

# AT A GLANCE

*Ticks Bite and We Fight!*



## Our State News

*By Sherry Sievewright, Board President*

*The Wisconsin Lyme Network was formed in hopes to help the Lyme community become more aware of the illness that rocks our state and the health concerns of all WI residents. It was formed by just a few women who had passion to get something done and to get the word out, to get doctors trained to deal with the problem and to help WI residents understand prevention options. To this day, the passion to make a difference still exists, however, our vision in what we have done until this point has changed. We realize that we are just one organization amongst many. Our visions of the past 9 years have not taken off in the direction we had hoped and for that reason, we are making some changes in our organization.*

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Over the last four years, the Wisconsin Lyme Network has tried to rebrand with a new logo, new website, new leadership, new vision and a new passion filled with hope. We have spoken to over 200 leaders at the Scout leaders training camp, we have had speaking engagements where we have been able to present and discuss Lyme Disease and tick borne illnesses to crowds ranging from 12-50. We had a table at the Pewaukee market several weeks to hand out information and speak with market attendees, sent one doctor for training, met with many patients, hearing their stories, shared Lyme literature doctors with hundreds of patients, sponsored a patient medical conference in La Crosse at a patient's request, and have tried to support our Lyme community as best we can with very few healthy hands.

We are going to keep up our Facebook presence and continue to send out newsletters with research and things of importance, especially with a push for support of the new tick-borne clinic in Woodruff, Wisconsin. They are doing exciting things and we want to support them in every way possible. We will no longer provide information on treating providers in the state.

We feel at this time there are very few doctors that are treating appropriately, and we do not like seeing patients in the hands of those who are only treating to make money at the patients' expense.

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We received this request for help in a story that is being written about Lyme disease. If you would like to participate please see the information below:

Hi, my name is Bram Sable-Smith.

I'm a reporter with Wisconsin Public Radio and Wisconsin Watch.

I'm working on a story now about Lyme disease I want to hear from you about your experiences with Lyme disease: the good, the bad, and the areas that might get overlooked in the media.

If you're interested in sharing your story with me, I've got a quick Google survey you can fill out at (<https://tinyurl.com/u4wrf6s>), or you can email me at [bsablesmith@wisconsinwatch.org](mailto:bsablesmith@wisconsinwatch.org).



Thanks!

### **Support WLN through the Amazon Smiles program**

Use this [link](#) when making purchases and Amazon will donate a portion of eligible purchases to WLN!

We will still do presentations upon request at the availability of those who are still volunteering their time.

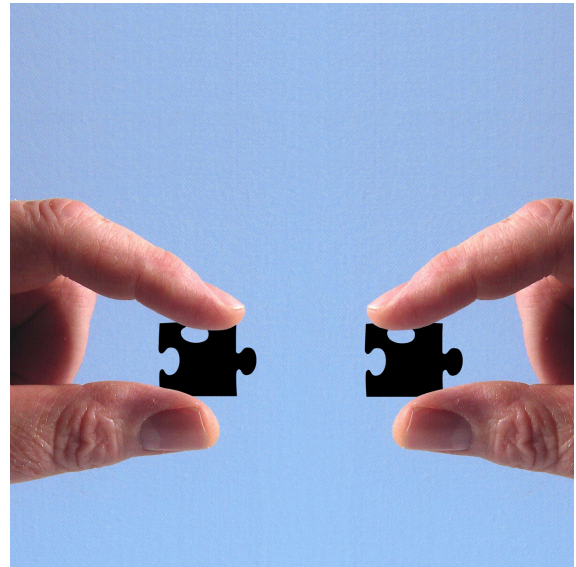
Our attempt to host a walk, run or gala have all but slipped through out fingers at the lack of wiling participants and we are unable at this time to pull them off without support. We are working on attending at least one trade show to help bring awareness to our state. We have also reached out to the organizers of the Ryder Cup taking place this fall in WI and are working on trying to get them to allow us to be present to share prevention materials.

Those of us who are involved will be able to do as much as possible to continue bringing awareness within our state through facebook and our website. We are just scaling down our vision.

