

2018

Developed by the  
Carantouan Greenway

# Lyme Disease



## Lyme and Tioga County

Tioga County is facing a growing public health concern for Lyme disease, which accompanies the growing tick population in our region. In response, the Carantouan Greenway has sponsored the "Youth Ticks and Lyme Disease Educational Awareness Campaign", bringing information resources and presenters to 1,330 students at 6 Tioga County schools.

Questions?

[valleylyme@gmail.com](mailto:valleylyme@gmail.com)

## In This Issue

- Prevention
- FAQs
- Diet
- Local Support Groups

And More

Image: Image: nysenate.gov

## Supporting Lyme-Tick Youth Education

The project involves a collaboration with Southern Tier Lyme Support, A Hope for Lyme, PA Lyme Resource Network, Tioga County Public Health Department, Binghamton University, Waverly and Tioga Central School Districts and the Carantouan Greenway. The program has been funded by Community Fund of the Community Foundation for South Central New York (CFSCNY) and the Floyd Hooker Fund of the Community Foundation for the Twin Tiers (CFTT).

Information resources, presenter time and tweezers were donated by the Tioga County Public Health Department. Packaging materials were provided by the Morning Times.

For more information, visit:

[www.carantouangreenway.org](http://www.carantouangreenway.org)



Tioga County Public Health Educator Kylie Holochak, with Waverly student Cameron McIsaac. The project is dedicated to Cameron's grandmother, Barbara McIsaac, for her spirit and inspiration.

## What should I do if I am bit by a tick?

- 1) It's important to remove the tick as soon as possible. The longer the tick is attached, the higher the likelihood that pathogens will be transmitted to you.

## How to Remove a tick

1. Use pointy tweezers
2. Grab the tick as close to the skin as possible
3. Pull straight up with a slow steady motion  
[http://tickencounter.org/prevention/tick\\_removal](http://tickencounter.org/prevention/tick_removal)
4. Consider Tick Testing



*Marty Borko Presents  
on Lyme Disease at  
Waverly Central School  
District*

## How NOT to remove a Tick

1. Do NOT Burn the tick
2. Do NOT put anything on the tick including dish detergent, essential oils, vaseline
3. If you do any of these things and irritate the tick, the tick may regurgitate the contents of their stomach and transmit pathogens to you.

## After removing the tick properly

1. Clean the bite area with rubbing alcohol or soap and water
2. Wash your hands and the tweezers as well

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### **Do NOT throw the tick away**

1. Put the tick in a ziplock bag with a moist cotton ball or piece of paper towel and send for testing.
2. You can send the tick out for testing to any of the following:
  - 2.1. Ticknology [www.ticknology.org](http://www.ticknology.org)
    - 2.1.1. Test for 12 pathogens \$35
  - 2.2 Umass [www.tickreport.org](http://www.tickreport.org)
    - 2.2.1 \$50-\$200 depending on number of pathogens
  - 2.3 Cornell: <https://ahdc.vet.cornell.edu/programs/tick/public.cfm>
    - 2.3.1 \$100-includes up to 6 ticks at one time
  - 2.4 Igenex <http://www.igenex.com/testing/tick-testing/>
    - 2.4.1 \$68 per pathogen up to 20 ticks at once
3. Or you can save the tick in the freezer and watch for symptoms (Notate date and any other details)
  - 3.1. If there are any signs of illness-consider testing the tick and see your physician immediately.



