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.

LDA Board of Directors Bios

Patricia V. Smith, BA
President

Patricia V. Smith, a Monmouth University graduate, is in her 23rd year as President of the all-volunteer run national non-profit Lyme Disease Association (LDA) and is a member of the HHS Tick-borne Disease Working Group in Washington, DC, where she co-
chaired the Disease Vectors, Surveillance, & Prevention Subcommittee. She is a member of Columbia University’s Lyme & Tick-Borne Diseases Research Center Advisory Committee, member of the Food & Drug Administration’s (FDA) PESP Partnership to promote avoidance of tick exposure, and member of the Tick IPM Working Group with federal and non federal members, from the IPM Institute of North America, to eradicate tick-borne diseases. She was appointed in 2016 as a member of the US Army Medical Research and Materiel Command (USAMRMC) Tick-Borne Disease Research Program (TBDRP) as a member of the Congressionally Directed Medical Research Program Programmatic Panel. She has twice testified before Congressional committees in Washington on Lyme disease.

Ms. Smith is also former Chair, (NJ) Governor’s Lyme Disease Advisory Council. She was EPA’s PESP 2011 Lyme prevention conference session co-chair with CDC. In 2011 she presented a Lyme session to the New Jersey Education Association’s Annual Meeting. She is a member & former officer of ILADS, International Lyme & Associated Diseases Society, a professional medical and research organization. She was a member of the on-line journal *Contagion Infectious Disease Today* Chronic Lyme Expert Panel on video.

Ms. Smith is former President/12-year member of the Wall NJ Board of Education where she earned state board member-certified status. She is a former officer of Monmouth County School Boards Assn. and was a member of the Federal Relations Network for New Jersey School Boards Association/National School Boards Assn.

During her LDA presidency, Ms. Smith has led the effort to raise funds for researchers nationally, with 119 research grants awarded – research acknowledged in 53 scientific journals. She has organized 20 continuing medical education (CME) accredited Lyme scientific conferences for doctors and researchers with international faculty, held in different areas of the US, most jointly sponsored by Columbia University, the 20th in Philadelphia in September 2019. She has spoken at many conferences on Lyme including those presented by the University of New Haven (CT), the California
Lyme Disease Association (now LymeDisease.org), Midcoast Maine Lyme Education and Support, Colorado Tick-Borne Awareness Association, Lyme Connections, Lyme Society, Inc., and International Lyme & Associated Diseases Society, ILADS. She has been a speaker at hundreds of public, school, business, & government events.

Ms. Smith led the LDA in its effort with a partner organization, to endow the Columbia Lyme & Tick-Borne Diseases Research Center in New York, which opened in 2007. She developed the ABCs of Lyme Disease pamphlet for parents and educators (updated in 2019) and co-authored an article in it, and she also developed the Lyme Primer brochure now featuring 20 tick-borne diseases, the Tick Mark bookmark, and helped design LDA Tick Awareness cards. More than 2.5 million education items have been distributed.

Ms. Smith has testified for and secured passage of state and federal bills for Lyme research and physician’s right to treat. She has been invited to state capitals in CT, MA, MD, MN, NH, NJ, NY, PA, RI, to present oral testimony and education on Lyme and has provided written testimony in many others. Based on her written testimony, LDA was included in ground breaking Maine legislation as a website resource on Lyme disease on Maine’s DPH website. She was invited to testify on two occasions before the NY Assembly Health Care Committee and also before the Rhode Island (Governor’s) Lyme Disease Advisory Commission and has spoken before the California Lyme Disease Advisory Council. Over time, she has personally met with many State Health Commissioners and with Governors in NH, RI CT on Lyme issues and with then Governor Pataki’s office on many occasions along with several NY state legislators. She has also presented before the Pennsylvania House of Representatives Majority Policy Committee and was an invited speaker for Lyme forums hosted by a member of the Massachusetts House of Representatives and the Majority Caucus Administrator for the Pennsylvania House of Representatives.
and the Minnesota State Senate Health Committee.

