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Committee Secretary
Senate Community Affairs References Committee
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Dear Sir/Madam,

**New Inquiry: The Growing Evidence Of An Emerging Tick-Borne Disease That Causes A Lyme-Like
Illness For Many Australian Patients**

I am presenting a general overview of Borreliosis (Lyme Disease) and co-infections. I believe this to be an evolving and emerging illness within the Australian community. Over the past twenty years I have treated over three and a half thousand patients with Chronic Fatigue Syndrome, many of whom have been diagnosed with tick borne illnesses. Having treated this illness in depth, I believe we have a hidden endemic illness impacting on the Australian population.

As an emerging illness, the insight of my twenty years experience shows me that it has been unknown and grossly misunderstood within the general medical community. In an attempt to diagnose what has been either presumed to be a psychological illness or disparate symptoms that have not been pieced together, misinformation, misdiagnosis and failed treatments have led to a current situation where significant numbers of the Australians are suffering. We need to address that this illness is a true pathology and provide appropriate medical support . The following is a number of submission points in regards to how to move forward in understanding this illness. They are inclusive of improving the science of diagnosis and the development of appropriate treatments in the Australian context of Borreliosis. Please recognise that these are early steps in beginning to understand and treat this disease and the views expressed are solely my own, from years of observation, treatment and hands on experience treating patients with this evolving illness. I am in contact with colleagues in the USA and Germany and also attend numerous conferences which have all helped to form these ideas.

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1. AUSTRALIAN TICK BORNE ILLNESSES RENAMED

Most importantly we have limited this disease by naming it Lyme Disease. I propose the name be changed for a more appropriate definition that is inclusive of American Lyme Disease yet validates that this disease may come from other countries inclusive of the probability that we in Australia have our own Borreliosis and co-infections. The term 'Borreliosis and Co-Infection with Multi System Disorder' or a similar name, would let the debate over Lyme disease subside so we can take a more open view of this disease. I say this because Lyme Disease was described in an outbreak in Connecticut in the USA some years ago. This is a generalised term that is used in the USA and does not translate to the Australian context. If Australians have acquired their illness in the USA some of the diagnostic and treatment protocols may be appropriate as described for Lyme disease for that country. There are many patients that I see who acquired their illness in Europe, Asia, sometimes the USA and Australians who have never left Australia. Those Australians presenting with this illness who have not travelled overseas, who have positive diagnostic criteria, from both local and overseas laboratories, are currently being treated by Australian General Practitioners.

2. AUSTRALIAN INCIDENCE OF TICK BORNE ILLNESSES

One of the major difficulties in understanding the extent of this illness is that it is not notifiable because it is not defined as a single entity disorder. In other words, we have no idea how many people may have symptoms that fit this category. My proposal is that all GP's in Australia be contacted and an approximation of the number of patients they are treating with what appears to be Chronic Fatigue Syndrome, Fibromyalgia or possible Tick Borne Illness, Atypical Neurological Disorders, Atypical Auto-Immune Disease, particularly sero-negative Auto-Immune Disease and Atypical pain syndromes that have not been able to be defined under normal diagnostic criteria be brought together to identify how many Australians are currently affected by these disorders. It is possible that many of these patients have a Borreliosis and/or Co-Infections or some other form of stealth infection. To gain knowledge on the numbers of people affected would greatly impact the seriousness and gravity of patient need and the urgency required to deal with this evolving illness.

I propose that all GP's be contacted for a voluntary estimation of the number of patients they may have with these disorders and this be collected by a central database. I propose that if patients were interested purely on a voluntary basis, they would be able to be contacted and given a questionnaire to assist in gaining more information about their illness to measure more accurately their diagnosis.

I propose that this collection of data may well be able to be funded through private donations, government support or even possibly the offices of the Royal Australian College of General Practitioners, if that be an option. To date we have minimal information regards the number of people impacted by these disorders. Without this information Australians remain unsupported in their diagnosis and treatment. This lack of information in regards to the number of people experiencing this illness severely impacts not only patients but the families and carers.

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3. ACCURATE DIAGNOSIS

I propose that due to the lack of diagnostic tools and testing in Australia for the current diagnosis of Borreliosis and co-infection within the Australian context, that overseas laboratories which do appear to be assisting in the diagnosis of these disorders in Australian patients, be investigated for use here. This would occur by using IGeneX testing from the USA, Infecto Lab and/or Armin Lab testing kits from Germany. That these tests are performed under the same criteria as the USA or Germany and that the results are interpreted under their current diagnostic guidelines.

It would appear that the current use of the Eliza Test, from the Sydney University Tick Borne Illness Diseases Unit, that I have been involved with for the past two years, has shown that the Eliza test is currently inadequate to assess whether the patients have Borreliosis. It has been noted that the Immuno-Blot testing or Western Blot Testing and that PCR (Polymerase Chain Reaction) testing are far more useful guides in the diagnosis of Borreliosis. Co-Infections also show more accurate diagnosis through Western-Blot testing as opposed to Eliza testing. I suspect that this situation is due to the immunosuppression that occurs with Tick Borne Illnesses and that the Australian tests would appear to be only useful at the end of a long treatment process when the patient's immune response has recovered and that there often is a positive Eliza result but unfortunately this is unhelpful in the first instance.

