Prescription & Medical Bill Assistance

The Lyme Disease Association, Inc. is providing the following list as a courtesy to those seeking resources that may be helpful in treating and covering the cost of treating Lyme disease. The LDA neither warrants nor endorses the Prescription & Medical Bill Assistance resources contained on this list nor the quality of service you will receive from them. We do not make recommendations, only referrals.

America’s Pharmacy
A nationwide prescription savings program that has helped people save up to 80% on out-of-pocket medication costs. https://www.americaspharmacy.com/

Free Prescription Medications
Free prescription medications listings are provided by Needy Meds. Needy Meds is NOT a drug assistance program, they are an information provider. They provide information on manufacturer based drug assistance programs to help consumers in obtaining medications that are not covered by any insurance plan or would otherwise be too expensive. Consumers are provided information on applying for each medication/program. Program requirements may differ from drug to drug. LDA is not affiliated with Needy Meds.

Medical Bill Assistance
Medical Needs Foundation
PO Box 303
Mountain Lks, NJ 07046
Provides assistance with medical bills around Morris County NJ
Compassionate Use Program for Mepron
For Healthcare Professionals that would like to make a request for compassionate use of a GSK investigational medicine. https://gsk-cu-portal.idea-point.com/

Lyme Test Assistance
The Lyme Test Access Program (Lyme-TAP) is a nationwide patient assistance program to provide assistance for initial Lyme-related lab tests to patients who demonstrate true financial need. http://www.lymetap.com/

LymeLight Foundation – Grants
Anyone diagnosed with Lyme disease up to age 25 and can demonstrate a qualified financial need. Applicant must be an active patient of a Lyme-literate MD, ND or DO. http://lymelightfoundation.org/grants/

LivLyme Foundation
Provides treatment grants for those under age 21. https://livlymefoundation.org/

Ticked Off Foundation
Provides grants and counseling to Lyme patients in crisis – Ages 26 and up. https://www.tickedofffoundation.org/

United Healthcare Children’s Foundation Medical Grants
Provides medical grants to help children gain access to health-related services not covered, or not fully covered, by their families commercial health insurance plan. Families can receive up to $5,000 per child ($10,000 lifetime maximum per child), and do not need to have insurance through UnitedHealthcare to be eligible. Children must be 16 or younger and living in the United States. Help can be for physical, occupational and speech therapies, surgeries, counseling, prescription medications, or medical equipment including: wheelchairs, orthotics, eyeglasses and hearing aids. http://www.uhccf.org/apply/
Disclaimer: Resources that are not part of the LDA may or may not be supportive of a chronic Lyme diagnosis but may support other conditions and factors that children may need, like wheelchairs and other modalities. It is up to the consumer and their medical practitioners to evaluate their child’s needs and if this program would be beneficial.

County-Level Distribution of Ixodes and Lyme Disease Spirochetes in US

This new summary article by employees of the CDC, presents the first county-level map of the distribution of Lyme disease spirochetes in host seeking Ixodes ticks between 2004-2019 in the contiguous United States. Data compiled for this summary was from literature searches; publicly available tick-borne pathogen surveillance databases (ArboNet Tick module); and internal CDC pathogen testing databases to map the county-level distribution of Lyme disease spirochetes reported in host-seeking Ixodes pacificus and Ixodes scapularis across the contiguous US.

Investigators narrowed their search to include only host-seeking ticks, because ticks in this state are most likely to bite humans, and because host-seeking ticks provide enhanced spatial precision compared to ticks collected from mobile hosts. Data used was restricted to studies that collected ticks by flagging, dragging or CO2 Traps. Ticks that were collected from mobile hosts such as wildlife, pets, and livestock were excluded because county of exposure could not be confirmed. County level pathogen infection data was included from these sources when provided.
Authors report *B. burgdorferi* s.s. infected *I. scapularis* from 384 counties in 26 eastern states of the Northeastern, North Central and Mid-Atlantic regions. *B. burgdorferi* s.s. infected *I. pacificus* were reported from 20 counties 2 western states, primarily from northern and north-coastal California. *Borrelia mayonii* was reported in *I. scapularis* in 10 counties in Minnesota and Wisconsin, where records of *B. burgdorferi* s.s. were also reported.

