

## Department of Health

Forum to consider the outcomes of the Australian Government's response to the Senate Community Affairs Reference Committee final report:

*Inquiry into the growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australians.*

18 April, 2018

Melbourne

Facilitated by Helen Wood, CEO, TMS Consulting Pty Ltd

# Table of Contents

1	Introduction.....	3
2	Background .....	3
3	Workshop Agenda.....	4
4	Attendees .....	5
5	Discussion Outputs .....	6
5.1	Introduction .....	6
5.1.1	Opening Remarks- Professor Brendan Murphy .....	6
5.1.2	Address to the Forum - The Hon Greg Hunt, MP, Minister for Health .....	7
5.2	Presentations.....	8
5.2.1	Professor Lindsay Grayson – ‘A Multi-Disciplinary Program for patients with “Lyme-like” illness (LLI)”, Austin Health ID Program .....	8
5.2.2	Dr Richard Schloeffel, OAM – ‘Vector Borne Disease’.....	9
5.2.3	Dr Julie Glover, Research update from NHMRC.....	10
5.2.4	Group Discussion – ‘insights gained so far’ .....	11
5.3	Workshop Discussion – Multi-disciplinary Approach.....	12
5.3.1	What would success look like for patients? .....	12
5.3.2	What are the benefits of the multidisciplinary approach?.....	12
5.3.3	What are the challenges or your questions? .....	13
5.3.4	How do we get started? .....	14
5.4	Workshop Discussion – Education and Awareness.....	14
5.5	Nomenclature.....	15
6	Outcomes .....	16
7	Closing Remarks .....	16
8	Facilitator Observations.....	17
9	Conclusion.....	17

# 1 Introduction

On Wednesday 18<sup>th</sup> April 2018, The Department of Health convened a consultation forum to consider the outcomes of the Australian Government's response to the Senate Community Affairs References Committee final report: *Inquiry into the growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients.*

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 and points presented by the different stakeholders.

## 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

Number	Time	Agenda Item
1	0930–1000	<p>Opening remarks</p> <ul style="list-style-type: none"> <li>+ Professor Brendan Murphy, Australian Government Chief Medical Officer</li> </ul> <p>Address to the Forum</p> <ul style="list-style-type: none"> <li>+ The Hon Greg Hunt MP, Minister for Health</li> </ul>
2	1000–1010	<p>Introduction to the Forum</p> <ul style="list-style-type: none"> <li>+ Ms Helen Wood (Facilitator)</li> </ul>
3a	1010–1200	<p>Discussion: A nationally agreed multidisciplinary care approach</p> <ul style="list-style-type: none"> <li>+ Ms Helen Wood</li> </ul> <p>Guest speakers:</p> <ul style="list-style-type: none"> <li>+ Professor Lindsay Grayson (15 min)</li> <li>+ Dr Richard Schloeffel (15 min)</li> </ul>
3b	1200–1220	<p>Research update from NHMRC</p> <ul style="list-style-type: none"> <li>+ Dr Julie Glover, NHMRC</li> </ul>
Lunch	1220–1300	
3c	1300–1330	<p>Discussion: Education and awareness for medical and other health professionals</p> <ul style="list-style-type: none"> <li>+ Ms Helen Wood</li> </ul>
3d	1330–1345	<p>Discussion: Nomenclature</p> <ul style="list-style-type: none"> <li>+ Ms Helen Wood</li> </ul>
4	1345–1400	<p>Next Steps</p> <ul style="list-style-type: none"> <li>+ Ms Helen Wood</li> </ul>

## 4 Attendees

State and territory health authorities, representatives from relevant medical colleges, international representatives and some patient groups were invited to participate in this forum. The full invitee list can be found at Appendix A.

Attendees at the forum included:

### **Australian Government**

Minister Greg Hunt, Minister for Health  
Prof Brendan Murphy, Chief Medical Officer  
Dr Anthony Hobbs, Deputy Chief Medical Officer  
Ms Sharon Appleyard, First Assistant Secretary, Office of Health Protection (OHP)  
Ms Sarah Norris, A/Assistant Secretary, Health Protection Policy Branch, OHP  
Dr Gary Lum, Principal Medical Advisor, OHP  
Ms Cindy Toms, Director, Health Protection Policy Branch, OHP  
Mr Phil Wright, Assistant Director, Health Protection Policy Branch, OHP

### **Invited Guests**

Prof. Lindsay Grayson, Director, Department of Infectious Diseases & Microbiology, Austin Health

