Our State News

By Sherry Sievewright, Board President

The Wisconsin Lyme Network would like to send condolences to the Collins Family. Kristin Collins has been a voice and face in the Lyme community, bringing awareness and education to WI residents for well over 10 years now. She was a co-founder of WLN and still contributes greatly to the mission that we serve.

Kristin’s mom was her rock and biggest supporter when she was afflicted with Lyme disease. Unfortunately, Kristin and her family have had to say goodbye to their mom/wife/grandmother, Carol Jean Jacobson. Carol gave back greatly to her family, husband, children and grandchildren, community, neighbors and friends. She will be fiercely missed by all who knew her.

The WLN would also like to thank the Jacobson/Collins family for their generous donation, and contribution in memorial funds. Checks are still arriving, and we are so grateful.

From all of us who serve in the mission field of Lyme, its people like Carol who we thank. For their support and unending encouragement. She will be dearly missed.

- Sherry Sievewright
Looking for some great volunteer opportunities? Wisconsin Lyme Network needs you!

The Wisconsin Lyme Network is in need of individuals who are interested in leading the way in the State of Wisconsin to educate, bring awareness and share with others the debilitating effects of Lyme disease.

Through educating our communities, we will be sure to heighten awareness so that our medical facilities and health care professionals can no longer look past the symptoms and dismiss the cause. We need people who are willing to step up within the entire state, working with the Wisconsin Lyme Network.

If you feel this to be your calling, please sign up through our website or email us to let us know where you are located. Send us some of your ideas of how you can get assist us in this cause. We need more volunteers who are up to the task, who know Lyme disease and who are willing to share their stories.

Hope to meet you soon!

-WLN Board of Directors

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Lyme Research

Why Mainstream Lyme/MSIDS Research Remains in the Dark Ages by Alicia Cashman

Recently, a study came out by Wormser et al. on the efficacy of a 14-day course of amoxicillin for patients with erythema migrans (EM). The study purports to be the first clinical study in the U.S. that validates this regimen but admits numerous foreign studies have already done so (1).

The most glaring issue with this study is the continuing fixation on the acute stage while completely ignoring treated patients who remain ill. I refuse to say the words “late stage” as experience has shown “late stage” can happen within two weeks after a tick bite. Bob Giguere of IGeneX told our support group the story of a little girl who developed facial palsy and lost the ability to walk or talk within 4-6 hours of tick bite (2).

Whether or not you label that escalating case “late stage” or not, the infection was able to cross the blood brain barrier and cause severe symptoms in short order.

There were other numerous problems with the study:

1) The small sample size of only 24 patients.
2) The authors continue to use the “bullseye” rash when only 27-80% get the rash, depending on who’s counting, leaving out a large subset of patients (3).

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3) Regarding EM rashes, the study ignores evidence assessments and guideline recommendations that state clearance of the rash does not mean clearance of infection (4).

4) The continual denial of the pleomorphic (shapeshifting) & polymicrobial (numerous pathogen involvement) nature of this illness (5). Pleomorphism allows the organism to hide to reemerge later. Coinfection involvement can make cases more severe. Both issues should be factored into any treatment plan.

5) The lack of lengthy follow-up required due to the plethora of recorded treatment failures in the literature as well as the complete denial of the recommendation to continually treat patients who have not fully recovered until symptom resolution (2).

Microbiologist Tom Greer has written on the issue of treatment failure for years and states that from the very beginning, treatment failures were seen in nearly every antibiotic study done. He also states that the longer the patient follow up, the higher the treatment failure (6).

You would think the totality of these facts would set researchers on a different course yet researchers such as Gary Wormser seem determined on conducting yet more research with a severely limited patient group, short-term treatment and follow up, pushing the EM rash criteria, and ignoring those with persistent symptoms.

MSIDS patient and advocate Carl Tuttle has been working tirelessly to let researchers, the IDSA, the tick borne disease working group, and politicians know these significant facts by rebutting the continuing skewed & faulty research. He writes these entities personally and has also started the online petition Calling for a Congressional Investigation of the CDC, IDSA, and ALDF: https://www.change.org/p/the-us-senate-calling-for-a-congressional-investigation-of-the-cdc-idsa-and-aldf.

If you've always wondered what you can do to affect change, you can add your name to the over 70,000 who are refusing to accept the current standard of research and care. Then, if you have the energy, write these folks yourself. Tuttle includes all the pertinent information for you to cut and paste the material that will let your voice be heard.

