

Department of Health

Patient Group Forum

Debilitating Symptom Complexes Attributed to Ticks (DSCATT)

27 July, 2018

Sydney

Facilitated by Helen Wood, CEO, TMS Consulting Pty Ltd

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1 Introduction

On Friday 27 July 2018, The Department of Health convened a patient consultation forum to hear from patients groups representing those suffering with debilitating symptom complexes attributed to ticks (DSCATT). The forum was facilitated by Helen Wood, TMS Consulting.

This report details the key discussion outputs from the forum and provides a summary of key presentations together with key messages regarding practical steps in the development of a multidisciplinary care model and priorities/approaches to support ongoing education and awareness about DSCATT.

2 Background

In 2016, the Senate Community Affairs References Committee published its Final Report relating to the senate inquiry into the *Growing evidence of an emerging tick-borne disease that causes Lyme-like illness for many Australian patients*. The report examined three main areas:

1. Providing a background into the committee's original inquiry, and an overview of the evidence considered by the committee in its interim report.
2. The diagnostic process for Lyme disease, with the objective of establishing why these processes and test results are so controversial.
3. Examining treatment options available for patients suffering Lyme disease-like illness, and the evidence around non-mainstream treatment, the position Australia's medical authorities take on such treatment, and how the existing impasse might be breached.

Through this examination, the committee released 12 recommendations. The purpose of the forum was to discuss the Australian Government's response to some of the recommendations, and in particular recommendation 5.

3.56 The committee recommends that the Australian Government Department of Health facilitate, as a matter of urgency, a summit to develop a cooperative framework which can accommodate patient and medical needs with the objective of establishing a multidisciplinary approach to addressing tick-borne illness across all jurisdictions.

3 Workshop Agenda

Patient Group Forum to address people suffering with debilitating symptom complexes attributed to ticks (DSCATT)

Date: Friday, 27 July 2018

Time: 10:00am to 3:00pm

Venue: Stamford Hotel Sydney Airport, O’Riordan St & Robey St, Mascot NSW 2020

Number	Time	Agenda Item	Lead
Morning Tea	09:30 – 10:00		
1	10:00 – 10:10	Video Address	The Hon Greg Hunt, MP Minister for Health
2	10:10 – 10:25	Opening remarks	Professor Brendan Murphy Chief Medical Officer Department of Health
3	10:25 – 10:35	Introduction to the Forum	Independent Facilitator
Mini Break	10:35 – 10:45		
4	10:45 – 12:00	Scene setting - Summary of the April 2018 DSCATT Forum - Patient Accounts	Independent Facilitator - Group Discussion
Lunch	12:00 – 12:30		
5	12:30 – 12:50	The NHMRC targeted call for research into debilitating symptom complexes attributed to ticks	Dr Julie Glover NHMRC
6	12:50 – 13:50	Options for a multidisciplinary approach to care	Independent Facilitator - Group Discussion
Mini Break	13:50 – 14:00		
7	14:00 – 14:50	Education and awareness for medical and other health professionals	Independent Facilitator - Group Discussion
8	14:50 – 15:00	Forum close	Independent Facilitator

4 Attendees

The attendees at the forum were as follows.

Commonwealth

- + Professor Brendan Murphy (Chair), Chief Medical Officer, Department of Health
- + Dr Jenny Firman, Principal Medical Advisor, Office of Health Protection, Department of Health
- + Ms Sarah Norris, A/Assistant Secretary, Health Protection Policy Branch, Office of Health Protection, Department of Health
- + Ms Cindy Toms, Director, Office of Health Protection, Department of Health
- + Mr Phil Wright, Assistant Director, Office of Health Protection, Department of Health
- + Mr Sam Develin, Advisor
- + Dr Julie Glover, Executive Director, Research Foundations, NHMRC
- + Tanja Farmer, Director, Targeted Research Programs and Support, NHMRC

Stakeholders (attended in person)

- + Dr Mualla McManus, Karl McManus Foundation
- + Sharon Whiteman, Lyme disease Association of Australia (LDAA)
- + Catherine Stace, Lyme disease Association of Australia (LDAA)
- + Elaine Kelly, Sarcoidosis Lyme Australia
- + Alex Patsan, Hunter Region MSIDS
- + Coreena Haylen, Hunter Region MSIDS
- + Lea England, Vic Lyme Support
- + Karen Smith, Lyme Australia Recognition & Awareness (LARA), Global Lyme & Invisible Illness Organisation (GLIIO)
- + Petrina Sheil, Lyme Australia Recognition & Awareness (LARA), Global Lyme & Invisible Illness Organisation (GLIIO)
- + Bev Parkinson, Tickborne Illness Community Network Australia Inc
- + Chris Cole, Tickborne Illness Community Network Australia Inc
- + Nikki Coleman, Canberra Area Lyme disease support group
- + Patrick, Canberra Area Lyme disease support group
- + Jacqui Van Teulingen, NSW Far South Coast Lyme group
- + Roanna Pepper, NSW Far South Coast Lyme group

- + Alistair Mills, NSW Riverina Lyme Support Group

Stakeholders (attended remotely)

- + Kate Daniels, Multiple Systemic Infectious Disease Syndrome (MSIDS)
- + Rachel Penney, Multiple Systemic Infectious Disease Syndrome (MSIDS)
- + Julie Mullumby, Southwest Coastal MSIDS Support Group (WA)
- + Ted Donnelly, Southwest Coastal MSIDS Support Group (WA)
- + Ailsa Burgess, Chrysalis
- + Peter Owen, VIC Lyme Support
- + Stephen Le Page, ME/CFS and Lyme Association of WA, Inc
- + Vicki White, The Kojonup Lyme Supporters Association Inc
- + Richard Robbins, Tickborne Illness Community Network Australia Inc
- + Richard Healing, Tickborne Illness Community Network Australia Inc
- + Stephen Mason, Tickborne Illness Community Network Australia Inc
- + Sharyn Paxman, Lyme Australia & Friends Group
- + Tracey Winner, Lyme Australia & Friends Group
- + Brett Osler, Chrysalis
- + Brett Hardman, Gold Coast Lyme group

Facilitators

- + Helen Wood, TMS Consulting
- + Lynda Mary Wood, TMS Consulting

5 Discussion Outputs

5.1 Introduction

5.1.1 Opening Remarks - The Hon Greg Hunt, MP, Minister for Health

The Minister provided a welcome to all participants, via video, to what he described as a very important forum. The Minister indicated that the outputs from the forum would provide a pathway to the future, informing patient needs for research, diagnosis and treatment. Minister Hunt welcomed input, constructive thoughts and suggestions from everyone present.

5.1.2 Opening Remarks – Professor Brendan Murphy, Chief Medical Officer

Professor Murphy welcomed all participants, both in the room, and remotely and expressed gratitude for the time they were contributing to a very important discussion. Following an acknowledgement of country, attendees were provided with a background to the day, with reference to the Senate Community Affairs References Committee's Final Report relating to the senate inquiry into the *Growing evidence of an emerging tick-borne disease that causes Lyme-like illness for many Australian patients*. Professor Murphy noted that some of the 12 recommendations from the report were discussed at the April 2018 forum, however not all recommendations would be discussed at the current forum due to the lack of direct evidence regarding transmission by tick bites. The core focus for both sessions was regarding Recommendation 5, which called for the convening of a forum to devise a multi-disciplinary care approach that accommodates patient needs and medical standards.

Professor Murphy reiterated that the purpose of this Forum was to include discussion of the outcomes of the April forum and outline some of the work the Department of Health has agreed to undertake. The Forum was also to provide patient groups with an opportunity to have their views heard and to provide input into key discussions about the way forward. In addition, it was a chance to receive an update on research activity into these debilitating symptom complexes.

Professor Murphy acknowledged that the need for care is real, the symptoms people experience are real and it is essential that patients receive care that is both evidence-based and compassionate. The suffering of patients was acknowledged and the focus of forum discussion must be the development of supportive and consistent treatment options. It is still

not known if these symptom complexes are infectious or tick derived and the Department supports research to find related evidence and keeps an open mind to new evidence. Without this research treatment strategies that assume infection cannot be supported and the Department welcomes a finding that would define appropriate treatment pathways.

Professor Murphy acknowledged that the treatment experience for some patients has been unsatisfactory and it is important that there is a comprehensive search for diagnosis through clinical assessment. The Department supports the need for comprehensive multidisciplinary assessment of patients with these symptom complexes. It was also acknowledged that appropriate psychological support needs to be provided as any patient suffering from a long term chronic illness can benefit from this type of support.

The current approach that involves exclusion of currently diagnosable diseases, followed by a supportive care approach, is all that current evidence can support. Prof Murphy reiterated the importance of research to further understand the cause of the symptoms being experienced by patients.

5.1.3 Introduction to the Forum – Ms Helen Wood, TMS Consulting

Participants in the room and online were welcomed and the format of the day was outlined. The Forum would provide the opportunity for individual and group perspectives to be heard through open and respectful discussion. The key points for the day were outlined, which included:

- + To hear the experiences of patients.
- + Provide feedback on the outcomes of the April Forum.
- + Receive an update from the NHMRC on research.
- + Discussion of a multidisciplinary approach to care.
- + Discussion of education and awareness needs and supporting materials.

5.2 Scene Setting

5.2.1 Summary of April 2018 DSCATT Forum

A brief overview was provided by the Facilitator regarding the outcomes of the April, 2018 Forum. The outcomes included:

- + It was largely agreed that a multidisciplinary approach was a step in the right direction and that actions should be taken to establish a trial clinic. To assist with establishing a

clinic, forum participants encouraged Prof Lindsay Grayson and Dr Richard Schloeffel to publish their experiences in treating patients with these complex symptoms. This would also increase the profile of the issue in the medical community.

- + Attendees identified that more education and awareness is required to support GPs, patients and the public in tick borne illness diagnosis, treatment and tick bite prevention, as well as the ongoing management of patients with debilitating symptom complexes. Participants also noted that there should be increased public health messaging on tick-borne diseases, preventing tick bites and removing ticks safely.
- + Because of the perceived stigma associated with referring to illness as Lyme disease, forum attendees agreed that the condition should not be referred to as Lyme or Lyme-like disease, however currently there is no consensus on what it should be called. There is a need to respectfully and effectively treat patients and to increase medical knowledge and evidence related to the condition and its treatment.
- + Everyone agreed to the need for further research to determine what is causing these debilitating symptom complexes.

5.2.2 Discussion: April Forum

Attendees reflected on the outcomes of the April forum and made the following discussion points:

- + A question was raised as to why there is not more funding allocated to determine if this was an infectious disease. The response indicated that there is a need for more research directed towards the whole disease complex. There is no doubt that ticks do transmit disease and researchers are considering this.
- + Concerns were raised about the stigma many patients faced when presenting with this condition and that this stigma went beyond GPs to specialists, hospitals, medical colleges and universities. The stigma meant that patients are not getting effective treatment yet many other non-diagnosable conditions are getting treated.
- + It was also noted that patients cannot wait for effective treatment while research is completed to prove causation. There was consensus that effective treatment was required as soon as possible.
- + A question was raised regarding clinical assessment of these patients and whether or not the patients are being assessed comprehensively. There was differing views however, ultimately it was agreed that both patients and clinicians should approach an assessment with an open mind and ensure that diagnosable conditions are excluded.

- + Regarding why the Department of Health hadn't done an epidemiology study to understand more about symptoms, regions where patients come from, it was explained that a primary requirement of an epidemiological study was to have a definable case. Some patients are suffering from chronic fatigue, some patients know that they have had a tick bite and some do not. Without a case definition it is difficult to conduct an epidemiological study and it is also the reason it cannot be made nationally notifiable.
- + It was expressed that children do not make up diagnosis symptoms yet Lyme-like disease is the last diagnosis after many years of mis or non-diagnosis and they are often treated for symptoms they don't have. In response it was acknowledged that there are genuine and real symptoms, but because there is no proof of cause, treatment is problematic.
- + There was a query as to why more hospitals are not testing for Rickettsia and it was noted that GPs on the Northern Beaches of Sydney regularly test for Rickettsia however many other GPs are not aware of it. Tick typhus is a self-limiting mild disease which is often missed and it was agreed that work should be undertaken with the RACGP to raise awareness.
- + Concerns were raised regarding patients not being able to get appropriate treatment even though they contracted Lyme disease overseas in a Lyme endemic area. It was noted that Lyme disease acquired from overseas is recognised and post treatment should be provided however the definitive diagnosis is sometimes not accepted.
- + In relation to the above two discussion points, it was agreed that more work on education and awareness was needed for tick-borne diseases in Australia.
- + Comments were made regarding the results of worldwide research and a request for it to be considered and applied in Australia. Specifically, some patients feel it creates doubt on the current position held by the Department. Because of the significant patient impacts, it was asked how long before action could be taken and global research be considered. Professor Murphy indicated that international research is always reviewed and considered but that it is only relevant to the country in which it is undertaken. For example, 80% of tick disease in North America is Lyme disease and there is no evidence of Lyme causing borrelia in Australia.
- + There was also a discussion on the use of antibiotics and that some patients had experienced improvement in symptoms with antibiotic treatment overseas and then relapsed when treatment was withdrawn in Australia. In responding to the discussion on the use of antibiotics, Professor Murphy noted that when there is no evidence to

support the appropriate treatment there would be ethical and clinical considerations in deciding to continue antibiotics in these situations.

- + It was generally agreed that more research is needed to determine the cause of illness to be able to, in turn, provide evidence-based treatment.
- + Comment was made that there should be a database established for 'intractable disease' (the digital registration system in Japan was noted as an example) however, there is a need for defined criteria for meaningful data and it is important to study a data set with similar symptoms. In relation to data collection, the size of the data set was discussed as size is relative to how effective analysis could be. Too big a data set would make the dataset less useful. It was noted that Dr Schloeffel's model would be a good example of where a group of people with similar symptoms that could be studied.

5.2.3 Patient Accounts

Three attendees were chosen by the facilitator to share their account from the Patient Accounts Booklet with the group. The key points are included below, and the full accounts are provided in the Patient Statement Booklet (Appendix A).

5.2.3.1 Sharyn Paxman (Lyme Australia & Friends Group)

Sharyn is a livestock owner whose property adjoins a national park, and often encounters and has been bitten by multiple species of ticks, spiders, fleas, mites and lice. She has confirmed tick bites of the species identified by published Parasitologists specialising in ticks: *Rhipicephalus australis*, *Haemaphysalis longicornis*, *H.bancrofti*, *Ixodes holocyclus* & *Amblyomma nymph*, and suffered a spreading EM rash from *Amblyomma* tick. Unfortunately, this tick was not tested, only identified. Sharyn expressed her unsatisfactory experience with laboratory testing, where she was tested by four different NATA-accredited labs during a 12 month period for *Bartonella*. Each test returned: "*This specimen was unsuitable for testing due to non-specific staining. A further sample may prove useful.*" When queried by two different GPs, the labs have given two different responses: "*Patient's blood is resistant to staining*"; and, "*Possibly a Native strain of Bartonella that does not react to this stain*".