**Important caveats that the authors state in regard to this mapping effort:**

- “The reported distribution of *B. burgdorferi* s.s and *B. mayonii* in host seeking ticks is almost certainly an underestimate of the actual distribution of these disease agents.”
- “Though support for and participation in tick and tick-borne pathogen surveillance has increased in the US in recent years, collection and pathogen testing efforts have been limited with most efforts focused on US regions where Lyme disease cases are most commonly reported.”
- “In some instances, lack of records could represent lack of sampling effort or low prevalence of pathogens within sampled tick populations.”

The authors were confident in the distribution of tick presence records, but for counties where Lyme disease spirochete has not been documented in ticks, they were unable to determine whether this represented a true absence of pathogen or a merely a failure to detect the pathogen. Lack of data is especially evident in the Rocky Mountain region, Western plains and Southwestern region in regard to both tick presence and pathogen detection; and in the Southeastern region and Western states for pathogen detection. Continued surveillance and reporting will likely result in additional counties to be added to the map, and reporting densities of infected host-seeking ticks for many jurisdictions may be
In comparison to a broad distribution of vector ticks, the resulting map shows a more limited distribution of Lyme disease spirochetes.

Reported distribution of Lyme disease spirochetes, B. burgdorferi s.s. and B. mayonii in host-seeking I. scapularis (eastern United States) or I. pacificus (western United States), relative to the previously reported distribution of these vector species. Ticks were considered present in a county if at least one tick was recorded (Eisen et al. [2016] or CDC [2020]). Counties where ticks have been reported without records of infection may be reported as such either if ticks were not tested or if the pathogen was not detected in tested samples.

Read Entomology Today Press Release here

New Estimates of People Diagnosed/Treated for Lyme: 476,000 Annually
**476,000 People Diagnosed & Treated for Lyme Annually:** The Centers for Disease Control and Prevention (CDC) published in the February edition of its *Emerging Infectious Diseases* two new papers pertaining to Lyme disease.

CDC states on its How Many People Get Lyme Disease? webpage (reviewed Jan 13, 2021), “A recently released estimate based on insurance records suggests that each year ~ 476,000 Americans are diagnosed & treated for Lyme disease. This number is likely an over-estimate of actual infections because patients are sometimes treated presumptively in medical practice. Regardless, this number indicates a large burden on the health care system and the need for more effective prevention measures.”

The researchers found ~ 476,000 people are diagnosed with and treated for Lyme disease each year in the U.S. The prior Lyme estimates by CDC from 2005 to 2010 indicated “~300,000 people get Lyme disease each year.” Both estimates are based in part on insurance claim data. Based on CDC’s estimates the LDA calculated a 59% increase in the estimated number of people diagnosed & treated for Lyme disease annually. (See Fig. 1)

The CDC clearly states on its website, “It’s important to
emphasize that 476,000 is the estimated number of people treated for Lyme disease and likely includes some patients who were not actually infected.” Read the two papers below for their discussion on this new estimated number.

The two 2021 research papers on which the new 476,000 estimate is based are:


The two research papers on which the prior 300,000 estimate was based are:

- Lyme Disease Testing by Large Commercial Laboratories in the United States
  Estimated the number of people who tested positive for Lyme disease based on data obtained from a survey of clinical laboratories.
- Incidence of Clinician-Diagnosed Lyme Disease, United States, 2005–2010
  Estimated the number of people diagnosed with Lyme disease based on medical claims information from a large insurance database.
CDC Creates New Tick-Bite Data Dashboard: The CDC posted a new page, syndromic surveillance of emergency department visits for tick bites, to its website, last reviewed on January 4, 2021, showing tick bites by time, age/sex and region. (See Fig. 2)

According to a CDC official, “Unlike some tickborne disease surveillance data, the data shown in the charts [on the above webpage] are updated weekly, rather than annually. These data can indicate when people in different parts of the country might be at highest risk for tick bites. We think this is the closest we have come to providing real-time risk data for tickborne diseases ....” CDC also indicated they are working with data providers to make this type of data state-specific verse region-specific.

