 3 years.
- Collaborate with disease groups that may have a causal link to micro-organisms.

⁹ Medical Research Future Fund <https://beta.health.gov.au/initiatives-and-programs/medical-research-future-fund/about-the-mrff>

¹⁰ Macquarie University, University of Sydney and St Vincent's Centre for Applied Medical Research

Figure 1 Conceptual model of integrated platform



Recommendation 2 - Invest in professional education to enhance medical knowledge of vector-borne illness

In 2016 the Senate Inquiry into Lyme-like illness recommended the Government work with medical associations and colleges to ensure that general practitioners have a better understanding of how to treat patients presenting with complex and chronic symptoms following a tick bite. It is critical that medical professionals are trained to recognise, diagnose and treat tick-borne illness. Without a medical community competent in diagnosing and supporting patients with tick-borne illnesses, the burden of illness for a patient is substantially increased.

Statistically, 46 percent of patients in Australia report seeing seven or more medical professionals prior to obtaining a diagnosis for their illness. Once diagnosed, 10 percent of patients are forced to travel overseas for rapid immersive treatments to stem their debilitation. However, many patients are too sick or can't afford to travel overseas for treatment and must seek treatment domestically; when seeking treatment in Australia 20 percent report traveling more than 500km to see a doctor who is educated in vector and tick-borne illnesses.¹¹

2.1 Primary Health Network Practitioner seminars

A [practitioner seminar](#)¹² focusing on the diagnosis and management of vector borne illnesses and chronic inflammatory response syndrome has been developed and was piloted in Sydney in 2018. The aim of the seminar was to develop the skills of the integrative medical practitioner in the clinical management of complex illnesses. The seminar included the diagnosis and management of vector borne disease, case studies and small group discussions to enable practitioners to use the tools and knowledge to better support their patients.

The blueprint for this type of seminar is already developed and could be scaled-up and delivered via Primary Health Networks nationally. It attracted 40 Category 1 CPD points approved by the RACGP QI&CPD Program 2017-2019 triennium. Investing in just 10 seminars, at a cost of \$50,000 each, located in areas where vector-borne diseases are common would quickly educate up to 500 practitioners and alleviate the burden for patients who cannot access medical treatment locally.

2.2 National Vector-borne Disease Summit

An International summit designed to bring scientists, doctors, allied health professionals, as well as patients and caregivers together, presents a unique opportunity to learn about contemporary policies, research and treatments occurring in vector borne diseases all over the world.

Hosted by the LDAA's Scientific Advisory Committee¹³, a body of International biomedical science and clinical medicine experts, a summit would take advantage of international knowledge on diagnosis, clinical pathways, emerging treatment protocols, research underway and future research proposed. Considerable research is occurring on Lyme disease internationally and Australian researchers would benefit in learning from and collaborating with their international peers.

Outcomes of the summit would help inform the Australian Government, healthcare sector and insurers of the need for accurate diagnosis, proper treatment and compassion for Australian patients caught up in the policy delays that hamper their diagnoses and restrict their treatment options.

¹¹ LDAA [Submission #528](#) to the Senate Inquiry on the growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients

¹² Spectrumceuticals Seminar: System approaches to Chronically Ill patients using Integrative medicine
<https://spectrumceuticals.com/event/spectrumceuticals-2018-practitioner-seminar/>

¹³ Scientific Advisory Committee: <http://www.lymedisease.org.au/wp-content/uploads/2018/04/Media-Release-SAC-20180418.pdf>

Immersive practitioner education workshops are proposed, as part of the summit. Attendees will have the opportunity to learn through the evaluation of patient case studies. Using a precision medicine approach and the multi-systemic infectious disease (MSIDS) diagnostic model¹⁴ developed by Dr Richard Horowitz, practitioners will be guided through the diagnostic process, mentored by international experts.