4. TREATMENT OF BORRELIOSIS AND CO-INFECTIONS

Treatment of Borreliosis and Co-Infections is controversial worldwide. In the United States there are two schools of thought. That of the CDC criteria for management is four to six weeks of treatment and the ILADS protocol which indicates much longer periods of therapy to assist patients in recovery from severe chronic infections. In the Australian context in 2013 the Australian Chronic Infectious Diseases Society (ACIDS) was founded and a set of initial guidelines written for the Australian context to give some understanding to General Practitioners throughout Australia, the probability of this illness, how to diagnose it and some basic guidelines on how to treat Chronic Borreliosis and Co-Infections. I have included the current ILADS guidelines which were updated in September 2015, as well as the ACIDS guidelines (of which I am a founding member) which have been issued to support GP's in diagnosis and treatment. These have been included as an attachment for your viewing and rationale. In the diagnosis and treatment of Tick Borne Illnesses I ask that it be recognised that antibiotics alone do not assist these patients in becoming well. They can present as extremely disabled and potentially life threatened, especially in the Neurological Borreliosis Patients which I am seeing in relatively larger numbers. The guidelines presented from the USA and from Australia are a first step that needs to be undertaken by all the intellectual medical capacity within the Australian context to reach a deeper understanding and capacity to embrace this disease and to assist patients toward recovery.

Please find attached a small number of guidelines as a supplementation to further facilitate this submission;

1a. ACIDS Guideline

1b. ACIDS Guideline V1.51

1c. ILADS Guidelines

1d. Germany Guidelines

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5. PROTECTION FOR TREATING PRACTITIONERS

One of the most difficult situations we have in Australia at the moment, is there seems to be thousands of patients presenting with Chronic Fatiguing illnesses, Atypical Neurological Disorders, Chronic Pain Disorders, Fibromyalgia and Auto-Immune Disease that could well be due to stealth infections, Borreliosis or some other co-infections. General Practitioners who are at the coalface diagnosing and treating these disorders are being threatened with restrictions or even de-registration for caring for these patients. This situation creates enormous distress amongst patients and carers, who have often after much duress found a supportive GP who is willing to treat them. These GP's have been put on restrictions regardless of their treatment success and constrained to use criteria pertaining to overseas guidelines which do not fit the current Australian context.

When this situation arises patient's health is put into jeopardy, many regress unnecessarily and some even die because they are no longer on the long term treatment strategies which have proven to hold the symptoms at bay or cure the disease. However it is the long term treatments (inclusive of some antibiotics), general psychological care and rehabilitation, which is such an important part in the management of these Chronic Tick Borne Illnesses and stealth infections that is under scrutiny.

It is my view that all Doctors treating Chronic Borreliosis and Co-Infections as well as some of these other disorders be given the full support of the medical community without fear or favour that they not be persecuted or criticised for their stand in assisting patients who have very complex and difficult illnesses. This is an evolving illness which treating doctors through dire need are finding ways to help patients and put themselves on the line in the face of unnecessary criticism by our specialist colleagues because of lack of scientific vigour in the diagnosis and treatment of these disorders thus far.

It is my view that these doctors choosing to assist their long suffering patients be given all necessary protection supporting their stand to offer care to often very disadvantaged, disabled and suffering Australian patients.

6. FUTURE RESEARCH

Understanding these evolving illnesses involves improving the science. As part of the Tick Borne Disease Unit at Sydney University and a founding member of ACIDS, I strongly support the view that rigorous science needs to be undertaken in regards to understanding these diseases. The Australian people who are suffering these disorders are relying on diagnostic tools to be developed appropriate to the illnesses we are seeing here in Australia (not restricted to an old paradigm where out dated tests are used to disallow the correct diagnosis). It is very important that the science be developed in how to manage, treat and bring about a positive resolution for these patients based on a scientific analysis over a long period of time with the assistance of GPs, Infectious Disease Specialists and Pathologists who can work together to end this division.

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These proposals are a guideline only to the future stand for 'Evolving Borreliosis'. I hope the committee will take note of some of my suggestions as I am currently working with a team to assist as many patients as possible, also advising numerous GP's on how to treat acute and chronic Tick Borne Illnesses and attempting to recruit our specialist colleagues in supporting us in the more difficult and life threatened patients. The travesty of the past twenty years of denialism has left many patients extremely frightened, abandoned and not receiving appropriate care. These proposals hopefully will end that situation and enable us to move forward to assist Australian Patients with these disorders in an appropriate and caring fashion with the backing of the developing science.

Yours Faithfully,

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Please find attached a small number of papers as a supplementation to further facilitate this submission;

- 2a. An Understanding of Laboratory Testing for Lyme Disease **1998***
- 2b. Antibiotic Retreatment of Lyme Disease in Patients with Persistent Symptoms: a biostatistical review of randomized, placebo controlled, clinical trials **2012***
- 2c. Benefit Of Intravenous Antibiotic Therapy In Patients - Referred For Treatment Of Neurologic Lyme Disease **2011***
- 2d. Efficacy Of Prolonged Intravenous Antibiotic Therapy In Patients With Neurological Lyme **2011***
- 2e. Long Term Antibiotic Therapy In Lyme Disease **2014***
- 2f. Lyme Testing*
- 2g. Potential Benefits Of Retreatment Highlight The Need For Additional Lyme Disease Research **2014***
- 2h. Reappraisal Of Post Lyme Treatment Trials **2012***
- 2i. Treatment Trials For Post Lyme Disease Symptoms Revisited **2013***