Syndromic surveillance is a term unfamiliar to the general public. In its September 2004 MMWR CDC describes syndromic surveillance, “Although syndromic surveillance was developed for early detection of a large-scale release of a biologic agent, current surveillance goals reach beyond terrorism preparedness. Medical-provider reporting remains critical for identifying unusual disease clusters or sentinel cases. Nevertheless, syndromic surveillance might help determine the size, spread, and tempo of an outbreak after it is detected (5), or provide reassurance that a large-scale outbreak is not
occurring, particularly in times of enhanced surveillance (e.g., during a high-profile event). Finally, syndromic surveillance is beginning to be used to monitor disease trends, which is increasingly possible as longitudinal data are obtained and syndrome definitions refined. The fundamental objective of syndromic surveillance is to identify illness clusters early, before diagnoses are confirmed and reported to public health agencies, and to mobilize a rapid response, thereby reducing morbidity and mortality. Epidemic curves for persons with earliest symptom onset and those with severe illness can be depicted graphically …

Stakeholders need to understand the advantages and limitations of syndromic surveillance systems. Syndromic surveillance systems might enhance collaboration among public health agencies, health-care providers, information-system professionals, academic investigators, and industry. However, syndromic surveillance does not replace traditional public health surveillance, nor does it substitute for direct physician reporting of unusual or suspect cases of public health importance.”

Lyme Disease Association, Inc. (LDA) Response:  It is important that data surrounding Lyme and other tick-borne diseases be continuously collected and distributed to safeguard the health of the public. Since the above material has just been released by the CDC, the LDA will review the material and comment further if necessary in the near future.
Click on Image to Watch CDC Video

Tweet: The burden of Lyme disease in the U.S.

Other Links:

2016 Final Lyme Case Numbers: Wondering If Surveillance Can Get More Confusing?

LDA Maps for Lyme Cases

CDC Surveillance for Lyme Disease – US
LymeAid 4 Kids Provided $400,400 in Grants Since 2004

About LymeAid 4 Kids (LA4K) – The Lyme Disease Association started LA4K fund in 2003 and has distributed monies for children all over the U.S. since 2004. Developed with the help of author Amy Tan, the fund is for children who do not have insurance coverage or receive reimbursement for Lyme disease treatment/diagnosis and whose families have economic difficulties. Donations can be made on-line to LDA to help the LA4K fund, as there are so many applicants in the U.S. that the fund does run out of money frequently. (In 2005, LDA awarded monies to two families in Canada, but there are so many families in need in the U.S. that LDA limited it to U.S. families only).

Click here for application

Total Funds distributed since 2004 totals $400,400

In 2020, 17 applicants were awarded grants for a total of $17,000:

2 California

4 Connecticut

1 Florida
In 2019, 38 applicants were awarded grants for a total of $38,000:
1 California
2 Connecticut
1 Florida
1 Idaho
8 Maryland
1 New York
23 Pennsylvania
1 Virginia

In 2018, 7 applicants were awarded grants for a total of $7000:
1 Pennsylvania
2 Maryland
1 North Carolina
1 Tennessee
2 Mississippi

In 2017, 18 applicants were awarded grants for a total of $17,400:
4 Oregon
5 Connecticut
1 New York
1 Pennsylvania
4 Maryland
1 Indiana
1 Kansas
1 Idaho
In 2016, 45 applicants were awarded grants for a total of $45,000:
6 New York
2 Ohio
2 Oregon
1 Texas
5 California
1 Illinois
2 North Carolina
1 Michigan
1 Mississippi
2 Tennessee
5 New Jersey
7 Virginia
4 Pennsylvania
3 Massachusetts
1 Maine
1 Connecticut
1 Florida

In 2015, 26 applicants were awarded grants for a total of $26,000:
6 Maine
4 Ohio
1 Connecticut
1 Michigan
2 Washington
2 New York
1 Illinois
1 North Carolina
3 Indiana
1 California
1 Oklahoma
3 Oregon

In 2014, 9 applicants were awarded grants for a total of $9000:
1 Texas
1 Washington
1 Wisconsin
In 2013, 9 applicants were awarded grants for a total of $9,000:

5 California
1 New Jersey
2 New York
1 Wisconsin

In 2012, 11 applicants were awarded grants for a total of $11,000:

