



The Nelson Family Project

Lyme Disease & Co-Infections

Tips & FAQs

Prevention first!

People: <https://www.lymedisease.org/lyme-bas.../.../personal-protection/>

Pets: https://lymediseaseassociation.org/.../Current/LDA_PetSpot.pdf

I found a tick! Now what?

<http://www.ilads.org/lyme/what-to-do-if-bit-by-tick.php>

https://www.lymediseaseassociation.org/.../LDA_TickRemoval.pdf

Where can I get my tick tested?

<https://www.ticknology.org/order-test.html>

<https://www.tickreport.com/pricing>

https://igenex.com/.../upl.../2018/01/TICK_TEST_REQUEST_FORM.pdf

Note: Alpha Gal Meat Allergy is not included in the testing.

<https://www.lymedisease.org/tick-bites-meat-allergy/>

Tick Report has tick tests for tick-borne viruses available, but Ticknology does not have that yet.
Ticknology is cheaper and does each test on each type of tick, though.

If the tick is attached for less than x hours, I'm good- right? FALSE!

<https://www.partnershipfortick-bornediseaseseducation.org/...>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4278789/>

<https://sites.google.com/site/getitrighttreatthebite/>

Common Misconceptions

<https://www.lymedisease.org/lyme-disease-myths/>

<http://danielcameronmd.com/importance-second-opinion-proph.../>

Are there other ways to get the infections?

<https://sites.google.com/s.../drjoneskids/transmission-methods>

How do I know if I have one of the infections?

<http://igenex.com/>

*Tip: You can get the most bang for your buck by ordering the bundle. For example Lyme Panel A combines WB IgM, WB IgG, PCR serum, PCR w blood. Individually, those tests are roughly \$200 each, but if you get the bundle, you would pay roughly \$550. So, you would be saving \$234.

*A Lyme Literate Doctor will know what tests to order based on each situation (including testing for issues with similar symptoms).

* Igenex includes bands 31 and 34 on the western blot which most labs don't because of the failed Lyme vaccine that was taken off the market.

<https://www.galaxydx.com/>

*We like this one for Bartonella testing because they look for multiple strains.

<https://sites.google.com/.../lab-te.../tests-explained--dr-crist>

<https://sites.google.com/.../lab-t.../are-lyme-tests-accurate-no>

<https://lymemd.blogspot.com/.../lyme-with-igm-western-bloat-b...>

When do I suspect Lyme?

For general information, start here:

<https://www.lymediseaseassociation.org/.../LymeRPrimer-2013.p...>

https://www.lymediseaseassociation.org/.../LDA_B.../ABC_2009.pdf

Dr. Joseph Burrascano, MD developed a symptom list which can be filled out to give you an idea whether you have Lyme, or a co-infection. Please fill it out and bring it to your provider.

https://www.lymediseaseassociation.org/images/NewDirectory/Resources/DrB_SymptomList2005Pdf.pdf

This comparison list of Lyme disease and co-infection symptoms may help you decide what tests you need.

<http://lyme-symptoms.com/LymeCoinfectionChart.html>

Diagnosis & Symptoms

<https://www.partnershipfortick-borndiseaseseducation.org/...>

<https://www.lymedisease.org/lyme-ba.../lyme-disease/diagnosis/>

<http://www.angelfire.com/biz/romarkaraoke/whento.htm>

What are the best treatment guidelines, so far?

<http://www.ilads.org/lyme/treatment-guideline.php>

*No guidelines are perfect, but at least ILADS takes different circumstances into account and understands that not everyone is the same. They also do a better job of staying up to date on current research. We would love for them to talk more about OSP A and how that plays into all of this, though.

How do I find a doctor?

*Hopefully, you are one of the lucky ones whose doctor will take it seriously. (That means not subscribing to the CDC way of thinking) If not, have no fear- there is a plan B.

Maine References-

www.mldse.org/p/blog-page_29.html

*Support Groups are also good places to figure out who the best professionals in your area are. See list on last page.
Out of State-

*Note: Both of these also have Maine names along with other states and countries.

<https://www.lymediseaseassociation.org/doctors>

http://ilads.org/ilads_media/physician-referral/

What if I need financial assistance to help with my diagnosis or treatment?

<https://www.lymedisease.org/financial-assistance/>

*Another Tip: Don't be afraid to ask the Lyme doctor whether they have a super bill (if they don't take insurance), or if they have a sliding scale (if money is fairly tight).

What does "Lyme-Friendly" mean?