She has twice been invited to present to CDC Vector-Borne Diseases Division, Ft. Collins (2007, 2013); met with then CDC Director Dr. Julie Gerberding/5 Congressmen in DC; organized & led a team that met with HHS Asst. Sec. of Health with CDC/NIH officials teleconferenced in; met with military leaders in DC; and briefed the Senate HELP Committee Members and House Subcommittee on Health. She met several times with US Army CHPPM/Public Health Command at Aberdeen Proving Grounds. She met in DC with the NIH Program Director and research coordinator and presented educational PowerPoints on Lyme to employees at the Environmental Protection Agency (2008, 2014), to the Dept. of Energy, and to Homeland Security in 2014. In 2014, she helped develop language for a federal bill on Lyme and led the nationwide effort which successfully passed the bill through the House. Ms. Smith spoke at a number of press conferences with Senator Charles (Chuck) Schumer (NY)—now Senate Minority Leader—including one in 2014 on the doxycycline shortage for Lyme patients. In 2012, she testified before the House Foreign Affairs Committee, Africa, Global Health & Human Rights Subcommittee on issues affecting Lyme patients. In 2013, she testified before the House Energy & Commerce Health Subcommittee on HR 610 to establish a federal Lyme & Tick-Borne Diseases Advisory Committee. She co-authored an article which was read into the Congressional Record on Lyme disease research priorities from the patient perspective. In 2015, she spoke at the American Association for the Advancement of Science in DC on patient research priorities. In 2016, she spoke before the Women in Government’s annual conference. In 2016, she led the negotiations with House leadership for the Lyme language subsequently passed in the 21st Century Cures Act which creates a federal working group on tick-borne diseases with patient and advocates reps at the same table as government officials.

Chosen Jackson NJ’s Chamber of Commerce 2008 Woman of the
Year, she has also received commendation from the NJ legislature, a Special Congressional Recognition certificate from RI Cong. Langevin, and had a flag flown over the US Capitol by request of NJ Cong. Chris Smith in honor of her Lyme work. Ms. Smith helped to organize and presented at educational forums held by 3 congressmen (Langevin, Pitts, C. Smith). She has received awards from Dr. Brian Fallon, Columbia, from various Lyme groups, and was given the Courage in Advocacy Award in 2015 from Connecticut based Lyme Connection and Focus on Lyme Excellence in Advocacy (AZ) award in 2017.

Other activities include providing input into a NJ law requiring teacher education for staff who teach students with Lyme disease, performing school in-services for educators on Lyme disease, and working with parents of students who are classified due to Lyme disease. Working with author Amy Tan, she created LDA’s LymeAid 4 Kids, a fund for children with no health coverage for Lyme, a fund that has awarded $383,000 for uninsured children to date.

Richard H. Smith, BA
Executive Vice President, Treasurer

Richard has a BA from Rutgers University. After being honorably discharged from the US Army (Army Security Agency), he worked for New Jersey American Water Company for 38 years. He also served as the president of the local utility union for several years. He is past president of his local homeowners association and has served on the LDA Board of Directors for 7 years.
Corey Lakin, AB
2nd Vice President, Technical Support, LDA

Corey Lakin, graduated from the University of Chicago with an AB in Geophysical Science. He was a scientist with the New Jersey State Department of Environmental Protection (Ret.). Corey has been an LDA Board of Directors member for 20 years and currently serves as LDA’s second vice president for technology. He is responsible for the audio visual portion of the LDA’s scientific conferences.

Ruth Waddington, RN
Corresponding Secretary, LDA

Ruth graduated from Ocean County College with an associates in applied science degree, AAS, and passed the Nursing Boards to become an RN. She is currently employed as a nurse in a large OB/GYN group practice. She was formerly office manager & nurse for an internal medicine/geriatric medical office 31 years until the practice closed. She was also a nurse in a pediatric office and worked at Monmouth Medical Center in Long Branch, New Jersey, in labor & delivery and in post op surgery and neurosurgery. She is currently employed at a Family Medicine practice. Ruth has been an LDA Board of Directors members for 18 years and has served as its Corresponding Secretary for that time.
Jeannine Phillips, BA
Recording Secretary

Jeannine completed her BA in chemistry and has post graduate work in chemistry, physics, marine and environmental sciences. She has been awarded numerous grants for environmental and water studies. Her career has spanned organic chemistry custom syntheses, analytical chemistry such as pollution, food, water quality and pharmaceutical analyses, as well as trace metal analysis of Atlantic fish stock. Jeannine has performed process validation studies and research for the pharmaceutical industry. Volunteer service includes former vice chair of local environmental commission and officer of local watershed association. Currently, she chairs LymeQuest Support Group & Advocacy Project. She has been a LDA Board of Directors member Board member for 17 years and currently serves as Recording Secretary. She has received the Woman of Distinction Award, (Mayor and Town Council, 2003) and Outstanding Citizen Volunteer (Mayor and Town Council Award, 2011).

