## Sarcoidosis Lyme Australia (SLA)

### October 2015

### Submission

to

## House of Representatives Standing Committee on Health

re

### Inquiry into Chronic Disease Prevention and Management in Primary Health Care

and

### 18 September 2015 Public Hearing



#### **SLA's Introductory Comments**

There appears to be consensus among stakeholders about the defining attributes of chronic disease. Those attributes encompass:

- Duration of illness lengthy or remitting/relapsing course;
- Symptom persistence continual, migratory or remitting/relapsing;
- ▶ Illness resolution partial, nil or remitting/relapsing; and
- > Cumulative effect on the patient and comorbidity.

Sarcoidosis Lyme Australia (SLA) posits that the range of chronic diseases discussed in Australian Government, Department of Health, and Australian Medical Association (AMA) literature is problematically narrow, and that some conditions listed as chronic diseases may also be symptoms of diseases not included in their literature on chronic diseases.

The Australian Institute of Health and Welfare (AIHW) released a statement in August 2015 advising that about half of all Australians have a chronic disease, with the release statement incorporating eight chronic diseases:

- 1. Arthritis
- 2. Asthma
- 3. Back problems
- 4. Cancer
- 5. Chronic obstructive pulmonary disease
- 6. Cardiovascular disease
- 7. Diabetes
- 8. Mental health conditions

SLA contends that AIHW's list does not include most of the diseases affecting its chronically ill members. Patients with pulmonary and cardiac Sarcoidosis, perhaps, would be included in the cardiovascular and pulmonary disease categories but many of SLA's members suffer from non-pulmonary/cardiac Sarcoidosis and do not fit into the other listed categories. They may have arthritis or diabetes as symptoms of Sarcoidosis but it is anomalous that their symptoms make the disease list, while their actual disease does not.

AIHW's list excludes auto-immune diseases, many presentations of Sarcoidosis and other diseases of immune dysregulation, and infectious diseases such as Borreliosis and other vector-borne diseases...essentially, excludes our entire member base, except, perhaps, those with pulmonary/cardiac Sarcoidosis and no systemic involvement.

AIHW's list needs to be extended to include a ninth category:

9. Systemic diseases - auto-immune; immune dysregulation; inflammatory; and infectious.

The Department of Health's submission to this Inquiry states that around 80% of the total Australian chronic disease burden is amassed by the following five chronic conditions:

- 1. Cardiovascular disease
- 2. Diabetes
- 3. Asthma and other chronic respiratory conditions
- 4. Chronic kidney disease
- 5. Arthritis and musculoskeletal conditions

The Department of Health's list fails to include systemic diseases and to indicate that the conditions listed may be symptoms of systemic diseases (and not just non-systemic morbidity). It would be entirely possible for a patient suffering from Sarcoidosis to suffer from all five chronic conditions listed by the Department of Health. In such a situation, the Sarcoidosis is the leading morbidity and the disease contributing most significantly to the total disease burden.

The AMA's submission to this Inquiry refers only to chronic diseases mentioned in the AIHW and Department of Health lists. Again, systemic diseases are not included in the categories of chronic diseases discussed.

It is of note that the AIHW, Department of Health and AMA make not a single mention of the role infection may play in some chronic diseases. The words infectious disease do not appear at all in the Department of Health or AMA submissions to this Inquiry. That omission sums up the consideration medical practitioners give to infectious disease in their formation of a disease differential when presented with a chronically ill patient – no consideration at all. Should the medical practitioners be blamed when consideration of such is ignored by the structure and governance of the Australian medical system?

#### Terms of Reference for the Inquiry:

## Examples of best practice in chronic disease prevention and management, both in Australia and internationally.

Unless a patient has an easily recognisable and treatable disease, the Australian medical system is an unwieldy, expensive system for patients with chronic diseases. Our system is failing patients, failing the taxpayers who fund Medicare, and failing doctors who are required to function within it.

#### Disease Labels

The Australian healthcare system is designed around disease labels. A label is required before certain medications can be prescribed and before some specific tests can be ordered. The disease label has become more of a priority than the ill patient.

As indicated above, systemic diseases (auto-immune, dysregulated immune, inflammatory and infectious) have become an ignored area of medicine. GPs prefer to refer on rather than diagnose but which specialty to refer to is problematic. GPs are failing at referring patients with systemic, chronic diseases to the most appropriate specialist.