### **State and Territory Health Authorities**

Dr Vicky Sheppeard, NSW Health  
Mr Xavier Schobben, NT Health  
Dr Debra El Saadi, Queensland Health  
Dr Louise Flood, SA Health  
Dr Scott McKeown, Tasmania Health  
Dr Mihaela Ivan, Victoria Health  
Dr Paul Armstrong, WA Health

### **Medical College Representatives**

Dr Lyn Waring, Royal College of Pathologists of Australia  
Prof Richard Doherty, Royal Australasian College of Physicians  
Dr Cameron Loy, Royal Australian College of General Practitioners

### **NHMRC**

Dr Julie Glover, NHMRC

### **Key Stakeholders**

Dr Richard Schloeffel, Australian Chronic Infectious and Inflammatory Diseases Society  
Dr Mualla McManus, Karl McManus Foundation  
Ms Sharon Whiteman, Lyme disease Association of Australia  
Ms Jacqui van Teulingen, Lyme disease Association of Australia

## 5 Discussion Outputs

### 5.1 Introduction

#### 5.1.1 Opening Remarks- Professor Brendan Murphy

Professor Brendan Murphy, Australian Government Chief Medical Officer opened the forum and reaffirmed the purpose of the day. He noted that the day was to be a discussion of the key outcomes of Senate Inquiry report with a particular focus on the development of a cooperative framework which can accommodate both patient and medical needs with the objective of establishing a multidisciplinary approach to addressing tick-borne illness in Australia across all jurisdictions.

Professor Murphy acknowledged that there is a lack of evidence of Lyme disease or Lyme like disease in Australia but reiterated that the forum and relevant authorities must collectively ensure that the Australians who experience the debilitating symptoms, which are acknowledged and often severe, receive evidence based and compassionate care.

Professor Murphy went on to note that 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. Professor Murphy acknowledged that the treatment experience for some patients in the health system has been unsatisfactory. He also affirmed that the medical community does have an open mind to new scientific evidence when it is produced (e.g. the recent new evidence of mammalian meat allergy caused by tick bites is now accepted).

He noted that a comprehensive, rigorous and multi-disciplinary approach to symptoms is required, with appropriate psychological support provided. Professor Murphy concluded by announcing that the Department of Health is planning an additional forum later in the year, likely to be in Sydney, involving a broader number of patient support groups regarding ideas that came out of the Senate Inquiry and this Forum.

### 5.1.2 Address to the Forum - The Hon Greg Hunt, MP, Minister for Health

The Minister addressed the forum and encouraged members to consider three key areas – context, research and outcomes. The Minister noted that the forum is the first of two major roundtables, with the current session encompassing a combination of very experienced and senior medical staff along with leading patient groups. It was confirmed that the second roundtable will have a broader focus on patient support groups.

Regarding context, the Minister expressed that a large group of patients are unable to receive adequate or appropriate treatment for their condition. The focus is not to get in between the medical professional and their patient, as this relationship is sacrosanct but rather, the focus is to ensure that adequate information and support is available to physicians to inform treatment. Additionally, there is a need to enhance the awareness of medical practitioners and patients who previously felt that they could not talk about this issue. The Minister noted that the medical community must recognise and treat patients who have debilitating conditions even if a diagnosis or definitive treatment is not known.

Regarding research, the Minister noted that the evidence regarding the cause of the debilitating symptoms is not conclusive; therefore \$3 million will be provided by the NHMRC for targeted research. The Minister 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. He also acknowledged that the primary response today should be from medical authorities, as this will inform discussion pertaining to actual patient pathways. The Minister went on to question how we provide better outcomes for conditions in relation to fatigue, suppressed immune system and the emotional and mental health impacts. This is in response to many instances of chronic conditions, such as depression and anxiety, and it is important to recognise this. It is important to seek more input from patient groups and understand their needs and perspectives. The Minister noted that patients are evidence of the emerging disease situation and that we need to ensure primary care providers are contributing to the research.

## 5.2 Presentations

### 5.2.1 Professor Lindsay Grayson – ‘A Multi-Disciplinary Program for patients with “Lyme-like” illness (LLI)’, Austin Health ID Program

Professor Grayson introduced the topic by noting a personal story of a time when his wife was diagnosed with Lyme disease while living in the United States.

He went on to cover the Austin experience with ‘LLI’, in which between a third and half of patients had other conditions that were not properly diagnosed. After an extensive investigation, it was found that:

- + 30–50% of potentially serious medical conditions that have been either:
  - o Previously undiagnosed
  - o Diagnosed but inappropriately treated
  - o Diagnosed but denied by the patient such that no treatment was sought/given
- + 10–20% had a serious defined psychiatric illness needing specialist care
- + 80–90% had undergone substantial financial hardship paying for:
  - o Investigations from unaccredited laboratories – with doubtful results
  - o In some cases, prolonged antibiotic treatment that has had no/minimal objective benefit

Due to these factors a true multidisciplinary approach is required, with rheumatology, oncology and psychiatry being core areas. In addition, everyone with chronic illness is affected, and requires a supportive environment; therefore primary care physicians (GPs) with interest in long-term care of patients with chronic disease are required.