3 Idaho
1 Illinois
1 Iowa
2 New York
1 Massachusetts
1 Tennessee
1 Wisconsin
1 Florida

In 2011, 35 applicants were awarded grants for a total of $35,000:

1 British Columbia
3 California
2 Connecticut
2 Georgia
5 Iowa
4 Illinois
2 Massachusetts
2 Missouri
1 New Hampshire
4 New Jersey
1 New York
3 Ohio
2 Pennsylvania
1 Rhode Island
In 2010, 29 applicants were awarded grants for a total of $29,000:

- California for a total of $3,000
- Connecticut for a total of $5,000
- Georgia for a total of $1,000
- Illinois for a total of $3,000
- Maine for a total of $1,000
- Missouri for a total of $1,000
- New Hampshire for a total of $2,000
- New Jersey for a total of $3,000
- New York for a total of $4,000
- Pennsylvania for a total of $1,000
- Rhode Island for a total of $1,000
- South Carolina for a total of $1,000
- Virginia for a total of $3,000

In 2009, 20 applicants were awarded grants for a total of $20,000:

- Connecticut for a total of $4,000
- Massachusetts for a total of $3,000
- Rhode Island for a total of $1,000
- New Jersey for a total of $2,000
- California for a total of $2,000
- New York for a total of $2,000
- Pennsylvania for a total of $3,000
- Nevada for a total of $2,000
- British Columbia for a total of $1,000

In 2008, 36 applicants were awarded grants for a total of $36,000:

- Ohio for a total of $1,000
- Rhode Island for a total of $1,000
- Maine for a total of $1,000
- Massachusetts for a total of $3,000
- New York for a total of $6,000
- Tennessee for a total of $1,000
- California for a total of $2,000
- Pennsylvania for a total of $2,000
4 Connecticut for a total of $4,000
1 Florida for a total of $1,000
4 Kansas for a total of $4,000
1 New Hampshire for a total of $1,000
4 Texas for a total of $4,000
3 Georgia for a total of $3,000
2 New Jersey for a total of $2,000

In 2007, 45 applicants were awarded grants for a total of $45,000:
1 California for a total of $1,000
6 Connecticut for a total of $6,000
1 Florida for a total of $1,000
2 Georgia for a total of $2,000
4 Illinois for a total of $4,000
3 Indiana for a total of $3,000
1 Iowa for a total of $1,000
2 Massachusetts for a total of $2,000*
3 New Hampshire for a total of $3,000
1 New Mexico for a total of $1,000
5 New York for a total of $5,000
2 Ohio for a total of $2,000
8 Pennsylvania for a total of $8,000
1 Rhode Island for a total of $1,000
1 Texas for a total of $1,000
1 West Virginia for a total of $1,000
1 Wisconsin for a total of $1,000
2 Canada, (have US doctors) for a total of $2,000

In 2006, 19 applicants were awarded grants for a total of $19,000:
1 Connecticut for a total of $1,000
3 Pennsylvania for a total of $3,000
8 Massachusetts for a total of $8,000
3 New York for a total of $3,000
1 California for a total of $1,000
1 Arizona for a total of $1,000
1 Maryland for a total of $1,000
1 Illinois for a total of $1,000
In 2005, 28 applicants were awarded grants for a total of $28,000:

2 Rhode Island for a total of $2,000
1 Texas for a total of $1,000
2 New Jersey for a total of $2,000
1 Maine for a total of $1,000
6 California for a total of $6,000
3 Massachusetts for a total of $3,000
5 Connecticut for a total of $5,000
2 New York for a total of $2,000
4 Pennsylvania for a total of $4,000
2 Canada (have US doctors) for a total of $2,000

In 2004, 9 applicants were awarded grants for a total of $9,000:

1 West Virginia for a total of $1,000
3 Texas for a total of $3,000
2 Connecticut for a total of $2,000
1 Massachusetts for a total of $1,000
1 Illinois for a total of $1,000
1 North Carolina for a total of $1,000