The gaining or not of a label can be reliant on which specialists patients are sent to, the knowledge and experience of those specialists, the tests the specialists order and the specialists' interpretation of the test results. In many cases, the patient and their symptoms do not factor into the equation at all. Specialists do not have broad enough knowledge about the diseases which fall into their speciality, or symptoms which fall into their specialists from one specialty of medicine. Abnormal test results are frequently ignored and their insignificance or reason for ignoring the results not explained in the letter to the referring GP.

Specialists frequently practice watchful waiting, expecting patients to progress into proposed labels of various diseases. Meanwhile, symptoms are ignored, other test results ignored and the patient remains without appropriate treatment. Diagnosing should be a proactive exercise, not watchful waiting for the disease to announce itself with a waving flag, while the patient suffers and despairs.

Problems/Questions to be addressed which currently impede best practice:

- 1. Which is more important the ill patient or the label?
- 2. Why do GPs miss signs when patients describe symptoms?
- 3. Why do GPs not have enough information about specialists to refer patients to the most appropriate?
- 4. Why do specialists not have enough general information about the entirety of their specialty, or knowledge about symptoms which may fall into their specialty from causes which lay outside of it?
- 5. Why do we not have clinics for people with systemic diseases, allowing patients to see the several specialists they require and committing the specialists to communicating and

collaborating? Why can't the cost of these clinic specialist fees be capped for the patient and subsidised by Medicare?

#### Patient Example 1:

Patient 1 is positive to Borrelia, has a very low CD57 count, extremely elevated calcitriol, elevated angiotensin converting enzyme and no granulomas found on imaging, nor chest x-ray/pulmonary abnormalities. The Infectious Disease specialist refuses to consider Borrelia, and the Immunologist feels unable to help, advising that Borrelia and calcitriol are outside his specialty. The neurologist feels lots of people have 'funny cranial nerves' and the neurological test abnormalities are non-specific. Which type of specialist should manage this extremely unwell patient? They have all refused to take responsibility for the patient.

#### Patient Example 2:

Patient 2 has a diagnosis of biopsy-proven Sarcoidosis. Hospitalised for treatment of pulmonary embolism, the patient is discovered to have hypercalcemia. The patient is referred to an oncology clinic, with the doctors suspecting cancer. Why did the patient not receive a work-up connecting the hypercalcemia to the Sarcoidosis? Hypercalcemia is a well-known complication of granulomatous disease.

#### Sarcoidosis

American Sarcoidosis clinics are firm in their belief that Sarcoidosis is an immune reaction to a trigger which may be environmental, allergic, infectious or caused by any number of things. A well-known, treating, published pulmonologist from Michigan University Health System prefers to use the term SarcoidosEs to reflect the multiple causes. Logically, he also believes that the road to wellness may be different according to patient and cause. He expects that one day the treatments will be so diverse, according to patient and cause, that Sarcoidosis will no longer be a medical condition in its own right.

Conversely, in Australia, our doctors cling to Sarcoidosis as being a definitive diagnosis and ignore the role of cause. While a trigger of an airway insult most likely would respond best to immunosuppression, Sarcoidosis triggered by an infection most likely would respond to antibiotics as part of the treatment.

Yoshinobu Eishi (2013) has found *Propionibacterium acnes* in sarcoid granulomas, indicating this bacterium as a possible cause of granuloma formation in many sarcoid patients. It would seem entirely possible that Borrelia or other vector-borne infections may be capable of causing granuloma formation in genetically susceptible patients. Unfortunately, there is no research to prove or disprove, and Australia is yet to acknowledge any form of Borreliosis. Eishi (2013) concludes that the antimicrobial properties of tetracyclines are effective for treating Sarcoidosis, halting intracellular proliferation of the bacterium, in addition to the already-known anti-inflammatory effect.

Similarly, Derler, Eisendle, Baltaci, Obermoser and Zelger (2009) found Borrelia-like organisms using focus-floating microscopy (FFM) in tissue sections of cutaneous Sarcoidosis. Positivity for Borrelia was 34.2% for cutaneous Sarcoidosis, 1.6% for Borrelia negative controls and 92.3% for Borrelia positive controls. The study gives a detailed description of the spirochetes found and their degenerative products. In a direct comparison between FFM and PCR, PCR failed to produce the same high yield, with positive Borrelia controls 93.3% using FFM but only 46.6% using PCR; negative Borrelia controls 0% using FFM and PCR; and cutaneous Sarcoidosis 20.7% using FFM and 0% using PCR. The study concluded with the proposition that B. burgdorferi is a possible etiologic agent for cutaneous Sarcoidosis.