Furthermore, she did not perceive to have any benefit from multi-disciplinary care (MDC). Sharyn had been investigated for multiple conditions, including hepatitis, lupus, hand foot and mouth, neurological, gastro intestinal disorders; and as a result has visited many specialists including a world-renowned Ophthalmologist, a professor of Hepatology/Gastroenterology, a published Neurologist, a Cardiologist, and a Dermatologist - all at the request of a

Rheumatologist and with underwhelming results but of great expense. Of particular disappointment was that none of the specialists investigated the root cause of the conditions, but still prescribed dangerous medications that are contra-indicated in certain conditions – only making the symptoms worse whilst making her vulnerable to other viruses and infections and further complications. Sharyn upheld that GPs need to be better informed and supported by a standard panel of tests that will result in more individualised treatment plans. She concluded by noting that all ticks should be considered as potential disease carriers, and not just paralysis ticks.

5.2.3.2 Bev Parkinson (Tickborne Illness Community Network Australia Inc.)

Bev presented her account from a parent's perspective of her adult daughter's experience with a tick bite in Tasmania. This has resulted in over a decade of being bedridden with ongoing symptoms of constant severe pain, brain fog and fibromyalgia, and hospitalisations including septicaemia and meningitis. Her daughter was misdiagnosed with chronic fatigue syndrome and sought support and treatment only offered in overseas clinics, resulting in diagnoses of borrelia, bartonella and babesia infections. Her husband and 2 of their 3 daughters are also ill from tick borne infections passed on from her daughter.

Bev highlighted the very significant impact of her daughter's condition on the extended family, both financially and emotionally. She concluded by requesting the long term acknowledgement of the disease and encouraged health professionals to listen and keep an open mind.

5.2.3.3 Kate Daniels (Multiple Systemic Infectious Disease Syndrome – MSIDS Inc.)

Kate is the president of MSIDS, which is the only organisation for DSCATT sufferers who supplies a phone contact, and received a lot of calls from patients and carers who need an immediate response. The organisation was started six years ago as the WA Lyme Association, and since has gone Australasia-wide and is now referred to as Multiple Systemic Infectious Disease Syndrome Incorporated (MSIDS Inc.) Kate introduced her section by acknowledging that the patient stories have already been well covered in the Senate Inquiry, as well as in the patient booklet developed for today's session. She questioned whether the community was still at the stage of sharing patient experiences, and encouraged the group to move on to the next steps.

Regarding the patient statements, Kate presented two cases of sufferers who expressed no hope in the treatment of their condition and ended their own lives. In one case, the patient

wrote on his blog: *"I can't help waiting for medical science to find the underpinnings of this disease so that future suffering may be prevented for many people."* She expressed the impact of the disease in terms of loss of career, home and relationships, and questioned how these people end up in this situation – because they felt there was no hope.

Kate expressed her frustration at having to neglect all aspects of her life to uphold the advocacy work for Lymeworld, in an unpaid role that should be filled by the Department of Health. Specifically, Kate spoke about the Department's role in providing education to the medical industry and general public, and urged the department to take more action so that the sufferers can focus on their treatment, rather than spending the time researching and educating people. She identified a clash of cultures between people in the medical industry who are trained in a particular way of thinking, which is reductionist and trying to find the most simplistic solution, however does not work when dealing with a complex of multiple causative symptoms.

Kate spoke about the Department's current core messages for education of health professionals, particularly the official position and diagnostic guideline: *"Classical Lyme disease cannot be acquired in Australia."* (*Borrelia burgdoferi sensu lato*) The impact of this position is that physicians disregard symptoms associated with locally acquired tick bites, and disregard other potential tick-borne infections; overall GPs are afraid to test and treat for tick-borne infections.

Kate concluded by raising awareness to the paper: *Brazilian lyme-like disease or Baggio-Yoshinari syndrome: exotic and emerging Brazilian tick-borne zoonosis* (Yoshinari, Mantovani, Bonoldi, Marangoni, Gauditano, 2010). The key message from the paper was in the statement: *"...Physicians should be informed about the non-existence in the country of conclusive reports of classical LD with typical clinical and laboratorial characteristics found in the Northern Hemisphere."* As a finishing message, she asserted that what translates at the moment from the message that is being put out is the minimisation of risks associated with Australian ticks; physicians/clinicians disregard symptoms associated with locally acquired tick bites; disregard for other potential tick-borne infections because it's all just about Lyme disease.

5.2.4 Discussion: Patient Accounts

Attendees reflected on the patient outcomes and made the following points:

- + Discussion regarding the ethical considerations of blocking antibiotic therapy when there is clear deterioration when such therapy is withdrawn. The medical position is that, without evidence of infection, it is generally considered to be inappropriate to prescribe antibiotics.
- + It was noted that the Department of Health has now released position statements on Lyme disease and DSCATT. Confirmation was sought on whether or not these statements had been provided to medical colleges. The Department confirmed that they had been provided along with the outcomes of the April 2018 Forum.
- + The Department has undertaken engagement with GPs and colleges on DSCATT, in particular to ensure that GPs treat patients with respect and comprehensively assess their symptoms.
- + There was some discussion on allowing experimental treatment to be used when all other treatment options have been used and it is a last resort treatment. The CMO noted again that evidence needs to exist before treatment can be considered.

5.3 NHMRC targeted call for research (TCR) into debilitating symptom complexes attributed to ticks

Dr Julie Glover, Executive Director, Research Foundations, NHMRC (Appendix B)

5.3.1 Work of the NHMRC

- + NHMRC is the leading funding agency for health and medical research in Australia; funds research that leads to the evidence, publishes health guidelines and provides guidance on research ethics
- + Works collaboratively as part of the health portfolio with the goal of funding being related to human health
- + Funds basic, clinical and public health research and research involving clinical trials
- + Funds individuals, teams and networks
- + All funding (approximately \$800 million annually) is contestable with the involvement of 80 institutions and with most grants spanning five (5) years or less.
- + Research funding is extremely competitive with over 5000 applications received per year: peer reviewed by a panel of experts with each scheme having assessment criteria.

5.3.2 Targeted Call for Research into Debilitating Symptom Complexes Attributed to Ticks (DSCATT):

- + Historically, in areas related to DSCATT there have been very few applications received - less than 20 in 20 years
- + In 2017, one grant was awarded by NHMRC relating to “tick-borne illnesses” worth more than \$600K (\$639,428)
- + NHMRC has initiated a Targeted Call for Research (TCR) into DSCATT identified through the NHMRC’s Online Pathway. The Hon Greg Hunt MP, Minister for Health asked that NHMRC establish a committee of independent experts to frame the research subject.
- + NHMRC, in consultation with the Department of Health, identified and invited members to serve on the Expert Advisory Group, which included a range of scientific experts, including infectious disease physicians and consumer representatives.
- + The NHMRC Expert Advisory Group built on the work of the Senate Enquiry and defined the research question, providing the basis for the scope of the TCR.
- + Research scope: what is the epidemiology of DSCATT, causes, symptoms, nature of the disease, occurrence, and impact on health? The knowledge created from this research will guide the development of effective tools for diagnosis and treatment.
- + NHMRC’s Peer review processes is guided by the assessment criteria outlined in the grant opportunity. The areas of focus are: scientific relevance, record of achievement of the team.
- + Peer review is a confidential, independent and impartial process, underpinned by fairness and transparency. NHMRC has a robust conflict of interest process for peer review members to ensure research integrity.
- + The peer review process has commenced, decisions will be made by the end of the year, with research to commence in 2019.

5.3.3 Discussion: Research Update

Attendees reflected on the research update and made the following points:

- + It was suggested that consideration be given to what other centres are doing in the area, for example Griffith and Newcastle Universities.
- + There was discussion on the issue of conflict of interest regarding peer reviewers and the importance of transparency and how research findings can be implemented. The TCR intends to put research into practice (i.e. researchers provide the evidence and then apply for funding to research what it means in terms of impact).

- + The importance of maintaining confidentiality and the issue of researchers having to review researchers. The process currently does have an independent Chair and an appropriate system to prevent bias.
- + The criteria for applications can be found on Grant Connect and a link will be distributed to participants. The panel will consider international experts on panels, depending on what expertise is needed.
- + Regarding timeframe, patients will be recruited into research as soon as possible and when the research comes up with something definitive, action would happen quickly.

5.4 Options for a multidisciplinary approach to care

Three models were presented for discussion:

5.4.1 Personalised medicine model – Ms Catherine Stace, LDAA (Appendix B)

Ms Stace presented the work on the Glioblastoma (GBM) Adaptive Global Innovative Learning Environment (AGILE) and how patient groups can work with the Department and NHMRC in the development of effective care models.

The importance of rising above complexity to give patients hope was emphasised and the opportunity to leapfrog to new models by using innovative models. By co-devising a model, based on biomarkers, the guess work is taken out of treatment whereas a siloed approach takes much longer. Exploring where there are shared attributes with other groups leads to an adaptive learning environment. Equity of access to research funding is needed to find experiential models, personalised medical spaces and early diagnosis

Stakeholder engagement is critical to address a shared problem, looking to change from the current approach to a whole system approach, working with a core group of scientists to map complexity and develop design solutions. The LDAA prefers an approach that uses a PAN (referring to 'all in') disease and personalised medicine model, which appears to be critical component when treating patients with system complexes.

This generated very positive discussion about the possibilities of what could be achieved if patient groups worked in collaboration.

5.4.2 Dr Mualla McManus – Karl McManus Foundation (Appendix B)

Dr McManus presented a model to address the Senate Enquiry on how to care for patients now and indicated that a multidisciplinary model is only as good as all its members.

In describing the model, Dr McManus emphasised that the medical registrars need to be young, passionate and not entrenched by bias and they need exposure to overseas experience (6 months) where Lyme disease is evident. They also need to be supported by other health professionals in the operation of the model. It was noted that a facilitator would oversee and manage the model and information would be provided to the RACGP and marketing information to GPs.

The patient would visit the GP who has knowledge around system complexes, would undergo a holistic assessment, be diagnosed and subsequently managed by a multi-disciplinary team (MDT). Data would be collected and as more patients go through the pathway, more extensive data would be obtained. The MDT could also disseminate information to the Primary Health Networks. This also links into the Senate enquiry recommendation regarding data collection.

5.4.3 Prof Brendan Murphy: Chief Medical Officer (Appendix B)

Professor Murphy outlined the schemata presented at the April 2018 Forum and indicated that there is a cognitive bias against any tick-borne disease by doctors and this is why there is a need for comprehensive assessment to exclude any other disease/disorder. He went on to explore the Clinical Pathway for DSCATT patients and emphasised that psychological treatment is critical with long-term chronic illness. In order for a collective view on how MDC could be delivered, Professor Murphy indicated openness to collaboration in the development of a pathway.

5.5 Practical steps to develop a Multidisciplinary Care (MDC) model

Attendees were asked to discuss the practical steps that they believed were most important in the short term moving forward. Summarised responses were as follows:

- + Education, raising awareness and MDC should be undertaken together. This should also include the public so that they know how to avoid ticks and the disease.
- + Continuing professional development points should be introduced for doctors and the Department website updated with information, along with a media campaign.
- + The pathway should be based on clinical assessment, not just on serology. There needs to be capacity to have a model for GPs whereby testing is done by a Registered Nurse and then the patient is passed to the GP for diagnosis.
- + There are potential challenges for rural patients, for example where will be the clinics be located.

- + It will be important to utilise the experience of doctors already working within a MDC model for education and to raise awareness.
- + There are multiple strains and testing may only cover a small number of strains – serological testing is flawed and diagnosis must be clinically based on assessment.
- + There is a need for a holistic multidisciplinary approach with further training for GPs and training to incorporate Allied Health and other Health Professionals, for example naturopaths. Harvest of world best practice/best knowledge will support this approach.
- + There is a need to develop processes for acute, chronic and end stage of the disease.
- + It is important to harvest data from the patient group and make it understandable and transparent.
- + Concern was expressed that more time was needed to come up with a model and input needs to include clinicians who have experience.
- + There was also concern that the model had already been determined by the Department and reassurance was given that the Department has come to the Forum with an open mind to what the model will look like.
- + Of the models presented in the forum, it was considered that these could be amalgamated in a collaboratively developed model and that this could be addressed through a co-design approach.
- + It was suggested that a specialist physician with experience in Lyme disease/DSCATT should be included in a MDC model along with geneticists, a patient coordinator and psychologists rather than psychiatrists.
- + It was agreed that there would be some benefit in bringing similar disease groups together such as the Myalgia Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) group and emerging biotoxins group for a ‘think tank’ to discuss similarities and future support pathways.
- + It was agreed that the priority must be given to the care for children.

5.6 Key priorities and approaches to support education and awareness

Attendees were asked to discuss the priorities for education and awareness that they believed were most important moving forward. Summarised responses were as follows:

- + Updating the Department of Health website to include information on other tick-borne illness.
- + Clinical pathways should be considered and diagnosis not just based on serology. Advice given to patients that negative test results do not necessarily rule out Lyme disease.
- + Research combined with worlds best practice treatment – education of GPs and the public to ensure that everyone is on the same page.
- + Tick bite awareness and prevention protocols within schools.
- + A Hotline should be developed and marketing carried out through TV and social media.
- + Prevention and implementation of prophylactic treatment education.
- + Prevention, including warning signs in National Parks and education/awareness for employees.
- + Genomics is very important work to be included.
- + Utilising GPs experienced in treating DSCATT patients to train other GPs.
- + In Australia, there should be smart traveller advice, including advice for travellers arriving from overseas.
- + There should be education on serological testing and the various forms including reservoir hosts and the pathogens.
- + Part of tick awareness should be information on appropriate non-toxic tick removal tools.
- + Consideration of whether or not the Blood bank should screen for tick-borne illness.

6 Closing Remarks

Professor Murphy closed the Forum by thanking everyone for their positive and productive contributions, noting there is still a lot of work to be done. He indicated that he would report back to Minister Hunt on today's proceedings, and expressed his excitement for the possibility of a 'think tank' with other similar groups to consult and collaborate on a way forward.

7 Outcomes

In summarising the discussions at the forum, the following outcomes were agreed:

- + The multidisciplinary approaches presented at the forum needs further exploration and to be collaboratively developed but should be pursued.
- + Ministerial support will be sought to convene a 'think tank' which will include other disease like groups (e.g. ME/CFS, Biotoxins) to develop and co-design the way forward.
- + Further research is required however treatment pathways cannot wait until the research is completed and needs continued focus.
- + Education and awareness is the highest priority with a strong focus on prevention, children, community awareness and GP knowledge and acceptance.

