

# About PA Lyme Resource Network

PA Lyme, founded in 2012, is a 501(c)(3) non-profit organization chartered for charitable and educational purposes. We are a coalition of all-volunteer, non-profit organizations across the state committed to education, patient advocacy, support and prevention of Lyme and other tick-borne diseases.

- 1) **Education and Prevention:** We provide speakers, seminars, resources, patient networks, research and legislative updates for the general public, medical professionals, schools, private businesses and government entities.
- 2) **Advocacy:** Patients must be fully informed to make good healthcare choices. We encourage patients to advocate for themselves, supporting this goal by providing them with up-to-date information.
- 3) **Support:** Coping with a complex, poorly understood illness is overwhelming. We support regional and independent PA Lyme groups that hold local meetings and provide support, education and resources to their local communities.

For legislative updates, visit [www.lymeactionpa.com](http://www.lymeactionpa.com), a state-wide Pennsylvania legislative coalition.

 Lyme Action PA

## PA Lyme Resource Network Regions

### Delaware County Region

 PALRN Delco Region  
Contact: [delcolyme@palyme.org](mailto:delcolyme@palyme.org)


### Harrisburg Region

 Harrisburg Area Lyme Disease Support Group  
Contact: [harrisburglyme@palyme.org](mailto:harrisburglyme@palyme.org)


### Lancaster County Region

Contact: [lancasterlyme@palyme.org](mailto:lancasterlyme@palyme.org)


### Lehigh Valley Region

 Lehigh Valley Lyme Support Group  
Contact: [lehighvalleylyme@palyme.org](mailto:lehighvalleylyme@palyme.org)


### Montgomery County Region

 PA Lyme Resource Network - Montgomery County Region  
Contact: [montcolyme@palyme.org](mailto:montcolyme@palyme.org)

### Tioga County Region

 A Hope 4 Lyme  
Contact: [tiogacountylyme@palyme.org](mailto:tiogacountylyme@palyme.org)

### York County Region

 York Lyme Disease Support Group  
Contact: [yorklyme@palyme.org](mailto:yorklyme@palyme.org)

Additional support groups listed on [www.palyme.org](http://www.palyme.org)



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 PA Lyme Resource Network

 @PALyme1

Local Support Group Information:

# Providing Lyme and Tick-Borne Disease Education, Resources and State-Wide Support Groups



## Did you know...

- ▶ PA is the #1 state in diagnosed cases of Lyme disease for the past 5 years
- ▶ Deer ticks have been detected in all 67 counties
- ▶ Deer ticks carry Lyme and 10 other co-infectors
- ▶ A study in a northeast PA national park revealed that 63% of ticks were infected with Lyme
- ▶ Children ages 5-14 are most at risk
- ▶ Columbia University found a 22 point drop in IQ in children with Lyme
- ▶ A 2011 study found over 80% of chronic fatigue patients improved substantially when treated for presumed persistent Lyme disease
- ▶ Several studies have connected Lyme disease to autistic spectrum disorder

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

## What is Lyme Disease?

**LYME DISEASE** is a bacterial infection, most often contracted from a tick bite. Lyme may initially cause a “flu-like” illness, and left untreated it can affect multiple body systems and organs: the brain stem, heart, gastrointestinal tract, joints, muscles and more. The bacteria are spirochetes (SPY-ROH-KEETS) called **Borrelia burgdorferi**.

**CO-INFECTIONS** are the other infections that can be contracted at the same time one is infected with Lyme. Many ticks now carry one or more of the following: Bartonella, Babesiosis, Ehrlichiosis, Anaplasmosis, Rocky Mountain-Spotted Fever, Protomyxzoa Rhuematica, Q-Fever, and Mycoplasmosis.

## Symptoms\*

**BULL’S EYE RASH:** 50% of Lyme patients never see a bull’s eye rash; it’s diagnostic if it appears. Initial “flu like” illness, bell’s palsy (facial paralysis), fever, extreme/ persistent fatigue, headache, stiff neck and shoulders, sore throat, nausea, vomiting, muscle aches, muscle twitching, insomnia, sleep disorders, speech disorders, word finding difficulty, memory issues, dyslexia (letter, number or word reversals), nightmares, suicidal thoughts, TMJ, dry eyes, GI problems, brain fog, newly developed allergies, hormonal fluctuations or changes, depression, anxiety, exercise or alcohol intolerance, night sweats, swollen glands, heart palpitations, low body temperature and more.