It is of note that SLA's members who have been diagnosed with Sarcoidosis have been denied Borrelia tests by their specialists.

Michigan University Health System's dedicated Sarcoidosis clinic uses a multidisciplinary approach to diagnose and treat each patient individually, with physicians from many disciplines collaborating. The diagnostic process is extensive and exhaustive, and includes both biopsy proof of granulomas and exclusion of anything else that can cause granulomas, including fungal and bacterial infections.

Best practice for managing Sarcoidosis should involve:

- 1. Proving the disease by biopsy and exclusion of all other granuloma-forming diseases. This is impossible when Australian Infectious Disease specialists will not consider Borrelia of any type or most vector-borne diseases.
- 2. Imaging appropriate to the patient. Patients with unremarkable chest imaging, accompanied by pathology associated with but not specific to Sarcoidosis, and who are highly symptomatic should be allowed a full body PET scan. PET scans appear to be reserved for oncology patients, while Sarcoidosis patients are forced through a hierarchical series of non-productive imaging, which never arrive at the apex of the hierarchy the PET scan. For some patients, the middle-ranking tests are an uneconomical waste of time and money, and a hindrance to ever arriving at a diagnosis.
- 3. Embracing non-mainstream ideas and ensuring peer-reviewed studies are funded and run to test some alternative treatments some Sarcoidosis patients are trying. Patients have tried reducing D1,25 dihydroxy via the use of Olmesartan, and these patients have pathology results which demonstrate this use of the medication works, sparing the patient the detrimental side effects of steroids, especially those for whom Plaquenil is contraindicated. Long-term steroid use can cause diabetes, osteoporosis and various serious side effects, and is not suitable as a maintenance medication. Sarcoid patients (and patients with other diseases which raise D1,25 dihydroxy) need more medication options to deal with the calcium metabolism issues caused by their disease. Many know that Olmesartan works very well but studies need to be conducted to ascertain the lowering dose, the maintenance dose and the long-term safety aspects, as well as the long-term safety aspects in comparison to steroids. Unfortunately for patients, any doctor who previously prescribed Olmesartan for this purpose is now fearful of having malpractice complaints lodged against them by peers and medical boards, despite its long-term use by patients causing less adverse side effects than if the patients had used steroids for long periods.
- 4. Allowing doctors to bypass some red tape and current regulation by their provision of rationale and treatment results for off-label use of medications, treatment regimes and tests.
- 5. Acknowledging that the internet has changed the face of medicine in allowing patients access to information, journal studies and research. Further to Point 4 above, if research from other countries demonstrates results that might benefit an Australian patient, and the medications involved are general, mainstream medicines, then using rationale/results authority, doctors should be allowed to treat the patient in the manner the patient wants to try. Doctors should be encouraged to database the successes and failures to provide data for Australian research.

#### **Borreliosis and Vector-Borne Diseases**

Any discussion of best medical practice in relation to Borreliosis must start by acknowledging the possibility of Borreliosis. On that, Australia has failed.

While the former Clinical Advisory Committee on Lyme Disease formed to investigate the presence or absence of Lyme disease, we have not progressed beyond talking and debating the disease name, with the exception of the publishing of research results from Murdoch University which found DNA from a Borrelia species associated with relapsing fever. The CMO, in August 2015, advised that while the clinical significance of this finding is yet to be determined, it should not be overstated. SLA contends that it should also not be understated.

For patients, the only change is that they are now in an even worse position than a couple of years ago. Less doctors are willing to attempt treating patients with vector-borne diseases as they have seen colleagues hauled before medical boards, with restrictions placed on their practice. Doctors are not willing to risk prescribing even at the edge of PBS guidelines, let alone outside them. Infectious disease specialists continue to refuse to help. Patients with vector-borne diseases have been left with almost no doctors to treat them, with those who will treat located too far and with fees too expensive to be a viable option for many patients. There is nothing that can be said about best practice...it is more about there being no practice at all.

The Department of Health has published updates on its website but the updates are not open-minded or neutral. The publications are based on the premise that Borreliosis is absent because it has not yet been found, and not on the basis that the vector-borne diseases causing illness have not yet been properly tested or researched to be found. Vector-borne disease should be disproved, just as much as it should be proved. The many patients who have failed to achieve an alternative diagnosis are evidence that vector-borne disease has not yet been disproved in Australia. Their positive international laboratory results are further evidence that vector-borne disease cannot be yet disproved. The results from the National Serology Reference Laboratory comparative study have not yet been made available.