8 Facilitator Observations

The following observations are made by the facilitator in the spirit of being an independent observer. Observations relative to the forum are:

- + All attendees are passionate about the condition causing debilitating symptoms and have the interest of patients at the forefront.
- + Patient groups were challenging but also collaborative in their discussion and open to different approaches and next steps.
- + The Department provided responses to a wide variety of questions with a strong focus on the need for evidence and importantly effective care and awareness raising while research is being conducted.
- + There was agreement that there needs to be further research and better treatment pathways for patients – that the symptoms are mixed and varied and need an effective MD approach.
- + There was genuine and collective excitement at the prospect of a combined Think Tank with other like disease complexes (ME/CFS, Biotoxins and DSCATT).

Overall the participation of all attendees was high and it was a valuable forum for adding to DSCATT related conversations.

9 Conclusion

The feedback on the forum was generally positive with strong interaction and contribution from all attendees. In final comments and in relation to discussions immediately following the forum the feedback was very positive and there was positive excitement about next steps. On conclusion attendees were appreciative of the opportunity to be heard and to discuss this complex issue.

10 Appendix

10.1 Appendix A – Patient Statement Booklet



Australian Government

Department of Health

**Patient Forum to address people suffering with
debilitating symptom complexes attributed to ticks
(DSCATT)**

Friday, 27 July 2018

10:00am to 3:00pm AEST

Stamford Hotel Sydney

Joining Instructions

Details to join via videoconferencing ZOOM:

Join from PC, Mac, Linux, iOS or Android:

(<https://zoom.us/j/6428642604?pwd=MVdneUIONFIVWIF5RG91TXJ5b0J2Zz09>)

For those that require a test run for accessing videoconferencing this will be available at 9.00 am (AEST), joining details to ZOOM test are the same as above.

Details to join by telephone:

iPhone one-tap:

Australia: +61280152088,,6428642604# or +61871501149,,6428642604#

Telephone:

Dial (for higher quality, dial a number based on your current location):

Australia: +61 (0) 2 8015 2088 or +61 (0) 8 7150 1149

Meeting ID: 642 864 2604

Patient Statements

Patient Forum Personal Lyme Story

1

Summary

- I acquired Lyme-like illness from a tick bite in Pomona Qld (4568);
- I immediately became sick with flu-like symptoms after the tick bite and had a bull's eye rash at the tick bite site within 12 hours. I did not connect the tick bite with my subsequent decline of health, and no doctor asked about tick bite history;
- I was sick for 4 years before I diagnosed myself because a friend pointed out online information about bulls eye rash;
- I have positive DNA Borrelia Burgdoferi blood tests from US lab; I also have positive tests for Rickettsia (multiple strains); I have been clinically diagnosed with Babesia and Bartonella;
- I saw 17 doctors prior to diagnosis;
- I had been diagnosed with CFS, query atypical Lupus, atypical Sarcoidosis, depression, fatty liver (although scans ruled out fatty liver);
- No doctor would help, I had given up and was saying my goodbyes, my mother-in-law found a natural protocol online and within 18 months, while still disabled, I had quality of life back;
- I did have a Lyme-literate doctor for a short period and was about to have more intensive medical support, but he had treating restrictions placed by AHPRA so that support was withdrawn;
- Following that I had a sympathetic doctor, but she is scared to treat Lyme-like illness because of AHPRA situation and would like support/training for Australian doctors so she feels more confident;
- Currently I avoid doctors and don't share my diagnosis when I do have to attend an appointment.

My Story

In 2002 I had a tick bite on my right arm that was 'different'. I immediately began to feel ill with strong flu-like symptoms and developed a strange rash. With a semi-rural property, multiple pets and kangaroos regularly visiting, I had had tick bites previously, but never symptoms like this. I researched online and found that it was a 'bulls eye rash'. It said it was 'rarely fatal', so I just continued with supplements to support my immune system and symptoms.

Over the next few months I started to become unwell, but I didn't connect it to the tick bite. I was fatigued and couldn't find a reason. I experienced a second very severe and 'weird' flu-like illness. I had headaches, light sensitivity, and skin sensitivity amongst other symptoms. I couldn't even tolerate a sheet on my skin and had a rash on my hands.

I had multiple visits to my GP over the next 2 years with early symptoms of fatigue, significant weight gain (25kg) and elevated liver enzymes. In the first 4-6 years of trying to find answers, I had had referrals to multiple specialists including Infectious Disease Specialists (2 saying 'no Lyme in Australia'), Gastroenterologist, Cardiologists, Retinal Ophthalmologist (who greeted me saying 'there's no Lyme in Australia'), Endocrine and Integrative GP (who stood up and kicked me out of the office). I had brain scans, CT scans

of abdomen, stress echo, and extensive blood, urine & stool specimens. My GP was compassionate but distancing, as she had run out of ideas for my rapidly declining health. Anti-depressants were recommended multiple times by multiple doctors.

The Impact

I've been sick for 16 years now, my hopes and dreams for my future have been decimated and my children are scared for me. I have always been a committed, high achiever at whatever I put my hand to, but I currently have to lead a very disabled life. I can't stand long or walk far and I'm easily confused. Through loss of income and medical expenses, we have had to sell our entire property investment portfolio (10 properties), withdraw super and we are facing losing our home at present. We were on track to be 'self-funded' in retirement but at this point, without a miracle, this reality appears to be shattered.

How can one very able, very successful, very happy and very motivated individual get flattened by a mystery disease – so ghastly and horrific, so extraordinarily painful and disabling... that self-euthanizing was considered? From high end corporate work, vigorous exercising, full family and social life - to tick and flea bites, then a shocking collapse.

- The humiliation of feeling like you is truly dying - but hospital continues to send you away.
- The neuralgic pain that is head to toe - but not visible in tests.
- The inability to hold head up and encephalitic symptoms - and told it must be hay fever.
- 24/7 excruciating pain – crying out at worst
- Strength and coordination disappearing from body - but suggested its overwork.
- Bone and joint pain that makes it hard to turn neck – but told its sleeping position
- A brain that loses its cognitive abilities down to 40% – but told its stress. This little understood disease is the stuff of horror movies.

From my understanding I caught hard to detect infections that don't mount an immune response. My immune system wasn't showing it was fighting an infection. And it wasn't. I was failing. This lack of blood work indicators, I assume, is why underdiagnosed.

I very patiently endured visiting the hospital system IDS, with a multitude of tests done over a year. With final diagnoses 'not clear.'

I have been clawing back my family's health and hopes by fighting for our lives travelling to distant cities and countries that understand the stealth nature of tick borne diseases.

Once under a doctor that had broadened knowledge, I treated the diseases I proved positive for.

1. Rickettsia most strains
2. Tick typhus
3. Babesia Duncanii
4. Borrelia species
5. Bartonella
6. Numerous viruses
7. Toxoplasmosis
8. CPN
9. Candida overgrowth
10. Brain Spect-CT - posterior temporal > frontal hypoperfusion
11. Stenosed internal jugular vein
12. Skull base Osteomyelitis / necrotic bone, non-viable, woven bone, empty lacunae- confirmed by both bone biopsy and scans. I was aghast hospital still sent me home with these latest results, as bloods don't show I'm fighting an infection. How can skull pain, and skull symptoms, confirmatory scans and skull bone biopsy of 'past or present osteomyelitis be disregarded?

Perhaps it's time to realise these infections ingeniously evade the immune system or detection, or some pathogen has disabled our immune system from working at all.

We are on the home stretch of recovery now as I've found doctors prepared to help me. The ability to work again and be there for my children again is a gift I'm appreciative of 7 years fighting.

It took AIDS patients a long time to get recognised. I consider our plight very similar, I consider part of this disease VAIDS "Vector Acquired Immune Dysfunction Syndrome" - Not discounting the acquired and numerous opportunistic infections that have relevance to this disease.

This Lyme-like debate has gone on 20 years In Australia. Can we stop it now please, and get on with helping us? Help us even whilst the science catches up?

Region Requirements

- Doctor medical training of tick borne dis- eases/DSCATT
- Awareness campaigns
- Dedicated TBD/DSCATT treatment centre
- Pain, trauma and counselling service
- Rehabilitation services
- Affordable healthcare for these not well un- derstood diseases
- A government website that validates the disease/s we suffer and the appropriate path- ways
- Education to doctors to validate us, so that no doctor ever again scoffs or rolls eyes when saying we are desperately sick and suffering post tick bite

Thank you.

1. The NHMRC targeted call for research into debilitating symptom complexes attributed to ticks:
 - Seroprevalence Surveys should be the high- est funding priority and most initial research funding should be allocated for this purpose. Research into what pathogens ticks carry is secondary - the ticks aren't sick. Broad based Seroprevalence Surveys looking for all Borrelia (300+ strains), Babesia (100+ species), and Bartonella (35+ species) species as well as other infections will deliver the best value to the taxpayer;
 - Assuming Australia's seroprevalence rate is comparable to the global average, then this disease costs Government \$25 billion per annum in lost tax revenue, social security, social housing and unnecessary medical expenses. Over the next 20 years, this will cost
 - \$641 billion. A larger investment in research is easily justified based on future savings to Government and the Taxpayer and a basic risk management plan. See Senate Inquiry Submission Number 724 or contact our group for detailed costings; and
 - Patients will be sceptical of any research conducted by individuals with a history of denying the existence of Borrelia or Lyme in Australia.

2. Summary of the outcomes of the April

2018 DSCATT Forum:

- There is already abundant evidence of Borreliosis, Babesiosis, Bartonella and other infections in Australia. Michelle Will's PhD thesis contains information on Borreliosis Seroprevalence Surveys conducted in 1993 and earlier. Submissions from patients and doctors also confirm this illness exists in Australian patients. Borrelia was first found in Australia in 1953. Statements that there is 'a lack of evidence' are false, not based on science and have been for over 25 years. Where are DOH's Seroprevalence Surveys?
 - Agree on education of the public and doctors that ticks are dangerous. Funding this education will produce savings by preventing disability or treatment first place. The ROI is staggering starting at 5,667% in the first year and rising to 1,330,707% over the lifetime of a patient (Submission 724); and
 - We would like to have seen more participants with experience and expertise in Borreliosis and associated infections at the April forum. It was noted that overseas expertise has not been leveraged.
3. A nationally agreed multidisciplinary care approach:
 - Will only work for patients that live near clinics. Most patients will rely on a local GP for diagnosis and

treatment so we should plan accordingly. ROI on treating chronic cases is 58,605%; and

- What diagnostic criteria will be used at these clinics for Borreliosis and Associated Diseases? There is concern that this will be used as an attempt to delay progress and place patients into a 'psychiatric' basket. Concerns about fake science being developed within these clinics. Patients don't trust DOH.
4. Education and awareness for medical and other health professionals:
- Due to our geographic distribution and the high cost of travel for patients, most diagnosis and treatment needs to be done by General Practitioners located near the patient. A set of interim Borreliosis and Associated Diseases Guidelines needs to be put in place as a matter of urgency. ACIIDS or Burrascano Guidelines could be rapidly adapted for this purpose. Every month of delay costs Government \$2.091 billion. The incentives to act quickly are very high;
 - Wellvone (Atovaquone) needs to be placed on the PBS ASAP for Vector Borne Diseases (VBD). The high cost of this medicine is a major barrier to patient recovery. It has long been on the PBS for AIDS patients;
 - There are over 300 strains of Borrelia and commercial testing for 5 strains or only 1.7% of known strains. All tests must state 'Diagnosis should be based on clinical symptoms and patient history, a negative result should not be interpreted as an absence of infection'. ARRL must stop providing misleading advice to patients and doctors. Need to leverage off the major overseas labs until expertise is developed here;
 - Australian CFS Guidelines Para 2.4 currently exclude serological testing for Lyme Disease on 'Level IV' evidence – a 'consensus opinion'. This needs to be changed to 'Highly Recommended'; and
 - Opportunities for Australia to become a leader in VBD and become a medical tourism destination

Carer 'experience' of MDT approach in Victoria

4

After several years cycling the merry-go-round of doctors, specialists, multiple head-scratching diagnoses, and treatment protocols that resulted in zero improvement but, instead, the development of even more serious medication-induced symptoms for my wife's debilitating illness, we decided to seek another opinion from a Melbourne GP who specialised in chronic, multisystemic and vector-borne illness.

This doctor ordered tests through an overseas lab to confirm a suspected diagnosis of tick-borne illness, and my wife commenced a trial of anti-biotic treatment while awaiting results. During the six-week trial, she experienced a marked improvement in symptoms and in bloodwork, so a tailored treatment protocol was continued. After eight months, my wife (who was previously wracked with pain, wheelchair-bound or bedridden), had experienced a radical improvement in health. With pain levels reduced to 3/10 and her wheelchair retired, she was taking her first steps with a walker and attending regular physio sessions. We were hopeful she'd found the right road to recovery.

When we headed off to our next appointment with the Melbourne GP, that's when our night-mare began! Upon arrival, we were told that our doctor could no longer treat my

wife and we must report immediately to the Austin Health Clinic. We were too shocked by this news after a fruitless 200km drive, so we returned home and made an appointment to attend this clinic a couple of weeks later.

By this stage, my wife had begun experiencing a rapid deterioration in health following cessation of treatments prescribed by the Melbourne GP. After a two-drive, with my wife's pain levels at 10/10, we had to take a number and endure another two-hour wait in the 'cattle-run'. In our 10-15-minute appointment with the Austin Health Infectious Disease Specialist, we were told "Lyme disease doesn't exist in Australia"; the test results, earlier GP's diagnosis and clinical evidence of radical improvement in symptoms were dismissed. He said she should go back to her Neurologist and we were summarily dismissed – no tests; no investigations for other vector-borne infections; nada! The appointment with the Neurologist a few weeks later was a traumatic experience, with him angrily slamming his fist on the desk as he insisted, "There is no Lyme disease in Australia!!"

As soon as we returned to our country town, we began the experience of being 'red-flagged' in the Australian medical system. Our overseas-trained GP apologised that he would be unable to continue my wife's treatment because he'd been warned that, in

doing so, he'd risk both his medical licence and his Citizenship application. The community health service manager summoned me and said we had put their jobs in danger by asking them to manage the administration of IV and intramuscular antibiotic treatment. She'd been instructed to remove my wife's PICC line immediately and, if we resisted, she would have me arrested and my wife removed so they could forcibly extract the device. When my wife's condition continued to decline due to cessation of antibiotics and over-prescription of opiates via the pain clinic, we were sent home twice from the local hospital ED and only admitted on the third occasion when the ambulance officer took the staff to task.

After weeks of watching my wife's life slipping away, with the help of a whip-around, I managed to scrounge the petrol money and drove 1600kms to Sydney with my wife slipping in and out of consciousness in the back of the car. She collapsed as she walked into the Sydney GP's surgery, had to be resuscitated and was immediately transferred to a Sydney hospital where she spent two weeks in ICU and another four weeks in undergoing intensive investigations.

One page is nowhere near enough to provide the detail of what this nightmare has been like for both of us; I've barely skimmed the surface. But if this is what multi-disciplinary care looks like in Victoria, we don't need any more of that kind of discipline.