Professor Grayson went on to say that the current funding system does not work in this multidisciplinary environment, with the Medicare and state-based funding system being inhibitory to this approach. In addition to this, while laboratory diagnostics are sufficient, there is variable quality and the results need to be followed up to clarify. Further to this, non-accredited laboratories are putting out questionable results. Antibiotics are administered unnecessarily and overprescribing is common which can be harmful.

The solution to this is firstly to re-establish trust between patients and the medical system. This will involve an improved system of multi-disciplinary specialist clinics, with patients and medical staff being open to new approaches and mutual respect. Furthermore, specific research efforts, especially new metagenomics diagnostics, are required to seek fuller understanding regarding the impact of Australian ticks, as not all of undiagnosed illnesses are due to them. Professor Grayson concluded that education is key to understanding different types of Lyme disease, as most GPs are not aware of particular nuances in this regard.

In response to Professor Grayson's presentation, members of forum discussed the tension in Australia pertaining to the need for more research.

A copy of Professor Grayson's presentation is at Appendix B.

### 5.2.2 Dr Richard Schloeffel, OAM – 'Vector Borne Disease'

Dr Schloeffel presented a wide range of information in relation to his experience with patients and the challenges of vector borne diseases (VBD) where the research is unclear and it is not possible to accurately quantify the scale of the disease. Some key points made by Dr Schloeffel included:

- + There is an unrecognised endemic illness in Australia
- + It is impacting thousands of lives although the numbers are unclear
- + Unknown how many people actually have a VBD versus another illnesses (or both)
- + Medical denialism is leading to under-diagnosis and mistreatment
- + Political and medical intervention is necessary

Dr Schloeffel noted that VBD is one of the fastest growing diseases in the world and is highly transmissible. If something is not done to manage the disease there is likely to be a significant burden on the public hospital and health sector.

In discussing his ideas on next steps Dr Schloeffel announced that he and other concerned GPs and specialists are setting up a research centre for VBD – they intend to create a biobank, taking samples from multitudes of patients, looking for what's different in these patients from other patients, looking at ticks from the areas where people are getting sick and overall develop a much better understanding of the cause and therefore the treatment.

Dr Schloeffel also noted that in running his multidisciplinary treatment clinic his conclusions are:

- + We must support the concept of a multidisciplinary approach to treatment clinics
- + They must be patient focussed not doctor focussed and engender trust amongst affected patients
- + They must have appropriate architecture, be warm and welcoming with specialist doctors who are prepared to spend the necessary time required with patients (which is often substantial)
- + We must look to the world for their experience and collaborate to develop/implement world's best practice

Discussion following Dr Schloeffel presentation included general consensus that a multi-disciplinary approach/care team was essential comprising:

- + General Practitioners
- + Specialist Doctors
- + Allied Health – Psychologist, Physiotherapist, Nutritionist, Exercise Physiologist
- + Psycho-Social Support for patients, family and carers

Discussion also centred around the need for more research and to educate the community that ticks are dangerous.

A copy of Dr Schloeffel's presentation is at Appendix B.

### 5.2.3 Dr Julie Glover, Research update from NHMRC

Dr Glover provided an overview of the NHMRC approach to funding noting that NHMRC commits approximately \$800m in new health and medical research grants each year. Dr Glover noted most grants are funded through a suite of standard schemes, where researchers develop proposals in their area of interest and applications are assessed by experts against published criteria including quality and significance of the research. While there are ample opportunities for researchers to apply for funding, schemes are also very competitive. For example NHMRC's largest scheme, Project Grants last year received over 3,300 applications with a funded rate of only 16%.

Dr Glover noted that NHMRC had received very few Lyme or tick-borne disease applications over last 20 years, around 16 applications in total with very few funded. Last year the NHMRC awarded a Project Grant of over \$600,000 to Prof Holmes at Sydney University to study metagenomics of Australian ticks.

Dr Glover also spoke about NHMRC's Targeted Call for Research Framework and the different ways that priority research areas can be identified, including through community and professional groups, state and territory governments and NHMRC's committees. NHMRC received submissions on research into tick-borne illness from the Lyme Disease Association of Australia and the Karl McManus Foundation.

