About Us

Generation Lyme is a patient-led 501(c)3 nonprofit organization with a mission to empower patients and supporters facing Lyme and other tick-borne diseases. Through inclusive community building, we aim to combat the isolation caused by tick-borne diseases and help people feel welcome, supported, and uplifted. Since 2020, our Meet-Ups have served over 10,000 participants worldwide.

Our Meet-Ups

Our virtual Meet-Ups are spaces where patients and loved ones can connect with people who understand.

The Meet-Ups we offer include:
- Monthly Topic Meet-Up
- Burning Questions Meet-Up
- Women’s Meet-Up
- Parents Meet-Up
- Late Night Meet-Up
- BIPOC Meet-Up
- International Meet-Up
- Supporters Meet-Up
- College Meet-Up
- Men’s Meet-Up
- LGBTQIA+ Meet-Up
- Meet-Up for Advocates
- COVID Cautious Meet-Up

These are great places to ask questions, share what’s on your mind, just listen, and make new friends.

Connect

genlyme.org
info@genlyme.org

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If Lyme or another tick-borne disease has impacted your life, there’s a place for you at Generation Lyme.

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Lyme Disease

A public health crisis impacting people worldwide and a community coming together to heal

About | Symptoms | Support
Lyme Disease, or Borrelia burgdorferi, is a bacterial infection transmitted by ticks.

- **The CDC estimates 476,000 reported new cases of Lyme in the US each year.** This number does not account for long-term or undiagnosed cases. And cases are on the rise.
- **Most available testing is unreliable** (around 50-60% accurate depending on how recently a patient has been infected).
- **There is no cure for Lyme disease.** Current treatments available only work for approximately 85% of patients with acute infections. Treatments are insufficient for long-term patients.
- **Lyme disease is commonly misdiagnosed** due to insufficient medical training, inaccessibility of accurate testing, and stigma. Lyme is known as “The Great Imitator” because it can mimic the symptoms of other conditions like MS and ME/CFS, lupus and fibromyalgia.
- **Early diagnosis and treatment are key.** Delaying diagnosis and treatment can cause the infection to become physically, psychologically and financially devastating.
- **Lyme disease is more than a short-term illness.** The acute and late-stage or long-term presentation of Lyme are not the same.
- **When a Lyme disease diagnosis is missed or delayed, the illness can progress and disseminate** throughout the body. When the infection spreads, a patient can experience ongoing, widespread, multi-systemic symptoms. This can result in long-term illness, disability, or death.
- **Lyme patients commonly struggle with disbelief and dismissal.** But what they’re struggling with is real and poorly understood by the mainstream medical community. Interpersonal and systemic support are crucial.

**Symptoms and Testing**

**Acute symptoms**
- Rash (confirms infection)
- Fatigue
- Fever
- Enlarged lymph nodes
- Headaches
- Muscle aches
- Stiff neck
- Joint pain
- Bell’s palsy or facial drooping

**Late-stage or chronic symptoms**
- Neurological: Cognitive impairment, sleep problems, mood changes, depression, anxiety
- Cardiac: Shortness of breath, heart palpitations, fluttering in the chest, carditis
- Musculoskeletal
- Endocrine
- Lymphatic
- Reproductive
- Urinary

**Testing challenges**

Typical testing for Lyme disease measures antibodies. CDC diagnostic criteria is flawed, recommending that doctors first order an ELISA to screen for Lyme and then confirm with a Western blot. But there are more sensitive labs and criteria. For details, visit projectlyme.org/resource/how-do-you-test-for-it.

**Lyme Rashes**

Bullseye, or erythema migrans, rashes look different on people depending on their skin tone and other factors.

According to John Aucott, MD, associate professor of medicine at Johns Hopkins University School of Medicine, “80% don’t look like [bullseyes], and they constantly get misdiagnosed as spider or bug bites.”