A nationally agreed multidisciplinary care approach: While Prof. Murphy noted the MD care approach should include psychological support, Prof. Grayson saw psychiatry as being one of the core areas. Noting "Psychiatrists with special expertise in so called conversation disorders."

There are many that find the positioning of a psychiatrist at the core of a multi-disciplinary approach concerning. The immediate assumption is that people are mentally ill. Why not a psychologist to support them, rather than a psychiatrist to simply medicate them? Patient horror stories about being told that they are mentally ill are endless and have people, including myself, extremely concerned. As the invitation asked for representative to share personal experiences, I have shared a little of my personal story (and those of other patients) below:

My Experience

After many years of being sick, I was slowly getting my health back I decided to see a neurologist for help with some of my remaining problems including Sensory Processing Issues (unable to tolerate too much input/loud sounds etc.), Vertigo, Dystonia (Cervical & Laryngeal). When the neurologist saw the Spect Scan summary: *The pattern of widespread inhomogeneous cortical hypoperfusion with involvement of the basal ganglia, but sparing of the frontal*

lobes is nonspecific, but can be due to the encephalopathy of Lyme Disease he was not impressed (to put it politely). While he insisted that Spect Scans were 'useless" (I also had another scan after treatment which showed "Perfusion had returned to within normal limits) he agreed to send me for further neuro-psychological testing. The final report from the student psychologist (testing was cheaper via uni students) went along the lines of: I have discussed your inconsistent test results with the 'neurologist,' and as there is no known pattern to the inconsistencies, the conclusion was: I must have been trying to 'fake the tests'. Basically I needed to stop making up stories' and to see a psychiatrist - Wow ! Sign me up! Give me that magic pill that will allow me to listen to music (something I miss dreadfully) and fix all my sensory processing and Dystonia issues and get back to living a normal life!

Another Patient experience with the same neurologist I saw

"I have positive blood test, history of tick's bites and bull's eye rash. He said I have so many different neurological and other symptoms that he could not pinpoint a certain part of brain affected and therefore it is all psychosomatic and I should go see a psychologist and ALL my symptoms will get better. I asked him why I have hypoperfusion throughout my brain and he said he didn't know why and to not worry and forget about my SPECT scan report as it means not ing. I

was shocked and lost for words. My doctors were very concerned about me as my neuro symptoms included right side arm and hand tremors, tongue fasciculation's, speech changes, Bell's palsy, trouble walking, nerve vibration, jaw tremors, muscle spasms, memory loss . Stuff you can't fake! He said he sees people like me all the time and he likes to tell us "you're not mad, you're not sad and you're not bad, you just need to see a psychologist and deal with deep seeded issues".

Patient Experience

After a 30hr involuntary movements fit I was told to count backwards in 7's from 100. It would apparently reprogram my brain. I had up to 4 adults trying to hold me down at times and the hospital witnessed it all. I had letters from lmd, positive lyme tests and the hospital refused to look at any of it. This was their solution. ... After being sent to a psychiatrist who said I was mentally 100% a neurologist said he had bipolar himself so he could see it in my eyes that I had it too. I used my intelligence to manipulate the psychiatrist....

Patient Experience

I had seen 8 doctors in a span of approximately 18 months. My health declined so much that I could barely get out of bed. I was told by one doctor to go home and drink (alcohol) every night, even when I had told him alcohol was making me violently vomit even with one mouthful! One asked me had I found God? Two told me my health issues too complicated for a GP. Between the absolute

financial ruin, having to face the reality of "am I going to be like this for the rest of my life", feeling completely inadequate as a wife and mother, I wanted desperately to just end it all. In my mind it wasn't just my suffering. It was that of my whole family who I see struggling to rub two cents together because of me! I couldn't bare the guilt. I just wanted all the pain, every- one's pain, to just all go away. I started thinking of dying all the time. I wanted to and was pre- pared to suicide to end all of the pain. If it wasn't for this support group and the support of some very amazing people, I may not have been here to tell you this story. I had to get myself through without the support of the medical community that seems to be there for everyone else around me, but not me. Because I'm tick sick and it's all in my head.

Sadly these experiences could go on forever. Unlike the patient experiences shared, a number of our community are no longer alive. GLiO Founded Red Shoe Day: A Day of Remembrance. These people didn't want to die, they simply wanted to escape their suffering and rather than helping, the medical community ridiculed them to the point that they thought death was better than facing another health professional ever again. Can you imagine? I can. I see it almost daily.

It was noted in the forum report that CFS/ME patients face similar issues with an illness being accepted. I would like to highlight a recent publication regarding the PACE Trial (CFS/ME) which noted: "The PACE Trial debate reveals deeply embedded differences between critics and investigators. It reveals

an unwillingness of the co- principal investigators of the PACE trial to engage in authentic discussion and debate”.

Please do not let us have a 5 million dollar flawed/ recently discredited “PACE Trial” in our community. People are wary and have been given many reasons not to trust the healthcare system. The MD approach must

start with open minds, not with preconceived ideas of people belonging in a ‘mentally ill box’. No other area of medicine relies on science that is as old as the information on LD/TBD in Australia. Authentic engagement and a willingness to look at ALL the science to find the underlying cause/s is required. To say that lives depend on it is not an overstatement.

Our kids: the greatest at-risk group in coastal communities

6

We note the Departments report on multi-disciplinary clinics which at present appears to be a collection of rudimentary ideas, void of any substantial detail, which makes it difficult to comment upon. However, pursuing a repetitive model of IDS clinics that run out of hospital-based systems that are already underfunded, as outlined by Professor Grayson, and inaccessible to people in this region is tokenistic and extremely inadequate.

While talk of a multi-disciplinary team approaches to clinics expected to be established in Australia is positive, it is difficult to see exactly how they might be patient centred. In progressing any discussions about Australian clinics, it is imperative that the needs of children and their unique developmental situation is promptly and properly recognised and accommodated.

As such, the group would like to draw attention to the plight of children in the discussion of Lyme like illness in Australia.

The greatest impact occurs to children who, after a tick bite, might acquire a long term chronic illness that goes unrecognised, or is dismissed as a childhood ailment, or worse, is misdiagnosed. On the NSW far south coast for example, there is a significant cohort of children who are being treated for Juvenile Rheumatoid Arthritis; according to nurses

who work with those children, very few of them have RA markers in their bloodwork, yet a differential diagnosis of Lyme like illness has never been considered.

Furthermore, the large cohort of families all with Lyme like illness on the NSW far south coast, gives rise to the question of familial transmission; either congenitally, sexually, or both. Children suspected of acquiring this illness congenitally are in urgent need of assessment and treatment before they are left permanently disabled.

Children require special consideration in the diagnostic situation, in treatment and in the way in which they are accommodated within a system primarily designed for adults. The multi-disciplinary team should automatically include paediatricians and paediatric nurses when a child is the patient. Where appropriate, medical professionals with neonate experience should be available if the child is a new born, or if the child is born to a mother with a suspected or proven vector borne illness.

In terms of the far south coast patients, many of our patients are burdened with multiple members of their families suffering from vector borne illness. In many cases there is more than one child in the family affected, and families find themselves in the diabolical situation of balancing whoever is sickest with

what they can afford to pay for treatment at any one time. As such, these families are already unfairly burdened by socio economic status, given many parents are carers for their affected children, and cannot be expected to bear the cost of travel, accommodation and any associated expenses for their children to attend the proposed clinics, especially if they are to be situated in metropolitan areas.

We urge you, as you consider the design and location of these clinics, to ensure that each jurisdiction pays attention to patient transport schemes, hospital accommodation schemes and other outpatient style arrangements to support those of us who have no choice but to travel for our children to access such a clinic.

Education and awareness

Efforts directed towards education and awareness should also include points about the unique situation for children.

Firstly, awareness and prevention educational campaigns designed for and targeted at children should be included in any education for schools, and groups that focus on children

– scouts, guides, outdoor sport clubs, nippers (coastal), pony clubs, and especially for our location in national and recreational parks – generally all coastal locations.

There are many education campaigns that have been designed and developed for children in jurisdictions overseas. Likewise, in those jurisdictions there are extremely well qualified paediatric doctors treating children who've provided very detailed evidence about the symptomology of children with Lyme like illness, through the various developmental stages. This data should automatically be included in any education to assist Australian doctors in assessment and diagnosis of children with Lyme like illness to avoid unnecessary labels, misdiagnosis and mistreatment.

In our small south coast group there are extraordinary examples of the type of harms committed upon our children through misdiagnosis, mistreatment and mislabelling. Better education of medical professionals in diagnosis and treatment is critical as well as awareness and prevention information for everyone - parents, children, caregivers and medical professionals.

Research/Awareness in the Multidisciplinary approach.

7

Professor Murphy: "...despite the variety of views on the evidence and the science, or lack thereof, *we do need to understand the infectious or tick derived cause of these symptoms and do more research.*

Greg Hunt: "...reaffirmed that there is a strong *need to identify the cause, prevalence, diagnosis and treatment, and as such frame the research to provide evidence and advice* about what to do about this class of symptoms.

NHMRC Dr Glover: "the scope of the call is anticipated to be multidisciplinary, *focused on diagnosis, management and treatment, and recognising physical, physiological and emotional* aspects of disease.

The above notes the importance of requiring further research in order to understand/identify the 'infectious or tick related', the 'cause', 'prevalence', 'diagnosis', however the NHMRC call for Targeted Research, specifically states that the funds are not to go towards researching pathogens in ticks? While research can certainly begin to look at the scope of symptoms the patients experience and how they are best managed and treated, diagnostics are limited to laboratory tests that are looking for 'known pathogens'.

Research in regards to pathogens carried by Australian ticks and reservoir hosts is outdated:

In 1996 Playford and Whitby wrote: "*Tick bites are a common problem in Australia and an important cause of morbidity in medical and veterinary practice. Complications include local inflammation and infection, paralysis and trans- mission of various pathogens. Over the past three decades, several new tick-borne diseases have been recognised both in Australia and overseas... However, our understanding of the microbiology and epidemiology of many of these diseases is incomplete*".

The chance to further understand these diseases has never really been provided, with the reasoning for this offered up by R. Russell at a Keynote Address in Florida in 1997 in which he concluded: "*Despite the greater incidence of tick-related problems, there is also little to be optimistic about with prospective tick research. The groups working with tick-problems, investigating the toxin and allergens in x. holocyclus saliva, the rickettsial infections, the spirochaetal infections, and the viruses, have all been disbanded as funding has disappeared, and retirements and redundancies have taken their toll*".

I note that Dr Glover also mentioned at the forum that the NHMRC funded a Project Grant to Prof Homes to study metagenomics of Australian Ticks. This research grant appears to be a promising start and it is hoped that the breadth of it allows ticks from all states and numerous ecological niches around Australia to be analysed in a timeframe that will also benefit the multi-disciplinary approach, especially regarding diagnostics.

As well as an examination of ticks, it is imperative to examine reservoir hosts in order to ascertain the presence of pathogens in the environment. A quote I cited in my Counter-argument "To predict and prevent human risk of exposure to vector-borne diseases, *it is vital to identify the reservoir hosts of the pathogens*" (Salkeld et al).

I have provided research of potential reservoir hosts and ticks worthy of examination in my research papers *Lyme Disease: A Counter Argument to the Australian Government's Denial, and Lyme Disease/Borreliosis: An overview of Lyme and direction for further research required in Australia 2012*. As well as being available on my website since 2012, this information has been submitted to various government 'forums', including the scoping study response in 2014. The recommendations made in the papers have been given little acknowledgement, until 2016.

At this time, a journal article looking at the 'Scoping Study and other evidence of Lyme

in Australia' was published: "*Is there a Lyme-like disease in Australia? Summary of the findings to date (2016)*" M Chalada (CQU), J Stenos (ARRL), R Bradbury (CQU). I was intrigued to see that the sections - *Borrelia in introduced animals, Borrelia in Native Animals, Spread of Borrelia by migratory birds, Likely tick vectors of B. burgdorferi s.l. in Australia* – had utilised a great deal of my research that I had submitted to the scoping study. However, rather than conclude that there was a need for further research with regards to the animals I had researched/mentioned as known reservoir hosts, their conclusion was that "if Lyme Borreliosis was present in Australia its presence would be prominent in livestock". This might be a valid conclusion, if people were actually looking for *Borrelia* in these animals. Interestingly, the authors did come to the same conclusion that I did with regards to the *H. longicornis* tick: "The detection of *B. burgdorferi* s.l. in *H. longicornis* ticks of Japan and China supports the possibility that *H. longicornis* could carry Lyme Borreliosis in Australia". (Though as my paper was written/published on website in July 2012: It didn't mention Japan as that information hadn't been published then).

While the authors (One from "ARRL": a laboratory that has consistently denied Lyme in Australia), re-purposed a lot of my research for their own paper: The interesting thing is: They acknowledged a lot of my research (by re-using it), and yet even with the information in a published journal article, there has still been no investigation of the *H. longicornis* tick or the potential reservoir

hosts in Australia. Nearly 25 years has passed since Russell et al performed ear punch biopsies of 17 animals looking for evidence of *Borrelia*. We know so much more now about potential reservoir hosts and that new *Borrelia* species (and other pathogens) are found almost yearly at the moment: Despite this, we haven't kept up to date with

the rest of the world in this field, simply saying that Australia is the only habitable continent it doesn't exist in? In order to truly honour the Multi-disciplinary aspect of caring for patients: All scientific evidence that might shed some light for patients should be up to date.

Thank you for the invitation to attend the Patient Group Forum on Debilitating Symptoms Complexes Attributed to Ticks (DSCATT) on the 27th of July in Sydney. With regards to the request: "In order to ensure that each of you are able to share your experience, I ask that you submit a short account (one page maximum) of your experiences with consideration to the items being discussed on the agenda. These accounts will be de-identified and circulated in a booklet format to all participants prior to the forum."

On communicating with other patient group representatives to clarify exactly what was required for this one page account, the details became a little unclear. Some reported that they had sort clarification and were advised that the 'experiences' referred to were personal experiences, though they were welcome to submit a patient group/organisation view also.

In order to cover both aspects of this 'experience' I have taken the liberty of proving a one page account on behalf of both Lyme Australia Recognition & Awareness (LARA) and Global Lyme & Invisible Illness Organisation (GLiIO). If I had to define both of these separately, LARA is more about the science and research I have written (I was doing my PhD when I became ill), while GLiIO is more patient centred.

These differences may be a little clearer with a little background information. Below is

some of what I outlined in my opening paragraph in a letter to NHMRC and Greg Hunt requesting to be on the NHMRC Advisory Committee.

