Senate Community Affairs References Committee

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, 2 November 2016, Sydney

Karl McManus Foundation

Question 1

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?

Comments such as that of Associate Professor Samuel Zagarella are too generalistic to have any meaningful contribution to the current discussions since his comment can refer to non-mainstream treatment of dermatological manifestations of tick borne diseases (TBD) as he is a dermatologist.

For this discussion we shall focus on the wider Australian Medical community. With that reference it is clear that mainstream medicine is not static but constantly changing. Therefore dismissing non-mainstream treatment protocols as not working without understanding the full pathology of chronic tick borne diseases would be unfair. It is accepted that there are pathogens in Australian ticks making people ill and we have not identified those pathogens hence we lack understanding of their virulence and character.

In a situation where the causative agent is not well characterised treatment protocols are not likely to be within the realm of mainstream medicine. This is assuming that criteria of mainstream medicine are based upon identification of the pathogen the fulfilment of Koch postulates. Unfortunately it would be very difficult for TBDs to fulfil Koch postulates as they involve multiple pathogens with non- specific symptoms especially in the chronic stage.

Current infectious disease treatment protocols on bacterial infections only would not be applicable to TBD treatment as TBD commonly compose of bacteria, protozoa and viruses. Furthermore the bacterial composition of TBD can vary making it even more difficult to devise specific bacterial treatment. In addition the composition of the pathogen type and load can vary between patients as the zoonotic nature of this infection cannot predict which pathogens a patient is likely to be infected with.

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There is also increasing evidence of bacteria under stress, with one antibiotic such as a beta lactam, can display polymorphism- change shape and become a cyst where the function of the beta lactam antibiotic becomes redundant. This phenomenon has been observed with many bacteria that develop antibiotic resistance such as the members of the pseudomonas family.

Furthermore, current mainstream medicine treatment protocols are competent in treating extracellular infections but are weak in treating intracellular infections which have disseminated into tissues other than blood. This area of medical microbiology needs urgent research as it will also help to address antibiotic resistance.

Other characteristics of multiple pathogenic infections include biofilm formation via quorum sensing whereby different families of bacteria and other pathogens communicate and live in complicated societies in our tissues.

Therefore instead of stating that TBD treatment protocols "don't work" because they don't conform to the requirements of mainstream medicine, the approach should examine the characteristics of multiple pathogen infections in a zoonotic platform and understand the unusual nature of these infections and encourage clinical research to validate these non-mainstream protocols so that affected patients can be treated without discrimination.

The non- static nature of mainstream medicine can be illustrated by the examples of Manuka honey use for skin ulcers and Maggot therapy for chronic wound care. The latter was conceptually a mainstream therapy approximately a hundred years ago and fell out of usage with the advent of antibiotics. It could be argued that it has subsequently been rediscovered and readopted by mainstream medicine, though there is still some resisting its adoption which is seemingly founded on ignorance rather than any valid scientific principal.

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As indicated previously that TBD are multi pathogenic infections therefore deciphering different diagnostic profiles created by different combinations of pathogens and the host response is of vital importance for everyone.

Question 2

Could you please set out the treatment guidelines you recommend?

Currently the KMF has not validated any treatment protocols to treat chronic TBDs and cannot recommend any.

The role of KMI is to provide an environment conducive to perform clinical research and decipher which protocols are suitable for which diagnostic profiles. This is on the basis that TBDs are multi pathogenic with inconsistent symptoms between patients, that is, they have symptom profiles that are non-specific. But there are traits which can be used to develop different diagnostic profiles and employ different protocols to matched cohorts. Which treatment protocols will be validated can be determined by a panel.

Keen to see current best practise to be implemented immediately the KMF recognise that the Infectious Diseases Society of America (IDSA) present best practise treatment protocol for treatment of ACUTE forms of Lyme disease while International Lyme and Associated Diseases Society (ILADS) have developed best practise protocol for CHRONIC conditions. It is noted that the ILADS practice of long term antibiotic therapy is disputed by some and the two societies are split over TBDs treatment.

In Australia Australian Chronic Infectious Diseases Society (ACIDS) have devised treatment guidelines which have not been validated by KMF therefore we cannot comment about those guidelines.

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For Australian conditions there is a pressing need for research to validate and deliver combined protocols appropriate for the Australian Medical profession. The Karl McManus Foundation is happy to facilitate and participate in such developments.

Question 3

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?

We know of hundreds of Doctors who are interested in what the Karl McManus Foundation is doing however the majority are concerned and this is an increasing concern, about acknowledging or treating tick borne diseases (particularly when it is called Lyme Disease) because of the professional repercussions from the regulatory authority.

Despite the denials there has been intimidation by APHRA through so called counselling sessions and the threat of litigation and costs, should the practitioner seek to contest APHRA claims. None of this is reflected in the formal statistics and tribunal hearings quickly referenced by APHRA when questioned about such claims.

Generally Doctors in Australia are also split into two groups, the mainstream who will consider acute treatment and offer palliative care for chronic TBDs (ie: post Lyme syndrome). While holistic doctors are aware that when pathogens have disseminated into other tissues a broad approach may be needed which may require not only prolonged treatment of disseminated infections but also supporting the immune system and providing the right nutrients for patient recovery. It has tended to be this later group of Doctors who have shown the most interest in the work of the Foundation.