Putting the puzzle together in what will best serve our state has been a dilemma we have all faced at the WLN. We want to help so many and yet we feel that we have been held back from putting the pieces together. We hope that in the next few years there will be a turn in the outlook for patients and that they will be able to see the complete picture with guidance on making the pieces fit to help them heal.

We thank all of those who came before us, and those who put hours of passion into bringing awareness to our state. Their efforts do not go unnoticed.

-Sherry



Exhibiting at  
**Outdoor Life & Stream Expo**  
Madison, Wisconsin  
April 3-5, 2020

## UPCOMING EVENTS

WE WILL KEEP YOU INFORMED AS  
DETAILS BECOME AVAILABLE FOR  
UPCOMING EVENTS.

The Tick Borne Illness Center of Excellence in Woodruff, Wisconsin, is seeing patients and is off and running with their research.

Take a look and see what's new:

## Tick Testing:

We currently DO offer clinical tick testing for \$69. If the tick being tested is a deer tick, then we test for *Borrelia burgdorferi*, Anaplasmosis, and Babesiosis. If the tick being tested is a non-deer tick, then we test for *Borrelia burgdorferi*, Ehrlichiosis, and Rocky Mountain spotted fever. We can also do a 6 pathogen panel for \$120.

For anyone wanting to send in a tick for research or for clinical diagnosis, the best way to send the ticks to us is by placing them on a piece of toilet paper/something that they will cling to and placing them in a plastic bag.

## Research:

The Center is currently recruiting for a multitude of different research studies:

The OMI-TBI Biobank– an ever growing collection of blood samples donated to be tested in a wide variety of ways. The biobank gives us the ability to find answers to current scientific unknowns in a timely and accurate manner. The biobank is held to a very high standard of testing– thoughtful and intuitive minds at work to pursue ideas that can be used in the scientific community and are regarded as accurate and trustworthy.

Acute Tick-Borne Illnesses– current diagnosis and treatment of acute tick-borne illnesses is challenging with many unknowns. In order to bridge this gap and create better clinical standards, we are seeking to recruit as many acute tick-borne illness patients as possible to join our Biobank Study. CDC Study on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in Children and Adolescents. We are seeking 200+ participants, ages 10-17, to be a part of this study on fatiguing illnesses. See flyer for more information!

CDC III Comparison Study on Multiple Sclerosis, Rheumatoid Arthritis, and Post- Cancer Fatigue– we are seeking 50 participants from each group, ages 18+, to be a part of this study on fatiguing illnesses. See flyer for more information!

CDC Study on Healthy Children and Adolescents– we are seeking 50+ participants, ages 10-17, to be a part of this study. These participants will provide a healthy baseline to compare to kids suffering from a fatiguing illness.

