

PRESS RELEASE:

***Focus On Lyme* executive director to speak at Capitol Hill science forum**

Arizona-based group advocates for a definitive test for Lyme disease being developed by TGen

WASHINGTON, D.C. — May 18, 2016 — Tammy Crawford, Executive Director of *Focus On Lyme*, will speak this week at a Capitol Hill science and policy forum in an effort to secure funding for a definitive test for Lyme disease.

Focus On Lyme is supporting work by the Translational Genomics Research Institute (TGen), a Phoenix-based non-profit biomedical research institute, to create an accurate genetic test for this disease, which the U.S. Centers for Disease Control and Prevention estimates affects nearly 300,000 Americans each year.

“No other infectious disease affects so many people in this nation and yet has no accurate means of diagnosis,” said Crawford, of Gilbert, Ariz., whose daughter, Jessica, contracted Lyme disease four years ago. “Failure to sufficiently fund the research needed to accurately detect and treat this debilitating disease will only mean higher national healthcare costs in the future.”

Both the National Institutes of Health (NIH) and the Department of Defense (DoD) have recently asked for funding to develop an accurate test for Lyme disease.

Crawford is scheduled to speak Thursday, May 19, between 3-6 p.m. at the Lyme Disease Science and Policy Challenges Forum at the Rayburn House Office Building. Details of the forum are at: <http://www.lymeactionnetwork.org/events.html>.

Focus On Lyme has been instrumental in generating \$200,000 for TGen to support research into the development of a quick, affordable and accurate method of diagnosing Lyme disease, which is the most common vector-borne illness in the U.S.

Today, no perfect test for Lyme disease exists due to three main barriers: multiple strains of Lyme bacteria often confound test results; the existence of related bacteria may cause false positive test results; and most Lyme infections typically present at a level not detectable by current testing methods.

Scientists at TGen's Pathogen Genomics Division, or TGen North, in Flagstaff, Ariz., are using the power of DNA sequencing to develop and validate a test to measure the presence and severity of tick-borne Lyme disease at the genomic level.

By analyzing a sample's DNA, the new test should be able to pinpoint Lyme disease,

identify multiple Lyme strains, detect other tick-related infections, and show non-Lyme causes of disease.

“With recent advances at TGen and genomics overall, we can finally develop a diagnostic test that will put more actionable information into the hands of the physician than previously possible,” said Dr. Paul Keim, Professor and Director of TGen North and Director of the Center for Microbial Genetics & Genomics at Northern Arizona University (NAU), which is helping develop the test.

The bacterium that causes Lyme disease occurs naturally in mice, squirrels and other small animals. The infection spreads as ticks feed on these animals and then bite humans.

This infection can manifest with a bulls-eye rash or a non-specific rash, but not always. Flu like symptoms, such as fever, headache, body aches and fatigue can last a few days to a few weeks.

Undiagnosed and untreated cases can lead to fatigue, painful and swollen joints, memory loss, insomnia, heart palpitations, difficulty with concentration and other changes, including those that mimic other diseases, complicating a clinical diagnosis.

This is why an accurate diagnostic tool is essential.

“We chose to partner with TGen because they have the best and most experienced pathogen researchers in the world,” Crawford said. “TGen has a proven record of success. I am convinced there is no one more qualified to develop an improved diagnostic test for Lyme disease.”

Lyme disease was first described in 1977 following investigation of a cluster of arthritis cases among children living near Lyme, Conn. Further study indicated that arthritis was a manifestation of a tick-transmitted disease.

If detected early, most cases of Lyme disease can be successfully treated with antibiotics. Lyme disease can be prevented by: using insect or tick repellent, promptly removing ticks, applying pesticides, treating pets for ticks, and reducing tick habitat. The ticks that transmit Lyme disease also can transmit other tick-borne diseases.

Focus On Lyme hosted a scientific conference about Lyme disease in February in Paradise Valley, Ariz., bringing together researchers, clinicians and others to discuss diagnosis and treatment for Lyme patients.

Additional facts about Lyme disease:

- Lyme disease is caused by bacteria called *Borrelia burgdorferi* that is only transmitted to humans when they are bitten by an infected tick.

- Lyme disease currently is diagnosed by medical history, physical exam, and sometimes a blood test. It may take four to six weeks for the human immune system to make antibodies against *Borrelia burgdorferi* and therefore show up in a positive blood test. Patients with the Lyme rash often have a negative blood test. Diagnosis currently is based on the characteristic appearance of the rash.
- Researchers didn't identify the cause of Lyme disease and connect it with ticks until 1981. The bacterium that causes the disease is named for Willy Burgdorfer, the scientist who made the connection.

For more information, please visit *Focus On Lyme* at: focusonlyme.org.

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About *Focus On Lyme*

Focus On Lyme was formed in 2015 to discover solutions in diagnostics, prevention, treatment and advocacy for Lyme disease sufferers. The best Lyme diagnostic tools that exist today are only 50 percent accurate and for those that are correctly diagnosed, there is not an accurate tool to evaluate the effectiveness of their treatment. *Focus On Lyme* is striving to provide immediate diagnosis and treatment to Lyme patients worldwide delivering a higher quality of life and minimal long-term effects. *Focus On Lyme* is sponsored by Leadership Children's Foundation, a non-profit organization dedicated to helping children by donating money to causes that help preserve childhood and improve the quality of life for young people across the nation. For more information, visit: www.focusonlyme.org.

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About TGen

Translational Genomics Research Institute (TGen) is a Phoenix, Arizona-based non-profit organization dedicated to conducting groundbreaking research with life changing results. TGen is focused on helping patients with neurological disorders, cancer, and diabetes, through cutting edge translational research (the process of rapidly moving research towards patient benefit). TGen physicians and scientists work to unravel the genetic components of both common and rare complex diseases in adults and children. Working with collaborators in the scientific and medical communities literally worldwide, TGen makes a substantial contribution to help our patients through efficiency and effectiveness of the translational process. For more information, visit: www.tgen.org. Follow TGen on [Facebook](#), [LinkedIn](#) and [Twitter](#)

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