‘CONQUERING LYME DISEASE: science bridges the great divide’

Brian A. Fallon, MD, and Jennifer Sotsky, MD
with Carl Brenner, Carolyn Britton, MD, Marina Makous, MD, Jenifer Nields, MD, and Barbara Strobino, PhD.
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(Review by Dr John Duley PhD, January 2018)

The cover of this new book sums up its strengths as:
Lucid and important, filled with moving case histories and vignettes, about an infectious illness that is threatening many lives.

The expert authors
Before discussing a new book about Lyme disease (LD), it is essential to present the ‘academic credentials’ of the book’s authors, who are doctors and scientists, and far more knowledgeable than the self-appointed Australian ‘experts’ who nonetheless will want to see who wrote it. So this section is for the benefit of the Australian ‘experts’, and the average reader or patient can skip this if they wish.

The two authors are highly-respected medical academics, all experts in LD, with various ties to the prestigious Columbia University Medical Centre, in New York City, one of three American research centres focused on Lyme disease that have been established with patient support. The authors are: Brian Fallon, director of the Centre for Neuroinflammatory Disorders and Biobehavioral Medicine and director of the Lyme and Tick-Borne Diseases Research Centre; Jennifer Sotsky, a resident physician at the same medical centre.

The authors acknowledge a range of other LD experts whom they consulted when writing the book. These include several psychiatrists specialising in LD, because a substantial section of the book is concerned with ‘persistor bacteria’ and ‘chronic symptoms’, the latter including neuro-borreliosis (or LD attacking the brain, which Australian ‘experts’ seem particularly keen to ignore). The book’s consultants include: Carl Brenner, a former member of the Research Advisory Board of the National Research Fund for Tick-Borne Diseases, and current director of the U.S. Science Support Program (USSSP); Carolyn Britton, Associate professor of Clinical Neurology at Columbia; Marina Makous, a neuropsychiatrist recently relocated to Exton Philadelphia where she specialises in treating adults with the neuro-borreliosis complications of LD; Jenifer Nields, an assistant clinical professor of psychiatry at Yale University School of Medicine; and Barbara Strobino, previous Associate Director of Research at the Columbia Lyme Research Centre.

The Australian ‘experts’
Perhaps one of the most shocking aspects of this book is what is absent: although the book discusses LD in nations around the world, there is not a single mention of Australia. This is not because LD does not exist here, but unfortunately because there are a number of influential doctors/professors and health bureaucrats in Australia who feel it is their duty to deny everything about LD. “Don’t look, don’t find” seems to be the motto of the Australian government (LNP and ALP). So this book will not
impress the self-appointed and government-appointed Australian ‘experts’, who will continue to sneer at the mounting evidence here for LD.

The role of patients
The people who wrote this book all work in the epicentre of the LD catastrophe, and the reader will soon realise the authors know what they are talking about. But for this reviewer, the most moving part of the entire book appears on page 105, in a section titled ‘What are the Lyme Wars?’ It is worthwhile quoting the passage in full, because so many patients and members of the Lyme Disease Association of Australia deserve to be encouraged by its words:

“As the disease spread and as more patients’ lives were profoundly disrupted by this illness, patients wanted to know what was being done to help them. Faced with few answers and doctors who dismissed their concerns, patients became alarmed and angry and began to mobilize. They started support groups to educate and support one another. They wrote books and made documentary films. They started local, state, and national organizations. They organized national medical conferences for doctors, bringing leading researchers from around the world together to educate clinicians and the public about Lyme disease. They created websites, wrote blogs, and some are now using the Internet to gather research data. Some mounted protests outside of academic medical centres known for a more narrow position on Lyme disease diagnosis and treatment.

“Others contacted their legislators to help in the fight against insurance companies who were denying coverage for extended antibiotic therapy, to put provisions into state law that would make it less threatening for doctors to treat patients for Lyme disease with repeated or extended courses of antibiotics, and to encourage the CDC [the US Centres for Disease Control and Prevention] and the National Institutes of Health to support research studies focused on the development of better diagnostic tests and more effective treatments, particularly for those with chronic symptoms. And others raised money to support high-quality research to help answer the questions of concern to them.

“Although most of this book focuses on clarifying what researchers have accomplished, what the patient community has accomplished to help advance progress on the understanding and cure of this disease is extraordinary. Most of these community health activists and leaders were mothers who had very sick children. They devoted themselves for years—without pay—to fighting this disease. They learned as much as they could about medicine. They brought research articles to their doctors, hoping for help and an open ear. They hurdled obstacles thrown in their paths. They joined forces with local legislators and with community advocates in other states.

“Some academics and public health representatives view this ‘activism’ by patients and their families with hostility and suspicion. Some would say that they have made the objective mission of science bend to the subjective passion of patient beliefs and concerns. Some would say that patients should not have such a big role in shaping the national research agenda. Some researchers and physicians would say that the angry patient advocates have made their lives miserable.

