

Colorado Tick-Borne Disease Awareness Association

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Designated Federal Officer, Tick-Borne Disease Working Group;
Director, Office of HIV/AIDS and Infectious Disease Policy,
Office of the Assistant Secretary for Health,
U.S. Department of Health and Human Services

Dear Members of the HHS Tick-Borne Disease Working Group,

My name is Monica White and I am respectfully submitting my name for consideration for a position on one of the working group sub-committees as a **patient/patient advocate**.

I am President and Co-Founder of Colorado Tick-Borne Disease Awareness Association (COTBDAA), a nonprofit 501(c)3 organization established in 2016. We work to elevate awareness, provide education on disease and tick-bite prevention, conduct citizen science research and advocate for change. We provide support to Lyme patients and their families within Colorado and throughout the Rocky Mountain Region. We are an affiliate member of the national Lyme Disease Association (LDA), and a member of the Public Tick IPM working group. Both of these affiliations allow me to increase my knowledge of the issues and collaborate with others to identify gaps and work towards solutions together

I am a former United States Forest Service (USDA), wildlife biologist and wildland firefighter. I spent my childhood and career in the outdoors and traveled nationwide throughout my life in pursuit of outdoor recreation experiences. However, not once during my education at the University of New Hampshire, nor career in Colorado, did I receive any prevention training regarding ticks and tick-borne diseases. Though I was born and raised on the East coast, the majority of my adult life was spent in Colorado, a state that has been highly insulated from the knowledge of Lyme and other tick-borne diseases. I was in the dark. This lack of awareness and education by me and the multiple physicians I consulted with led to severe, debilitating illness, and ended my career.

I am a patient, a wife and a mother of those impacted by late stage and persistent Lyme and co-infections. I was misdiagnosed and denied access to Lyme disease testing for 7 ½ years as my health condition deteriorated. I consulted with more medical care providers than I can recount, visiting multiple elite medical centers throughout the country without an accurate diagnosis before finally being tested for Lyme disease and making my way to a Lyme Literate Medical Doctor. I spent years in and out of hospitals, with multiple ER visits, I was subjected to multiple unnecessary invasive tests, surgeries and procedures, then left to cope with nothing but painkillers when no diagnosis could be made. I was repeatedly denied testing for these diseases, regardless of the fact that I was in a high exposure work environment, had been born in and traveled to endemic areas and had received multiple tick attachments throughout my life. Testing was not afforded to me until I reached complete debilitation, and even then only by the insistence of my nurse advocate, assigned to me through my insurance company, directing my primary care physician to sign the lab orders. Testing would never have been provided to my children, that suffered from the time of infancy, nor my husband if my tests had not come back positive for Lyme and co-infection. The knowledge, resources and protocols available to and/or accepted by mainstream medical doctors regarding these diseases failed me. Recognition and acknowledgment of this disease is lacking in Colorado and throughout the Rocky Mountain Region which is leaving an increasing number of individuals, families and children to suffer solely because "Lyme does not exist here". I missed my access to early testing, diagnosis and treatment. My children and husband missed their access to early testing, diagnosis and treatment. This delay devastated our family and is still impacting our lives today. Long term IV antibiotic treatment saved my life. Long term treatment has improved the health of one of my children and my husband. However, even with long-term individualized care, my son still suffers. We all manifested disease in different ways, we all had variable response to serological testing, and we all responded differently with variable treatment protocols.

Alternative care has supported our healing. Resources, proper testing, diagnosis and treatments are inaccessible and or unaffordable to too many people, especially those residing in non-endemic states. Infection has changed our lives and the lives of so many others forever.

Once I was physically able, it became my mission to help others. The resources we needed in Colorado were not available to help us prevent disease, for us as patients nor to our medical care providers when we needed them. I co-founded COTBDAA, an all-volunteer operated non-profit in 2016 to elevate awareness in Colorado about Lyme and other tick-borne diseases; to educate our medical care providers and our outdoor working and recreating communities; and to assist patients in navigating this difficult path to evaluation, diagnosis and access to treatment. Through educational grants and sponsors we host an annual Lyme & Other Tick-Borne Diseases: Rocky Mountain Forum, where we bring in the leading experts in their fields related to Lyme and tick-borne disease to educate attendees and medical providers. We provide these resources FREE to all attendees each year. Due to our efforts, and the efforts of the active support groups in Colorado, we received a two part investigative news report that has helped elevate recognition of Lyme and Other Tick-Borne Diseases in the State. These resources are critical to everyone, regardless of where they live, work or travel.


I have provided outdoor employees (wildlife biologists, foresters, recreation managers, wildland firefighters) at both Federal (USFS, USDA and BLM, USDI) and State (CPW) natural resource management agencies the tick-borne disease education and prevention training that was not offered when I was employed. These employees are at increased risk of tick exposure due to careers that require extensive work in the outdoors, close contact with livestock and wildlife, and travel to endemic areas of the country for National disaster response (wildfires, floods, etc.). And although these agencies do have agency direction provided in their health and safety handbooks or manuals, we found that knowledge of the existence of these resources were unknown until I inquired and that the direction was outdated, erroneous and incomplete. Addressing these deficits in the Federal safety manuals and handbooks and promoting tick awareness, prevention and safety education and direction to Federal agencies is critical.

Ixodes spp. which are the primary carriers for Lyme disease, are known to occur in almost 50% of the counties in the US, however much of this data was derived from existing sources, not current active surveillance in many parts of the country. There are gaps of data regarding both distribution and prevalence of these ticks as well as other competent tick vectors capable of transmitting Lyme and other TBDs that have yet to be assessed as a human health risk. **This issue is especially important in regions of the country that have not been deemed endemic for Lyme.**

I have initiated passive tick surveillance research in collaboration with Bird Conservancy of the Rockies and our local pet community. Through these efforts we have been able to demonstrate the occurrence of competent tick vectors in migrating birds and on canine companions. One collection of *Ixodes scapularis* in November 2017 also tested positive for Lyme disease. Though this pet had recently traveled from Indiana, it demonstrates how easily ticks are transported into Colorado on companion animals.

Because I live in a non-endemic state, knowledge about risk, prevention, diagnosis, testing and treatment for Lyme & Other TBD's were not available. I suffered for 7 1/2 years with symptoms of neurological Lyme disease and multiple co-infections before diagnosis was attainable. Lyme was not considered, and testing was repeatedly denied solely because I lived in Colorado. One of my children is still battling illness with no end in sight. His illness has impacted his ability to attend school, participate in sports and interact socially...it has stolen his childhood. Treatment has been extremely difficult and costly to obtain, requiring travel to the East coast for care. Lyme and its many co-infections have devastated our family and our finances, and yet we are still more fortunate than others. This problem will not change for other families until these issues, especially in regions of the country that are not known to be endemic, are addressed. It would be an honor to assist in this effort.

Sincerely,



Monica White

President/Co-founder