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Circling back to the practical and important issue of treatment failure faced by many patients, there is hope. Dr. Burrascano recently made a must-see video for patient and doctor alike. Within this short 40 minute video he explains the sordid history of the mishandling of Lyme as well as the years of treatment trial and error within his own practice. He debunks much of what is blindly accepted in main-stream medicine, including the extremely biased and faulty science in Wormser’s study.

Video found here:
https://www.ilads.org/dr-burrascano-happy-holidays/

*Highlights:*

Dr. Burrascano’s office was 10 minutes from Shelter Island where Willy Burgdorfer collected ticks. Patients with mysterious symptoms graced his practice from inception.

Early Lyme was described in Europe even as far back as the 1800’s as causing dermatological, neurological, rheumatological, & neuropsychiatric problems. He claims that early history was lost.

In the U.S. as far back as 1965 a condition known as Montauk Knee was described as well as a circular rash that would clear up more quickly with penicillin. In 1970 the first paper was published about a physician who was infected while grouse hunting in our very own Wisconsin. Thankfully, the patient presented with EM rash and Dr. Rudolf J. Scrimenti, a Minnesotan dermatologist familiar with the European literature, effectively used penicillin during the acute phase of the illness (7).

Polly Murray of Connecticut contacted the CDC about an abnormal amount of sick kids with rashes and joint pain in the early 70’s and the CDC sent epidemiologist and rheumatologist Dr. Alan Steere to determine cause. Scrimenti wrote Steere and even went to Yale to warn him of the European studies and that Lyme clusters could exist in the U.S. Despite the warnings, Steere concluded what was occurring in Lyme, Connecticut was nothing more than an unrecognized form of juvenile arthritis. Later, Willy Burgdorfer found the cause to be Borrelia burgdorferi (Bb), commonly known as Lyme disease.

As early as 1985 Pathologist Alan McDonald developed a culturing technique that showed spirochetes in the blood. He proved patients can test negative (seronegativity) yet still have active infection as shown in blood culture. Seronegativity remains controversial to this day.

Some patients under Dr. Steere’s treatment in the 80’s got better but many didn’t. So he arbitrarily divided patients into two groups: Major symptoms: Cardiac, arthritic, Bells palsy and Minor symptoms: everything else. He claimed that successful treatment was the clearing of major symptoms, but 95% of patients with major symptoms found symptoms to clear on their own without any treatment, demonstrating his treatment theory was bogus. All those with “minor” symptoms he labeled post Lyme syndrome - a label which has persisted to this day, but there has never been a description explaining what this syndrome is from an immunological standpoint that applies to every patient.

Burrascano worked with dermatologist Bernard Burger and Pathologist Alan McDonald, and they cultured EM biopsies and antibiotic sensitivity studies. Decades ago they knew amoxicillin worked better than penicillin, doxycycline worked better than tetracycline, and while erythromycin worked in a test tube it didn’t work well in patients. Burrascano never ascribed to Steere’s pre and post Lyme categories but rather would treat and then wait a few weeks to culture. All the cultures came back positive. He learned even way back in the 80’s that these patients had continuing persistent Lyme infection.

He also manipulated drug levels. While some patients in Burrascano’s in house studies had detectable levels, others required higher doses to achieve the same level. If you don’t have detectable blood levels of antibiotics, you will not be killing pathogens. The CDC guidelines, be it the 200mg of daily doxycycline or the 500mg of amoxicillin given in the Wormser study, are both faulty in that they are a one size approach negating entirely the issue of effective drug blood levels. Burrascano is concerned the CDC is setting patients up for severe chronic Lyme.

While the recent Wormser et al study used 500mg of amoxycillin three times a day, Burrascano, decades ago, found patients had more improvement on 1000mg three times a day. When he added 500mg probenecid three times a day, which increases antibiotic blood levels, they improved even more. Regarding dosages, he explained about an unpublished study with Stoneybook where there was a failure rate of 100% of patients taking 300mg of doxycycline a day for 21 days. Yet, how many people are given this exact treatment today? He found patients required 400mg as a starting point with many needing 600mg.

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Armed with this intel, he then did clinical studies manipulating treatment time with amoxicillin and probenecid. Due to the varying clinical outcomes he defined treatment success as getting back to pre-illness state for 3 months without relapse. He found 14 days didn’t do much, with 17% doing well after 1 month, and 66% of males plateauing at 4 months, but hormonally active women not until 6.