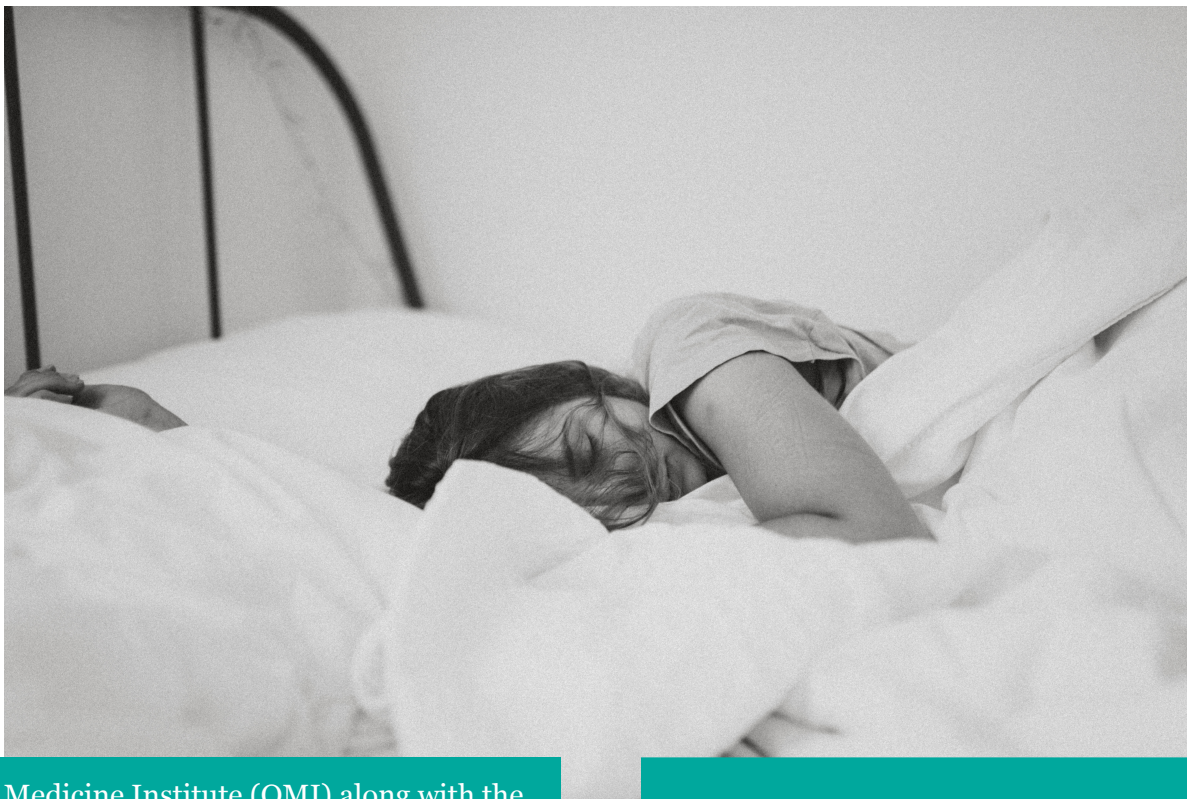
To get in touch with the research team at the Tick-Borne Illness Center please call 715-203-1616 or email [tbiresearch@openmedicineinstitute.org](mailto:tbiresearch@openmedicineinstitute.org).





# Are you a kid who struggles with Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME)?

**Consider volunteering for this research  
study!**



The Open Medicine Institute (OMI) along with the OMI-HYF Tick-Borne Illness Center (TBI) and the Center for Disease Control (CDC) are looking for children with CFS/ME between the ages of 10 and 17 years old to participate in our research study.

The study aims to use the data collected to better understand and treat fatiguing illnesses. If you or someone you know is interested in being a part of this study, please contact the research team at [research@openmedicineinstitute.org](mailto:research@openmedicineinstitute.org) or (650) 433-8930 x3004 to set up an appointment!

## **To Participate:**

- **Visit an OMI site for a free physical exam**
- **Complete a small blood draw**
- **Collect saliva swabs at home**
- **Fill out questionnaires via our secure online portal**
- **Receive a \$75 Amazon Gift Card upon completion**

# Currently have Multiple Sclerosis, Post-Cancer Fatigue, or Rheumatoid Arthritis? Help move research forward!



#25999216.0  
IRB Approved at  
the Study Level  
Nov 22, 2019

The Open Medicine Institute (OMI) along with the OMI-HYF Tick-Borne Illness Center (TBI) and the Center for Disease Control (CDC) are looking for participants with MS, RA, or Post-Cancer Fatigue to be a part of our research study. The purpose of the study is to better understand fatiguing illnesses through research on participants' biological samples and questionnaires.

Volunteers who participate will:

- Visit an OMI site for a free physical exam
- Complete a small blood draw
- Collect saliva swabs at home
- Fill out questionnaires via our secure online portal
- Receive a \$75 Amazon Gift Card upon completion

If you or someone you know is interested in being a part of this study, please contact  
**[research@openmedicineinstitute.org](mailto:research@openmedicineinstitute.org)** or  
**(650) 433-8930 x3004** for more information.

# WE HAVE PRETREATED SOCKS

## *Community Outreach*

The Wisconsin Lyme Network has been able to partner with a company that manufactures factory bonded repellent socks.

We have Womens/girls socks that are more colorful and look similar to the ski socks as well as mens/boys crew socks.

If you are interested, please go to our website and you can order them directly from our web store. If you have any questions, you may email us at [info@wisconsinlymenetwork.org](mailto:info@wisconsinlymenetwork.org).

Remember: Prevention is key to protecting yourself.