Timothy (Tim) Lynagh, MBA
Member, LDA Board of Directors

Tim received an MBA degree from George Washington University in Washington, DC, and held several analytical positions within the Federal government. At the Department of Labor, Tim was as an Economist in the Bureau of Labor Statistics and a Loss Prevention Analyst/Operational Auditor in the Office of Inspector General. He helped set up an Information Resources Management Review Program in the General Services Administration, working closely with OMB to design the program. Tim wrote a significant portion of the guidance for Federal agencies to follow in establishing and operating an IRM Review Program.

Tim worked for fifteen years in DHHS, first as a team leader in helping to oversee
HHS’ operating divisions’ activities relating to information technology, including planning and procurement. Tim was a Supervisory Analyst in FDA’s Office of Legislation, serving as a one-person team as the liaison for the Center for Veterinary Medicine, and later working for the CFSAN-CVM team, handling dietary supplements as well as CVM issues. Tim was the principal liaison to Congress for a number of cross-cutting issues, including antimicrobial resistance and transmissible spongiform encephalopathies. Tim worked closely with CVM in developing animal feed regulations to control the possible spread of BSE, and also was the liaison to Congress in developing and passing animal drug user fee legislation, as well as legislation for Minor Use, Minor Species drug approvals.

After serving a Brookings fellowship on Capitol Hill, Tim returned to the Hill to work as Deputy Chief of Staff and Legislative Director for Congressman Chris Smith (NJ). Congressman Smith did and does chair House caucuses on Alzheimer’s disease, autism, Lyme disease, and numerous international affairs caucuses, as well as chairing the foreign affairs subcommittee with jurisdiction for global health. Tim had the staff lead in successfully moving Congressman Smith’s autism legislation and getting autism placed in the Congressionally Directed Medical Research Program. Tim also helped to develop several bills for Congressman Smith to try to improve the seriously impaired environment for making progress in the ability to manage Lyme and other tick-borne diseases. Since leaving Capitol Hill, he works part-time for the Franciscan Foundation for the Holy Land and helped the Lyme Disease Association. He has served on the LDA Board of Directors for 3 years.

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About the LDA

The Lyme Disease Association, Inc. (LDA) is designated by the IRS as a 501(c)(3) non-profit, a charity focusing on research, education, prevention and patient support.

History
The Lyme Disease Association began as Lyme Disease Association of Central Jersey in 1991 and then became Lyme Disease Association of New Jersey in 1993. Formed by patients and doctors who saw the need to organize, fund research and educate people, by 1997, it had influence far beyond NJ borders. In 2000, the Board changed the name to Lyme Disease Association, Inc. (LDA) with a broader mission expanding research funding (LDA-funded research has appeared in 53 scientific journal publications to date) and including expanded patient support (LA4K). At that time, LDA decided to remain an all volunteer organization without paid employees so that almost all of its incoming revenue would be dedicated to the mission. It remains volunteer-run with some professional consultants who provide specific expertise when needed.

Mission Statement

The Lyme Disease Association, Inc. (LDA) has been granted 501(c)(3) non-profit status by the IRS. Its mission is promoting awareness of and controlling the spread of Lyme and other tick-borne diseases (TBD) and their complications through education and other means; raising and distributing funds for Lyme and tick-borne diseases (TBD) research, education and other related Lyme and TBD issues; assisting underprivileged patients in connection with Lyme and other TBD.

Accomplishments

On average, 97% of funds raised go directly to programs. LDA presents fully accredited annual scientific/medical conferences, funds research nationally, provides monies for children without insurance coverage for Lyme, provides free literature, has free information line, hosts free online doctor referral and heads an umbrella organization, LDAnet, of 45 associated organizations nationwide that work together on national issues. The LDA is a GuideStar Exchange Gold participant, signifying GuideStar’s highest level of transparency. LDA has also been designated as a federally approved national charity for workplace giving in the Combined Federal Campaign. (CFC) for 14 years. Additionally, LDA is an EPA partner in its PESP program to safely eradicate tick populations and reduce the risk of pesticides and is a part of an integrated pest management tick working group with government and public members. To that end, it helped in the planning of the EPA’s prevention conference and spoke at and co-hosted a session of the conference with the Centers for Disease Control (CDC). The LDA President was also a co-author of the
article produced from a network developed under EPA, Network to Reduce Lyme Disease in School Aged Children. The article “You Can Make A Difference to A Child by Reducing the Risk of Lyme Disease appeared in the May 2010 journal of the National Association of School Nurses.