SLA is concerned that the details of the National Serology Reference Laboratory comparative study have not been made available to the patient community. We are not reassured that the study or its quality will be adequate and feel that the patient community should have been invited to comment on the study before it began. We are disheartened that this is the only study in progress since the formation and cessation of the CACLD. We see the Department of Health's continual comment of not being a funding body as unacceptably lame. The translation is that patients' suffering is not being taken seriously and that the government does not view this situation as the national medical emergency that patients view it to be. When disasters occur, nationally and internationally, the government finds funding to help. The government is not prioritising the plight of patients with vector-borne diseases.

The information about Lyme disease is very unobtrusively placed on the Department of Health website. To find it, one would have to be actively searching for it. Again, this demonstrates lack of priority.

Conversely, the antimicrobial resistance information has had prime position on the Department of Health website for months. While SLA understands that antimicrobial resistance is very concerning, the advice to doctors to prescribe less antibiotics is very worrying for patients with chronic diseases best treated by antibiotics.

The Antimicrobial Resistance Strategy 2015-2019, Objective One, Section 1.3, lists review of microbiology and antimicrobial prescribing and dispensing content of university, college and professional body courses, to identify gaps and need for new content. SLA suggests that best practice would incorporate new course content indicating that the early presenting symptoms of many vector-borne diseases are flu-like and that prescribing doctors need to be very careful to distinguish patients with influenza who do not require antibiotics from patients with acute vector-borne disease who do need antibiotics, and need antibiotics within a small window of time or risk leaving the patient with chronic disease if that window is missed.

Currently, GPs have not received adequate information from the Department of Health. The only message received is that Lyme disease has not been found. GPs have not been advised that other forms of Borrelia and other vector-borne diseases have not yet been researched and so cannot be disproved. Vector-borne diseases simply are not on the average GP's list of considered illnesses. The average GP does not prescribe antibiotics after a tick bite. While the Australian situation remains under review, this is a dangerous, unethical and unacceptable situation. The Department of Health needs to address the fact that the current antimicrobial resistance information is increasing the chances of more Australians missing out on early antibiotics after vector bites and becoming chronically ill.

The Antimicrobial Resistance Strategy 2015-2019, Objective Two, requires a section specifically included as an interim policy for current patients of vector-borne disease. Implementation of the points included under this objective will further restrict the most appropriate medications for patients with vector-borne diseases.

Best practice for managing vector-borne diseases should involve:

- 1. Publicising that vector-borne diseases in Australia remain under investigation, especially Borrelia species, rather than publicising that Lyme disease has not been found.
- 2. The Australian government and the Department of Health making such a statement as that in Point 1 to the media.

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- 3. The Department of Health ensuring every GP in Australia receives the information that vectorborne diseases remain under investigation and that suspected patients of such should receive appropriate and adequate care. GPs are the gateway to care.
- 4. The Department of Health alerting every GP in Australia that many vector-borne diseases present with flu-like symptoms.
- 5. The Department of Health ensuring every GP in Australia is informed about the treatments for acute vector-borne diseases, i.e. the basic antibiotics that prevent possible chronic problems.
- 6. The Department of Health either providing an interim policy for physicians or collaborating with medical boards to help ensure that doctors are left to use their own best judgement without fear of reprimand or both.
- 7. The Department of Health organising a list of the various NATA accredited laboratory tests available currently for vector-borne diseases, advising the differences between tests and the strains of Borrelia the tests incorporate for Borrelia tests, so that doctors and patients can attempt to utilise the best of the poor Australian tests.
- 8. The immediate provision of testing from at least one international laboratory while Australia continues its investigations.
- 9. The employment of a non-CDC international expert by the Department of Health to act as an advisor to GPs and specialists in need of assistance.
- 10. The understanding that patients cannot be expected to wait for unfunded research to be conducted.
- 11. Better utilisation of other pathology tests and their usefulness in diagnosing complicating factors.
- 12. Allowing doctors to bypass some red tape and current regulation by their provision of rationale and treatment results for off-label use of medications, treatment regimes and tests.

## Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management.