In 2017 NHMRC agreed to undertake a \$3 million Targeted Call for Research and assembled an advisory committee to define the research questions of the call. Membership of this advisory committee included researchers, clinicians such as Professor Grayson, and consumers

nominated by LDAA and the Karl McManus Foundation. Advice from this committee is being finalised and will form the basis of a Targeted Call for Research into Debilitating Symptom Complexes Attributed to Ticks which NHMRC is planning to open shortly. Dr Glover noted that 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.

Dr Glover also mentioned that NHMRC takes a proactive approach to partnerships and is happy to work with partners to co-fund research or undertake peer review for partners.

#### 5.2.4 Group Discussion – ‘insights gained so far’

Attendees at the workshop were asked to discuss in mixed groups the insights gained so far from the presentations and what their associated conclusions or questions were.

Summarised responses included:

- + It is important that we have a case definition. When people present to a GP with undifferentiated symptom complexes, having an agreed case definition will prompt the GP to be alert to these people and ensure that they have early conversation with specialist.
- + Some jurisdictions face geographic challenges in terms of VBD and general awareness
- + There are state variations, e.g. Tasmania has been successful in identifying previously unknown organisms with proven and practiced mechanisms to find causes of diseases.
- + This is unlikely caused by a single microorganism and non-microbial causes must be considered.
- + The acute phase with a tick bite is different from someone with long term established chronic disease, need to recognise that it is time consuming to untangle appropriate causes.
- + We need to get the science right – research centre of excellence – what is wrong with these people, what markers are different from normal processes? Same bacteria may be present but each patient is unique.
- + Parallels with chronic fatigue syndrome, MD issue – similar to VBDs
- + Helpful to remember that chronic fatigue was similarly regarded in the early period until individuals emerged from the medical profession taking interest in chronic fatigue syndrome and things built from there.
- + Multidisciplinary clinical approach – how can that be set up? How to mobilise in each state/territory? Who would lead the clinic – who is the appropriate discipline to lead a multidisciplinary group - GP big role in this but need others in a MD approach

- + How will we effectively embrace international expertise?

Participants also encouraged Dr Grayson and Dr Schloeffel to publish papers on their approaches.

### 5.3 Workshop Discussion – Multi-disciplinary Approach

As a lead into the presentation Dr Hobbs was asked to present a proposed model of care to generate discussion. Presentation is provided at Appendix B.

Attendees were asked to consider the following questions:

- + What would success look like for patients?
- + What are the benefits of the multidisciplinary approach or physicians and patients?
- + What are the challenges?
- + How do we get started?

Responses are summarised below.

#### 5.3.1 What would success look like for patients?

Attendees workshoped in mixed groups the above question. Responses were as follows:

- + For patients to be accepted and heard by medical professionals
- + For treating physicians to have appropriate knowledge in treating this patient group - knowledge and experience in helping patients recover is required
- + For there to be a clear pathway for assessment
- + For patients to receive patient-centred care – a model of care that is compassionate and provides effective treatment
- + Ultimately patients want to progress to recovery and return to the quality of life they experienced prior to the onset of these symptoms
- + The multidisciplinary approach should generate acceptance and this would have an immediate positive effect on patients
- + National/international insights are proactively used to support Australian efforts

#### 5.3.2 What are the benefits of the multidisciplinary approach?

Attendees workshoped in mixed groups the above question. Responses were as follows:

- + Feeling of recognition for patients and ability access MD approach rapidly

- + One dedicated team that ensures someone listening to the patient - patients feel heard and are safely diagnosed and treated.
- + Integration of psychological support for patients is essential given the long term effects of the condition on the mental health of patients.
- + Rapid knowledge acquisition for patients – getting answers quickly, have everything in one place.
- + Already a MD approach in other medical areas where learnings can be observed – oncology approach to MD care, systems in place – physician led coordinated approaches, can be combined with outpatient/inpatient services.
- + Combination of thinking for colleagues from different disciplines, patient – hears and interacts with different medical practitioners which is important to recovery

### 5.3.3 What are the challenges or your questions?

Attendees workshoped in mixed groups the above question. Overall it was noted that there is a need for further research on this issue and it would be beneficial for experts who have worked in this field to publish their work so the medical profession can get a better understanding and appreciation of the approaches in addressing the issues of people with debilitating symptom complexes.

Other responses were as follows:

- + Further international research is needed
- + Remote and regional areas need to be considered differently with respect to health system capacity/availability of services
- + Case definition needs to be agreed and published
- + There is an abundance of patients and scarce resources – definitions required to allow effective treatment.
- + Funding is a challenge.
- + Recruitment of people to start these clinics is a challenge – resourcing the MD approach will need someone with reasonable term commitment to approach, important that trainees are also aware of this approach.
- + Need enough evidence to convince state and territory health departments to set something up. Trial evidence to show that there is a patient outcome/benefit.
- + Encourage process of educating GPs and get issues into the mainstream so that GPs operating in this space do not feel isolated or ostracised. We need training and knowledge base, and protection for those that say it's not a legitimate illness.
- + Diagnostic capability – challenges with pathology.