*Waverly  
students  
inspect ticks  
through  
microscopes*



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### Protect Yourself

#### 1. How to Dress

- 1.1. Wear Light colored clothing
- 1.2. Wear Long pants
- 1.3. Wear Long sleeved shirt
- 1.4. Wear a hat
- 1.5. Tuck pant legs into socks
- 1.6. Wear Clothing treated with Permethrin
  - 1.6.1. Spray your clothing with Permethrin-Lasts 5 or 6 washings
  - 1.6.2. Purchase pretreated clothing-Lasts 70 washings
  - 1.6.3. Send your clothing to be treated-Last 70 washings  
[www.insectshield.com](http://www.insectshield.com)
  - 1.6.4. Dr. Frid Kidswear [www.drfrid.com](http://www.drfrid.com)

#### 2. Tick Repellent for bare skin

- 2.1 Deet- at least 20%
- 2.2 IR3535
- 2.3 Picaridin
- 2.4 Natural Repellents
  - 2.4.1 May not be as effective as the chemical repellents
  - 2.4.2 Will need to be applied more frequently

#### 3. After being outdoors

- 3.1 Remove your clothes immediately preferably in the garage and leave your shoes in the garage or outside too
- 3.2 Put your clothes in the dryer on high heat for 10 minutes
- 3.3 Shower within 2 hours of coming indoors, to eliminate loose ticks
- 3.4 Do a tick check on yourself, children and pets
- 3.5 Behaviors putting children at high risk of Lyme:
  - 3.5.1 Walking in the woods
  - 3.5.2 Playing in grass and leaves
  - 3.5.3 Playing sports outside
  - 3.5.4 Playing with pets

## FAQs

### **My child did not see a tick. Could he/she still have Lyme disease?**

- Yes. Less than 50% of Lyme patients recall a tick bite

### **What does it mean if my child gets a bullseye rash?**

- The rash is diagnostic for Lyme disease. If you see a bullseye rash, your child has Lyme disease
- No testing is necessary
- Treatment should begin immediately

### **My child did not have a bullseye rash. Could he/she still have Lyme?**

- Yes. You can still have Lyme disease without the bullseye rash.
- Less than 50% of patients get a rash
- The rash may appear differently than a bullseye.
- The rash may appear at the site of the bite or in another location.
- Multiple bullseyes can appear
- A rash could be hidden in the hairline and not visible
- Source: <https://www.ncbi.nlm.nih.gov/pubmed/17945460>

### **Why is my child still sick after receiving initial treatment of antibiotics?**

- The Lyme is still active and will require additional treatment
- They could have coinfections like Babesia, Bartonella, Rocky Mountain Spotted Fever, Anaplasmosis, etc...

### **What should I do if my child does not fully recover after the initial treatment?**

- Request additional treatment from your doctor
- Find a Lyme Literate Doctor

### **How can I find a specialist?**

- Contact your local support group for information

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- Contact ILADS [http://ilads.org/ilads\\_media/physician-referral/](http://ilads.org/ilads_media/physician-referral/)
- Send an email to: [referral@palyme.org](mailto:referral@palyme.org)

### What are coinfections?

- Ticks can carry many bacteria, viruses, fungi and protozoans all at the same time and transmit them in a single bite. The most common tick borne diseases are:
  - 1.1. Lyme
  - 1.2. Bartonellosis
  - 1.3. Babesiosis
  - 1.4. Rocky Mountain Spotted Fever
  - 1.5. Ehrlichiosis
  - 1.6. Anaplasmosis
  - 1.7. Relapsing Fever
  - 1.8. Tularemia
  - 1.9. Disease carried together like this are called coinfections.



*Marty Borko presents ticks and students analyze tick habitat exhibit*



## What are the symptoms of Lyme disease?

- Symptoms can be nonspecific, vague and changing
- severe fatigue unrelieved by rest
- insomnia
- headaches
- nausea, abdominal pain
- impaired concentration
- poor short-term memory
- inability to sustain attention
- difficulty thinking and expressing thoughts
- difficulty reading and writing
- being overwhelmed by schoolwork
- difficulty making decisions
- confusion
- uncharacteristic behavior
- outbursts and mood swings
- fevers/chills
- joint pain
- dizziness
- noise and light sensitivity
- And many more.