The workshops provide a unique opportunity for Australian patients to undergo diagnostic assessment and expert review by leading Lyme physicians, accompanied by their own practitioner. Patients either undergo diagnostic assessment or have their case reviewed as part of the practitioner workshop. International experts remain mentors to practitioners presenting their patient cases for review.

Practitioners who've undergone this type of immersive training, assessing patients in unison with expert's report that these types of workshops are some of the "best educational experiences I have ever attended". Commenting on the style of workshop and its focus on mentoring, one doctor notes "the excellent and detailed teaching of these doctors along with their vast experiential wisdom is invaluable. The training program is enjoyable yet intensive"¹⁵.

Similar practitioner training programs that include immersive patient assessment processes are part of the learning are available in Australia for other medical conditions. Patients who have had the opportunity to attend such workshops and undergo assessment also report positive experiences and rapid improvements in their chronic condition. One patient says she "believes that it's one of the best steps towards healing we've taken so far. The doctors were fantastic with loads of input and suggestions for us both. We would not have done it without your wonderful support, explanations and follow up"¹⁶.

An investment of \$420,00 would attract the right International experts, enable a 3-day summit, medical practitioner training program and patient assessment outreach program.

¹⁴ Horowitz, R.I.; Freeman, P.R. Precision Medicine: The Role of the MSIDS Model in Defining, Diagnosing, and Treating Chronic Lyme Disease/Post Treatment Lyme Disease Syndrome and Other Chronic Illness: Part 2. *Healthcare* 2018, *6*, 129,

¹⁵ <https://www.walshinstitute.org/medical-practitioner-testimonials.html>

¹⁶ Patient Outreach Programs – BioBalance Australia <http://www.biobalance.org.au/patients/testimonials>

Recommendation 3 – Invest in patient-centred support services, education and assistance

Evidence received during the House of Representatives Inquiry into Chronic Illness demonstrated ‘tick-borne or Lyme-like disease to be an example of a chronic illness which has significant, life-changing effects on its sufferers, but which is commonly misunderstood in the medical community and relatively unknown in the broader community’.¹⁷

The Inquiry also highlighted that the care of people with chronic disease in Australia is uncoordinated and disconnected. For people with a Lyme-like illness it is made worse by the lack of awareness, education and the multiple nature of infections which can affect every bodily system and necessitate care under multiple different specialists.

Research that might provide answers to the complexity of Lyme-like illness in Australia is years away. In the meantime, a concerted policy effort, funding and a coordinated approach is needed. A patient-centred, holistic care model is required so that people suffering from debilitating and chronic illness after a tick bite can improve their health outcomes and not fall through the cracks of the medical system.

The management of chronic disease not only falls upon the health care system to provide the medical and support services, but also relies on patients to understand their condition and participate in the management of their own health. This section recommends funding to underpin a series of patient support services provided by patient organisations, primary health care pathways and allied health providers.

Summary of actions	Cost
Patient Advocacy service trial for 10 patients p.a.	\$.05m*
Coaching and support service trial	\$.04m*
Crisis counselling service	\$.072m*
Lyme Disease Association of Australia - operations	\$.160m p.a. for 3 years / \$.480m
SUB TOTAL	\$.642m

3.1 Patient support – Patient Advocacy services

Many Australian patients with Lyme-like illness find themselves in isolating and daunting situations managing a variety of examinations, medications, diagnoses, treatments and costs. Many of them also suffer discrimination and derogatory treatment at the hands uneducated medical professionals who dismiss their illness and apply psychiatric labels to their suffering.

For many this is an overwhelming and untenable situation. Some patients have no family support and become dependent on a ‘system’ that doesn’t cater to them, to advocate for them. In some situations, patients are living with an entire family suffering from tick-borne illness and have difficulty in managing this particularly difficult chronic health situation.