Tests and medications are restricted by disease label, hierarchical protocols and regulation. SLA has stated above and states again that doctors need a means to be able to bypass some red tape and current regulation by authority application which could involve initial provision of rationale and continuation rationale supported by test results. There should be a Medicare reimbursement for doctors for the time this process would involve. Patients with infectious and immune diseases have highly individual disease course, complications, test requirements and treatment needs. Overly tight regulations translate into inadequate tests and treatment.

When Australia does not have specific tests or adequate tests, a regulation needs to be developed to import tests. The imported tests should be covered by Medicare.

A Medicare item could be created, encouraging doctors to spend time keeping a brief database of some details pertaining to patients with immune diseases, infectious diseases, no diagnosis or possible/probable/ever-changing diagnoses. Australia has no statistics on these patients. The Department of Health would need to create the database outline and the data requested. Patient advocacy groups would like to be able to make suggestions about data collected but subsequent to the database creation. The need for a database and statistics is urgent. The Department of Health can have no idea of the extent of the vector-borne disease problem in Australia because no data exists. Data could easily be collected under the Medicare payment system by GPs and specialists.

# **Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care.**

The Department of Health states that Primary Health Networks should increase the effectiveness and efficiency of medical services for patients, improve the coordination of care for patients, and focus on patients at risk of poor health outcomes.

Vector-borne disease patients, systemically ill patients and undiagnosed chronically ill patients are together a large group, made up of sub-groups, who fall into the category of high risk of poor health outcomes, with ineffective and sadly lacking medical services, unfortunately not receiving the right care in the right place at the right time. GPs are unaware. Specialists refuse to treat. Hospitals turn away. The system prevents the few helpful doctors from helping.

#### The role of State and Territory Governments in chronic disease prevention and management.

Epidemiological data is vital in gauging the extent of the chronic diseases currently ignored – vectorborne, systemic and immune dysregulation. As discussed above, data could easily be collected through GPs if incentive was offered in the form of Medicare payment.

The Australian government / Department of Health has failed to provide an interim policy for current patients with vector-borne disease. The Department of Health publications of August 2015 are inadequate for this purpose.

The failure to provide a diagnostic case definition is disappointing. It is understood that the indigenous pathogen is unknown, so just as we require an interim policy, we require an interim diagnostic case definition which focuses on patient symptoms and non-infectious pathology results. Obviously, the diagnostic case definition will evolve over time as specific and adequate tests become available. Possibly, we will need several diagnostic case definitions, as most likely several pathogens will prove to be involved.

# Innovative models which incentivise access, quality and efficiency in chronic disease prevention and management.

As stated above, doctors need a means to be able to bypass some red tape and current regulation by authority application which could involve initial provision of rationale and continuation rationale supported by test results. There should be a Medicare reimbursement for doctors for the time this process would involve. Patients with infectious and immune diseases have highly individual disease course, complications, test requirements and treatment needs. Overly tight regulations translate into inadequate tests and treatment.

#### **Public Hearing**

The Public Hearing of 18 September 2015 conveyed that the Australasian Society of Infectious Diseases is very resistant to the possibility of Borreliosis in Australia until research provides evidence. That view reinforces the urgent need for an interim policy for current patients.

Professor Gilbert's (p4) assertion that infectious disease physicians see many patients with chronic symptoms for which no definite cause can be found is a damning statement about the infectious disease physicians. These physicians cannot find what they do not look for, do not run pathology tests for and furthermore do not have appropriate tests to run. Would Professor Gilbert care to speak with some patients who have consulted with hospital infectious disease physicians or read some correspondence sent to the physicians subsequent to waste-of-time appointments?

A SLA member consulted with a Westmead infectious disease physician who wanted to pursue invasive investigations for Whipple's disease and refused to ever consider Lyme disease, even if the biopsy for Whipple's disease came back negative. This patient has travelled extensively and had been overseas for 3 months before becoming ill. The infectious disease physician insisted that the patient had only been to non-endemic areas, which was nonsensical as the patient's cousin had been bitten by a tick and diagnosed with Lyme disease in one of the places (UK) to which the patient had travelled.

Perhaps we need a medical board review of the case notes of the patients who have consulted with infectious disease physicians and then we can consider using the word malpractice. Vector-borne disease patients have been very generous in spirit in not lodging complaints against mainstream doctors who have missed or ignored test results, or caused us adverse events through inappropriate treatments and medications. It is diabolical that peers from the science sector will not afford that same generosity of spirit within its own ranks. SLA feels that current patients are rapidly being drained of that generosity of spirit.