*\*not an all-inclusive list*

**IN CHILDREN:** Untreated/undertreated Lyme disease can have a profound impact on a child’s life, cognitive function and ability to perform successfully/meaningfully in school and with others. It can diminish normal age appropriate socialization. Compromised function includes: severe fatigue, ADD/ADHD, decreased attention span, difficulty thinking, expressing, reading, writing and making decisions, uncharacteristic outbursts, confusion, tics, insomnia, nightmares and other symptoms. Early identification and diagnosis is imperative to the future health and wellbeing of the child.

## 25% percent of Lyme disease cases involve children under age 14!

## Patient Challenges

**LYME TESTS:** The 2-tier standard serology used to detect Lyme disease is inadequate. The first test regularly used, the ELISA test, is 65% sensitive compared to the standard 95% sensitivity expected for most screening tests. Sero-negativity is a widely recognized issue. **Standard tests fail to properly diagnose over half of Lyme positive cases.** The US Centers for Disease Control (CDC) has said, “the diagnosis of Lyme disease is based primarily on clinical findings,” and yet many doctors incorrectly rely on unreliable and inaccurate blood tests to determine if a patient has Lyme disease.

**MISDIAGNOSIS:** Lyme disease is called “the New Great Imitator.” Its symptoms often mimic those of many other diseases. Common misdiagnoses include: Multiple Sclerosis, Lupus, Rheumatoid Arthritis, Fibromyalgia, Alzheimer’s, ADD/ADHD, Depression, Anxiety, Parkinson’s, mental illness, Chronic Fatigue Syndrome and more.

## Patient Self Advocacy

**PATIENT ADVOCACY IS CRITICAL:** The diagnosis and treatment options for Lyme and co-infections is continually evolving. It’s imperative that patients and/or family and friends educate themselves and become an advocate for their health rights.

**PATIENT RIGHTS:** “The patient has the right to make decisions about the plan of care before and during treatment, and is entitled to the chance to discuss and request information about the specific procedures and/or treatments, the risks involved, the possible length of recuperation, and the medically reasonable alternatives and their risks and benefits.” ~ **The American Hospital Association’s Patient’s Bill of Rights**

**TWO STANDARDS OF CARE:** There are two legitimate schools of thought regarding Lyme disease. A more restrictive interpretation is held by the IDSA (Infectious Disease Society of America) while a broader viewpoint is held by ILADS (International Lyme and Associated

Diseases Society). There are often multiple schools of thought in medicine, leading to options and choices in treatment approach. A patient’s right to informed consent and autonomous decision making are part of the ethical practice of medicine and are applied in other diseases where choices and options are standard. Patients have a right to be educated and involved in formulating their plan of care.

## Steps for Prevention

**YARD:** Minimize desirable tick habitats by raking leaves; removing pools of standing water; cutting grass regularly; trimming edges around fences, buildings, sidewalks; controlling weeds; removing dead plant material/twigs and branches; treating shrubs/flowers and any landscape plantings; using Damminix tick tubes.

**SELF-PROTECTION:** Wear light-colored clothing, tuck pants into socks and use repellents (Ultrathon, BioUD, Natrapel, Bug Guard Plus, Cutter Backwoods, and some natural repellents – neem, eucalyptus, lemongrass, camphor, cedar oil may have benefit). Clothing treated with Permethrin is effective. Spraying shoes provides high reduction in tick attachments.

**CONDUCT TICK CHECKS:** Remove clothing in garage and shower when coming indoors. Put clothes in dryer for 1 hour at high heat. Check children, pets and self. Ask vet for repellents to repel/kill ticks on your pet.

## Resources

- **International Lyme and Associated Diseases Society (ILADS)** [www.ilads.org](http://www.ilads.org)
- **Columbia Lyme & Tick Borne Diseases Research Center** [www.columbia-lyme.org](http://www.columbia-lyme.org)
- **University of Rhode Island Tick Encounter Resource Center** [www.tickencounter.org](http://www.tickencounter.org)
- **Lyme Disease Association Southeastern PA (LDA-SEPA)** [www.lymepa.org](http://www.lymepa.org)
- **LymeDisease.org** [www.lymedisease.org](http://www.lymedisease.org)
- **Lyme Disease Association (LDA)** [www.lymediseaseassociation.org](http://www.lymediseaseassociation.org)
- **LymeActionPA** [www.lymeactionpa.com](http://www.lymeactionpa.com)