For more information on LymeAid 4 Kids click here

Disulfiram for Lyme and Babesiosis Treatment: Retrospective 3 yr Review
In a retrospective review on the use of Disulfiram as a repurposed drug in the treatment of Lyme and Babesiosis, most patients experienced benefits with regard to their symptoms. It was found that although patients on high dose experienced higher risk for adverse reactions than the low dose patients, they were also more likely to show “enduring remission” which is defined as remaining clinically well for ≥6 months without further anti-infective treatment. Adverse reactions from disulfiram treatment observed in the high-dose group were fatigue (66.7%), psychiatric symptoms (48.5%), peripheral neuropathy (27.3%), and mild to moderate elevation of liver enzymes (15.2%). It was also found that patients with co-infection of babesiosis and bartonellosis tended to require higher doses of disulfiram to achieve clinical improvement of their symptoms.

The authors concluded that disulfiram monotherapy is useful in the treatment of Lyme disease through individualized and flexible approach with shared decision-making with patients. They also suggest that further study and treatment trials seems warranted. This article was co-authored by Dr. Kenneth Liegner, LLMD, who serves on the LDA Scientific and Professional Advisory Board.

A review article has just been published by the Journal of Medical Entomology describing the ticks and tick-borne diseases of Colorado which includes tick-host associations, geographic distributions and medical/veterinary importance. In this article, 28 species of endemic ticks in Colorado are described as well as an additional 5 species that are occasionally detected, 13 exotic species that have been intercepted and 2 new state records: *Argas radiatus* and *Ixodes brunneus*.

This review creates a baseline for Colorado endemic ticks and tick-borne diseases, ticks that have been classified as visitors to the state via travel related introductions that may not have established populations, as well as identifying potential invasive species and human and veterinary health risks.

In review of available research and records of tick collections in Colorado, it was found that some information was outdated, incomplete or inaccurate. Authors have recommended that increased surveillance for ticks in Colorado
would likely be beneficial to add to the knowledge base on resident tick species and potential new species as ticks continue to expand in geographic range in association with migrating birds, habitat modifications and other changing environmental factors.

The review article was co-authored by advocate and LDAnet member, Monica White. Monica is President and Co-Founder of Colorado Tick-Borne Disease Awareness Association, an affiliate of the national Lyme Disease Association, Inc..

A new direct test for Lyme disease was announced by Galaxy Diagnostics Inc., the Nanotrap® Urine Test for Lyme Borreliosis. This is a urine-based Lyme antigen test, that Galaxy states “provides the most sensitive direct detection of Borrelia burgdorferi infection at all stages of the disease.” The test is easily administered through collection of urine; and identifies positive cases missed by CDC-recommended two-tiered testing, reducing concern for false positive results via direct detection of OspA proteins.

Published data shows that the Nanotrap® Urine Test is very effective for confirmation of early stage Lyme borreliosis in patients with EM rashes. Galaxy states that their unpublished validation data shows that the Nanotrap® Urine Test often confirms active infection in patients with negative CDC recommended Two-Tiered Testing results.

Clinical utility of this test for other presentations of Lyme, including Lyme arthritis, Lyme carditis, and neuroborreliosis, needs further research.

*This information is provided by LDA for informational purposes only. The LDA does not recommend or endorse this test but provides it for informational purposes only. Contact your health care provider for medical advice.*

Galaxy Diagnostics News Release: November 10, 2020

Application of Nanotrap technology for high sensitivity measurement of urinary outer surface protein A carboxyl-terminus domain in early stage Lyme borreliosis
Eastern VA Medical School (EVMS) Updated COVID19 Protocol

The Lyme Disease Association (LDA) is providing you with this updated November 2, 2020, COVID-19 protocol developed by the Chief of Pulmonary and Critical Care Medicine, EVMS. The EVMS Medical continually updates this guideline as new information emerges, primarily to provide new information to physicians.

This information is provided by LDA for informational purposes only. The LDA does not recommend or endorse this protocol but provides it for informational purposes only. Contact your health care provider for medical advice.

For further information
https://www.evms.edu/covid-19/covid_care_for_clinicians/

Dr. Horowitz In Vivo Dapsone
Combination Therapy Study Published

Richard Horwitz, MD, et al., have published a new case study and retrospective chart review of 40 patients on double dose dapsone combination therapy (DDD CT) in the journal Antibiotics.