- + Time is a challenge for treating physicians because consultations will be lengthy.
- + How to measure what's happening at present?
- + How to define which patients get referred into a MD program?

#### 5.3.4 How do we get started?

Attendees workshopped in mixed groups the above question. Responses were as follows:

- + Include a research pillar in the multidisciplinary model
- + A trial is required to understand the approach and how to optimise it including:
  - o Ensuring model is sustainable – with appropriate referral back to primary care
  - o Evidence of outcomes to generate state and territory interest in funding
- + Engage more effectively with domestic and international experts
- + Consider a flexible model that allows for jurisdictional differences.
- + Consider the harm of doing something versus the harm of doing nothing, i.e. consider measurements such as QALYs and DALYs
- + Consideration should be given on how to approach multidisciplinary clinical care – including:
  - o the best way to engage States and Territories,
  - o how to set up such an approach,
  - o who would lead the clinic, or what is the most appropriate discipline to lead a multidisciplinary clinic.
- + Effective education and training of doctors

### 5.4 Workshop Discussion – Education and Awareness

Attendees then discussed what was needed or important in relation to education and awareness.

The following key points were made:

- + We need a diagnosis guides for GPs – resources that describe the different symptoms and how to test for it – an overview to support GPs at the point of presenting patient for both classical Lyme disease and DSCATT.
- + MD approach – need to agree a flow chart of what the patient pathway should be? There is a myriad of conditions to consider so a flow chart would be a good start.
- + The key and first message is that the condition is genuine and within the patient group some have related diagnosable conditions that are treatable - huge benefit in MD assessment from ground zero. MD approach makes patients feel listened to.
- + Education of GPs on interpretation of blood test results is needed.

- + Would be beneficial to have preventative messages distributed by health professionals on how to avoid tick borne illnesses especially where risk is higher.
- + We should proactively remind people it's tick season – avoid ticks, if get tick bite and remain sick see your GP.
- + GPs should encourage short course of antibiotics (2-6 weeks) to stop development of disease.
- + Public Health messaging pertaining to ticks currently varies from state to state e.g. Pittwater council (northern beaches of NSW) send out pamphlet on how to avoid and remove ticks and spraying to reduce ticks.
- + Information does exist for example the UK NICE guidelines however world's best practice isn't happening in Australia – time we changed this.
- + Tactics to increase the familiarity of doctors with the disease for example shadowing treating doctors. GPs attend annual conferences to learn more about diseases – we should be highlighting the condition at these conferences.

## 5.5 Nomenclature

The final discussion on the day was in regards to how the condition should be referred to as Lyme disease is a misnomer and causes confusion and discord.

The attendees discussed the following:

- + Relating the condition to Ticks (DSCATT) is limiting – more vectors appearing internationally
- + Vector borne diseases are different globally and it is a generic term – isn't really appropriate in this context.
- + No agreed decision on how to name – group of system complexes that need to be resolved.
- + Look for common theme – debilitating and undiagnosed are key words.
- + Should we call the condition after someone's name?
- + A name was suggested - Multiple Systemic Infection Disease Syndrome (MSIDS or MSDS) – there was debate on this with limited conclusions made. It was noted that both the words “infectious” and “tick” were limiting.
- + 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.

## 6 Outcomes

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

- + Dr Grayson and Dr Schloeffel were encouraged to publish on their approaches to increase profile of the issue in the medical community
- + A multidisciplinary approach was a step in the right direction and should be trialled more fully as soon as possible
- + The condition should not be referred to as Lyme or Lyme-like disease
- + More education and awareness is required to support:
  - o Diagnosis and treatment by GPs of patients presenting with classical Lyme disease, including information on pathology interpretation and patient treatment protocols
  - o Diagnosis (where possible), treatment and participation in the ongoing management of DSCATT patients
  - o Public health messaging on tick-borne diseases, preventing tick bites and removing ticks safely

## 7 Closing Remarks

Professor Murphy closed the session. Some key comments included:

- + Thank you everyone for attending – the morning went well with lots of positive and respectful discussion
- + We all need to focus on getting an outcome from the meeting and work up how we approach setting up MD clinics in the future
- + We need evidence to see how jurisdictions can help more - please come back with ideas
- + We will hold a second forum and consult with a broader representation of patient support groups

## 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 parties to the discussion are passionate about the condition and have the interest of patients at the forefront
- + Patient groups were collaborative and open to different approaches and next steps
- + The medical representatives in the room generally agreed that research and case papers were required to influence the broader medial community
- + There was general consensus that there needs to be further research and better treatment pathways for patients – that the symptoms are mixed and varied and need a MD approach
- + An important focus at this time in relation to the life of this condition is to balance the need to respectfully and effectively treat patients with the need to increase medical knowledge and evidence related to the condition and its treatment.