In its search for a cure for chronic Lyme disease and for prevention, the LDA has funded dozens of research projects coast-to-coast at institutions including Columbia University College of Physicians & Surgeons (NY), New Jersey Medical School (NJ), University of Washington (WA), Northeast Wildlife DNA Laboratory (PA), University of California, Davis (CA), Georgia Southern University Research & Service Foundation (GA), Johns Hopkins University (MD), Kendall County Health Department (IL), University of New Haven (CT), and Stony Brook University (NY), New York Medical College (NY), Boston Medical (MA), Rockefeller University (NY), University of North Florida (FL), and Shanandoah School of Pharmacy (VA). Much of LDA-funded research has been featured in peer-reviewed journal publications (50 to date), e.g., Journal of the American Medical Association, Proceedings of the National Academy of Science, Emerging Infectious Diseases, Psychiatric Clinics of North America, Infection, Journal of Neuropsychiatry & Clinical Neurosciences, Journal of Clinical Microbiology, Journal of International Neuropsychological Society, Neurology, Immunology, Open Neurology Journal, PLOS One, & Genetics. 118 research grants have been awarded since LDA’s inception.

Genome work initially funded by LDA has shown that different strains of Borrelia have the ability to exchange genetic material among themselves, a trait greatly benefiting their survival and probably confounding the body’s ability to eradicate the organism. LDA funding of genome mapping has led to 17 strains being mapped.

In 2007, Columbia University announced the opening of the Lyme & Tick-Borne Diseases Research Center in New York, the first in the world devoted to the study of chronic Lyme disease. LDA co-funded the Center. LDA has given a grant to create a tissue bank there to store samples for Lyme disease research, now ongoing. The LDA has funded cutting edge published work with University of New Haven into the presence of *Borrelia burgdorferi* biofilms, which may be one of the survival mechanisms of the Lyme organism even after long-term treatment and loaned the University specialized equipment for its work.

The LDA has presented 20 fully CME accredited (continuing medical education) scientific conferences for researchers, doctors, and health care providers,
featuring international speakers on the topic of Lyme and other tick-borne diseases, most jointly sponsored by Columbia University Vagelos College of Physicians and Surgeons. The 14th LDA conference was held in Minnesota in 2013, the first CME conference in the Upper Midwest and the 15th and 16th were held in Providence, RI in 2014 and 2015. The 2016 conference was held in St. Paul, Minnesota, the 2017 conference was held in Philadelphia, Pennsylvania, and the 2018 conference was held in Providence, Rhode Island. The 20th LDA conference was held on Sept 21 & 22, 2019 in Philadelphia, Pennsylvania. The LDA website contains video clips of the various conferences. A few conferences have had certifications for other professionals such as social workers, psychologists, dentists, nurses.

Since children ages 5-14 are at the highest risk of acquiring Lyme disease, the LDA created LymeAid 4 Kids, a fund that helps children without insurance. Initiated in conjunction with internationally acclaimed author Amy Tan, a Lyme victim, the LDA fund has awarded $383,000 in grants. LDA has compiled a website section, Lyme in the Schools, containing tools which can be accessed for free by schools, parents, and the general public. Resource articles, statistics, and an LDA educational PowerPoint, How A Tick Can Make You Sick, can be run for free in the classroom from the computer as can a prevention video for kids that the UMDNJ created in partnership with the LDA under an EPA grant. LDA’s book for children with chronic Lyme, Lyme Disease Is No Fun, Let’s Get Well! can be ordered on the site as can free pamphlet for parents and educators, The ABCs of Lyme Disease.

The LDA’s extensive resource list also includes free materials (postage charge as of 2014) such as newly updated LymeR Primer, Tickmark, and Tick Card; National Case Map, Case Number graphs, Personal & Property Prevention Posters, Symptoms Lists and at cost materials including conference DVDs, and books. The site also houses an extensive collection of tick and rash pictures and tick-borne microbes. Finding doctors who are experienced in treating tick-borne diseases is difficult, thus LDA created an automatic doctor referral system to help people nation wide.

LDA has educated through public, school, corporate and government seminars. It has developed billboards including an electronic one on Times Square in 2012 featuring the spread of chronic Lyme. Annually, LDA awards education grants to many other Lyme groups, universities and other organizations to further their mission against tick-borne diseases. 238 education grants have been awarded to date, including 95 educational conference scholarships to the LDA/Columbia continuing medical education conferences.
LDA reps have been asked to testify in many states, and been invited to be a part of press conferences with congressmen, governors and other officials. LDA had led the charge on the introduction and passage of many pieces legislation at the federal and state levels, including the 2014 Lyme bill that passed the House, and has been successful in meeting with officials at all levels of government. The LDA President testified before the US House of Representatives Foreign Affairs Global Health & Human Rights Subcommittee Lyme hearing in 2012 and before the US House of Representatives Energy & Commerce Health Subcommittee in 2013. LDA has been twice invited to meet with the Vector-Borne Division of the CDC in Ft. Collins, CO, to discuss the spread of tick-borne diseases and other issues. LDA led the team to negotiate the Lyme language which passed in the the 21st Century Cures Act in 2016 which creates a federal Tick-Borne Diseases Working Group which has a patient voice at the table. The LDA President was appointed a ~3 year term on the Congressionally Directed Medical Research Program panel to oversee disbursements of funds for Lyme disease research. Most recently, the LDA President was appointed as a committee member to the Federal Health and Human Services (HHS) Tick-borne Disease Working Group which presented it’s first report to Congress in November of 2018.