The study found that of the 40 patients analyzed, an 8-week course of dapsone combined with doxycycline and rifampin effectively improved symptoms in 98% of patients, as well as led to long-term remission in 45% of the total patients studied, even though most of the individuals were ill for a decade or longer. The research included a segment of 12 patients with the presence of EM rashes. Of these, 100% showed improvement with 58% remaining in remission. The study abstract states, “In conclusion, double-dose dapsone therapy could represent a novel and effective anti-infective strategy in chronic Lyme disease/post-treatment Lyme disease syndrome (PTLDS), especially in those individuals who have failed regular dose dapsone combination therapy (DDS CT) or standard antibiotic protocols.”

The above-mentioned dapsone combination therapy study is a
follow-up *in vivo* clinical study to the initial groundbreaking *in vitro* culture study published in September 2020, which definitively showed that *Borrelia burgdorferi* (*Bb*) forms biofilms to shield the organism and that combining antibiotics with the leprosy drug dapsone effectively kills the bacteria by disrupting the biofilm.

Both studies by Horowitz, examining biofilm, and ‘persister’ forms of *Bb*, are critical in revealing the underlying cause of resistant chronic Lyme disease symptoms. The most recent follow-up study also demonstrates the importance of accompanying tick-borne infections (TBD), such as *Babesia* and *Bartonella*, and the role these co-infections can play in causing resistant, long-term illness.

**What comes next for dapsone combination therapy?**
The next step is for Dr. Horowitz and his team to perform a randomized, placebo-controlled trial using DDD CT, done in parallel with studies aimed at finding answers for resistant tick-borne co-infections. Horowitz is hopeful that this will positively demonstrate that the elusive “cure” for Lyme disease, which has evaded researchers and clinicians for decades, may finally be within reach and offer the potential to end a medical debate that has caused suffering in millions of patients worldwide.

Read the most recent *in vivo* clinical study, “Efficacy of Double-Dose Dapsone Combination Therapy in the Treatment of Chronic Lyme Disease/Post-Treatment Lyme Disease Syndrome (PTLDS) and Associated Co-infections: A Report of Three Cases and Retrospective Chart Review” in the journal, *Antibiotics*.

Read the initial *in vitro* study, “Effect of Dapsone Alone and in Combination with Intracellular Antibiotics Against the Biofilm form of *B. Burgdorferi*” in *BMC Research Notes*. 
Researchers Examine the Effects of the COVID-19 Pandemic on Timely TBD Diagnosis

This illustration, created at the Centers for Disease Control and Prevention (CDC), reveals ultrastructural morphology exhibited by coronaviruses. (Photo Credit: Alissa Eckert, MS; Dan Higgins, MAMS)

A study published in the journal *Diagnostic Microbiology and Infectious Disease* addresses the observed negative effects of the COVID-19 pandemic on the timely diagnosis of tick-borne infections (TBD) in three adult patients.

The researchers examined the ways that various precautionary measures, which have been set in place to reduce the spread of the COVID-19 virus, can also have indirect health effects on patients who have been infected with TBD. This situation may
potentially result in the failure to properly diagnose TBD infections.

**Changes Due to COVID-19 Precautions**
Factors such as reduced outpatient visits, the need for patients to demonstrate negative COVID-19 test results (prior to undergoing certain medical procedures), and the increase in the telemedicine format for conducting appointments, were identified as leading to potentially harmful outcomes for patients who are infected with TBD. In one of the cases, failure to diagnose *erythema migrans* during a telemedicine appointment “is believed to have played a significant role” in the patient developing severe cardiac Lyme disease resulting in a six-day hospital stay due to heart block.

**Thorough Testing is Advised**
Calling attention to the need for providers and patients to be aware of potential adverse outcomes of only performing COVID-19 tests, which may delay a more thorough patient evaluation, the researchers argue that all appropriate testing should be done at the same time, not only after a COVID-19 diagnosis is excluded. Taking steps to more comprehensive testing at the onset of patient care may help to lessen the negative effects of the COVID-19 pandemic on timely TBD diagnosis.

Read the study, “Negative Impact of the COVID-19 Pandemic on the Timely Diagnosis of Tick-Borne Infections” in *Diagnostic Microbiology and Infectious Disease*.