Regarding Cefuroxime, he found that 3 weeks after treatment patients were still culture positive and complaining of symptoms after 14 days of high doses - a 100% failure rate. Eventually he discovered that Cefin did work on patients who failed amoxicillin if the dose was high enough for long enough.

Because patients weren’t getting better he took a week off work and sat down with his coworkers who created spreadsheets of all his patients. He found the following variables necessitated longer treatment:

- Multiple bites
- Active lyme arthritis with a high Sed rate
- Heart murmurs
- Hormonally active women

He found IV’s can give much higher blood levels of drugs than orals and that the following variables necessitated IV treatment:

- Spinal tap shows high inflammation (high protein)
- High Sed rate and synovitis (inflammation of synovial membrane)
- People sick for more than 1 year
- Age over 60
- Acute carditis
- Immune deficiency
- Those who used immunosuppressants
- Failed oral treatment

He also found Lyme has a 4 week cycle, where every 4 weeks patients experience a symptom flair. Burgdorferi found this in mice studies, and IGeneX found the same thing in urine antigen studies. Borrelia grow and are active, then become inactive. Four weeks later they activate. This has been shown recently in vitro. Think of Bb as a slow relapsing fever. This nuance is important because antibiotics only kill during the active phase.

You need a minimum of a month to bracket a whole generation cycle.

When patients reach a plateau, he recommends cycling therapy where you discontinue antibiotics until symptoms return. Then, return to full treatment. He states that many patients become symptom free after 4 cycles. He used this on himself with success.

Burrsacano found 3 other physicians doing the exact same thing with patients. This approach worked for all of them despite the different geographical areas they were in.

The government came up with a gold stain for detecting Bb, and found Bb excreted bioproducts and an S layer (slime to create a biofilm) even in the dormant phase. Their work even then showed infected animals had gold stained spirochetes in the following areas: bladder, brain, blood, heart, liver, spleen, urine, tears, in ticks.

The government in conjunction with Burrsacano conducted studies on 73 chronically ill lyme patients. Bb was found in 48 of 50 samples of tears, showing that 53% still had living borrelia antigens that could be seen on the gold stain. They also found if you tested patients who still had symptoms and then took a couple weeks break for treatment, 100% still were positive for Lyme (living organisms) by gold stain. The NIH abruptly stopped funding of gold stain, made them close the whole thing down, and never asked front-line lyme docs for specimens again.

Burrsacano states that in those early days they didn’t know anything about co-infections but patients did well on the lyme-only treatment at that time; however, the patients that did show involvement were the ones who appeared chronically infected. He found if patients were treated early and hard for Lyme the co-infections weren’t a problem for most.

Burrsacano then discusses the importance of proper exercise for Lyme patients and that without exercise, patients don’t recover. The goal of exercise is to increase T-cells so exercise cannot be too strenuous or too often. He recommends light exercise making sure to give enough time in between sessions for the body to recover. It is also important to get good sleep and to rest as needed.

He gave the story of how Macdonald presented his culture findings (direct testing) at a meeting of the NY State medical society where there were many detractors from Yale & Stoneybrook who didn’t want their patented serological tests to be usurped. They accused him of falsifying his results. Macdonald then went on to prove conclusively it was Lyme by morphology, silver staining, monoclonal antibodies staining, DNA PCR and finally electron microscopy. He quit the field and moved to TX leaving all his old files in Burrsacano’s basement until twenty years went by and he got interested again due to Alzheimer’s research & picked up his old files.

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Burrascano connected McDonald with Eva Sapi to develop a culture technique based on McDonald’s 1985 test. Advanced Lab contracted with Sapi to develop a commercial test using human specimens instead of lab specimens, and they went on to perform over 8,000 successful cultures of which published studies showed the test was 92% sensitive, and 100% specific. Advanced labs closed but sold the test to iGeneX & it is currently in the process of getting approval.

Dr. Burrascano’s timely and detailed video reveals clearly why many remain ill. There are nuances to treating MSIDS that researchers are still not taking into account, which means doctors are utilizing flawed and biased studies from the Dark Ages in treating patients. They continue to fixate on the acute phase, ignore published animals studies, international studies, and the advice and work of experienced Lyme doctors, advocates, and patients.