“However, some patients would say the same of many doctors, research scientists, and public health officials, viewing them as too often abusing their positions of power and authority to silence the voices of sick patients seeking help.

“What remains an incontrovertible truth is that since its initial discovery, patients have played a pivotal role in shaping our understanding of Lyme disease.”
The structure of the book
The book is divided into 14 chapters, and they are worthy of listing because the titles show that nothing is left uncovered. Many Australian doctors and health officials would regard even the chapter titles as provocative (e.g. chapters 5, 6 and 12), whereas patients and their families will sense that a fresh wind is blowing:

1. WHAT IS LYME DISEASE?
2. THE EARLY HISTORY AND EPIDEMIOLOGIC SURVEILLANCE
3. WHAT ARE THE SYMPTOMS AND SIGNS OF LYME DISEASE?
4. WHAT DO THE DIAGNOSTIC TESTS TELL US?
5. THE GREAT DIVIDE AND THE LYME WARS
6. WHY WOULD SYMPTOMS PERSIST AFTER ANTIBIOTIC TREATMENT FOR LYME DISEASE?
7. WHAT ARE THE TREATMENTS FOR LYME DISEASE?
8. OTHER TICK-BORNE INFECTIONS
9. WHAT OTHER NONINFECTIOUS DISEASES CAUSE LYME-LIKE SYMPTOMS?
10. LYME DISEASE PREVENTION AND TRANSMISSION
11. SUGGESTIONS TO THE PATIENT SEEKING EVALUATION OR TREATMENT
12. THE EXPERIENCE OF THE PATIENT WITH CHRONIC SYMPTOMS
13. FREQUENTLY ASKED QUESTIONS
14. THE GOOD NEWS EMERGING FROM LYME DISEASE RESEARCH

Contracting LD
The first parts of the book describe LD and its onset after a tick bite, and this may be very helpful to Australian readers who have been kept in the dark about the disease. The early symptoms are best described as ‘flu-like symptoms’: fatigue, headache, malaise, muscle and joint aches, swollen lymph nodes, and fever and chills, but without the coughs or congestion typical of influenza.

Importantly, the authors note that the ‘classic Lyme rash’ is not seen for 20-30% of cases, so the only sign of infection may be these flu-like symptoms. Infection often occurs after bites by the tiny ‘nymph’ stage of ticks that can be easily overlooked. As a result the authors warn, “Most doctors who work in areas where Lyme disease is common know that a flu-like illness during the spring or summer months suggests a possible tick-borne infection.”

During the developmental stages of the tick, the early larvae and nymphs feed on mainly ground-dwelling animals such small mammals (in Australia: echidnas, marsupial mice, bandicoots, bilbies, quolls, antechinuses, etc) and ground-feeding birds (ticks are common on Australian birds, even larger species such as the brush turkey). Recently, native Australian lizards have been found to carry *Borellia* spirochaetes, which seem to be undescribed species of the bacterium and thus may produce unique types of Australian LD! Dogs and cats are poor hosts of the *Ixodes* tick and represent a low risk for LD. The highest risk animal for transmission of LD to humans in America and Europe/UK are deer. But there do not seem to have been any studies in Australia of ticks carried by deer, despite the huge numbers of these introduced animals in this country.
Diagnostic problems
The poor diagnosis and consequently poor treatment of LD has largely been caused by dependence on old blood technologies. First-line ‘ELISA’ tests rely on the presence of antibodies developed by the body to Borrelia, but these usually do not appear for at least 3 weeks – at which stage the bacteria are known to have dispersed around the body and simple antibiotic treatment is then usually ‘too late’ to prevent the disease taking hold. The second-line test, ‘Western blotting’, is designed to detect proteins secreted by the bacterium. However, this typically is complex and has poor sensitivity, it assumes there are bacteria circulating in the bloodstream, AND it has not kept up with the large number of newly-discovered species of Borrelia shown to cause variants of LD, such as B. myamotoi (or Australian genotypes). These two tests have been found to have good sensitivity only for Lyme arthritis... but that is a late-onset symptom, and is absolutely ignored in Australia. Another test, ‘PCR’ to detect Borrelia DNA, is insensitive because the bacterium does not reside in the blood but rapidly disappears into tissues. Borrelia has been found in more easily detectable levels in spinal fluid of chronically infected patients, but most clinics and physicians are reluctant to take samples of ‘cerebrospinal fluid’ (CSF), because of the risk and pain for patients.

Treatment: The Great Divide
The title of chapter 5 is particularly worth noting: ‘The Great Divide and the Lyme Wars’.

The ‘Great Divide’ is described as the chasm of experience existing between the academic researchers who have focused on early LD and thus have seen nearly all patients recover with a short course of antibiotic therapy, versus the physicians working in LD endemic areas who were inundated with patients suffering from relapsing or chronic symptoms following from early LD. This introduces the concept of ‘chronic LD’ or ‘post-treatment LD syndrome’.

