

PROPOSAL FOR MEDICAL CENTER OF EXCELLENCE FOR TICK-BORNE DISEASE

Overview

Tick-borne diseases and conditions can result in serious, debilitating, or chronic illness and even death, and the risk is increasing nationwide. The American public, patients and medical care providers are lacking a single inclusive source for resources regarding tick-bite prevention, tick-borne disease/condition diagnosis, treatment, and patient access to care. As the number and prevalence of ticks and tick-borne diseases continue to increase across the US, many more people are being infected by not only acute and serious tick-borne pathogens/agents, but also an increasing number of people being disabled by chronic tick-borne illness and conditions. There is great controversy in all aspects tick-borne disease illness and treatment, and with this controversy there have evolved many sources of misinformation that leave both the patient and medical communities confused and at odds when navigating both prevention and medical care. Where controversy exists, there is a recognized gap in the science. The American public, patients and medical care providers need a Medical Center of Excellence for Tick-Borne Diseases that is inclusive of the full body of science so that they can make informed decisions regarding prevention of disease, diagnosis of disease, and treatment of disease regardless of where they live, work or travel. Patients across the country need access to early diagnosis and treatment by trained medical care providers to prevent disabling, chronic or life altering disease regardless of where they reside. Chronically ill patients of tick-borne diseases need access to proper evaluation and access to treatment options by medical care providers experienced in these cases. Medical care providers need access to all aspects of training regarding tick-borne diseases and conditions better serve their patients.

Access to tick bite prevention education, diagnosis and access to care is highly variable across the country. Many of the current prevention and education materials are either regionally or species relevant and do not effectively reach populations of people at risk in regions outside classified “endemic” areas for blacklegged ticks. Misinformation regarding regional tick risk, tick attachment times required for pathogen transmission, appearance of rashes, and the use of CDC surveillance testing criteria is widespread and inhibits many patients from getting early and accurate diagnosis and treatment, especially in regions that are considered “no risk” or “low risk” for certain tick species or pathogens. Medical care providers routinely rely on the tick incidence maps provided by the Centers for Disease Control (CDC) to “rule out” the possibility of certain tick-borne infections based solely on geography if recent travel to a classified endemic region is not noted by the patient. Medical care providers routinely dismiss Erythema Migrans (EM) rashes in patients that manifest this symptom in regions that are not classified as endemic for Lyme disease. Active surveillance of ticks and the pathogens they may transmit is not standardized, leaving many states/regions understudied and underreported for the true risk of the potential vectors and disease pathogens. Education of both the public and medical care providers is limited for ticks and tick-borne diseases nationwide, especially in low incident states. Access to early diagnosis and treatment is even greater impeded to persons that reside in what are considered “no risk” or “low risk” states.

The Objective

Reduce tick-borne disease illness by educating the public and medical care providers in all regions of the US and by providing access to accurate diagnosis and treatment to all patients of tick-borne illness regardless of where in the US they reside.

- Need #1: Development of standardized tick and tick-borne disease/condition education and prevention resources and materials across all regions of the US, with special emphasis on regionally relevant ticks and tick-borne diseases/conditions and risk environments throughout the US, including travel risks.
- Need #2: Development of standardized tick and tick-borne disease CME training for all medical care providers, with emphasis on Primary care, Urgent Care, ER, and pediatric doctors, nurses, PA's.
- Need #3: Patient access to early and accurate diagnosis and treatment of tick-borne diseases and conditions.
- Need #4: Medical care provider access to consultation with experienced medical care providers in the field of tick-borne diseases.
- Need #5: Standardized reporting of all laboratory confirmed and clinically diagnosed tickborne disease cases at a national level.

The Solution

Establish a Medical Center of Excellence for Tick-Borne Disease to lead tick-borne disease prevention, medical education and patient access to care resources.