In brief, since becoming ill and involved in the Lyme community in 2010 I have:

Written two research papers: Lyme Disease: A Counter Argument to the Australian Government's Denial, Lyme Disease/Borreliosis: An overview of Lyme and direction for further research required in Australia. 2012

Developed and maintained a website (July 2012) Lyme Australia Recognition and Awareness (LARA)

Established a patient support group, Lyme Australia & Friends (LA&F) in July 2012

Signed Australia up (3rd November 2012) for participation in the Worldwide Lyme Protest (WWLP) and was a National and International co-ordinator for the events held in May 2013 and 2014.

- Co-founded a non-profit association (Founded May 2013), Global Lyme and Invisible Illness Organisation Inc.
- Submitted a response to the Clinical Advisory Committee on Lyme Disease (CACLD) Scoping Study and was involved in the Lyme Patient Consultative Group telephone meetings throughout 2014;
- Attended (February 2016) an afternoon tea with The Hon. Malcolm

Turnbull MP Prime Minister. Gave him information with regards to the recent passing of a patient and spoke to him about the current Senate Inquiry regarding tick-borne diseases and Lyme like illness in Australian patients.

- On behalf of Lyme Australia Recognition & Awareness and Global Lyme & Invisible Illness Organisation I was allocated 45 minutes to speak / present at the Senate Inquiry hearing in Brisbane (15th of April, 2016)

As LARA/GLiIO was unable to provide input at the DSCATT Forum held on the 18th of April, I would like to briefly address the issue of Nomenclature.

Nomenclature: The Department noted it was open to changing the name however there was no consensus on any term. The CMO noted that the Department will continue to use DSCATT in the absence of an agreed alternative.

I can imagine there has already been the full gamut of discussion with regards to this name, and in reality patients simply want to regain their health, regardless of the 'name'. What I would like to note however is that there was no patient consultation prior to the acronym DSCATT being implemented and many within the patient community feel that

it was/is a subtle dig at patients to go away 'scatt'. For this reason, I would ask that further discussion be had, sooner rather than later, to settle on an 'agreed alternative'.

As I have interacted with Global advocates since 2011, I utilise the term Lyme Borreliosis Complex (LBC). This term allows recognition for patients around the world (where some countries use the term Lyme and others Borreliosis), as well as acknowledging that Lyme has numerous Borrelia species underlying it. The 'Complex' incorporates both how complex it can be to treat and also includes other issues (infections, immune issues, etc..) that the patient might have. By utilising a name that connects people globally, research and treatment information can be shared in order to learn and build on each other's research.

Hopeful that a 'name' can be agreed upon in the near future, though as I am sure you are aware: Patients don't really care about the name – they just want to be treated with compassion and get their health/life back.

Thank you for the opportunity to be a part of the forum discussion. Attached Please find the one page accounts for LARA and GLiIO. Though you have said the information can be de-identified: Please note it is not necessary and that I have no issue with my name being associated to anything I have written below.

In regards to the upcoming patient group forum on the 27th of July, we asked our members to contribute to the forum topic: "Education and awareness for medical and other health professionals" by asking them 'what they felt was the most important thing that the medical and other professionals needed to hear and understand. We received numerous responses to the question and have collated a number of them for your attention below.

Education and Awareness is paramount

Many patients have presented to doctors only to be told that "ticks can't make you sick". The science and investigation into the pathogens that ticks carry basically ceased in the 1990's in Australia. Ticks carry various bacteria, protozoa and viruses. Health care professionals (and the public) should be made aware that ticks can make you sick, and to treat patients with compassion, rather than contempt. Awareness that symptoms are different and harder to treat, (as is the same for other diseases such as Q fever) in chronic, rather than acute stage of infection.

Concerns are held with regards to the proposed multi-disciplinary approach, especially the inclusion of psychiatrists

Patient experiences with many professionals, have been horrific, with many people being told "It's all in your head". It seems that the denial stance of Lyme Borreliosis (aka DSCATT) allows some health professionals to be more comfortable in placing the blame

with the patient if they don't fit in a box or the physician cannot work out what is wrong with them. Instead of trying to understand and resolve the patients' health issues, the stance appears to allow many doctors/ specialists carte blanche in simply assigning patients to a "psychiatric/ conversion disorder" diagnosis rather than looking for any further underlying problems.

Differential Diagnosis

In order to maximise the potential for early detection, treatment and full recovery, the recognition of the possibility of Lyme as a differential diagnosis is essential.

Patient Quote: "It is so important for doctors who are thinking MS, CFS or Fibro (the diagnosis' thrown around when I suddenly got sick) to also think and consider tick borne or vector borne. Don't let people fall through the cracks at that critical early stage or simply dose them up with strong amounts of pain killers and anti- anxiety meds: Look for the underlying cause of the symptoms"

Testing and Clinical Diagnosis

Diseases such as Parkinson's, Alzheimer's, Multiple Sclerosis and Motor Neurone all rely on the clinician's interpretation of medical history, symptoms and response to treatment for diagnosis. As testing is so poor/ and we have no reliable knowledge/latest research of what pathogens are carried by Australian Ticks: Testing should be used in support of the diagnosis, not to rule it in or out.

To be treated simply with compassion

Patient experiences have been horrific and doctors need to be aware that the science/research in this field is lagging and that while waiting for more up to date research, that the doctors should treat the patient and not the outdated literature.

Some Patient Quotes:

"We need help now...at the moment we are just being ridiculed and abused"

"I have been told numerous times that it's psychogenic. I was sent home unable to walk or talk"

"Whatever they may think, they owe it to sufferers to do some research. I was told by

a doc that they hadn't heard of Babesia therefore it didn't exist. And Lyme is alternative rubbish"

"When a neurologist has run out of ideas, their only offer is antidepressants and a psychiatrist. When you tell them you are going to get tested for Lyme they tell you that you're wasting your time and when it comes back positive, it's suddenly a false positive. The most insulting comment I've had from an ER Doctor was "you're just a middle aged woman having a panic attack. Do you have any creditors chasing you?" -"I had a tick on the back of my neck." Dr immediately responded with "There isn't any Lyme in Australia."

The following outlines what is felt from being a patient and a support group facilitator for people with Tick-borne illnesses in Victoria.

Agenda Item-Update-The NHMRC targeted call for research into debilitating symptom complexes attributed to ticks

I am concerned that there does not seem to be any allowance in this NHMRC funding to investigate actual infections in ticks. In fact, it is specifically stated to NOT include this. What is the reasoning for this apparent exclusion? I would consider getting an understanding of where the most prevalent ticks are and if these ticks do carry disease to be important. Then surveillance and reporting would help with data analysis. It would also help provide evidence that if people are bitten in certain known tick infected areas, doctors in those areas and elsewhere, are warned of the higher potential of infection and to test and treat newly bitten people early, rather than later or as is the situation now not at all. I am also concerned in the methodology of the research to investigate existing patients which is eluded to “think or feel” they have a tick-borne infection. Many people with “like” illnesses would not be covered in this research and the senate inquiry found up to 50% of people with diagnoses of MECFS, Fibromyalgia and even MS and some other illnesses were found to test positive to various tick-borne infections. Will the research be a call out to these people

as well? I would like these people who also have like illnesses to be included in research. I also am concerned that if current patient blood testing is used, many infections would be missed especially in those long term ill as OS research is finding it hard to get positive results from pathology when patients exhibit tick-borne infection symptoms. But when treated with antibiotics based on symptoms, patients do in fact in a lot of cases improve, even with negative blood test results. The NRL report also indicated failings in current pathology methodology. One is using version 2 testing from the 1990's I think, while current AIDS testing is version 4 a more accurate testing method as just one such failing. The other is human interpretation and even faded western blot example comparisons

Agenda Item-Summary of the outcomes of the April 2018 DSCATT Forum

Like a snake bite, tick-borne infections are a mostly preventable and treatable illness when recognised, accepted and treated at first bite. With the amount of current new research and newly sourced old research, it is found that various tick-borne infections are proving to be persistent in a growing percentage of cases, even after short term treatment. In Australia where there has been, in general no treatment of patients, then the situation is already worse with patients going untreated, let alone tested for years due to the past denial of “no Lyme here” stance passed on, I assume, from the DoH. I know many patients in the patient groups who definitely benefited

from longer term pulsed and switched antibiotics. So, with Professor Grayson general statement that antibiotics are administered unnecessarily and overprescribed, this is a cherry-picked statement. Our patient group has case studies of those who have benefitted from antibiotics and noticeably declined in health when stopped. So, I do not agree with his general statement of antibiotics not assisting patients. Yes, we do need more than just antibiotics as this is has often unnecessarily become a complex illness with sometimes a mix of pathogens that is passed on from ticks and other vectors. His statement of financial hardship is also not only due to the factors he states of purchasing antibiotics and investigations into testing for tick borne illness. It is in fact mostly the needless investigations far removed from what actually is often most likely the cause in our patient group. It is the cost of going to a long list of so called specialists who have no understanding of how infections can affect the patient's symptoms so perform exploratory testing for things unrelated to the cause and sometimes even diagnosing people with the wrong illness. Often when they do their standard testing, which frequently can be normal, they suggest it is all in people's heads so their only treatment is go see a psychiatrist.

It shows complete ignorance and total lack of understanding. The fact is, before a tick bite these patients were healthy and working or going to school or the saddest just babies. Then often soon after a tick bite they become so unwell they cannot work or go to school.

People do not suddenly decide to make all this up. There are 2 parts to this illness. One simple. Bitten by a tick, get sick. They should get individualised treatment straight away and tested to confirm (if testing can be relied upon which I find it cannot often be) and the patient monitored and antibiotics, anti-malarial, other medications etc. continued until symptoms dissipate. With further follow up if reappear. The second is more complex because of potentially untreated tick or vector borne infections and the now damage these infections have done from being untreated. This is when a fully educated understanding compassionate and cross communicative team of people are needed.

Agenda Item-Discussion – A Nationally agreed multidisciplinary care approach

Each patient must be taken on a case by case basis and when and where needed, antibiotics must be at least one part offered as an overall infection treatment protocol. I also do not agree with Professor Grayson feeling that a multi- disciplinary approach of rheumatology, oncology and psychiatry being core areas. First in the team would have to be tick educated infectious disease specialists, as ticks and other vectors pass on infectious pathogens. At present these 3 other specialties, especially in Australia, have little to no understanding of infectious implications causing "arthritic like" and mental health issues. Named overseas as "Lyme arthritis, rheumatologists do not consider this condition. In case studies when the appropriate and timely administration of antibiotics were provided these

rheumatologically symptoms dissipated, but for rheumatologists it is not considered treatment here. Many patients in our groups have seen rheumatologists and none were aware of any links to infections let alone tick infections and their patient's arthritic like symptoms. These patients were only provided arthritic drugs or told to exercise which often make people worse. With so called psychiatric symptoms more new research is focussing on inflammation. Inflammation from tick-borne infections from research shows people have what is called overseas "Neuro Lyme" symptoms. Involving neurological and brain with mood and depression disorders due again to infection leading to inflammation. Psychiatrists so far seem to have little understanding of this link in Australia. Yes, for some, psychiatry and psychology can help people cope with their symptoms while proper treatment is being undertaken. But in itself in most cases using psychiatry alone is not treatment. I am unsure where oncology would fit in with tick infections unless research leads to untreated infections increasing the risk of cancer, which if so, should be investigated. Thousands of Australian patients do definitely have, in some cases numerous pathogens that are Lyme-like in symptom expression and if you are going to have a genuine multidisciplinary approach then the key specialists would be infectious disease, and if needed linking with neurologists and cardiologists as also "Lyme Carditis" is becoming quite prevalent and known overseas, along with other specialists as needed. But all would need the great understanding that these infections can

cause issues with the immune, nervous, endocrine and other body systems as well as the heart and brain. Left untreated the need for and cost of all these and other specialists would be immense compared to simply treating with cheaper antibiotics or similar when symptoms were first experienced after a tick bite or without symptoms, prophylactically like is done with many other potential infections like tetanus as one example. This approach MUST also be affordable and changes to Medicare has to be done to consider chronic illness cases.

Agenda Item Discussion-Education and awareness for medical and other health professionals

I am sick of the fact that as an admin of a tick- borne infection patient support group, that I have to "welcome" new people as patients into the group seeking help. This group should not exist. I said like a snake bite, tick and other vector borne infections for the most part, if people are warned, educated on prevention, correct removal and caught early, are preventable and treatable. Then they would not become long term chronically ill. So, I would like to see, prior to research results that the government try and prevent healthy Australians and tourists from becoming bitten and become patients in the first place. Australia has numerous warnings about crocodiles, snakes, spiders, sharks, etc. and so too should the government have warnings in key known tick areas about ticks. All governments have a duty of care to its citizens and they are failing this duty of care. How many more

families and children need to go through this devastation that the senate inquiry has only touched on the real number of people suffering. I also notice that only the NSW Government website has any reasonable information about ticks, while no other state government website does. This needs to be rectified and unified across all state websites NOW. There are no tourist warnings coming into or going out of Australia about Lyme or Lyme-like Disease or many other tick-borne infections. This can be rectified NOW and there is enough patient evidence to heed warnings. Many patients in our support

groups were bitten overseas but not treated here in Australia. As much as the government says they have that information on the Federal website, it is hard to find and the information is poorly filtering down to local GP's. Education must be stronger about this issue NOW. Testing has to be greatly improved and doctors should be allowed to treat symptomatically and appropriate guidelines provided to do so without fear of retribution from APHRA whether that infection was from a patient bitten overseas OR in Australia.

As a Representative of the Victorian Lyme Disease community in Victoria it is my responsibility to engage with you in a way that makes the opinions and concerns amongst our members clear. It is with great concern and hesitation that we agree to the farce that is the current forum where the vast major-ity of patient stakeholders are removed from the medical and political stakeholders. We will attempt to discuss in my one-page summary how patients are feeling in Victoria, and how the concern for our welfare is seemingly more urgent than ever before.

We are concerned about the quality and type of care we may receive under the ministrations of a Multidisciplinary treatment clinic set up primarily using Dr Greyson's model that he set out in his presentation to the Melbourne forum earlier this year. We note that his MD approach uses rheumatologists, Infectious disease specialists and psychiatrists as the basis of his approach and that he notes Psychiatrists with a specialty in Conversion Disorder would be his preference. He states of the 30 patients he inherited from a sanctioned DR none of them had a tick-borne pathogen using standard Medicare testing, and that up to 20% of these patients had a severe psychiatric disorder that had been undiagnosed. It concerns us greatly that Dr Greyson's respectful care is going to amount to little more than a diagnosis of modern day hysteria and a course of CBT to put right the patient's harmful illness beliefs. It is our

concern that if this model of care is the one used in Victoria that patients will disappear in droves and they will stop trusting the Australian medical establishment entirely. This is potentially a serious issue as many have life threatening medical issues such as allergies and seizures and will possibly result in people not going to hospital when they need to and the possibility of unnecessary deaths. It is important to note that if the MD team is made up of Drs who already have the faith and trust of the Victorian patients there is every likelihood that the MD approach would work and would see the health outcomes of patients in Victoria improve dramatically.