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

## 9 Conclusion

The feedback on the forum was generally positive with strong interaction and contribution from all groups. It was noted that the Department of Health will conduct a second forum to consult with a broader representation of patient support groups. This forum is scheduled for later in 2018 and will be held in Sydney. On conclusion many participants seemed satisfied with the opportunity to be heard and to discuss this complex condition.

## Appendix A - Invitees

Name	Organisation
<b>Australian Government</b>	
Minister Greg Hunt	Minister for Health
Prof Brendan Murphy	Chief Medical Officer
Ms Sharon Appleyard	First Assistant Secretary, Office of Health Protection (OHP)
Ms Sarah Norris	A/Assistant Secretary, Health Protection Policy Branch, OHP
Dr Gary Lum	Senior Medical Advisor, OHP
Ms Cindy Toms	Director, Health Protection Policy Branch, OHP
Mr Phil Wright	Assistant Director, Health Protection Policy Branch, OHP
<b>Invited Guests</b>	
Prof Lindsay Grayson	Director, Department of Infectious Diseases & Microbiology, Austin Health
Prof Lyn Gilbert	Clinical Professor Medicine (Immunology and Infectious Diseases)
Dr Bernie Hudson	Senior lecturer University of Sydney
<b>International</b>	
Dr Richard Horowitz	Medical director of the Hudson Valley Healing Arts Center, NY, USA
Dr Armin Schwarzbach	Director, Arminlabs, Germany
<b>State and Territory Health Authorities</b>	
Dr Paul Kelly	ACT Chief Health Officer
Dr Kerry Chant	NSW Chief Health Officer
Dr Hugh Heggie	NT Chief Health Officer
Dr Jeannette Young	Queensland Chief Health Officer
Prof Paddy Phillips	SA Chief Health Officer
Dr Mark Veitch	Tasmania Chief Health Officer
Prof Charles Guest	Victoria Chief Health Officer
Dr Brett Sutton	A/g Victoria Chief Health Officer
Prof Tarun Weeramanthri	WA Chief Health Officer
<b>Key Stakeholders</b>	
Assoc Prof Bruce Latham	RCPA President
Dr Catherine Yelland	RACP President
Dr Bastian Seidel	RACGP President
Dr Michael Gannon	AMA President
Assoc Prof Ruth Stewart	ACRRM President
Prof Cheryl Jones	Australasian Society for Infectious Diseases President
Julie Glover	NHMRC
Dr Richard Schloeffel	Australian Chronic Infectious and Inflammatory Diseases Society
Dr Mualla McManus	Karl McManus Foundation
Sharon Whiteman	Lyme disease Association of Australia

## Appendix B – Presentation

The following presentations are provided in the subsequent pages of this report.

- + Professor Lindsay Grayson – A Multidisciplinary Program for patients with “Lyme-like” illness
- + Dr Richard Schloeffel – Vector Borne disease in Australia
- + Dr Tony Hobbs – Proposed model of care

# A Multi-Disciplinary Program for patients with “Lyme-like” illness

## Austin Health ID Program

**Prof. M. Lindsay Grayson**

Infectious Diseases & Microbiology Department, Austin Health  
Department of Medicine, University of Melbourne, Australia  
Director, Hand Hygiene Australia



## A Multi-Dimensional Program for patients with “Lyme-like” illness

# Overview

- A personal story
- The Austin experience with “LLI”
- The problems
- The potential solutions

## The Austin experience with “LLI”

- >50 patients
- All are suffering
  - All have had their lives affected by their illness
  - Many for very prolonged periods
  - All patients frustrated by their illness and its treatment (or perceived lack thereof)
- Many patients (not surprisingly) - have become depressed
  - Many have become somewhat absorbed by their illness
- Australian Reference Lab results – 1-2 +ve for ?borreliosis
- No evidence of babesiosis or rickettsiosis
  - Based on laboratory evidence or failure to respond to medical therapy that is universally effective against these two diseases