Chapters 6 and 12 go on to demonstrate that chronic LD does indeed exist, with two main causes: the survival of so-called “persisters” Borrelia bacteria following antibiotic treatment, especially in tissues such as the brain, and the development of hypersensitivity to cytokine release after antibacterial therapy combined with chronic tissue damage (such as muscle damage and arthritis).

Following publication of findings in August medical journals such as the New England Journal of Medicine, this fact is now accepted by the vast majority of doctors in the USA, UK and Europe.

The ‘Great Divide’ can be seen in Australia, written into the federal Department of Health information on Lyme disease (www.health.gov.au/lyme-disease), which begins with a grand piece of ‘fake news’: “the concept of chronic Lyme disease is disputed and not accepted by most conventional medical practitioners, not only in Australia but around the world.” Fortunately, this sort of untruth is no longer propagated elsewhere.

The Lyme Wars
This emotive term refers to the long battles in America involving patients, doctors, researchers, and insurance companies (and in Australia, the AMA and health bureaucracy). The wars were based largely on the rigid diagnostic definition of LD by the American CDC, that ‘objective’ signs had to be present for diagnosis. Initially, the ‘Lyme rash’ (erythema migrans) was considered the single most important objective sign. Later, positive results for both of the two types of blood tests were required. These decisions were followed rigorously by the Infectious Diseases Society of America (IDSA) and the American Academy of Neurology.

Ranged against the CDC and IDSA, the Lyme Wars have been fought by the numerous (and cashed-up) American patients’ associations, under the umbrella of the International Lyme and Associated Diseases Society (ILADS). This is the primary medical voice for the “alternative camp,” and it
recommends variable duration antibiotic treatment of LD based on patient response and supports the use of more flexible guidelines to establish a clinical diagnosis. These patients’ associations have been the driving force in LD research, and of opening up debate and recognition of the disease in America. In the UK, the government openly recognises and warns about LD, and the major charities ‘Lyme Disease UK’ and ‘Lyme Disease Action’ are well-supported and supportive. The EU coordinates the fight against LD through its European Centre for Disease Control and Prevention (ECDC), while patient groups can use ‘LymeNet Europe’ to communicate and collaborate.

The antipodean version of the ‘Lyme Wars’ are typified again by Federal Government’s misinformation on LD (as above), which states: “The Australian Government recognises the existence of classical Lyme disease which is found in high rates in endemic areas (mainly the north east of the USA, some areas of Europe including the UK and some parts of Asia)…. The diagnosis and treatment for classical Lyme disease is readily available in Australia.”

The Government here is stating that ONLY “classical LD” contracted OUTSIDE Australia (and confirmed by the presence of a rash or two positive blood tests) will be recognised as LD and treated. All other cases will NOT be treated here. Thus the statement “readily available in Australia” is false, as it does not apply to the vast majority of Australians. In 2017 the Health Department even asked doctors to avoid using the term ‘Lyme’. There are several patients’ organisations in Australia, in particular the LDAA, who are taking the role of ‘David’ against the bullying ‘Goliath’ of the Federal Department of Health and the AMA. It remains a puzzle why the Health Department does not simply recommend what is becoming standard practice elsewhere: if a patient has flu-like symptoms suggestive of LD, start a 2-4 week prophylactic course of doxycycline, and await test results?

The Future

The good news: Some of the subheadings of the final Chapter 14 will give the reader hope for the future: “Recognition that Borrelia Persist; Repeated Antibiotics Can Help; Recognition of Persistent Symptoms after Treatment; New Prevention Strategies.”

Against the glum outlook of the poor diagnostic methods presently used, new technologies such as ‘metabolomics’ are promising improved detection and diagnosis. Time will tell. With recognition of chronic and post-treatment LD, advances are also being made in testing new antibiotic regimes and combined treatments. A new vaccine is being developed in the USA. The authors like to talk positively about ‘bridges’ rather than ‘the great divide’ and ‘Lyme wars’.

They conclude, “This is a hopeful time in the world of Lyme disease. The biotechnology revolution has catapulted scientific advances, creating new bridges between previously polarized stakeholders and enabling researchers, clinicians, and patients to work together as they collaborate on conquering this disease.”

For the interested reader, there are hundreds of learned References. There is also a Glossary of medical terms to help the non-medico, but the authors have done an excellent job in minimising technical and obscure medical terms, by using very clear lay language. The text of the book is almost 300 pages, but many readers will want to zoom into their areas of interest, so the Contents and Index sections are all hyperlinked for ease of use.

The book is available in print format and in the ‘Adobe Digital’ and ‘Kindle’ electronic versions which can be downloaded (the Adobe Digital app is free on-line). The cost is about $40-50 depending on the format and seller. It’s a large and not a cheap book, but a great reference for anyone wanting to learn everything that is presently known about Lyme disease.