We note that patients have told us horrific accounts of the treatment that they have received in hospitals with Infectious disease doctors, Rheumatologists and Psychiatrists that seem to amount to an abuse of privilege and in some cases outright negligence. We note that patient's stories submitted to the senate enquiry are littered with horrific encounters such as being yelled at and told "Lyme isn't in Australia", "your child's seizures are atypical therefore she is making it up", "so you believe you have Lyme disease, do you? (While clinician and nurse are openly laughing at the patient)". We would note that many times we have heard experts at round-tables talk about patients 'self-diagnosing', 'doctor shopping', and 'believing in their illness' and that these things have been said in a derogatory manner and in such a way as we believe there is a bias that is open and

dismissive and that if any other ill group of people suffered this treatment, it would be considered discriminatory. I would suggest that if we removed the disputed diagnosis from the equation you could see what we mean. I cannot imagine a scenario when a person in an acute care setting would be laughed at and told “so you believe you have epilepsy do you (while laughing)” or perhaps “so you believe you are transgendered (while laughing)”. The truth is that most patients have already suffered abuse at the hands of the experts you are engaging with or ones that are very like-minded. We would urge you to utilise doctors that patients trust, to ensure

patients are respected. We note the use of the term mutual respect in the Melbourne forum documents and note that it seems relevant to highlight that Doctors need to earn that trust from this patient cohort, many suffer ongoing trauma from dealing with the medical fraternity at the major hospitals and we have no reason to want to see more of this occurring. We suggest that in order to get the Victorian patient body to trust a MD approach that Dr Schloeffel or one of his colleagues would be best suited to overseeing the policies, practises and procedures intended for use on patients at these clinics.

Recommendation 5 – Senate Community Affairs References Committee Final Report Government address of this “*matter of urgency*” is spurious due to lack of timeliness:

30 November 2016 Senate Community Affairs References Committee Final Report.

16 November 2017 Government Response.

18 April 2018 Forum for select stakeholders, excluding all patient groups bar one.

27 July 2018 Patient Forum which would have been unnecessary if attendance for ALL stakeholders had been allowed in April 2018 at a forum which had been planned to cover all necessary issues, with suitable time allowed.

Has the **Government Position Statement** *Debilitating Symptom Complexes Attributed to Ticks* been circulated to the Royal Australian College of General Practitioners, Royal Australasian College of Physicians, the Australian Medical Association, and other appropriate colleges and medical bodies, with the suggestion that the information be circulated to their respective members, to “*ensure that adequate information ... is available to physicians*” (Minister Hunt) and to “*enhance the awareness of medical practitioners*” (Minister Hunt)? If not, why the delay? The Position Statement is the closest thing to a case definition available.

Multidisciplinary Care Approach

- Many patients have already undergone extensive investigation and no definitive non-infection diagnosis has been reached. Many of these patients have a list of abnormal test results that do not add up to a non-infection, immune label. The abnormal test results frequently span infectious and non-infectious conditions. It is unfortunate that the Government has not yet developed a strategy to catalogue patient test abnormalities.
- Many patients show evidence of past or current infection with babesia and rickettsia through the NATA-accredited Australian Rickettsial

Reference Laboratory. That patients tend not to respond to “medical therapy that is universally effective” (Prof Grayson) may be because the Australian situation is emerging, patients have been left untreated for long periods, and immune factors have developed.

- Page 6 of the NRL Final Report Investigation of the Performance of Assays for Lyme Disease in Australia concludes that “results reported by NATA accredited laboratories in Australia were consistent with those of other laboratories and tests internationally and there is confidence that active infections with *Borrelia burgdorferi* are appropriately detected or, alternatively, excluded using these tests in Australia more

than 80% of the time.” This discredits Professor Grayson’s claim of “doubtful results” and “fraudulent, misleading results,” although it is unfortunate that the NRL study investigated IgG tests when many Australian patients are IgM positive, and focused on *Borrelia burgdorferi* sensu lato, excluding other *Borrelia* species. The NRL’s 17 November 2016 response to the Senate Inquiry Question on Notice 7 states that “If an indigenous form of *Borrelia burgdorferi* exists in Australia it could easily be argued that despite all the work of the study ... the results are meaningless because the tests are not manufactured to detect strains of *Borrelia* other than those included in the tests in the study.”

- The current hospital infectious disease physicians have proved to be lacking in expertise in the area of tick-borne illness, as well as courtesy. It would be a difficult task to build a bridge between these physicians and the patients they have mistreated in the past.
- Multidisciplinary care would need to be administrated outside of My Health Record.

Many patients will be opting out due to distrust of the system and inaccuracies throughout their medical records.

- Patients should not be pressured into consulting with a psychiatrist unless there is demonstrable need.
- Physicians must understand that patients have successful use of medications (non- antibiotic) outside of their experience. If the patient is showing symptom reduction and test results are improved, then patients need to be freed from anxiety that another doctor will refuse their medication.
- A team approach is required, in which the patient is heard and their views considered by the physicians.
- Address of the cost factor for patients is required. Specialist fees are exorbitant and many patients also have private health insurance expenses, as well as costs of supplements and fees for allied health professional services. These costs are not possible from a disability pension, meaning many patients are simply going without – the healthcare services or other life necessities to try to pay for the healthcare expenses.
- Many patients are very ill and frequent travel to appointments far from home is impractical/impossible.

Disease/Treatment Guidelines/Flowcharts

– require flexibility for individual patient infection combinations and immune response and genetics

In March 2001 when living at Medowie NSW near Shoal Water Bay in the Hunter Valley Region I was bitten by something on my left upper gluteus medius on my waist line while gardening. Later that same week our pet family cat had to be put down due Lyme Parasthesia and neurological loss of control.

January 2004 I suffered an acute high temperature which lasted for almost 3 weeks.

Bedbound, migraine, exceptional muscle pain, dysentery, defecating in the bed, inability to walk.

RAAF Doctors did not understand what was going on.

I was diagnosed with Extreme Exogenous Depression and 6 months later Chronic Fatigue Syndrome. Between 150 and 200 days sick leave per year for the next 3 years I was finally discharged unfit for service December 2006 Extreme Exogenous Depression and 6 months later Chronic Fatigue Syndrome. 13 Defence Doctors and 7 Specialists had failed to uncover the nature of the condition. A 14 year career where I served every day with excellence came to an end.

I was Fighter Jet Multi Systems Concurrent Unserviceability Specialist on the aircraft variants.

Basically I was the person that was delegated the aircraft with the most complex systems unserviceability's and that's why the RAAF tried to keep me for 3 years.

Between 2006 and 2008 another 4 doctors had failed to uncover the nature of the condition.

In 2008 it was my privilege to come across Dr Donal Lewis Melbourne of CFS Discovery Australia.

In 2008 Professor Kenny de Meirleir the Global Leading CFS researcher joined Dr Donal Lewis at his practice.

Professor Kenny de Meirleir said "Better get him tested for Lyme". My IGeneX INC California tests came back positive for Lyme Disease, Borrelia with 8 bacterial co-infections, InfectoLab Germany confirmed Borrelia, 8 bacterial co infections, both tick born Pneumonias 100% likelihood of Bartonella. In 2009 or '10 Sydney Biologics confirmed a positive Borrelia test with co-infections and Pneumonias.

Between 2004 and 2015 I had Pneumonia 8 times. I have been pneumonia free since 2015.

In 2008 under Professor Kenny de Meirleir's experience I started weekly Magnesium Intravenous Infusions in Hartman's because my Magnesium and

Potassium channelopathies are measured as badly damaged. We have maintained this protocol every week for 10 years.

Since leaving Defence in 2006 I have been on a full time healing journey becoming a Mentor, Health Coach and Educator in specialist areas of Neuro Endocrine Immune Disease, Tick born Infection (Lyme) Disease, Post-Traumatic Stress Disorder, Auto Immune Disease, Gulf War Illness, Relevant Detoxification modalities, Nutrition, Auto Immune Paleo, Electron Chain Transport, Zazen Water Filter, Mitochondrial function, Breathing and Ice bath techniques, Gratitude, Heart Coherence, Walking, Sunlight, Relaxation Meditation, Yoga, Heart Coherent Intuition, Flow, Self-Love, DoTERRA essential oils, Relaxation Technique, Breathing, Nasal diaphragmatic breathing with Kundalini oxy- gen technique, Posture, Patience, Thankfulness, Gratitude, Hydrogen Peroxide, Liposomal Lipospheric Vitamin C therapy for Pneumonia, Lacto- Fermented foods, Sunshine, Self-Mastery through Mountaineering. Outdoors activity, Homeopathy, Ayurvedic, Ketogenic, No sugar, no/low starch, 9V9 high intake vegetables every colour, organic grass fed meat quality saturated fats, tallow, Ghee, Coconut oil, Sauerkraut, Cultured Wellness Coconut Yogurt & Coconut Kefir, Water based Kefir, Infra-Red Sauna, Lyme hyperthermia treatment, Hyperbaric oxygen therapy, Ozone O3 machine, Colonic Organic Coffee, Gall Bladder

flush, Wim Hof Ice bath technique, O2 Collective, BreathMe. com, F Scan3 or a Rife Machine, Pure clean spring water, GcMAF coconut yogurt Cultured Wellness bifidus and lactobacillus strains, Colloidal silver Fulhealth Industries, Faraday cage, Silver threaded sheets, Richard C. Miller, PhD Clin' Psych' for PTSD and Brain-Injury sufferers USMC, Dr Andrew Welsh Osteopath stretching techniques for people with parasite overgrowth.

1995 - 2006 - ROYAL AUSTRALIA AIR FORCE Qualified Avionics Engineer-Technical - 'Senior Technician' (Retired) - Royal Australia Air Force, 76 Squadron - MB 326H Macchi & BAe Hawk Mk 127 Lead in Fighter Trainer & 77 Squadrons McDonnell Douglas F/A-18A's Hornet. Runner Up Squadron Tradesman of the Year 2002 76Sqn RAAF

National Champions 1996 - Australian Defence Force Nordic and Biathlon Skiing Championship representing Royal Australia Air Force.

Supported East Timor (Interfet) - 1999, Afghanistan - 2001-2006, The War on Terror 2001-2006, Iraq: the Second Gulf Invasion, 2003-06.

1993 - 1995 - THE ROYAL AUSTRALIAN CORPS OF SIGNALS Qualified Linesman Telecommunications, Primary Trade - '93. Cross trained qualified Radio Signals Operator, Secondary trade - '93. The Royal

Australian Corps of Signals 139 Sig' Squadron, 6 Brigade 1st Division).

Unit level Special Air Service Regiment SASR CADRE Course training and preparation '93, '94. Supported Rwanda '93, Somalia '93, Cambodia '93.

1987 - 1993 APPRENTICED AND QUALIFIED CARPENTER AND JOINER, Mills and Sadler Builders P/L.

1984 - 1986 DEPARTMENT MANAGER ANTIQUES DEPARTMENT David Jones Bourke Street Melbourne.

Item 3. The NHRMC targeted call for research into DSCATT.

The majority of Australians many of whom are children, experiencing DSCATT are now chronically ill, but for the past two decades have been overlooked. The urgency for action from our government is vital. To date, our human rights have been ignored and our government has failed to fulfil its obligations regarding emerging diseases. Australian citizens are entitled to medical care no matter what their illness or where it was acquired. The development of better diagnostic and treatment protocols needs to be addressed as current testing is inaccurate and unreliable, we have found and all too often tick-borne illnesses are misdiagnosed. Even the NRL report has mentioned some failings and room for improvement in the testing methods. Ticks are second only to mosquitos in being considered carriers of zoonotic diseases, yet there appears to be limited understanding of the pathogens they transmit.

Item 5. A nationally agreed multidisciplinary care approach.

We endorse the concept of multi-disciplinary care, however, Professor Grayson whilst acknowledging the need for covering some core areas has overlooked the vital role an infectious disease specialist plays in patient care. Every patient presents with a variety of symptoms and has different needs, but a common thread is a desire for recognition and validation. The psychological damage endured by many is immeasurable. The Senate Inquiry submissions all with a

common thread, are proof that people are not “faking it”. The rift between patients and medical professionals must be healed. If the focus is not to get in between the medical profession and their patients, why are doctors reluctant to treat? What does AHPRA hope to achieve by targeting medical professionals?

As many patients and families are already facing financial hardships, my own included, this care needs to be affordable and have all services offered, preferably housed under the one roof. Currently, very few treatment options are available or offered by very few doctors. This lack of choice is unacceptable. Overseas clinics appear to be providing better treatment options than Australia and patients have experienced significant improvements by going overseas for treatments not available or accepted here. Consideration should be given to modalities such as hyperthermia, ozone and hyperbaric, and others. Everything offered overseas can be replicated in Australia and we should be embracing international expertise. While not everyone responds well to antibiotic treatment, there are just as many who do. Tick-borne illnesses are not a “one size fits all” situation

Item 5. Education and awareness for medical and other health professionals.

Tick-borne illnesses are considered to be the next pandemic, so it is imperative that they are addressed during training and should be a compulsory component of the curriculum for any health professional.

Mandatory reporting of tick bites and maintaining a database would assist in alerting doctors. The need for gathering and keeping statistics is essential. If Ross River fever and Q fever are reportable why not tick-bites (regardless of a name)? Development of an App similar to the French model would ensure the economic gathering of accurate information, which in this age of gadgetry would readily be embraced by an engaged, aware public.

Education and awareness need to include to the public, not just health professionals.

The burden on our health system would be alleviated if people avoided being bitten. An expedient, inexpensive method of promoting awareness, would be the installation of prominent warning signs in tick hot spots (similar to crocodile, jellyfish, shark signs)

Advertising campaigns in all media outlets have to be implemented - look at the

success of the Slip, Slop, Slap & The Grim Reaper television campaigns.

Brochures, posters, booklets should be produced, distributed to, and on display, in health centres, medical surgeries, hospitals, allied health practitioners, chemists, vets, tourist information centres, libraries, neighbourhood houses, and on community noticeboards.

Teachers from kinder to tertiary levels conducting school camps and outdoor activities need to know what to do if students are bitten, as do Scout, Guide and Cub leaders, bushwalkers etc. In fact, anyone partaking in outdoor activities should be informed.

Lastly the name. It's not about the name. It's about treatment and if a treatment works safely, then that is what we want and desperately need.

As a founding member of the TICNA, the father of a daughter diagnosed with Lyme disease in 2015 and the grandfather of 2 grandchildren suspected of contracting this disease "in utero", I have studied tick-borne illness extensively for the past two and a half years by online research, talking to Lyme literate doctors and researchers and many, many patients.

Sadly the medical community has been divided into 2 opposing camps to the detriment of the patients who have been forgotten and left without any effective treatment. These patients are suffering debilitating symptoms, facing financial ruin, marriage and family breakdowns, humiliation from medical specialists, bouts of anxiety and despair and many are choosing suicide. This is not good enough for a 1st world country that prides itself on its medical expertise and health care system.