## The Austin experience with “LLI”

### After extensive investigation:

- ~30-50% - potentially serious medical conditions that have been either:
  - Previously undiagnosed
  - Diagnosed but inappropriately treated
  - Diagnosed but denied by the patient such that no treatment was sought/given
- 10-20% have a serious defined psychiatric illness needing specialist care
- ~80-90% have undergone substantial financial hardship paying for:
  - Investigations from unaccredited laboratories – doubtful results
  - In some cases - prolonged antibiotic treatment that has had no/minimal objective benefit
- Current medical approach to managing these patients is inappropriate - need:
  - A multi-disciplinary approach, including:
  - Specialist physicians (e.g. infectious diseases, rheumatology and oncology)
  - Psychiatrists (with a special expertise in so-called conversion disorders)
  - Primary care physicians (GPs) with interest in long-term care of patients with chronic disease



## The Austin experience with “LLI”

After extensive

- ~30% of patients with chronic illness
- 10-20% of patients with chronic illness
- ~80% of patients with chronic illness have had some degree of hardship
- Involved in litigation from unaccredited laboratories – results unreliable
- Some cases - prolonged antibiotic treatment that has had no/minimal objective benefit
- Current medical approach to managing these patients is inappropriate - need:
  - A multi-disciplinary approach, including:
  - Specialist physicians (e.g. infectious diseases, rheumatology and oncology)
  - Psychiatrists (with a special expertise in so-called conversion disorders)
  - Primary care physicians (GPs) with interest in long-term care of patients with chronic disease

## A Multi-Dimensional Program for patients with “Lyme-like” illness

# Overview

- A personal story
- The Austin experience with “LLI”
- The problems
- The potential solutions

# Problems

- Funding model – inconsistent with the illness
  - Consider “block-funding” similar to other multi-faceted illnesses
- Specialist support services limited – esp. Psych.
- Laboratory Diagnostics - OK, but variable quality
  - Need specific funding
  - Enhanced focus on genomics
  - Non-NATA-accredited labs – fraudulent misleading results
    - Special Govt. attention needed to limit their activities/influence
    - A source of huge confusion, stress (emotional + financial) and incorrect, potentially harmful treatments
- Inappropriate antibiotic use = emergence of “Superbugs”

## A Multi-Dimensional Program for patients with “Lyme-like” illness

# Overview

- A personal story
- The Austin experience with “LLI”
- The problems
- The potential solutions

# Potential Solutions

- Need to re-establish trust between patients and the medical system
  - Improved system of multi-disciplinary specialist clinics
  - Patients & medical staff - need to be open to new approaches and mutually respectful
  - Non- accredited labs should be closed/fined
- Australian ticks – are potentially filthy creatures, but not all undiagnosed illnesses are due to them
  - Specific research efforts are required – esp. new metagenomic diagnostics
- Improved medical and community education



# Vector-borne disease in Australia

**Dr Richard Schloeffel OAM**

MBBS, FRACGP, FAMAS, Diploma Acup (China)



# Primary issues

- Unrecognised endemic illness in Australia
- Impacting thousands of lives
- Unknown how many people have VBD
- Medical denialism leading to under-diagnosis and mistreatment
- Political and medical intervention is necessary

# Context

**VBD is one of the fastest growing diseases in the world  
It is highly transmissible**

## **Incidence**

**USA – 300,000 new cases diagnosed pa or 0.01% of the total population**

## **Australia**



- 4,000+ patients treated by ACIIDS doctors over the past 6 years
- 1,500 patients currently under treatment, thousands on wait lists
- Undiagnosed cases may exceed tens of thousands

**There is potential for an logarithmic increase in the burden on the hospital and health network due to this illness**

# Chronic disease experience

- 1976: PNG – TB and Leprosy
- 1978 – 81: Intensive care training
- 1981 – 88, 1991 - 96: Rural general practice
- 1983 - 96: HIV/AIDS
- 1997 – 2018: Chronic and complex disorders, including VBD
- 2014: Australian Chronic Infection and Inflammation Disease Society (ACIIDS) formed

# Infection response





**Australian patient with tick bite induced  
erythema migrans rash**

# Clinical presentation

- Chronic Fatigue Syndrome
- Fibromyalgia
- Autoimmune Disease
- Multiple Sclerosis
- Motor Neurone Disease (ALS)
- Parkinson's Disease
- Alzheimer's Disease
- Chronic Pain Syndromes
- Autistic Spectrum Disorders

# Testing for Borreliosis

- Current testing in Australia is not suitable for Borreliosis detection
- Western Blot
- Polymerase chain reaction Test (PCR)
- ELISA is non diagnostic (current standard)