Professor Gilbert (p15) spoke of a rare care of neuroborreliosis, diagnosed by examination of cerebrospinal fluid. In view of the fact that most Australian patients have been very ill for years (implying whatever ails them is chronic) and in view of the fact that many patients have quite a repertoire of neurological symptoms, SLA would be most interested to know how many infectious disease physicians ordered cerebrospinal fluid examinations for patients presenting with possible Borreliosis, neurological symptoms and a positive laboratory result from any lab (NATA or non-NATA accredited). The SLA member discussed above is a highly neurological case and was not offered a lumbar puncture, instead being offered a gastroscopy for non-existent digestive issues for a very rare disease of which there was no hint of pathology evidence (and, interestingly, had the patient had the disease, the treatment would be long-term antibiotics).

The discussion on randomised, controlled trials (p21) needed a statement that such a study would be more effective using acute patients than chronic patients. Chronic patients have an interplay of genetics and immune complications which means it would be impossible to control for everything in the study. The current patient experience is that different combinations of medications work for different people. Immune complications do not necessarily equate to chronic fatigue syndrome (p15). Where is the evidence for CFS? Is there laboratory evidence of this? We are trying to make this nameless illness we have in Australia meet standards and diagnostic criteria that other illnesses do not have to meet.

2015 has seen several publications on the topic of post-Ebola syndrome versus chronic Ebola virus disease. Studies have shown that viral genome or infectious virus has been detected in the supposedly-cured-but-still-ill Ebola survivors, with fluids pertinent to the eye and testes being the main sites of continuing infection. There has been recognition that there is a need of research into other fluids and tissues which may harbour infection for extended periods and survive antibiotics, and also into the characteristics of the virus replication. The recent Ebola epidemic brought a lesson and a research direction.

Likewise, it is standard practice to treat Whipple's disease, especially CNS Whipple's disease, with long-term antibiotics. The usual judgement as to whether the patient is better is made on the basis of whether the patient is symptomatic or not.

Dr Graves made an important point that laboratories can only test what the referring doctor has requested (p12). SLA believes that the Department of Health has failed to advise GPs and infectious disease specialists that, not knowing what pathogen we are looking for, patients with tick bites (and possibly other vector bites) should have test requests worded to test for Borrelia and any infection pertinent to vector bites – or wording which allows the laboratory flexibility. If this is not possible, a Medicare item/authority should be created allowing the laboratory to add on appropriate tests. The current system has patients' diagnosis and wellbeing reliant on doctors who will not order tests or know not which tests to request.

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The discussion made it very obvious that everyone agrees we urgently need research into the whole spectrum of vector-borne diseases. Professor Irwin (p4) commented that we have 80 more types of ticks in Australia than other places (unique ticks), with double the bacteria of the German ticks, and viruses have not been looked at yet. No-one mentioned research of vectors other than ticks. SLA contends that that translates into a lot of pending but unplanned research.

The Australian government needs to provide the money for research. This is urgent. This is an emergency. The research will never be done unless funding is provided.

Policy and protocols cannot be formed and implemented until research provides evidence, and must remain a separate issue to the matter of current patients. The policy and protocols are for future patients who, hopefully, will have fewer needs than current patients because they will never progress to our level of illness if they receive early and appropriate treatment.

Current patients need an interim policy, one which includes long-term antibiotic treatment should they require such, access to more tests and medications, and Medicare subsidisation of herbal treatments and supplements. We need doctors to be encouraged to care for us and we need the surveillance taken off those of our doctors who are most informed and have had the most experience in our care. We also need Medicare to contribute towards our private specialist costs. It is not our fault the specialists are inadequate and we should not have to pay for that inadequacy.

Such an interim policy would be the humane road to take.

#### **References:**

Australian Government / Australian Institute of Health and Welfare. Website www.aihw.gov.au

Australian Government / Department of Health. Website www.health.gov.au

Derler AM, Eisendle K, Baltaci M, Obermoser G and Zelger B. High prevalence of 'Borrelia-like' organisms in skin biopsies of sarcoidosis patients from western Austria. *J Cutan Pathol* 2009, 36:1262-1268.

University of Michigan Health System. Website www.uofmhealth.org

Yoshinobu, E. Etiologic aspect of Sarcoidosis as an Allergic Endogenous Infection Caused by *Propionibacterium acnes*. *Biomed Res int* 2013: 935289.