We have a plethora of research information and thousands of patients with empirical data, but no official body is doing anything with it. You do not need to be a data analyst to see the common patterns of the disease, yet the continued arrogance about the data that is already available is mindboggling.

The Senate Inquiry of 2015/16 put forward 12 recommendations pointing to the urgency of the escalation of tick-borne disease. It took a year to get a Gov't response and 450 days later one recommendation has been acted upon when a paltry sum of \$3 million will be

allocated for research in 2019. This really is an insult to the tens of thousands of Australians with this devastating disease. With very little awareness and prevention information coming from official sources, there are going to be thousands more contracting this illness each and every year. We know from American statistics that the most susceptible demographic to tick bites are children aged 4 to 11 years of age. Do we want to condemn them to a life of pain and sickness? We have a new stolen generation evolving where chronic sickness is stealing these children away from a normal life expectancy.

3 contentious issues arose from the Inquiry: No Lyme disease can be contracted in Australia. No such condition as chronic Lyme disease. The efficiency of the Pathology testing used in Australia.

If the Health Dept. would read the mountains of peer-reviewed research data from all around the world, they could not help but see these issues do not stand up to scientific scrutiny.

Why the harassment and restrictions placed on our Lyme literate doctors by AHPRA? Many of these dedicated heroes have studied the disease overseas and treated thousands of Australian patients successfully. AHPRA has acted as prosecutor, jury and judge in sanctioning our doctors. Are the panel members of AHPRA conversant with the complexity of tick-borne

disease and able to correctly judge our doctors? I believe not.

The debate over tick-borne disease has relegated medicine to a secondary consideration and primarily is influenced by MONEY POWER ----- EGO.

This is shameful to our great nation and is condemning a large, escalating cohort of our citizens and their families to an intolerable existence.

As far as we are aware TICNA is one of the few organizations in Australia presenting awareness and prevention talks to community groups in an effort to educate

people about the dangers associated with tick bites.

Australia has the expertise to be a world leader in the area of tick-borne disease and I would advocate the following 4 undertakings:

1. The establishment of a world-class research centre for Vector-borne disease with international collaboration
2. The establishment of multi-disciplinary treatment clinics for the patients.
3. Education of the medical profession in best practice treatment and diagnostic protocols
4. A roll-out of awareness and prevention campaigns to the general public

In November 2014 I suddenly became gravely ill; I couldn't walk or talk properly, my memory was in rapid decline, my heart kept palpitating, I was lame and fatigued. The internal tremors were horrific and frightening. Despite this sudden onset of symptoms, doctors told me it was just stress and that my ECG was normal. My MRI showed a tiny lesion but I was told not to worry. I was gobsmacked to think that these devastating symptoms didn't appear on blood tests, ECG or an MRI. Despite telling doctors my symptoms, it simply didn't match their diagnostics.

I was lucky that I eventually got to see a practising LLMD doctor who took bloods, sent them off to a credible pathology lab and placed me on antibiotics. My test results were positive for Borrelia and Ross River Fever; my homeostasis levels were concerning, inflammation was high. The antibiotics helped fight the infection and I started to stabilise. It was another year before my memory started to return. I got used to the frightening sensation of internal tremors and brain swelling from a co-infection of Babesia. My heart rhythms were also concerning. I was a little old lady on the inside; I couldn't even walk up my apartment stairwell. I was in bed by 7pm every night as were my boys. The arthritis was so debilitating, even Yoga was too painful.

In June 2016, I had to step down from my career, at the height of a powerful research big data strategy to turn around outcomes for

brain cancer patients. Ironic that I was working in a future ready world of technology and medical innovation, highly respected in one disease group and being a medically abandoned patient in another disease group.

My two sons also began to experience decline in their health. One son ballooned in weight, had anger rages, started to experience cognitive decline with spelling and maths, and became very black under the eyes, patchy skin tone and strange red/blue marks on his upper legs and purple mottled skin. I later learned this to be a classic Bartonella symptom. My eldest son started to retreat from the world, enclosed in panic attacks and anxiety. He has a classic cat scratch rash on his back.

Unfortunately, our LLMD no longer accepts patients like me and we have no treating doctor. Every doctor I approach is too full to take on another patient. We are fending for our lives.

As a sole provider for my boys, I had to use my life savings to pay for the cost of living and treatments. With no financial support from the government, no insurance claim, my partner and I have sold our assets to fund alternative treatments and living costs.

The year we got bitten, 2014, we went on a road trip: Samurai Beach, Newcastle, up the coast to Coffs Harbour and Bellingen, Byron Bay then to the Sunshine Coast, Qld. We ended our trip at Manly on the Northern beaches. We had the best time only it was

marred by mosquito bites all along the coast. The bites were particularly large. We were also bitten by nymph ticks on the northern beaches and my youngest son had a red bullseye ring like mark on his wrist. I now understand this to be a sign of a Borrelia infection.

It was three weeks after our big trip that I became very ill with a flu, one that I am still trying to shake. Little did I know at the time

that our road trip took us to every hotspot of Lyme disease infections in Australia and marked the beginning of our enduring terrifying family health crisis. I worry mostly for my boys and all other children living with this disease. I sincerely hope that the decision makers in our government not only worry about the children and all people afflicted by this disease, but have the courage and fortitude to take affirmative action without any further delay.

Multi-Disciplinary Teams (MDT) model for addressing important TBD/DSCATT issues in Australia

17

We believe Multi- Disciplinary Teams (MDT) is the way forward in resolving the issues of TBD/DSCATT in Australia.

- MDT- composed of physicians of different specialties with a PhD, undertaking a PhD, intention to undertake a PhD. Members can be full time or part time. Members can take sabbaticals in order to grow their knowledge to counties where Lyme disease phenomenon does not dominate TBDs.
- The MDT model solves many important short comings of treating TBDs currently
- The team needs to explore the causes of patients' symptoms without considering conversion disorder or any other psychosomatic disease.
- Initially each patient can be treated in personalized manner as there would be no previous records. But as more data is collected about patients, subgroups can be created reducing the workload on the MDT
- The MDT can be supported by administrative, nursing staff and scientists.
- MDT need to work closely with RAGP and other medical organisations in order to disseminate information about their existence and their role in addressing TBD issues in Australia
- RACGP and other healthcare organisations need to educate their members in the procedure of TBD diagnosis in Australia.
- Data collection: MDT consulted patients data can be collected and analysed, MDT can act as a mini CDC.
- Research institutions/labs can tap into MDT patients for clinical research. Research results obtained can be used by MDT members in the treatment of DSCATT patients
- Furthermore PHN- primary health networks can use the regular reports of MDT to educate other health care professionals...
- Greater the understanding of this vector borne multiple infections better the treatment outcomes.

- MDT model can fit into the current public health structure using current employees.
- MDT is also another way of keeping data on patients who have been bitten by ticks and are in the early phase of the disease. That is having an Australia wide data collection system on the acute disease.
- More detailed record can be kept by MDT about DCATT patients relative to My Health Record.

Background

Livestock owner, Gold Coast Hinterland; property adjoins National Park and creek; abundant variety of wildlife close to house; Livestock deaths confirmed as Theileria Babesia, and Anaplasmosis.

Bite History

Multiple bites from Ticks, Spiders, Fleas, Mites & Lice; Confirmed tick bites - species identified by published Parasitologist specialising in Ticks: Rhipicephalus australis, Haemaphysalis longicornis, H.bancrofti, Ixodes holocyclus & Amblyomma nymph. Spreading EM rash from Amblyomma tick. Unfortunately, this tick was not tested, only identified.

Noteworthy Australian Testing experiences

Tested by four different NATA-accredited labs during 12-month period for Bartonella. Each test returned: "This specimen was unsuitable for testing due to non-specific staining. A further sample may prove useful." When queried by two different GPs, the labs gave given two different responses: "Patient's blood is resistant to staining"; and, "Possibly a Native strain of Bartonella that does not react to this stain". Several years later, we're still none the wiser. Where is the research to investigate novel endemic strains of Bartonella?

Also used ARRL's Lyme Disease testing protocol. On my results, I noted that the laboratory had introduced a three-tier testing protocol, which is contrary to the worldwide standard two-tier testing. Results stated "All 3 assays (ELISA, IFA and WB) need to be positive for a confident diagnosis of Lyme Disease". My Western Blot results were positive in IgM only, but I note all three test kits advise as Limitations: "In immunosuppressed patients and newborns, serological data only have restricted value".

My Multidisciplinary Specialist Merry-go-round

In the past year, I have privately consulted a world-renowned Ophthalmologist, a professor of Hepatology/Gastroenterology, a published Neurologist, a Cardiologist, and a Dermatologist- all at the request of a Rheumatologist.

When I first consulted the Rheumatologist, I was referred to a plethora of expensive and exhaustive tests, including: CT scans, biopsies, MRI's, nerve conduction studies, X-Rays etc. He concluded that I was an 'unusual case', as all my tests had returned with abnormalities. He was aware of my bacterial blood test results; however, chose to give me the diagnosis of LUPUS/ SLE. My Lyme-like symptoms had existed for a decade prior to seeing this specialist and none of my previous screening (as recent as four months prior) had ever shown the positive Anti-DNA markers used to indicate a diagnosis for a Lupus. The Anti-DNA tests ordered by the

Rheumatologist were Positive. When I enquired what might cause this, he stated: "It doesn't matter how the Lupus started, it's my job to treat it". He was not interested in discussing possible bacterial or viral infections as the cause of this change.

From that point, every referral to other specialists was prejudiced by his diagnosis of "LUPUS/ SLE" as the cause of my medical conditions/ abnormalities. No one was prepared to look outside the square, even though some of the abnormalities are outside the scope of LUPUS symptoms. This was noted on most of the test results: "Viral or Bacterial causes should also be considered". Many of my symptoms are consistent with those reported in scientific journals as less common manifestations of chronic Borreliosis e.g. Autoimmune Hepatitis.

The Rheumatologist did not request further bacterial tests or a viral screen; he started me on steroids, which increased Tachycardia;

then Methotrexate, even though side effects include: "A form of Hepatitis" - ironic when he'd referred me to a Hepatologist due to my Autoimmune. Hepatitis. When the Hepatologist discovered I was taking Methotrexate, he suggested Mycophenolate (an immune-suppressant chemotherapy drug). Within a week, I contracted a severe case of Measles, even though vaccinated; then a cold virus; followed by Gastroenteritis; a reactivation of EBV; and, to top it off, "Hand, foot and mouth" ...all without leaving the house. I have since dismissed that multidisciplinary team of Specialists due to ending up in a far worse condition with exacerbated and new symptoms.

None of these Specialists investigated the root cause of my conditions; however, they were all happy to give me dangerous medications that are contra-indicated in certain conditions, only masking the symptoms while leaving me vulnerable to other viruses and infections.

I rarely allow myself to look back for moving forward is challenge enough! I do however wonder far how different my life would be today had I been diagnosed correctly and treated efficiently and effectively 10 years ago... It's a question I will never have the answer for and it haunts me regularly to think that anyone else would have to travel that same or similar journey.

I had removed a tick from the back of my right ear without much fuss. I had very sore knees the following days and a few nights later went to bed for the last time as a fit, healthy and motivated Mum, wife, daughter, sister, friend and teacher. I loved life and thrived on being busy and loving all the special people in it. My two daughters were my world and I adored being a part of every aspect of their life. I woke that next day in indescribable body pain, swollen joints, hypersensitivity and an inability to move. My body felt like it was on fire, the right side was far worse, and I struggled to maintain the belief that I wasn't dying. I am sure I would have wanted to hold my girls and tell them it would be ok but in truth it was only later and still today that I wished I had of been able to do this. My nightmare had begun and I was in so much pain that it was all I could do to get through each moment. Even now to think of this and accept it happened is so very hard. Ambulance officers took over an hour to be able to get me into the ambulance - I couldn't move, walk or be touched. I will never forget the compassion the ambulance officers

showed me nor the fear I saw in their eyes as they struggled to give my husband and two beautiful girls answers as to what or why this was happening.

I was taken to one hospital where my symptoms deteriorated and subjected to the first round of tests that would continue for years to come, my body was in such poor shape that getting blood from me required a specialist and left me with black and blue arms. I was transferred and spent over 12 weeks in the John Hunter my condition unknown; the symptoms mimicked many parts of a variety of diseases. I was poked and prodded, slowly regained some use of the left side of my body. I was given many diagnoses which would inevitably change as did the test results.

Transferred to another hospital; given more drugs, tests and search for answers as to what had taken over my healthy body and taken me from my girls' day to day lives. The answer didn't come until many years and money later. By this time, I was in a new hospital under a Professor. I was on \$1000 worth of medication and pain relief. Finally, I was told by the professor that I had "Chenhall" disease a cruel debilitating disease that had no name, so he gave it one. I had to learn to live with it and manage the pain. I was lucky, I was never doubted for how ill I was but sadly the inability to be diagnosed correctly meant I was on medication that most likely worsened my condition, others masked the rapid

deterioration of my body and caused damage unnecessary. It challenged every part of my being to not understand or have answers. Blessed with a positive and humorous disposition I utilised this resource to manage what illness wrought on my body. An amazing support network of family and friends were not prepared to accept that pain management was how I would live the rest of my life. I was primarily wheelchair bound or walking aid, my home modified. A long way from playing an active part in my beautiful daughters lives.

The next part of my journey is long and incredibly difficult to put into words let alone one page. I received a diagnosis of Lyme and various co infections. Imagine what life had become that I celebrated being given a name for what was happening to me. How I laugh at the cruelty. I was about to find out what I was made of. Due to word limits I will share what was in fact years of pain and struggle. I visited Drs and endured more tests and most heartbreaking of all: was denied adequate treatment for the disease that tortured my body daily yet didn't exist. I clung to hope that shattered each time a Dr or hospital told me why I didn't have Lyme, I struggled to find ways to support my girls through acceptance of what had stolen their Mum yet didn't exist, I faltered at times, believing no one could help me and seemed more concerned that I not use the only true diagnosis I had been given. "You're incredibly sick but not Lyme." I got lucky. I found a Dr who

could help and that is what happened. It was a cruel and hard road. I sometimes doubted, the side effects crippling. I persisted and eventually tried to supplement my return to health by visiting Germany for treatment. I had little to lose other than more money and a lot to gain. I gained. I returned to Australia and could walk again. Completed follow up treatment, at times impossible with roadblocks of hospitals not supporting my illness, I subjected my family to learning how to run ivs, u-tubed medical procedures that were denied to me in a sterile setting. Slowly but surely, I began to regain my life. I returned to work part time, I watched my girls play netball, I attended family functions and learnt my body was no longer deteriorating and it seemed that if I nurtured the damage, I could balance a pretty good quality of life and most of all I could be a Mum in every sense of the word. Today I live with a little fear each day - I try not to let it own me. I can walk but I can't run. I don't ever want to go back to the unknown and untreated. I am damaged from years of mis-diagnosis, exposure to drugs like chemotherapy and ketamine; I have pain not normal for a 44-year-old woman. Damage from an illness left untreated, mistreated and denied for so long but here I am: living my life, looking forward not back too often. Today, I allowed, myself to look back briefly and I know: had I received more prompt and appropriate treatment, a correct diagnosis... earlier this story would have been a lot shorter and a lot less painful.

