Cara MacKenzie

Thursday 19th December 2024

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Subject: Submission to the Senate Inquiry into Access to Diagnosis and Treatment for Tick-Borne Diseases

Dear Committee Members,

I'm writing today as a family member who has watched my loved one, Tanner McMillan, suffer for years because of Lyme disease. I've seen his pain, his frustration, and the toll it's taken not just on him, but on his parents, siblings, and the whole family. I'm heartbroken to see them struggle in a healthcare system that simply doesn't understand or recognise the reality of tick-borne diseases. It's time for this to change, and I'm begging you to take action.

Personal Experience

Tanner was just 11 when a tick bite turned his life upside down. Instead of growing up like other kids, he spent years fighting an illness that no one seemed to acknowledge. I've watched his parents work tirelessly, desperate to find answers. But instead of support, they faced disbelief. Tanner's doctors said it was all in his head. They told his parents to ignore him, that he would "snap out of it." How can any parent do that? How can you ignore your child when they're lying on the floor in agony, unable to wake up, unable to move? It broke my heart to watch his parents helpless, having to fight a system that should have been there to support them.

Tanner's family has lived through years of pain, confusion, and frustration. His father, who has always been his rock, has had to push through endless medical appointments, only to be told that his son's suffering wasn't real. Every day was a battle. I saw the family cry, feeling like they were losing their son—and their entire family—bit by bit. Them trying to hold it all together, putting on a brave face even though they were crumbling inside. And Tanner's siblings, who had to watch their brother go through all this.

Awareness, Diagnosis, Treatment, and Management Since 2016

While there has been some recognition of Lyme disease since the 2016 Inquiry, the reality is that things haven't really improved for families like Tanner's. His family still faces the same struggles—long waits for diagnosis, dismissive doctors, and a complete lack of support for patients suffering from tick-borne diseases. It's heartbreaking to see how little has changed in terms of awareness. Tanner's family had to wait for nearly a year for a diagnosis, all while watching their son deteriorate. Even when the diagnosis came, it was like a light at the end of a tunnel that kept moving farther away.

I've seen firsthand the struggle of trying to get proper treatment. Even now, after years of dealing with this illness, Tanner's family still feels like they're fighting an uphill battle. Doctors don't know how to treat him, and the resources just aren't there. The current medical system doesn't know how to handle tick-borne diseases. We can't afford to let more families suffer because of that lack of understanding.

Adequacy of the 'Debilitating Symptom Complexes Attributed to Ticks' Clinical Pathway

The clinical pathway that's supposed to help patients like Tanner is failing. It's confusing, inaccessible, and doesn't meet the real needs of people who are suffering. Tanner's family has had to navigate a system that feels like it's designed to make their lives harder, not easier. The pathway should be a lifeline for patients and families, but for so many, it's just another barrier. The system needs to be rethought, simplified, and made genuinely supportive for people who are in pain and desperate for help.

Current Research to Advance Management of Complex Inflammatory Diseases

The research into tick-borne diseases is not where it needs to be. The Australian healthcare system is failing people like Tanner, who are desperately looking for treatments that can offer them relief. Research is slow, and it doesn't feel like it's moving fast enough to address the growing number of people who are being affected by Lyme disease and other tick-borne illnesses. The lack of funding, the lack of focus on patient needs—it's all just too much. We need more action, more research, more funding, and we need it NOW.

Other Related Matters

The emotional toll of Lyme disease on Tanner's family is something I'll never be able to fully describe. His parents live in a constant state of worry. His siblings have grown up watching their brother suffer and not understanding why things were this way. It's been hard for them to stay hopeful. And the worst part? They've felt so alone in this fight. The stigma around Lyme disease, the disbelief, the lack of support—it's isolating. Tanner has been through so much, and his family has borne so much pain, yet it feels like the world just keeps turning a blind eye.

Please, I am asking you to act. Tanner’s family should never have had to go through this. No other family should have to go through what they have. The government and healthcare system need to acknowledge this issue and take immediate action to improve the diagnosis, treatment, and support for people suffering from Lyme disease and other tick-borne diseases.

Conclusion

I don’t want another family to go through what Tanner’s family has been through. I don’t want another child to suffer without proper treatment, without recognition. Tanner is a strong, resilient young man, but his battle has been long and painful. He is fighting for his life, and he deserves the chance to have a future without the constant weight of illness holding him back. Please, act now, and give families the support they so desperately need.

Thank you for considering my submission.

Yours sincerely,
Cara MacKenzie