LDA Celebrates 30 Years of Service!

Lyme Disease Association, Inc., LDA, is proud to celebrate 30 years of advocacy and volunteerism to improve research, education, and patient support surrounding Lyme and tick-borne disease.

Dr. Nick Harris (2nd from L) and Dr. Terry MacKnight are flanked by LDANJ Officers Pat Smith and Corey Lakin at a Congressional Forum in Pennsylvania where they were about to speak in 1999. Dr. Harris & MacKnight went on to found ILADS, International Lyme & Associated Diseases Society

Early Years
By 1990, the total US reported Lyme disease case numbers were 7,943 cases – NJ was second in the nation for the highest number at 1,074 cases – and New York was first. (1990 LDA MAP) At that time, two groups of patients and doctors, in Northern and Central NJ, were already loosely organized and advocating
for Lyme patients – the latter group formed the basis for what is now LDA and was formally incorporated as Lyme Disease Association of Central Jersey Inc. As cases grew, the organization became the Lyme Disease Association of New Jersey Inc. and funded some of the first publicly funded Lyme research in the country on Lyme PCR published in peer review, and some of the first Lyme laws in the country were developed here and passed in NJ (View article on NJ Legislation Affecting Lyme in Schools).

In 1997, Pat Smith, founder & Chair of a NJ grassroots lobbying group and 12-year departing president of her town’s Board of Education, was elected President of LDANJ. In 2000, when US reported cases reached 17,730, she led the Board to a broader focus, with a new name, Lyme Disease Association, Inc. (LDA) – registered in states throughout the US – and focused on a national mission.

Programs
Since its inception, LDA has presented 20 fully accredited CME scientific conferences for researchers and health care providers. It continues to fund tick-borne disease research nationally, provide monies for children without insurance coverage for Lyme treatment, provide on-line brochure ordering for postage-only, host a free online doctor referral system and head the umbrella organization, LDAnet – a group of 40+ associated organizations nationwide that work together on national issues regarding Lyme and other tick-borne diseases.

Research Grants
In its search for a cure for chronic Lyme disease and other tick-borne diseases, the LDA celebrates funding 119 research projects coast-to-coast at various institutions (GRANTS AWARDED), and in 2007, LDA partnered with then Time for Lyme to open the first endowed research center for Lyme disease and tick-borne diseases in the US. To date, LDA-funded research has appeared in 53 peer-reviewed journal publications, (PUBLICATIONS FROM LDA RESEARCH) helping to move the field
forward.

**Education Grants**
The LDA also aides other organizations and institutions in their missions to educate about Lyme and other tick-borne diseases and has awarded 145 education grants for publications, conferences, billboards, and other activities. LDA has also provided 95 conference scholarships to health care providers, medical students, public health officials, and advocates. (EDUCATIONAL GRANTS)

**Shaping Public Policy**
LDA President, Pat Smith, is a second-term member of the Health and Human Services (HHS) Tick-Borne Disease Working Group (TBDWG) established by Congress in 2016. (LDA’S TBDWG PAGE) She was instrumental in the creation of the original Lyme legislation and its passage through the US House of Representatives and then its revision as it was placed into the 21st Century Cures Act. LDA led an advocacy effort to get the legislation passed in that Act which created the existent Working Group. She has also testified before 2 of the US House of Representatives Subcommittees on Lyme disease and effects on patients. She has also helped to write and has testified before many state legislatures on Lyme disease legislation. (TESTIMONY)

**Fiscal Responsibility**
The LDA has always consisted of patients and families of patients, volunteers who run the organization. It has never had employees but has consultants who provide expertise in necessary areas. The LDA averages 97% of its funds going to its programs. As LDA celebrates 30 years, we look for help from across the US to help unlock the secrets of Lyme and other tick-borne diseases.
30 Years of Service in Photos

Lyme Awareness Press Conference; Pat Smith, LDA, at Podium

Congressman Chris Smith (NJ); Pat Smith (LDA), Brian Dashore & Mother

LDA Celebrates 20 Years of Scientific Conferences
Pat Smith, LDA, and Brian Fallon, MD, MPH, Columbia University

LDA Partner Organizations Throughout the US

Congressman Chris Smith (R, NJ); Pat & Rich Smith, LDA

LDA / Columbia Scientific Conference
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.
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