*Binghamton University's Mandy Roome includes student gaming with Lyme symptoms dart board.*

## **What if my child has symptoms, but has a negative test result for Lyme disease?**

- Source: <https://www.lymedisease.org/lyme-basics/lyme-disease/diagnosis/>
- Testing is inaccurate
- Gold standard laboratory tests are not yet available. Current tests can miss a substantial % of active Lyme disease. The 2 tier serology blood test (Elisa and a follow-up Western Blot) is an indirect test which measures the immune response to Lyme bacteria. This test has been found to miss as much as 75% of confirmed cases of early Lyme disease
- Lyme disease is a clinical diagnosis—based on your medical history, symptoms and exposure to ticks. Because the typical diagnostic tests for Lyme are so insensitive, a negative test result does not mean you don't have Lyme. ([www.lymedisease.org](http://www.lymedisease.org) )
- Find a Lyme Specialist

## **What type of Diet should my child be on**

- Whole food diet is best
- Sugar free
- Gluten free
- Eat whole foods including fruit and vegetables
- Look on internet for paleo recipes



*Youth Lyme Disease and Tick Educational Awareness*



## Local Resources: Information and Support

### Valley Lyme Support Group

- [valleylyme@gmail.com](mailto:valleylyme@gmail.com)
- Support Group Meeting
- 1st Tuesday of the month 5:30-7:30pm at Spalding Memorial Library 724 S. Main St. Athens PA

### A Hope 4 Lyme

- <http://ahope4lyme.org/>
- Support Group Meetings: Please check their website for information

### Southern Tier Lyme Support Inc

- [www.southerntierlymesupport.org](http://www.southerntierlymesupport.org)
- Support Group Meeting
- 2nd Monday of each month at 5:30-7:30pm at Town of Chenango Municipal Building 1529 State Route 12 Binghamton, NY

### Support Groups on Facebook

- Southern Tier Lyme Support Group
- Baby Buhner, Cowden, Klinghardt and more
- Lymie Moms Unite

*Kylie Holochak  
Public Health Educator  
Tioga County Public Health  
Discusses Ticks with  
Students*



## **Additional Resources**

### **Book-When Your Child Has Lyme Disease**

- <https://www.amazon.com/When-Your-Child-Lyme-Disease/dp/0996224300>

### **Presentations**

- **Video of Dr. Frid discussing how Lyme Disease affects children**  
<https://www.youtube.com/watch?v=47RcqOAwbWY&feature=share>
- **Video of Dr. Kenneth Bock (2017) discussing Brain Inflammation: The role of the Dysregulated Immune system in Pans/Pandas, Lyme Disease and ASD** <https://www.southerntierlymesupport.org/past-conference/#2017>

### **Articles**

- <http://danielcameronmd.com/lyme-impact-school/>
- <http://danielcameronmd.com/?s=case+report+children>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4278789/>
- <https://www.lymediseaseassociation.org/index.php/about-lyme/lyme-kids-a-schools/525-lyme-disease-and-children-critical-issues>

### **Children's Lyme network**

- <http://www.childrenslymenetwork.org/>

### **Lyme Disease.org**

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

### **Get it Right Treat the Bite**

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

### **Lyme Action Network**

- [www.lymeactionnetwork.org](http://www.lymeactionnetwork.org)

### **Detoxification**

- <http://www.tiredoflyme.com/detox-methods.html>

### **Brochures on prevention (bottom of page)**

- <https://palyme.org/dare-2b-tick-aware/>

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### Financial Resources for Children

- **Lyme Light Foundation** <https://lymelightfoundation.org/grants/>
  - **Liv Lyme Foundation** <http://livlymefoundation.org/grants/>
  - **Lyme Tap** [http://www.lymetap.com/lyme-disease-lab\\_tests](http://www.lymetap.com/lyme-disease-lab_tests)
  - **Needy Meds** <http://www.needymeds.org/>
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### Special Thank You

With special thanks to the Southern Tier Lyme Support, A Hope for Lyme, PA Lyme Resource Network, Tioga County Public Health Department, Binghamton University, Waverly and Tioga Central School Districts and especially the Community Fund of the Community Foundation for South Central New York (CFSCNY) and the Floyd Hooker Fund of the Community Foundation for the Twin Tiers (CFTT).