- Recommendation #1: Development of standardized tick and tick-borne diseases education/prevention materials (electronic, website host, as well as printed materials). These materials should include all medically important tick species, human pathogens and tick-borne diseases/conditions known to occur within the US, as well as relevant global risks. These materials should emphasize tick checks and proper removal of ticks. These materials should be developed with input from well-recognized tick-borne disease patients or patient advocate groups and a physician well known in the clinical treatment of tick-borne diseases, including treatment of chronic infections/symptoms. These materials should be reviewed annually and updated as new information is discovered.
- Recommendation #2: Serve as a clearing house for all accredited tick-borne disease CME trainings. For example <https://learn.invisible.international/>
- Recommendation #3: Development of CME trainings for tick-borne diseases that result in chronic illness/conditions; pediatric tick-borne diseases; congenitally transmitted tick-borne diseases; and blood/tissue donation transmitted diseases. These trainings should be developed collaboratively with input and review by well-established physicians experienced in the diagnosis and clinical treatment of tick-borne diseases including treatment of chronic infections/symptoms, as well as well-established patients or patients advocates.
- Recommendation #4: Establish a doctor referral system and telemedicine hub to connect patients that have experienced a tick-bite or suspected tick-borne infection with a medical care provider experienced in evaluation, diagnosis and treatment of tick-borne disease, regardless of where a patient may reside. Patients must be provided references to both standards of care for tick-borne disease treatment guidelines to make an informed decision regarding treatment choices, including prophylactic treatment.

- Recommendation #5: Establish a physician consultation hub to connect primary care, urgent care, ER, and other medical care providers with an experienced tick-borne disease medical provider to consult on a tick-borne disease cases or suspected tick-borne disease cases (guidance for testing, diagnosis, and treatment, chronically ill patients)
- Recommendation #5: Develop a standardized reporting system and clearing house of all laboratory identified and clinically diagnosed tick-borne illnesses to assess true burden of tick-borne diseases/conditions on nationwide scale.

Expected Results

Reduction of both acute and chronic tick-borne disease illness/conditions in the American public.

Establishment of a Medical Center of Excellence would increase awareness and education regarding ticks and tick-borne diseases/conditions leading to prevention of disease, it would also educate medical care providers for early diagnosis and treatment of tick-borne diseases/conditions in their patients, as well as educate doctors to recognize and treat for late stage and or chronic illness resulting from tick-borne infections/conditions. This Center of Excellence would connect patients with experienced medical care providers, regardless of where they reside in the US, for both early diagnosis and treatment of tick-borne diseases and conditions, as well as access to care for late stage, chronic or persistent diseases or symptoms. This Medical Center of Excellence would connect front line medical care providers with experienced tick-borne disease medical care providers for consultation of known or suspected tick-borne illness in patients.

Program Benefits

- Result #1: Standardized centralized education/awareness will aid in prevention of tick-bites among the American public and will reduce misinformation that fuels controversy.
- Result #2: Standardized and centralized medical education (CME) will aid in early recognition of tick-borne diseases, improve early and accurate diagnosis, provide better access to treatment and better patient treatment outcomes.
- Result #3: Standardized and centralized medical education (CME) will aid in recognition, diagnosis and treatment of the growing chronically ill patient population.
- Result #4: Centralized doctor referral, telemedicine, and doctor consultation systems will provide better access to care for patients for both acute and chronic tick-borne illnesses.
- Result #5: Standardized reporting of all laboratory and clinically diagnosed cases would better categorize the risk, presentations of and burden of all tick-borne diseases nationwide.

Financial Benefits

- Result #1: Creating a Medical Center of Excellence for Tick-Borne Disease would reduce redundancy of agency resource expenditures in the tick-bite prevention and tick-borne disease education arena, cutting back on the financial resources needed to provide prevention resources and education.
- Result #2: Creating a medical Center of Excellence for Tick-Borne Disease would reduce the number of acute tick-borne disease cases, lost wages, strain on education system, and other

societal burdens associated with tick-borne disease.

- Result #3: Creating a Medical Center of Excellence for Tick-Borne Disease would reduce the number of chronic and debilitating cases of tick-borne infection and will reduce loss of wages, workforce and disability claims, education system and other societal burdens, for chronic or debilitating tick-borne illnesses/conditions.

Conclusion

I am a former federally employed wildlife biologist and wildland firefighter, patient, and caregiver of two children and husband that have all been infected with tick-borne disease. Lack of prevention, awareness, and education resources was a contributing factor to my exposure to tick-borne disease. Living in a region of the country that is considered “low risk” or “no risk” for many tick vectors and pathogens further impeded my access to education, as well as to early and diagnosis and treatment by experienced medical care providers. This delayed diagnosis resulted in a loss of health, career, and financial income. Tick-borne illness resulted in disability for me, as well as chronic health and education challenges for both of my children. A Medical Center of Excellence for Tick-Borne Diseases would be a valuable resource getting the public access to tick-borne disease prevention education; patients access to acute and chronic disease diagnosis and treatment, as well as to provide medical care providers education and access to specialist consultation in the service of their patients.

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