SUBMISSION TO SENATE INQUIRY INTO LYME DISEASE IN AUSTRALIA

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I want this submission to be made public

I expect that this inquiry is receiving lots of submissions from Lyme and Lyme-like sufferers, and their friends and relatives summarising their heart wrenching experiences and frustrations. I know all about this from personal experience because my wife has Lyme disease, undeniably, 100% certain. It has been diagnosed overseas by Lyme experts. My wife is Australian, born and bred, but our government and medical profession refuse to help her.

Instead, I thought it might be useful to bring a practical, substantive, commercial and somewhat sobering perspective to this discussion.

Background

Imagine a beautiful, happy young woman in the prime of her life with a young family, suddenly falling seriously ill. She sees many Australian doctors, none of whom can correctly diagnose the problem, and worse, all of those doctors mis-diagnose the treatment.

Imagine finally, through your own intensive and long hours of research and identification of the right doctors, discovering what is wrong, only to find that your government and medical profession won't accept the answer despite overwhelming evidence to the contrary

Imagine being fortunate enough to be able to source extraordinarily expensive medicine and visit hospitals and doctors overseas who do recognise the problem and know how to treat it, whilst all around you there are people who do not have this financial wherewithal and who are declining in front of your eyes while the government and AMA, at best shrug and turn a blind eye, at worst, deride you “There is nothing wrong with you “!!!!!!!!.

Imagine regularly receiving calls and references from frustrated people wanting to speak to you because you have been through what they or their loved ones are experiencing. People who like you previously, cannot find a doctor who will listen or who can and is willing to treat them.

My wife has Lyme disease – the weight of evidence is that she has had it for well over 10 years.

Now that she and I know so much about the disease we have got to know many people who also have it, and even more who we suspect have it but have not yet been correctly diagnosed and are naturally reluctant to believe this to be the case, because it would mean disbelieving their doctors who are telling them that Lyme does not exist in Australia.

It is increasingly clear to me that this problem is thousands of times worse than the government or the AMA suspects........or maybe they do?

My wife's sickness has been mis- diagnosed and therefore more importantly, mis- treated for all but the last 2 years. Similarly, we know of people who have been treated for diseases such as Chronic Fatigue, Multiple Sclerosis, Drop Foot, Ringworm and many, many other supposed problems, simply because of the AMA's reluctance to acknowledge the existence of Lyme and Lyme-like diseases and their refusal to allow testing for it.

There is a significant community of Lyme sufferers, thousands are involved, but this community is essentially "underground". Individuals are forced to keep a low profile….. too frightened to discuss the issues in public because of the derisory reaction of the vast majority of the medical community, and for fear that it might get the doctors who are helping them into trouble!!

It is well known that the AMA through the Australian Health Practitioner Regulation Agency (AHPRA), is targeting those doctors who diagnose and prescribe treatment for Lyme, and is actively trying to prevent the import of vital drugs needed to treat the disease eg Phosphatidylcholine. We know of at least 3 doctors who have ceased practicing or diagnosing Lyme, and others who are being threatened with being struck off for recognising and diagnosing Lyme.

How ridiculous is that? How does the AHPRA live with itself?? To think that it is appropriate to use their supposed expertise and professional skills to deride people who are clearly very sick, claim that there is nothing wrong with them and refuse to treat them properly is arrogance beyond belief.

Can this really be happening in a country such as Australia, where we have a supposedly reputable medical profession?

What does it mean to be a professional?

Let’s think for a moment about those words “profession” and “professionals”.

The professions are the very foundation of our economy and society. This is because they represent organisations implicitly trusted by our communities. Their members undergo years of rigorous training and development and comprise the best talent in our communities. Professionals are honourable, above politics and political agendas. Above all, society expects professionals to do what is right, irrespective of the pressures which society itself might bring to bear to try to make them do otherwise.

Anecdotally, 12 months ago I went for a regular health check at a private clinic in Sydney. When asked about my family medical history, I mentioned that my wife had Lyme. The doctor (in his late 50’s/early 60’s and obviously very experienced) said to me, "of course you know that we don't have Lyme in Australia".

How ignorant!! How arrogant!!

I stopped short of telling him what I really thought of him and changed the subject. This guy was charging $500/hour!!!

Why do so many ordinary Australians who have Lyme or Lyme like symptoms need to go to Europe for proper treatment? There can only be two answers – either our medical association is not smart enough to diagnose and treat the disease ie we do not have the requisite medical skills in Australia, or the government and the AMA have an underlying agenda which amongst other things is forcing our Lyme sufferers to go offshore for treatment. Under either of these circumstances the “professionalism” of our medical association and the vast majority of its members must be questionable.

I am a professional. In my profession we get sued when we get things wrong. Class actions are becoming common. Make no mistake the medical profession's position on Lyme is a class action waiting to happen. In NSW, often quoted as being the second most litigious state in the world after California, this is inevitable.

Summary

So how can the Australian government and medical profession continue to bury their collective heads in the sand in the face of overwhelming evidence of the existence of Lyme and Lyme-like diseases in our country, whether contracted here or not?

There are thousands of people with Lyme and Lyme-like diseases in Australia. Only a fool would believe/insist that every single one of these people has contracted the disease overseas. Are the government and the AMA really that naive?

In the extremely unlikely scenario that the government and AMA are correct and Australian ticks do not carry Lyme, there is still no reason for not recognising that there are thousands of people living in our country who have the disease irrespective of where they contracted it, and are seriously ill.

There is no reason why doctors should continue to mis-diagnose Lyme and Lyme-like diseases, and for the medical system to refuse to provide financial relief for those who are suffering, so that they can get the treatment they need.

(1) An urgent instruction should be issued to the AHPRA ordering its officers to encourage medical practitioners to watch out specifically for the symptoms of Lyme and Lyme-like diseases, and to prescribe acknowledged and appropriate treatment where such symptoms are identified.

(2) The medication required to treat Lyme and Lyme-like diseases should be made available under the national health system to all who need it.

(3) Treatment facilities such as those in Europe which make whole of body hypothermia available should be established in Australia for our Lyme sufferers.

It is not too late for the thousands of current and future sufferers, if something is done quickly to acknowledge and recognise the problem and bring much needed treatment to the few who can, and the thousands who cannot afford it.

I implore the Senate, through this inquiry to ensure that something is finally done!!