It is imperative that we continue to educate ourselves and others so we do not fall prey to ancient perceptions of a disease that has become a pandemic.

Medicine fails when it quits listening.

References:


Upcoming Support Group Meetings:
(More details on our website about the support group meetings near you.)

Madison:
Saturday March 9 (2019) from 2:30-4:30 East Madison Police Station, 809 S Thompson Dr.
Madison, WI 53718

If you are part of a group that meets monthly or weekly, please send us your schedule so we can post on future newsletters.
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.

Remember: Prevention is key to protecting yourself.

Wisconsin Lyme Network
wisconsinlymenetwork.org
LEARN ABOUT LYME WORKSHOP

Lyme and other tick-borne diseases continue to rise in our area. Hear from experts in this field, who will share evidenced-based information and education on this rapidly growing health concern. Whether you are looking for prevention tips or are suffering the effects of a tick-borne disease, this day is for you. Please join us as we discuss the number one vector-borne disease in the United States.

Date: Saturday, March 23, 2019
Time: 9am to 4pm
Location: Black River Beach Neighborhood Center
1433 Rose Street, La Crosse, WI
Cost per Participant: $10  *Gluten Free/Dairy Free lunch is included.

To register for this workshop, please visit our City of La Crosse Parks & Recreation website at https://www.cityoflacrosse.org/Parks or, call 608-789-8640.

**Registration Deadline: Monday, March 18, 2019

Guest Experts Include:

Dr. Elizabeth L. Maloney
Rebecca Keith, Family Nurse Practitioner
Phillip Pratt, Coppe Laboratories
Erika Schlick, IIN Certified Health Coach
Cookbook Author & Blogger

*This event is supported by the Wisconsin Lyme Network and the Minnesota Lyme Association.*
Workshop Presenters:

**Dr. Elizabeth L. Maloney** is the President of Partnership for Tick-Borne Diseases Education, a non-profit organization providing online and live evidence-based continuing medical education programming and materials on tick-borne diseases for physicians and other healthcare professionals. She is a graduate of the University of Minnesota Medical School and its affiliated Family Medicine residency.

Dr. Maloney also acts as a consultant to government agencies and private organizations. She recently served on the Pathogenesis, Transmission and Treatment subcommittee of the federally mandated Tick-borne Diseases Working group. She frequently speaks to the general public on tick-borne diseases, emphasizing the need for primary and secondary prevention.

**Rebecca Keith, Family Nurse Practitioner**

Keith obtained both her undergrad and graduate degrees from the College of St Scholastica in Duluth, MN. Having spent most of her life in Wisconsin and actively enjoying the outdoors, ticks and insects are no strangers to her. Rebecca began paying more attention to Lyme and co-infections by 2008. After experiencing success in treating patients she opened her practice in 2010. Rebecca primarily sees patients in Minong, WI. Rebecca is a member of ILADS, Lymedisease.org, and the American Academy of Nurse Practitioners. She utilizes integrative medical approaches in treating Lyme and the multi system dysfunction which accompanies it.

**Erika Schlick, IIN Certified Health Coach | Cookbook Author and Blogger**

Erika Schlick is a Certified Health Coach and Author of the Wandering Palate which features 28 days of travel inspired paleo meals to make it easy to stay on track and eat healthy. She herself was affected by Lyme in 2012 and was diagnosed in 2014. After 3 years of treatment, she has been in remission for over 2 years and has made it her life mission to help others affected by Lyme.

She is also the voice behind The Trail To Health ([www.thetrailtohealth.com](http://www.thetrailtohealth.com)) which is a health and wellness blog documenting her journey with Lyme disease and everything she learned about health along the way.

**Phillip Pratt, Coppe Laboratories**

Coppe Laboratories is dedicated to discovering and providing diagnostic and treatment solutions for illnesses caused by infectious agents. We offer quality diagnostic testing that exceeds regulatory expectations and provides clear answers with actionable results. We strive to eliminate barriers experienced by physicians and patients in the diagnosis and management of disease through scientific research and innovative diagnostic assays.

Coppe Laboratories uses their scientific expertise to transform novel procedures routinely used in the research setting into high-complexity, CLIA-certified diagnostic tests. This work, in conjunction with groundbreaking research and development, makes Coppe Laboratories a leading provider of diagnostic tests for arthropod-borne disease, women’s health and transplant.