New Website – Columbia TBD
Research Center

For patients and families, physicians and researchers in need of information about chronic Lyme disease.

A powerful and credible source of Lyme-related materials, it represents the only academic research center in the country to focus multidisciplinary research on chronic Lyme. Synonymous with the Center’s mission, the website offers up-to-date resources, new research results from Columbia University and elsewhere, frequently asked questions, an “ask the doctor” section (most popular to date), and commentary on
important events in the Lyme world. Feedback on the site is welcome.

Check out new website here

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Read Letter Below or Click here for pdf

[2019_SenateHelpCommittee_S.1657](#)

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**LDA Partner Organizations**

LDANet
Groups under the LDAnet umbrella  
*Working together for a common cause*

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<th>Chapters: Part of LDA</th>
<th>Affiliates: Separate 501 (c)(3) org. affiliated with the LDA</th>
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<td>LymeDisease.org formerly, CALDA (CA)</td>
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<td>Mid-Missouri Tick Illness Coalition (MO)</td>
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Contact Us

LDA’s mission does NOT include providing medical advice or researching your questions. We do not answer medical questions or identify ticks or rashes. Many questions can be answered by you researching the LDA site and its links to other sites. Please use the search box feature to find information on the website. We are
an all volunteer organization and do our best to respond to your questions and concerns.

DO NOT use the “Contact Us” Forms for Items Below: (We WILL NOT respond due to email volume)

- To ask any medical questions (we do not provide any medical advice)
- To ask for Doctor Referrals – use our automated system (Click here)

Available “Contact Us” Forms:

- General questions please Click here
- Website issues please Click here
- Dr. Referral technical questions please Click here

Other Contact Information

Lyme Disease Association, Inc.
PO Box 1438
Jackson, NJ 08527
888-366-6611 information line
732 938-7215 fax

www.LymeDiseaseAssociation.org

Columbia Lyme Research Ctr.
Campaign

The Lyme Disease Association designed a special 3 prong Campaign to help support scientific research at the Columbia Lyme and Tick-Borne Diseases Research Center.

1) LDA is Hosting 13th Annual Scientific Conference with Columbia University

   September 29-30, 2012 – Hyatt Bellevue, Philadelphia, PA

   Register    Agenda    Conference Presenters

2) LDA is Promoting a Special Fund Raising Campaign

   To benefit the Columbia Lyme and Tick-Borne Diseases Research Center. Please help the LDA provide funds for Columbia to unlock the secrets of Lyme disease by making a contribution today. Simply go to our donation page and choose the Columbia Lyme Center campaign. No amount is too small – we are all in this together!

   Click here to donate.

3) LDA is Facilitating a Drawing To Help Raise Awareness About the Center

   To take place on October 31, 2012 in which a lucky participant will be randomly selected to meet with Dr. Fallon and the Lyme and Tick-Borne Diseases Research Center Team. The chosen participant and one guest will take a free tour and be able to discuss the Center’s activities while relaxing and having lunch. To sign up for a chance to enjoy this specially planned day please fill form out below.

   Take a few minutes to check out Columbia University Lyme & Tick-Borne Diseases Research Center’s website

   Please note:

   ▪ Information from the form below will only be used to contact you if you
Transportation is not included as a covered expense in this event.

Dr. Referral Website Issues

We are an all volunteer organization and will do our best to respond to your questions in a timely fashion.

Problems or questions we cannot address and **WE WILL NOT** respond to:

- Requests for individual provider lists – You MUST use the automated system.
- Requests for medical advice.
- Requests for medical providers’ qualifications.
- Requests for information on insurance plans offered by medical providers.
- Distance issues to/from medical providers.

- Name
  
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- Email*
  
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- Your Problem*
Website Issues E-Mail Form

We are an all volunteer organization and will do our best to respond to your questions in a timely fashion.

- Name
  First   Last
- Email*
- Subject
- Comments*
- CAPTCHA

Submit