10.2 Appendix B – Supporting Presentations

10.2.1 TCR Update – Ms Julie Glover, NHMRC



Australian Government
National Health and Medical Research Council

NH|M|R|C

Patient Group Forum on Debilitating Symptom Complexes Attributed to Ticks

Dr Julie Glover
Executive Director
Research Foundations Branch

WORKING TO BUILD A HEALTHY AUSTRALIA

National Health and Medical Research Council

- NHMRC is the Australian Government's lead funding agency for health and medical research.
- NHMRC generates, analyses and applies evidence:
 - research funding
 - clinical, public health and environmental health guidelines
 - codes of research conduct and ethics
 - other policies and statements.
- NHMRC works collaboratively to deliver research funding with:
 - Medical Research Future Fund
 - other Government and philanthropic partners.

NHMRC research funding

- Goal of all NHMRC funding is the improvement of human health.
- Funding is provided for:
 - biomedical, clinical, public health and health services research
 - investigator-initiated and some targeted research
 - individuals, teams and networks
 - proof-of-concept research and research partnerships with end-users.
- All funding is contestable, based on independent peer review of:
 - significance and/or innovation
 - scientific merit and feasibility of the proposal
 - track record of the investigators
 - other scheme-specific criteria.

Targeted Calls for Research (TCR)

- A one-time call for grant applications to address a specific health issue
- TCRs aim to advance research in a particular area of health and medical science that will benefit the health of Australians
- Supports NHMRC's response to, and prioritisation of, emerging research needs

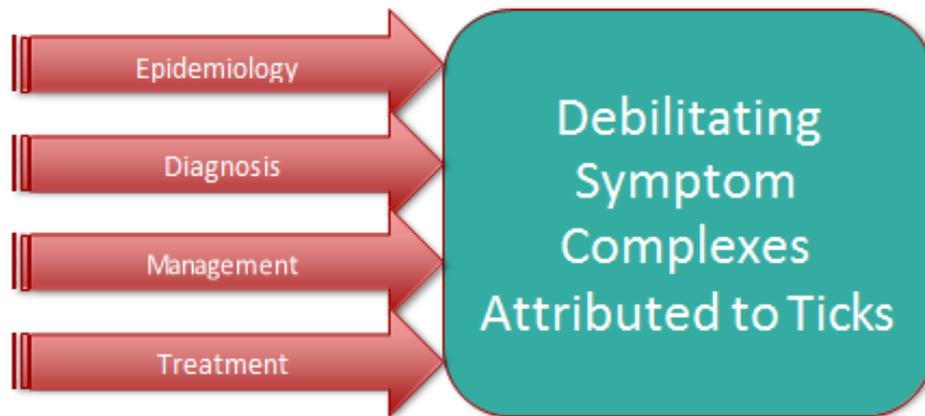
Advisory Committee for Research into Debilitating Symptom Complexes Attributed to Ticks

- Established in June 2017, made up of experts in the field, including two consumer representatives
- Met three times in late 2017 - early 2018

Functions of the Committee

- Identify unmet need or significant research knowledge gaps and emerging issues, both in Australia and internationally
- Contribute to development of a specifically defined TCR
- Contribute to detailed background to the call, scope, aims and objectives and desired outcomes

Research question:



DSCATT TCR key dates:

Opened 30 May 2018

Closed 25 July 2018

Peer review process commenced 26 July 2018

Grant Review Panel for DSCATT – core principles

Assessment Criteria

1. Scientific quality and relevance
2. Record of achievement of the team

Members

- Appropriate knowledge and expertise
- Confidentiality

Conflicts of Interest

- Disclosure of interests
- Real or perceived conflicts are managed accordingly

External Assessors

- Provides specialist expert advice to the panel on how well the applicant has addressed the assessment criteria

Further information

 NHMRC Website

 targeted.research@nhmrc.gov.au

10.2.2 Option for MDC – Prof Brendan Murphy, Department of Health



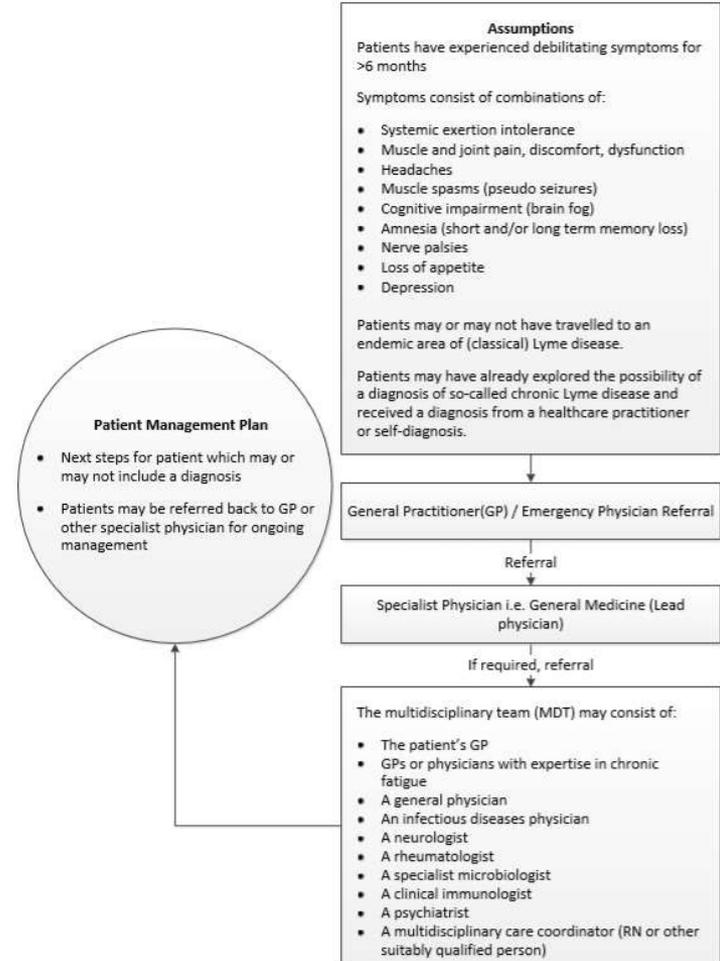
Australian Government
Department of Health

Professor Brendan Murphy
Chief Medical Officer

An approach for MDC

Options for Multidisciplinary Approach

Clinical pathway for DSCATT patients



10.2.3 Personalised medicine model – Ms Catherine Stace, LDAA



DSCATT patient forum

**Placing patient's in the centre
– a case study**

Together we can create a compassionate future



**To give patients real hope we
need to rise above complexity.**

We have an opportunity to leapfrog traditional method and co-design a model that is relevant, efficient and cost effective.



- **Take out the guess work in treatment and diagnostics.**
- **Shift from a soiled models to whole system approach.**
- **Create an adaptive learning system.**

Advocacy Pathway



Government
funding

Equitable
access

Tailored
personalised
treatment

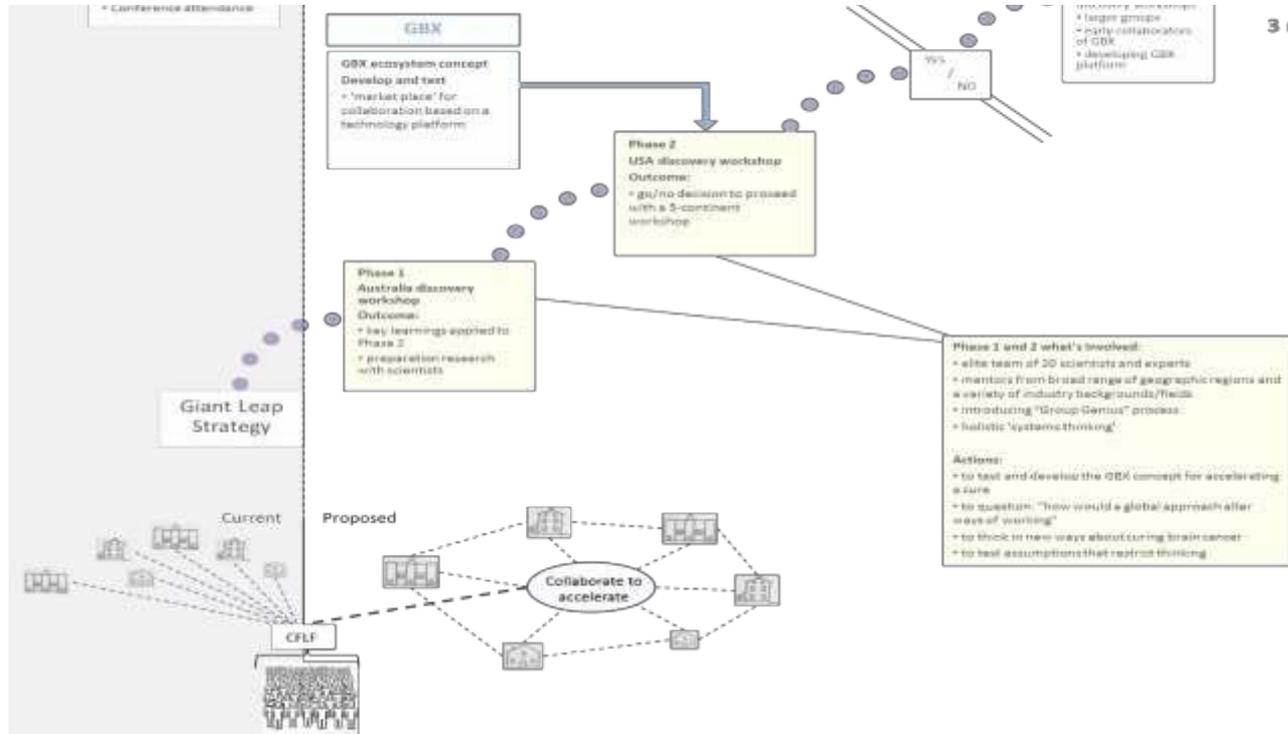
Early
diagnosis

Stakeholder engagement



LYME DISEASE
Association of Australia
Prevention. Innovation. Recovery.

3 million lives



The basics



Siloed



**PAN
disease
platforms**

Issuing
Grants



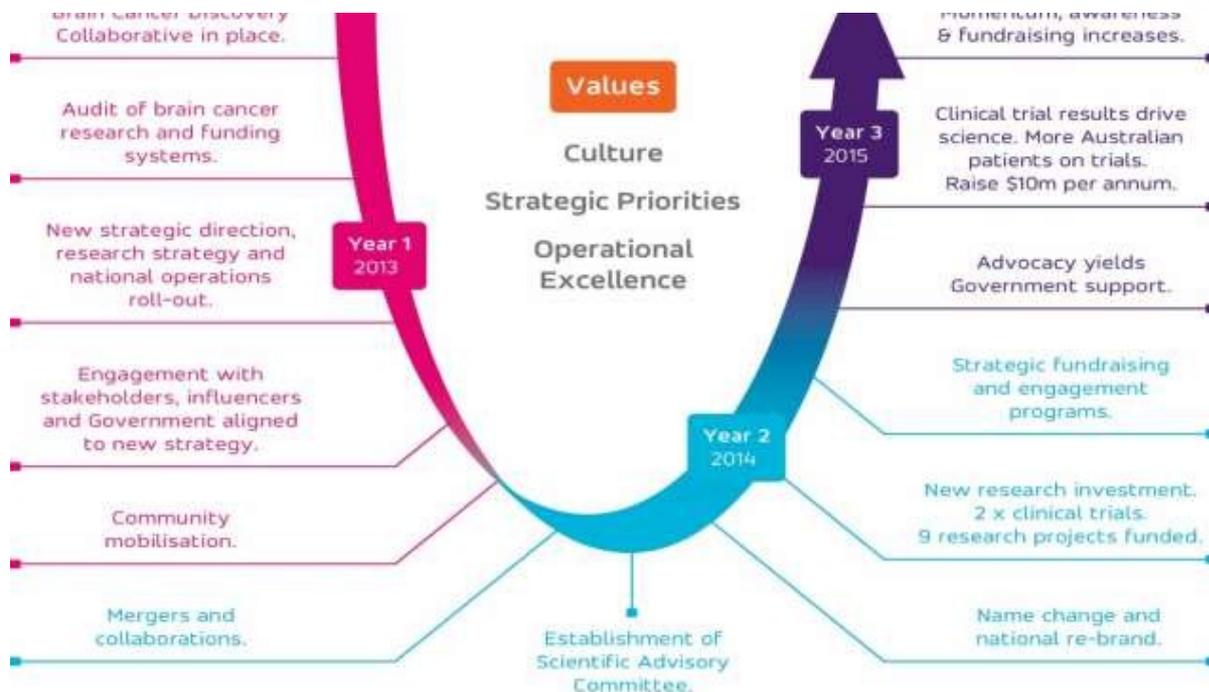
**PPP
Sustainable
Fundraising
models**

Investigator
Led



**Priority Led
collaborations**

Foundational accomplishments



Personalised medicine model



<https://www.youtube.com/watch?v=pAkDUkRsc>

10.2.4 Multi-Disciplinary Teams (MDT) Model for Addressing Important TBD/DSCATT Issues in Australia

Dr Mualla McManus, Karl McManus Foundation

KMF believes Multi- Disciplinary Teams (MDT) is the way forward in resolving the issues of TBD/DSCATT in Australia.

- + MDT- composed of physicians of different specialties with a PhD, undertaking a PhD, intention to undertake a PhD. Members can be full time or part time. Members can take sabbaticals in order to grow their knowledge to counties where Lyme disease phenomenon does not dominate TBDs.
- + The MDT model solves many important shortcomings of treating TBDs currently
- + The team needs to explore the causes of patients' symptoms without considering conversion disorder or any other psychosomatic disease.
- + Initially each patient can be treated in personalized manner as there would be no previous records. But as more data is collected about patients, subgroups can be created reducing the workload on the MDT
- + The MDT can be supported by administrative, nursing staff and scientists.
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- + RACGP and other healthcare organisations need to educate their members in the procedure of TBD diagnosis in Australia.
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- + Research institutions/labs can tap into MDT patients for clinical research. Research results obtained can be used by MDT members in the treatment of DSCATT patients.
- + Furthermore PHN- primary health networks can use the regular reports of MDT to educate other health care professionals...
- + Greater the understanding of this vector borne multiple infections better the treatment outcomes.
- + MDT model can fit into the current public health structure using current employees.
- + MDT is also another way of keeping data on patients who have been bitten by ticks and are in the early phase of the disease. That is having an Australia wide data collection system on the acute disease.
- + More detailed record can be kept by MDT about DCATT patients relative to My Health Record.