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Attn: Jeanette Radcliffe
Standing Committee On Community Affairs
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Dear Ms Radcliffe,

RE: Inquiry into growing evidence of an emerging tick-borne disease that causes a Lyme like illness for many Australian Patients - Questions taken on notice - Public Hearing, 2nd November 2016, Sydney

Question 1 Can you tell the committee what the recovery rate is for the patients you treat for symptoms of Lyme-like illness, whether your work has been peer reviewed, and what evidence exists to prove that the relationship between treatment and recovery is causative, rather than correlative?

In relation to the recovery rate of patients, of which the ACIIDS group of Doctors have treated over 4,000, the general consensus is that 60-80% of our patients have considerable or complete recovery with appropriate treatment. The peer review evidence of the treatment of this disease primarily comes from Europe and the USA and we have included these studies in our original submission to the Senate Inquiry. The difficulty lies in the fact that there have been no peer reviewed studies in Australia yet as the disease has not been recognised. ACIIDS has just received private funding and engaged a PhD student to assist with a retrospective study of 60 patients which will be an outcome study which we hope to have completed by early next year. This will look at the history obtained from these 60 Australian patients, their diagnosis, their treatments and their outcome, then hopefully we will have this peer reviewed with appropriate doctors even though there is very little support as so far even in the original proposition these patients actually have a tick borne illness. The data from overseas is similar to what observe and around 70% of my patients I believe have fully recovered and do not require any further long term antibiotics and definitely minimised the amount of any other medication use, and many of them have fully returned to the community, entering relationships, working, studying and having normal lives and also not passing this infection onto their sexual partners or their children.

Question 2 Some witnesses [Assoc. Prof. Samuel Zagarella, Australasian College of Dermatologists, Perth, 14 April] have suggested that non-mainstream treatment has not been proven to help. What is your view on this?

In relation to non mainstream treatment not been proven to help I am unsure where he gets this thought from, as there are a number of scientific publications from around the world discussing the diagnosis of tick borne illness with appropriate treatment depending on the severity, how acute or chronic the illness is and the associated morbidity symptoms that these patients often have, indicate powerfully that there is a strong correlation between diagnosis appropriate treatment and some degree if not complete recovery. Making a statement which appears to have no relevance to our current patients as I believe he is probably not even seeing the thousands of patients that we are currently treating and making the appropriate diagnosis in very sick patients and following guidelines which have been set up by competent doctors from around the world, particularly in Germany and the ILADS Doctors in the USA, that fundamentally provide the guideline for appropriate medical treatment which has been peer reviewed within their groups. Dr Zagarella may be referring to the erythema migrans rash which in relation to is a marked sign of tick borne illness particularly Borreliosis, but in my experience this is fairly rare, and if we do see this in the acute setting I believe that appropriate antibiotics given for two to six weeks would probably prevent the severity and the progression of this disease into a chronic form. Again part of our research work will be to look at a retrospective study in regards to current patients that we have treated and hopefully with peer review this will validate what we have been observing for quite a number of years, in the appropriate diagnosis and treatment of these patients.

Question 3 Could you please set out the treatment guidelines you recommend?

In regards to a treatment guideline, Dr Peter Dobie, Dr Hugh Durham and myself for the last four months have been working on an evidence based guideline which will be presented once it has been peer reviewed by two of our Infectious Diseases specialist who are apart of ACIIDS and presented it to Dr Gary Lum as discussed in the most recent Senate Inquiry in Sydney.

The guideline will cover a general discussion in regards to this syndrome and we wish to change it to Multiple Systemic Infectious Disease Syndrome which is more suitable than the Lyme label which seems to attract such and emotional and erratic sort of response from my colleagues. This illness arises from a number of vectors and this will be discussed, including ticks, lice and possibly bed bugs and some evidence of mosquitoes, with a couple of papers coming out of Thailand and Germany. As well as a discussion on Acute Diagnosis and Acute Treatment with appropriate antibiotics with lengths of time that will be determined by the severity of the disease. Also differences in treatment of children, a discussion in regards to removing ticks appropriately, mammalian meat allergy and anaphylaxis to tick bite as all these are relevant factors in this vector, the tick which seems to cause a number of adverse illnesses.

