Two Columbia Studies Need Participants!

Researchers at Columbia University Lyme and Tick-Borne Diseases Research Center are seeking research study participants for two studies. Women to serve as healthy controls are critical to conducting this first study on metabolomics, and patients with confirmed Lyme disease are needed for the second study on Lyme disease and Disulfiram. Please support these clinical studies.

Dr. Brian Fallon,
Investigator

Metabolomics study of Lyme disease: Columbia (Brian Fallon, MD) in collaboration with UCSD:

- Women in Manhattan NY area over next four weeks
- 6-10 healthy women ages 40-60 for controls come to Columbia lab for blood & urine testing, questionnaire, clinical evaluation, sensory testing
- Participants receive $75 & free copies of their bloodwork
- Email Lily Murray for details lm3448@cumc.columbia.edu
Lyme patient Disulfiram study:

- 14 week disulfiram study (Brian Fallon, MD)
- Ages 18-65 with confirmed Lyme disease, persistent fatigue, don’t have other major medical comorbid problems, acquired Lyme within prior 16 years
- All research treatment is provided free of charge
- Inquiries on disulfiram study can be sent to: lymecenter@cumc.columbia.edu or can be made by phone 646-774-7503
- Weblink for this study https://recruit.cumc.columbia.edu/clinical_trial/1661#

For details on these studies and other clinical research opportunities please visit Columbia University, Lyme and Tick-Borne Disease Research Center here.

LymeAid 4 Kids Provided $383,000 in Grants Since 2004

About LymeAid 4 Kids (LA4K) – The Lyme Disease Association started LA4K fund in 2003 and has helped children all over the U.S. and in Canada. Developed with the help of author Amy Tan, the fund is for children who do not have/receive insurance coverage for Lyme disease treatment for children and have economic difficulties. Donations can be made on-line to LDA help this LA4K fund as there are so many applicants, the fund does run out of money frequently. Click here for application
Total Funds distributed since 2004 totals $383,000

In 2019, 38 applicants were awarded grants for a total of $38,000:
1 California
2 Connecticut
1 Florida
1 Idaho
8 MD
1 NY
23 PA
1 VA

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
In 2014, 9 applicants were awarded grants for a total of $9000:
1 Texas
1 Washington
1 Wisconsin
1 Maryland
1 Illinois
2 Connecticut
1 New York
1 California

In 2013, 11 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
In 2010, 29 applicants were awarded grants for a total of $29,000:

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

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

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

In 2008, 36 applicants were awarded grants for a total of $36,000:
1 Ohio for a total of $1,000
1 Rhode Island for a total of $1,000
1 Maine for a total of $1,000
3 Massachusetts for a total of $3,000
6 New York for a total of $6,000
1 Tennessee for a total of $1,000
2 California for a total of $2,000
2 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
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
Study Shows Increase of Non-Lyme Tick-Borne Diseases

A study by Elizabeth Lee-Lewandrowski, PhD, MPH, et al, published in The American Journal of Clinical Pathology from the Department of Pathology, Massachusetts General Hospital and Harvard Medical School, evaluated trends in non-Lyme disease tick-borne disease (NLTBI) blood testing at Quest Diagnostics laboratory located in New Jersey.

The study took place over the course of seven years and included polymerase chain reaction (PCR) and serological tests. Testing data from Quest Diagnostics were analyzed both nationally and at the state level from 2010 through 2016.

The study showed that:

- testing and positivity for most NLTBIs increased dramatically over the course of the study,
- testing criteria was not as stringent as required for public health reporting, but the study showed that the number of positive cases generally exceeds those reported by the Centers for Disease Control and Prevention (CDC),
- frequency of NLTBI in US is seasonal but testing activity and positive test results are present throughout all months of the year, and
- positive results for NLTBI testing originated primarily from a limited number of states, signifying a geographic
concentration and distribution.

The study shows a significant increase in the number of reported cases of many NLTBI from 2004 to 2016, including a 6.6-fold (875 to 5,750) increase in anaplasmosis and ehrlichiosis combined. It also uncovered a significant underreporting of Lyme disease and Q fever to the CDC. Since reporting for tick-borne illnesses (TBI) generally use the same reporting system as Lyme disease, the researchers indicate the possibility that underreporting also occurs for other TBI.

