

Living with Lyme disease

Is there anything worse than not knowing what's wrong with you when serious symptoms kick in and affect your health and wellbeing? Yes – when you know what's wrong with you but the Australian system can't help you. SAMMI TAYLOR investigates

EUGENE Hansen has lived in Warrandyte his entire life. He's a successful small business owner, a coach at the Warrandyte Junior Football Club and is a familiar face in our local community. He is a loving husband and a father to three children.

But Eugene has lived with a painful secret – an incurable disease. His health is rapidly deteriorating; his quality of life is in decline, yet he's not receiving the help he so desperately needs.

Eugene suffers from Lyme disease, an infectious disease caused by bacteria and borne by ticks. Lyme disease is characterised by a steady break down of the immune system, causing those infected to become vulnerable to several co-infections. If left untreated, over time Lyme disease can cause a myriad of issues—seizures, migraines, cognitive impairment, arthritis and insomnia are all common for those with Lyme disease. These symptoms are often extremely painful and can, in some cases, be fatal.

But this is more than just your daily pains and aches.

"I'm in excruciating pain. I have seizures. I suffer excruciating migraines, between 21 and 25 days per month of migraines," Eugene tells the *Diary*.

"I get pneumonia pretty regularly. I can't battle illness. I avoid as many public places as I can—hospitals or any place where I could pick up any illness. I don't have the capacity to fight off any infections."

It took over 14 months, and 220 medical appointments, before there was even a glimmer of diagnosis or the hope of answers. Treatment, a cure and an end to this excruciating pain seemed like a lifetime away.

"I had CT scans, MRIs, blood tests...I had absolutely everything. The only logical conclusion they could come to was: 'you're nuts'. Neurologists throw their hands up in the air and tell you it's all in your head. But, really? Simply, I am in pain and it needs to stop."

Eugene's blood was tested in Germany and America to diagnose the disease—and both tests came back positive. However, Eugene's Australian tests showed no sign of infection.

The reason? As a technicality, the condition does not exist in Australia. Our doctors aren't trained to diagnose it and our pathology testing doesn't have the sensitivity to locate the infection in blood tests.

There's cruel irony in what comes next. In the northern hemisphere, Lyme disease is not only treatable but curable. If diagnosed within four weeks, a simple course of antibiotics eradicates the disease from your



“ He says he’s a strong advocate for families—well what about my family, Kevin? Come and spend some time with me and my family when I’m having a seizure or a migraine at 2 or 3 o’clock in the morning. Come with me and tell my children why I’m sick. ”

system: 28 pills and you're cured.

"It's like if you stand on a rusty nail here in Australia, you go and get a tetanus shot. All I needed was those antibiotics for four weeks. It's exactly the same as treating the common flu," Eugene says.

There are at least 1494 diagnosed cases of Lyme disease currently in Australia, according to the Lyme Disease Association of Australia.

Another Warrandyte man, Terry Ryan, 45, has also suffered Lyme-like symptoms for over a year. The similarities between him and Eugene are indisputable: they're both tradesmen, living and working on expansive properties in the Warrandyte area. They're both family men, devoted to their community and battling a mysterious illness that has destroyed their immune system and quality of life.

"I've been to dozens of hospitals, seen dozens of neurologists, cardiologists, immunologists. They pretty much told me it was all in my head and I needed to see a shrink," Terry told the *Diary*.

But the physical pain and symptoms many Lyme patients suffer are clear signs the disease is far more than a mind game.

"I'll collapse and have seizures and sometimes I'm just really out of it. I have no control over my body. It's like there's this big fog cloud over my head. It's like you're in a mist and you just don't know what's going on."

Terry and Eugene are just two among the potential cluster of Lyme disease patients in Warrandyte. The *Diary* is aware of and in contact with at least a further three members of our local community who are battling the condition.

Australia's medical boards, federal government and insurance agencies all deny Lyme disease exists in our country. For Lyme patients, these au-

only overcome his own illness, but fight to improve the lives of other Lyme sufferers.

"I want to just go and shut the gates of my property and get better. But I can't do that unless I get the acknowledgement that [Lyme disease] exists," he says.

"I'm going to scream into any microphone until they say that the easiest way to get this bloke to go away is to get off the fence, acknowledge it and fix the issue."

The Lyme Disease Association of Australia is pioneering that fight. The dedicated group of volunteers provides support for Lyme patients—connecting them to medical services, peer support and updating them with new information. A recent awareness campaign, launched in May this year, saw 20,000 postcards with Lyme awareness messages sent to politicians across the country.

"I believe the government needs to take action right now. They need to indicate there is a Lyme-like illness here and it's an emerging disease," says Sharon Whiteman, president of the Lyme Disease Association of Australia.

"Lyme patients need to be given the best standard of treatment. It is hard for anybody to understand that in a

country like Australia patients, who are obviously very ill, would go to a doctor and be told that their symptoms and all kinds of abnormal tests are being ignored. It is unbelievable, but it is the truth."

The next step for the Lyme Disease Association of Australia is to get our federal government to take notice.

"The politicians are skirting around the issue. We've been bashing [Kevin Andrews'] door down to meet him but he hasn't responded to me at all," Eugene says.

"[There are] constituents here who are suffering, who are in horrendous pain. He says he's a strong advocate for families—well what about my family, Kevin? Come and spend some time with me and my family when I'm having a seizure or a migraine at 2 or 3 o'clock in the morning. Come with me and tell my children why I'm sick."

The office of MP Kevin Andrews has sought advice from the Minister for Health, Hon. Susan Ley. They are in the process of investigating the issue of Lyme disease in our community.

"I understand and sympathise with the concerns of people and their families who are suffering from a chronic debilitating illness," Mr Andrews told the *Diary*. "But it must be up to the patient and their treating doctor to decide on an appropriate diagnosis and treatment."

There also is some consolation in the support from the Warrandyte community and those battling the illness are drawing strength from one another.

"I keep in contact with all the others," Terry says.

"Every now and again we catch up down the street or at footy or whatever, just to see if there's anything new and what's going on."

Eugene says: "And Terry has been a tremendous support. He's become a part of our support network. I want to try to arrest this thing. I don't want to give in. I'm in a constant battle with pain because I want it to stop. I want to get better."

"I'm prepared to do what I need to do. I'm going to show everybody here that I can beat it."

If you have any information on Lyme disease, or think you may be experiencing symptoms, please contact your doctor. More information on Lyme disease can be found at www.lymedisease.org.au