As for Chronic Borreliosis and the numerous co-infections that seem to arise from ticks in Australia and many of these now being documented by Prof. Peter Irwin, it is my view that we will be presenting an evidence based guideline based on the evidence produced by our colleagues in the

USA and Europe. As yet it has not be peer reviewed or supported by mainstream doctors in Australia. This is very unfortunate because it would appear from our group and our regular discussions, meetings and in creating this guideline that our success rate in helping these patients is quite significantly high and the morbidity from the treatment is far less that the morbidity or potential mortality by not treating this disorder. The guidelines will cover this as well as treatment of all the various difficulties that these patients have, from mood issues, Postural Orthostatic Tachycardia Syndrome (POTS), gastro-intestinal dysfunction, controlling pain, headaches and migraines, treatment of cognitive dysfunction as well as management of all the numerous multiple symptoms that these patients have.

Also included will be a discussion on proper follow up and rehabilitation to some extent and a way forward to a thought that this disease may well be a need to have a notification as we develop pathology tests more appropriate to the Australian condition that will be repeatable and can lead to a proper diagnosis and proper outcome. Pathology tests will be discussed with Australian and overseas labs making recommendations of which tests to replicate here as well as how these tests can be interpreted to the clinical setting.

The guidelines should be complete by the end of 2016, early 2017 as for the acceptance that is a wait and see situation.

Question 4 To what degree is the wider medical community interested in the work you are doing, do you have the sense that doctors are searching for answers for their patients?

This is a very difficult question as a majority of my patients are referred by other doctors who are either specialists or GP's that have a suspicion that these patients may have a vector borne illness causing significant morbidity without a proper diagnosis. Some of the patients sent to me do have a diagnosis from an overseas or local lab and have been partially treated or not treated at all and have quite significant symptoms, some in a life threatened situation, particularly in the motor neurone disease, Parkinson's Disease, Multiple Sclerosis and Autistic Spectrum Disorder (ASD) as well as the patients with severe Chronis Intractable Pain Syndromes without obvious cause.

The general interest in these patients is difficult as I think most GP's regard them as their Heartsink patients and recently I have been approached to start teaching en masse doctors who are interested in taking on more chronic diseases patients, to develop an understanding about the clinical diagnosis, the supportive pathology and the appropriate medical treatment of these patients which is not always long term antibiotics, but generally resuscitation and treatment of their multiple symptoms and then an appropriate treatment protocol to see if we can treat the underlying cause which could be viral, bacterial or parasitic infection or a reaction to yeasts and moulds. The nature of this illness and the controversy that goes with it and especially calling it Lyme Disease which is a disease in America, which I totally support Dr Lum's assertion that it is not here, unless caught in America and I believe we should change the name to Multiple Systemic Infectious Disease Syndrome as suggested by my colleague Dr Richard Horowitz as this would encompass these patients without the stigma that many other doctors around Australia have. Unfortunately our Infectious Diseases Specialists have not been supportive of this illness and they are definitely not supportive of the need as suggested by my colleague Dr Richard Horowitz as this would encompass these patients without the stigma that many other doctors around Australia have. Unfortunately our Infectious Diseases Specialists have not been supportive of this illness and they are definitely not supportive of the need for long term management. This has made it very difficult and dangerous to practice in this situation but unfortunately from my point of view, ethics always overcomes lack of knowledge in this area. The ethical assessment of patients, a proper clinical diagnosis, diagnostic criteria from pathology if that has helped and appropriate treatment for each patient with the principal of do no harm, is the appropriate way forward in the management of these chronic vector borne illness patients. At no stage should a patient be abandoned because they do not fit into a recognised guideline when there is no suitable guideline.

My view is that as we create the guideline and as we procure the evidence for the paper we have received funding for, with a PhD student, this will hopefully get published along with the further work of Prof. Eddie Homes, the Tick Borne Diseases Unit at Sydney University, the work of Prof. Peter Irwin as well as Prof. Steven Graves with his work in Geelong, I suspect we will reach a consensus over the next year or so, with hopefully the Senates support to encourage that.

My view as expressed in the Senate Inquiry that I am more than happy to have a discussion with my colleagues to broker a assessment and a thought process that is more relevant to these patients as apart from denialism which will help us move forward and hopefully treat as many of these patients as possible to relieve their suffering, treat their diseases appropriately and treat the patient suitably with respect even though they have not fitted in a previous established guideline in this evolving illness.

I wish to thank the Senators for their interest and support in this. I look forward to a positive outcome for the future of the diagnosis and treatment of Tick Borne Illness in Australia and all the many patients here in Australia that have acquired this from overseas. This still amazes me, as they often fall into the same basket as those that have acquired it here in Australia even though they have contracted this illness in an endemic area and have the same symptoms as the foreign patients but still fall short of being properly medically diagnosed and treated. Again thank you for your support and I look forward to your final assessment and conclusions.

Yours faithfully,

Dr Richard Schloeffel