The study outlines laboratory-developed tests (LDTs) that have not been cleared by the US Food and Drug Administration (FDA) but have been approved by Clinical Laboratory Improvement Amendments (CLIA) regulations.

Said LDA President Pat Smith, “Although the findings are not surprising to many in the Lyme community, it is imperative that we have this data to support the increases in many of these non-Lyme tick-borne diseases. Increased awareness will result in medical professionals being more likely to consider other tick-borne diseases in people who have been bitten by ticks.”

See entire AJCP article here.
Lyme Disease Association Announces 2018 Final Lyme Cases Reported by CDC.

The Centers for Disease Control & Prevention (CDC) has just released the 2018 final Lyme disease reported cases numbers. Total US reported cases was 33,666 – CDC has reported that only 10% of cases are actually reported— that translates into 336,660 actual new Lyme cases in the US in 2018.

Lyme Disease Association, Inc. (LDA) has ranked the top 15 states based on those CDC reported Lyme case numbers below.
<table>
<thead>
<tr>
<th>State Ranking</th>
<th>Reported Cases</th>
<th>Actual Cases (10x = actual cases)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pennsylvania</td>
<td>10,208</td>
<td>102,080</td>
</tr>
<tr>
<td>2. New Jersey</td>
<td>4,000</td>
<td>40,000</td>
</tr>
<tr>
<td>3. New York</td>
<td>3,638</td>
<td>36,380</td>
</tr>
<tr>
<td>4. Wisconsin</td>
<td>1,869</td>
<td>18,690</td>
</tr>
<tr>
<td>5. Connecticut</td>
<td>1,859</td>
<td>18,590</td>
</tr>
<tr>
<td>6. Minnesota</td>
<td>1,541</td>
<td>15,410</td>
</tr>
<tr>
<td>7. New Hampshire</td>
<td>1,428</td>
<td>14,280</td>
</tr>
<tr>
<td>8. Maine</td>
<td>1,405</td>
<td>14,050</td>
</tr>
<tr>
<td>9. Maryland</td>
<td>1,382</td>
<td>13,820</td>
</tr>
<tr>
<td>10. Virginia</td>
<td>1,139</td>
<td>11,390</td>
</tr>
<tr>
<td>11. Rhode Island</td>
<td>1,111</td>
<td>11,110</td>
</tr>
<tr>
<td>12. West Virginia</td>
<td>671</td>
<td>6,710</td>
</tr>
<tr>
<td>13. Vermont</td>
<td>576</td>
<td>5,760</td>
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<tr>
<td>14. Delaware</td>
<td>520</td>
<td>5,200</td>
</tr>
<tr>
<td>15. Ohio</td>
<td>293</td>
<td>2,930</td>
</tr>
</tbody>
</table>
*In recent years, an increasing number of NY Counties have used estimating to determine Lyme case numbers. The Council of State & Territorial Epidemiologists, in charge of surveillance, doesn’t permit estimation to be reported by CDC in the national counts. In 2018, NY State reported it had 7,320 Lyme cases including those 30 estimated county numbers. CDC reported 3,638 Lyme cases for NY State, which excluded the 30 counties’ estimated numbers. [link](https://www.health.ny.gov/statistics/diseases/communicable/2018/docs/cases.pdf)

Note: In 2016, MA changed reporting requirements and very few MA cases are now able to be included in the CDC reported Lyme cases (in 2018 CDC reported 16 cases in Massachusetts)

[Click here for Ranking of all US states/DC](#)

[Click here for pie chart of 2018 Reported Lyme Cases – Top 15 States](#)

[Click here to go to LDA’s Interactive Lyme Disease Case Maps](#)
Top 15 States

The LDA has used CDC total reported Lyme case numbers (includes “confirmed” and “probable”) to create a pie graph of the 15 states in the US with the highest case numbers for 2018.

Click here for pdf version of pie graph

Rockefeller University
Hospital Seeks Participants for Powassan Study

Researchers at The Rockefeller University Center for Clinical and Translational Science are conducting a paid study to learn more about the immune systems of people who have been previously infected with Powassan virus. The research team seeks participants who are at least 18 years of age with documented proof of a prior Powassan virus infection. Participation in the study includes up to two outpatient visits to The Rockefeller University Hospital and blood work. Compensation is provided.