¹⁷ See Inquiry into Chronic Disease Prevention and Management in Primary Health Care House of Representatives Standing Committee on Health report, May 2016, p.25

As such, professional Patient Advocates trained in Lyme-like disease can provide a beneficial service for this patient cohort. An in-person trial of Patient Advocates in five capital cities around Australia could establish the efficacy of this service in alleviating some of the issues faced by the most vulnerable patients.

If proven viable, Patient Advocates could be further contracted to develop advocacy education information to support other professionals working in associated disability support organisations nationally and who encounter people with Lyme-like illness.

Patient Advocates in Australia cost between \$100 - \$280 per hour depending on the complexity of need and our data indicates that the most vulnerable patients would need a minimum of 50 hours of support in a year (est \$5,000 per patient). We have immediate need of ten Patient Advocates to support young people currently residing in full-time medical care situations or entering a palliative care arrangement.

3.2 Coaching and support services

The active participation of a patient in their ongoing quest for health is a critical foundation to chronic disease management. Patient-centred outcomes rely heavily on the patient to manage their condition, yet Australian patients are confounded as the controversy about their disease means there is limited information about their condition.

Many patients turn to the handful of patient support organisations who provide information on all aspects of their illness at each stage. In some cases, Australian patients with Lyme-like illness have better health literacy about their illness than the medical professionals they visit. In other circumstance's some patients are ill-educated and provide inaccurate and unqualified information, often based on their own personal experience, to others.

However, most patients have no interest in the controversy, or the capacity for the tedious research required to manage their own health. They just want to get better and can benefit from health coaching that supports them to manage their illness, their symptoms, diet and associated lifestyle and medical regimens.

There is widespread use of Lyme related coaching services available in the U.S. and many Australian patients already consult U.S. medical practitioners about their illness. In overseas situations, coaches can be the interface between the patient and their medical practitioner who work together to develop a care plan and recommendations for the patient that are more accessible and affordable for them.

Some coaching programs have been developed to support the unique situation patients with a Lyme-like illness in Australia find themselves in. Patients who have participated in such a program tell us they "feel less isolated when they have someone who is knowledgeable and can relate to their situation"; and that coaching services "help them to keep on track between doctor visits" which can sometimes span months.

We'd like to trial the efficacy of these types of services more broadly with 10 patients, whose situation and outcomes pre and post coaching could be qualified, to determine how such services might help the dispersed cohort of Australia patients.

Estimated costs for coaching services per year is \$ 4,000 per patient.

3.3 Crisis counselling services

The LDAA maintains a website, social media pages and email account for the benefit of patients. Our volunteers are often called upon to support a patient in crisis and we sometimes have difficulty meeting their expectations and their needs.

The demand for crisis supports for patients is increasing and while we often refer patients to already established crisis support services like Lifeline, Beyond Blue etc we've found that patients prefer to speak with someone who has experienced their situation from a health perspective and who are able to help with a coordinated case management approach. Rarely is the need for crisis support a single event.

Most volunteers working within patient support groups are neither qualified or professionally equipped to support people in crisis or who are suicidal or are suffering from severe depression. We need better support for these patients. By training a cohort of volunteers in crisis support or providing access to coordinated crisis support services that can be integrated into a primary health setting and appropriately case managed, we can be collectively better positioned to help.

Training for up to 10 volunteers in crisis counselling and support is estimated to cost around \$6,000 per person. Enablement of telephones and associated plans to provide phone counselling is estimated at \$1,200 p.a. per volunteer.

Alternatively, a contracted allied health professional already trained in counselling, with some coaching from patients with a lived experience, could be employed to perform these services for a similar cost. Patient Advocates and counsellors could work together in a case management arrangement to garner community services and other supports the patient might be entitled to receive or need.

3.4 Lyme Disease Association of Australia – operations

The LDAA is a small charity run entirely by volunteers and has been operating since 2009. We rely on the generosity of people affected by Lyme-like illness to provide services, education, information and support to the patient community. We have an increasing number of participants in our community and patient forums and we consistently reach more than 20,000 people per month.