- Willing to recognize flaws in CDC/IDSA and ALDF thinking when it comes to Lyme, co-infections, and related issues
- Open to learning and looking at research brought to them
- Willing to work with other providers, including Lyme literate
- Not standing in the way of progress or being condescending
- Open to all types of illnesses that share similar symptoms or can be caused/triggered by Lyme

What does "Lyme-Literate" mean?

- Uses ILADS as a resource
- Stays up on research
- Willing to work with other providers when needed
- Treats Lyme and co-infections, but NOT by CDC/IDSA or ALDF standards
- Open to all types of illnesses that share similar symptoms or can be caused/triggered by Lyme

I need more information. Where can I find it?

The Nelson Family Project has created a Lyme Resource Card which contains links to eighteen reliable resources, the names of six good books on the infections, as well as a link to online training which can be accessed by healthcare providers and patients.

To receive a hardcopy, or an electronic version, of **The Nelson Family Project Lyme Resource Card**, please send an email to thenelsonfamilyproject@gmail.com.

How can I be a good friend to someone with a chronic illness?

<http://lymewarrior.us/>

- *This book about friendship and Lyme was written for kids, but an adult could benefit from it, too.
- * You can also find info about Smile Boxes for kids who have Lyme Disease and fundraisers for research.

Lyme Disease Support Groups in Maine

Please make contact before attending to be sure that they are active.

BREWER

Second Tuesday of the month, 6pm
Brewer Community School,
9 Pendleton St., Brewer, ME
FMI: Lisa Jordan (207) 561-9391
Email: ljordan@breweredu.org

BRUNSWICK

First Tuesday of the month, 6pm
Omega Wellness, Therapia, and Farm Fresh Cafe
12 Industrial Parkway
Brunswick, ME 04011
FMI: (207) 837-6542
Email: info@omegawellness.org
Website: www.omegawellness.org

BRUNSWICK

Midcoast Lyme Disease Support and Education
First Wednesday of the month, 6pm-8pm
Midcoast Hospital (conference rooms 1&2)
123 Medical Center Dr., Brunswick, ME
FMI: Paula Jackson Jones [207-446-6447](tel:207-446-6447) or
Angele Rice [207-841-8757](tel:207-841-8757)
Email: info@mldse.org

DAMARISCOTTA

Midcoast Lyme Disease Support & Education
Third Monday of the month, 1pm-3pm
Damariscotta First Baptist Church
5 Bristol Rd., Damariscotta, ME
FMI: Paula Jackson Jones [207-446-6447](tel:207-446-6447) or
Angele Rice [207-841-8757](tel:207-841-8757)
Email: info@mldse.org

ELLSWORTH

Lyme Disease Support Network
First Tuesday of the month, 6pm-8pm
Beth C. Wright Cancer Resource Center
23 Commerce Park, Ellsworth, ME
FMI: Daaby (207) 479-7130

LEWISTON/AUBURN

Second Monday of the month, 6:30pm-8:30pm
Olive Branch Cafe-ARK (formerly Old Pizza Hut),
791 Lisbon St., Lewiston, ME
FMI: Dennis & Cheryl Farley (207) 623-4679
Email: ready.set.go.healthy@gmail.com

LYMAN

Southern Maine Lyme Disease Support Group
Third Saturday of the month, 10:30am-12:30pm
Lyman Library
10 John St., Lyman, ME
FMI: Brian & Elaina Lagassie
Email: lagassie@roadrunner.com

NORTH YARMOUTH

Lyme Busters: Friends for Hope
First Monday of each month, 6:30pm-8pm
Skyline Farm
95 The Lane, North Yarmouth, ME
FMI: Doreen Wilcox (207) 829-4358
Email: dwilcox5@gmail.com

NORWAY

Last Tuesday of the month, 6pm-8pm
Fare Share Co-Op Store
443 Main St., Norway, ME
FMI: Tracy (207) 674-3781; cell (207) 381-7096
Email: tracy04219@yahoo.com

PORTLAND

First Wednesday of the month, 6pm-8pm
Maine Medical Center, McGeachey Hall
216 Vaughan Street, Portland, ME
FMI: Vicky (207) 797-5360
Email: portnorth101@gmail.com

ROCKLAND

Midcoast Lyme Disease Support and Education
Second Tuesday of the month, 6pm-8pm
The Knox Center (Long-term and Rehab Building)
6 White St., Rockland, ME
FMI: Paula Jackson Jones [207-446-6447](tel:207-446-6447) or
Angele Rice [207-841-8757](tel:207-841-8757)
Email: info@mldse.org