If you are interested in participating in this study and would like to learn more, please contact The Rockefeller University Hospital Recruitment Office at 212-327-7722 or send an email to RUCARES@Rockefeller.edu

This study article is provided for informational purposes only. Please do not contact the LDA about the study. Thank you.
LDA Analysis of Lyme Disease Data by Age from 2001-2017

Lyme Disease Association, Inc.
Analysis of Lyme Disease Data by Age from 2001-2017

Source Data: CDC Lyme Disease Reported Case Numbers 2001-2017 by Age
Ages 0-19 at High Risk

- Adults 20-90+ years
  - 272,872
  - 71%
- Children 0-19 years
  - 110,974
  - 29%

Source figures accessed 9/15/19 from https://www.cdc.gov/lyme/stats/graphs.html
Total case numbers: 383,846
© 2019 Lyme Disease Association, Inc.

Click here for pdf of pie graph

Prescription & Medical Bill Assistance

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 area

**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/](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/](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/](http://lymelightfoundation.org/grants/)

**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/](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.

Order LDA Brochures

The Lyme Disease Association provides the following brochures: LymeR Primer™, Tickmarks™, The ABC’s of Lyme Disease™. Any combination of free brochures can be ordered in quantities from one (1) to 200 maximum order. Sorry we cannot honor larger orders and no out of country orders. ($10 Shipping & Handling)
**LymeR Primer™ (pdf) Awareness Brochure:** symptoms, tests, tick identification, diseases ticks carry, prevention, tick removal, tick testing, general facts and symptoms about Lyme and many tick-borne diseases.

**Tickmarks™ – Bookmarks (pdf) Awareness Bookmark:** pictures of ticks, diseases they carry, proper tick removal.

**ABC’s of Lyme Disease™ (pdf) Brochure For Parents & Educators:** specialized information on children in areas of ophthalmology, psychotherapy, neuropsychiatry, gastroenterology, pediatrics, rheumatology, co-infections, education.

**TickCard™ (pdf) Business Sized Awareness Card** pictures of ticks, diseases they carry, symptoms and tick removal

**Order Limit –**

Any combination of free brochures can be ordered in quantities from one (1) to 200 maximum order. Sorry we cannot honor larger orders and no out of country orders.
(Tickmarks™ are no longer available for order. PDF can still be downloaded & printed)

For Example:

- 100 LymeR Primer™ & 100 The ABC’s of Lyme Disease™ = 200 brochures OR
- 75 LymeR Primer™, 75 The ABC’s of Lyme Disease™, 50 TickCards™ = 200 brochures

Please email brochures@LymeDiseaseAssociation.org with any questions or problems regarding your order.

Order Online –

ORDER FORM

- No out of country orders
- Brochures only available via online order form (mail-in and phone requests not accepted)
- Allow 4 weeks for delivery
- Unfortunately due to recent postal changes, our shipping rates have increased & we now have to charge $10 per order.
- Sorry, we do not invoice.

Sponsorship Opportunities for Brochures

- Lyme education requires companies to step forward and sponsor a brochure.
- If interested please email president@LymeDiseaseAssociation.org
- The LDA thanks our current sponsors:
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<th>Clonogen Laboratories, LLC</th>
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<td>Palo Alto, CA</td>
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<td>Midwest City, OK</td>
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<td>New Jersey Laboratories</td>
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<td>New Brunswick, NJ</td>
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Note: LDA does not endorse products or services.

Public Service Announcements For You to Share

The Lyme Disease Association has prepared video and audio public service announcements which we are presenting here for you to view, listen to and use for
any educational purposes.

A 30 Second Radio PSA on Lyme Disease
.wav format

Mary McDonnell Public Service Announcement

Star of the Peabody Award Winning TV show BattleStar Galactica works with the LDA to develop a public service announcement on Lyme Disease.

Ms. McDonnell stars as President Laura Roslin in the popular sci-fi series. She has starred in a number of movies including her Oscar-nominated roles in Dances with Wolves and Passion Fish. She serves as LDA's national spokesperson on Lyme disease.

Click here for video

The Global Spread of Chronic Lyme Disease

Click here for video