Data from our Facebook page indicates we had over 17,000 people following us in January, this represents an 800% increase in 2 years. Our volunteers are answering more than 100 emails per month (quadrupling in tick season) supporting patients who've been bitten by a tick and find themselves in an emergency or crisis situation or are newly diagnosed with Lyme-like illness. The data demonstrates the increasing interest in and awareness of Lyme-like illness and highlights the demand placed upon our volunteers.

We'd like to employ three part-time staff to help support patients and provide better, more timely information. Our reliance on the scarce charity of a chronically ill patient community places the organisation in a vulnerable position potentially unable to provide future support services. Without the certainty of funds, we are unable to commit the resources for paid staff or the continuity of the organisation and its mission.

Recommendation 4 – Invest in awareness and prevention education programs

The House of Representatives Inquiry into Chronic disease noted that prevention of chronic illness “requires education, monitoring and engagement with the community to ensure that contributory lifestyle/risk factors are avoided, or at least monitored and controlled before conditions can manifest or have irreversible contributions”¹⁸.

The Australian Health Promotion Association highlights that “chronic disease ‘prevention’ operates from an overall population health promotion perspective. Cost-effective health promotion interventions utilise broad behaviour-change levers that reach the whole population, such as legislation, public policy, education and comprehensive social marketing and improvements to the social and physical environment”¹⁹.

Prevention is recognised as a key strategy in overcoming the burden of chronic disease. It is the responsibility of the Australian Government to coordinate communication of health protection strategies and responses to emerging and current disease threats to the Australian population. However, due to the low level of information about the potential for illness from a tick bite, Australia has no prevention strategy.

Lyme-like illness, acquired through the bite of a tick, is entirely preventable if people are aware and informed. We consider that emerging Lyme-like illness requires a targeted and urgent response as an emerging health threat. This section outlines some modest strategies that will help to mitigate the risk of a public health crisis related to tick-borne disease. We propose targeted ‘in context’ efforts to inform people about protection strategies.

Summary of actions	Cost
Prevention signage – 20 trial sites	\$.12m
Tick tracking app	\$.2m*
Tick kits for schools	\$.38m*
SUB TOTAL	\$.712m

4.1 Prevention signage

A signage campaign, complemented by a local brochure drop, provides timely information in high risk areas and could help reduce the risk of tick bite by reducing the risk of exposure.

State and local governments could be tasked with erecting signage in tick endemic areas. They should be funded to conduct localised awareness campaigns on the signage with advice on protection



¹⁸ Ibid, p.26

¹⁹ Australian Health Promotion Association, [Submission 49](#), p. 1.

strategies. Local governments could be tasked with the responsibility for measuring behavioural change associated with the signage through observational surveys.

Alternatively, using our tick plot data, the LDAA and associated patient organisations could work with local organisations, councils, Land Care and recreational groups to develop user-centred prevention strategies and evaluate them for efficacy.

Estimated cost for up to 20 trial sites, complete with signage and brochures for local distribution is \$120,000.

4.2 Tick tracking app

Internationally, the development and availability of apps that enable citizen scientists to track ticks, bites and associated illness is increasing. Some apps focus on the disease itself, through symptom tracking and management, medication lists and reminders and some focus more on tracking the spread of ticks and their encounters with humans and animals. To provide much needed epidemiological data that might support surveillance in Australia, we are concerned with apps that focus on tick reporting and tracking of encounters.

To date, nine individual apps have been developed, generally by researcher, to get a better understanding of the prevalence of ticks, their bites and associated data required to spatially model disease. Many of the apps include educational information on ticks, advice on protective measures, tick identification charts and information on how to remove a tick if you are bitten. Evaluation shows that apps have high take-up rates and are appreciated educational tools that contribute to increased public knowledge about the danger of ticks and tick bites²⁰.