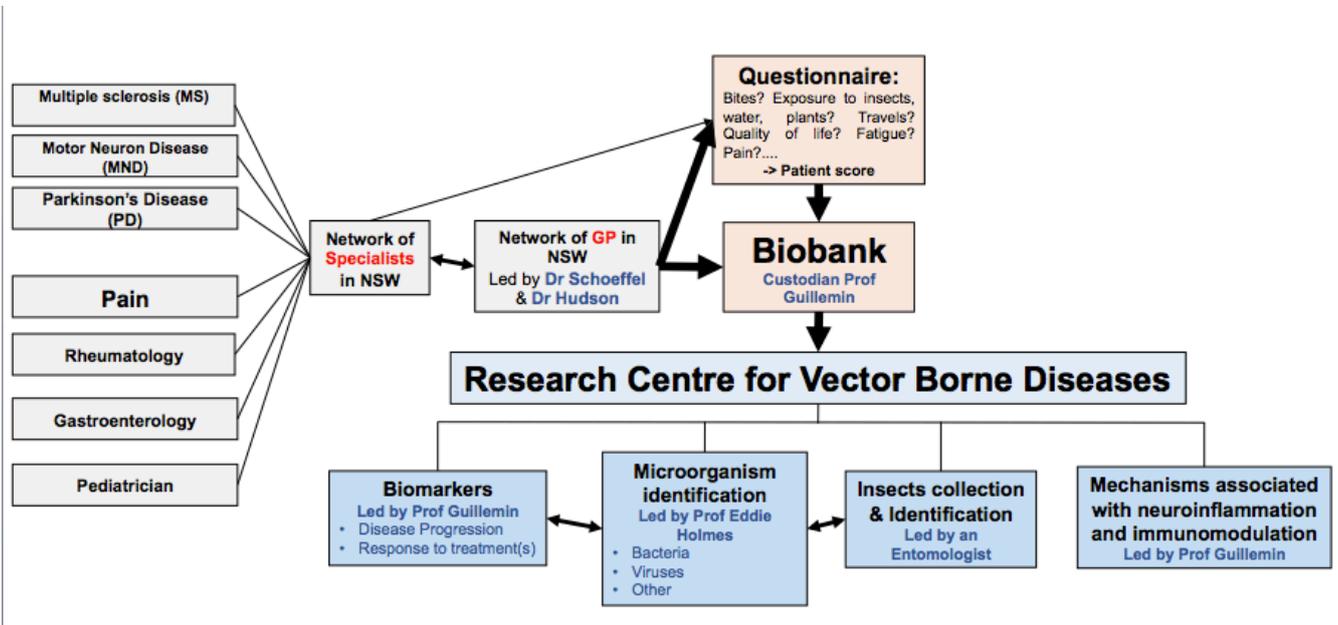
# Infective organisms found in VBD patients

- Borrelia including relapsing fever
- Rickettsias
- Bartonella
- Ehrlichiosis
- Anaplasmosis
- Babesia
- Coxiella Burnetti
- Mycoplasmas
- Viruses

# Where to from here?

For us:

- Establishment of the Research Centre for VBD
- Support for multidisciplinary treatment clinics
- Development of best practice VBD Guidelines
- International collaboration for research, learning and best practice



# Multidisciplinary treatment clinics

- Establishment of clinics based on Australian & world's best practice
- Designed with:
  - Patient focused centers
  - Appropriate safe environments for vulnerable patients and their carers
  - Multidisciplinary team approach

# Multidisciplinary care team

- Specialist Doctors...
- General Practitioners
- Allied Health – Psychologist, Physiotherapist, Nutritionist, Exercise Physiologist
- Psycho-Social Support for patients, family and carers

# The patients

- GP, Emergency Centers & Self Referrals
- Questionnaires – Online and In-house
- Full History and Clinical Assessment
- Appropriate investigations – General & Specialized Pathology, Scans, specific assessments
- Biobank
- Multidisciplinary team assessment

# Treatment

- **Integrative Treatment of the whole person, long term view, 2 – 5 years**
- Supportive therapies with lifestyle management and treatment of co-morbidities and symptoms
- Antibiotics – appropriate use
- Other treatments inclusive of hyperthermia, immunoglobulin therapy, others
- Rehabilitation and long-term support

# Where to from here?

For government:

- Recognition of VBD patients
- Community awareness and prevention campaigns
- Notification of these diseases to establish Epidemiological evidence
- Education of the medical profession

“Making tick-borne diseases notifiable will help to build the risk profile of tick bites and allow the impact of such diseases to be better understood” Professor Gilles Guillemin

Professor of Neurosciences, Macquarie University, Sydney

# Vision

- Australia is in a unique position to create world class Centers of Excellence for VBD
- Leadership in diagnosis and treatment for these patients is achievable
- Education of the community, preventative measures and early treatment should be the gold standard
- Australian Governments and the medical profession has the capacity to show this leadership

Proposed Model of Care:

Multidisciplinary approach

Dr Tony Hobbs

Clinical pathway for DSCATT patients