**Wisconsin Lyme Network**  
**[wisconsinlymenetwork.org](http://wisconsinlymenetwork.org)**

# Stories of Hope:

Parker's Lyme Story

Written by his mother: Brigitte Ryan

Parker is a 9-year-old little boy who loves basketball, riding his bike, swimming and being outdoors. He also has Lyme disease. He was diagnosed with Lyme disease in January of 2018 after months of trying to figure out what was causing his headaches and fevers. He ended up being hospitalized for a week and having to have a spinal tap done to see if his Lyme had traveled to his brain. From that test they were able to determine it hadn't traveled to his brain and he was prescribed 3 weeks of doxycycline. After a few days of being on the antibiotic his symptoms lessened and eventually he was feeling awesome again. About a week after finishing his course of antibiotics his symptoms came back. We made an appointment with his pediatrician to figure out what was going on. I went over with her that he was having the same exact symptoms and she said that it couldn't be Lyme symptoms still because he was treated and there for the Lyme was gone. To her there was no such thing as chronic Lyme.

At this point we were willing to try anything to get our son feeling better. We were referred to Alex Hartinger, an MFT practitioner, in Merrill. Over an hour drive one way for us to travel. She did something I like to refer to as witchcraft, but others call it muscle response testing. The testing was used to see what Parker was lacking in his body. From there she was able to distinguish what supplements would make him feel better. After about a week we started seeing great results and Parker's bad days were becoming less and less. Eventually he was symptom free and we chose to start weaning him off his supplements. We thought we had cured Lyme, and all would be well for our son. He was symptom free from April 2018-October 2018. Then he started having the same symptoms again but much worse. He was dizzy and so tired he was barely able to get off the couch some days. He began missing a lot of school and I began missing a lot of work. My momma heart couldn't handle being away when he wasn't feeling good. I ended up putting in my letter of resignation at a job that I loved so that I could be there for our son when he needed me.

We took him in to the urgent care clinic and they ran another Lyme test where he "tested positive" for Lyme. The urgent care doctor prescribed him a three-week course of antibiotics. His pediatrician didn't think he should be given another course of antibiotics so because of that we were referred to an infectious disease doctor and a pediatric neurologist. The infectious disease doctor told us he wouldn't need antibiotics because he didn't have Lyme anymore. He stated there was no such thing as chronic Lyme symptoms. The neurologist said his headaches were due to migraines and were of no connection with Lyme. The pediatrician referred us to a psychologist because the way he was feeling might just be in his head.

At this same time as this was being said to us, we were already getting outside of the box and taking him to any referral someone threw at us. We took him back to get tested again with Alex and we started him on a more rigorous course of supplements, added in NAET tapping technique with Dr. Khan at North Country Chiropractor, and purchased a rife machine and began running a Lyme code regimen on him daily. We investigated LLMD doctors but the closest was 4 hours away and at this point we were being depleted of funds as anything related to Lyme outside of a western medicine clinic is not covered under insurance and we were paying out of pocket for Parker's treatments. We just did not have the funds to pay for these specialized doctors.

There was at this point a Lyme clinic being put together that would be coming to Woodruff, WI which is only a 15-minute drive from our house. But it wasn't here yet and we were at a loss. Loans, Go Fund Me, having a benefit were all things we were considering. But he began slowly feeling better with the three treatments we were doing and was starting to have some great days.

Since December 15th, 2018 he has been feeling awesome. He had one flare up back in May of 2019. He sometimes complains of bone/joint pain occasionally but other than that he plays and does anything he sets his mind to. As of now his only treatment is doing the rife machine twice a month. The Tick-Borne Illness Center of excellence is now up and running in Woodruff. We had the honor to get a personalized tour of the facility since Parker is on the front cover of their magazine. The facility is incredible, and the staff are top notch. While I knock on wood a million times that Parker continues to feel AMAZING it also helps ease my worries that we have somewhere close we can take Parker in the future if problems were to arise.

There isn't a person in our area who doesn't know someone affected by Lyme. I hope research continues and that someday there is a cure. As the research continues, I also hope the CDC starts to recognize that Lyme can wreak havoc on a person and that there really is a thing called chronic Lyme.