The development of a tick app in Australia provides a modern alternative to brochures and posters and may help people undertake preventive measures to avoid a tick bite and a potential chronic illness. Other than our own research maps plotting the incidence of Lyme-like illness in Australia²¹, there are no statistics, or research programs tracking and reporting the incidence of tick encounters on a national basis. Without this basic data the incidence of tick bite encounters remains unknown, disease surveillance is ignored, and tick control measures are overlooked.

A well-designed Australian Tick app that takes a One Health, citizen science approach, can provide real time data on the prevalence of tick encounters, including tick bites and locations. It could also integrate with anyone researching ticks and solicit the collection of ticks for a national open repository encouraging research collaboration. Integrating into the [research programs](#) already proposed under this submission, we could identify any person who becomes ill after a tick bite, inviting them to participate in the biobank and longitudinal studies to rapidly inform outcomes for patients.

The LDAA has been scaling up their data collection from web-based surveys into app-based products. Moving to a multi-platformed app would accelerate data collection and improve the knowledge we have about Australians and tick bites and associated illness. Specific investment in this area could see an Australia app available prior to the start of the next tick season. Funding to make this a reality is \$200,000.

²⁰ [Prevention of tick bites: an evaluation of a smartphone app](#), Dutch Ministry of Health, December 2017

²¹ <http://www.lymedisease.org.au/stats/>

4.3 Tick Kits for schools

Our research indicates that children are under-represented in the Australian statistics we hold about patients with Lyme-like illness. In 2012 we reported 9.32% of Australian patients were under 18, in 2013 this dropped to 8.01%. In other parts of the world, children figure much more prominently in the patient cohort, for example, the United States Centres for Disease Control and Prevention (CDC) profile cases by age and gender from 2001- 2010 and report a much younger cohort of patients (33%) under age 20. The CDC state the reported cases of Lyme disease are 'most common among boys aged 5- 9' (Centers for Disease Control and Prevention, 2012). In Europe research studies indicate one of the highest groups most at risk of tick-borne disease are children 5-9 years old²².

Sadly, the forgotten patient is often a child who becomes ill following a tick bite but is reliant on the education and knowledge of their parents or caregivers. Many parents and caregivers do not have adequate information about what to do in the event of a tick bite and schools are rarely better informed as they rely on their respective health departments to advise them. Our hypothesis is that children are at considerable risk, of firstly acquiring a tick bite and then of becoming chronically ill because of the lack of knowledge of their caregivers.

For many children, a tick bite may result in a localised rash some swelling and a delayed flu-like response that parents dismiss as a sniffle and general malaise without further investigation. It may be weeks or months later that other symptoms occur which are not associated with the initial tick bite. Providing both prevention and awareness information to schools is one way to avoid a future generation of kids with a Lyme-like and chronic illness.

Anecdotal evidence suggests that schools are in a precarious position when it comes to their duty of care in preventing possible disease, especially for schools participating in outings to tick infested areas. For schools in endemic tick areas, like coastal strips, we'd ideally like to see a prevention approach like that adopted in the SunSmart²³ campaign using DEET based tick repellents instead.

The LDAA business case estimates this initiative to cost \$380,000, however it relies on significant liaison with state health and education departments to understand the regulatory environment for duty of care processes in school environments and requires their support.

In many other jurisdictions, it is the government who provides information about tick bite prevention and awareness information to schools. In Australia we have no such initiatives as our combined health departments still grapple with the fundamental question of whether this disease is even "attributed" to the bite of a tick. Meanwhile, Australian children are at the highest risk of exposure through a lack of awareness and prevention efforts.

For the many thousands of Australian patients there is no question they are sick nor any doubt about where or how they acquired their illness, we do not wish to place another generation of children at risk of Lyme-like chronic illness because of the inaction of our health authorities.

²² [Epidemiology of lyme borreliosis](#), Hubalek, 2009

²³ <http://www.sunsmartnsw.com.au/>