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 win.
- Transportation is not included as a covered expense in this event.
Grant Awards Program

The effectiveness of a charity can be judged by the success of its programs. One of the Lyme Disease Association’s (LDA) most effective programs is its Grant Awards. In its search for a cure for chronic Lyme disease and disease prevention and in its quest to educate, the LDA, using ALL volunteers, has since 1992 funded about 202 research and education grants coast-to-coast through researchers at more than 22 institutions including Columbia University College of Physicians & Surgeons, NJ Medical School (UMDNJ), Fox Chase Cancer Center, University of California, Davis, and University of Pennsylvania and at several government agencies.

The effectiveness of a charity can be judged by the success of its programs. One of the Lyme Disease Association’s (LDA) most effective programs is its Grant Awards. In its search for a cure for chronic Lyme disease and disease prevention and in its quest to educate, the LDA, using ALL volunteers, has since 1992 funded about 202 research and education grants coast-to-coast through researchers at more than 22 institutions including Columbia University College of Physicians & Surgeons, NJ Medical School (UMDNJ), Fox Chase Cancer Center, University of California, Davis, and University of Pennsylvania and at several government agencies.

Moving the tick-borne disease field forward requires not only funding cutting-edge research projects at institutions which have other resources and collaborators, but it also requires publication of the data and conference presentations so that other scientists can review it and use it as a basis for future projects to move the field forward.

Some of the LDA-funded research has been featured in more than 35 peer-reviewed journals, e.g., Journal of the American Medical Association (JAMA), The Proceedings of the National Academy of Science, Emerging Infectious Diseases, The

LDA Grants

---

**Literati Photo Album**

Acclaimed Literati with Lyme Authors Amy Tan, Meg Cabot, and Jordan Fisher Smith are part of LDA’s Literati with Lyme team. Literati with Lyme is an effort by nationally-known authors, publishers, editors, literary agents, other publishing professionals, and the national non-profit Lyme Disease Association to raise awareness of this growing infectious disease threat and to raise research funds for a cure.

On May 18, 2005, Amy Tan, Meg Cabot, and Jordan Fisher Smith joined in an LDA Literati Press Conference along with LDA President Pat Smith and Dr. Brian Fallon, Columbia University at the Princeton/Columbia Faculty Club in Manhattan.

On May 19, 2005, the Lyme Disease Association (LDA) hosted Literati with Lyme, a fundraising event at New York University, entitled “Writer’s Block of the Worst Kind.” The event featured Literati who have all had Lyme disease: Amy Tan (The Joy Luck Club and movie); Meg Cabot (The Princess Diaries series and movies); E Jean Carroll (advice columnist for Elle Magazine); Jordan Fisher Smith (Nature Noir: A Park Ranger’s Patrol in the Sierra); and Jennifer Weis (executive editor St. Martin’s Press). They shared the stage with two prominent medical authorities on Lyme providing a firsthand account of the disease and its impact on peoples’ lives and livelihoods.
In 2007, author Rebecca Wells, Ya Ya Sisterhood, joined the Literati effort, providing a video for the opening of the Columbia University Research Center.

Literati with Lyme Video

For the first time, see the authors of Literati with Lyme at the LDA/Columbia Press Briefing in New York City, May 18, 2005. Amy Tan, Meg Cabot, and Jordan Fisher Smith candidly discuss Lyme disease and their own personal stories. Also featured is Dr. Brian Fallon, Columbia University. LDA President, Pat Smith, presents the opening overview.

Video for RealPlayer

Video for Windows Player

Download RealPlayer

Download Windows Player

Literati Photo Album
Literati Books and Autographs for Sale

Acclaimed Literati with Lyme Authors Amy Tan, Meg Cabot, and Jordan Fisher Smith are part of LDA’s Literati with Lyme team. Literati with Lyme is an effort by nationally-known authors, publishers, editors, literary agents, other publishing professionals, and the national non-profit Lyme Disease Association to raise awareness of this growing infectious disease threat and to raise research funds for a cure. A number of publishers including Houghton Mifflin, Milkweed Editions, Penguin Group (USA) Inc. and Harper Collins donated books to the Lyme Disease Association to help in its work. Now you can purchase books/tapes by these authors with a personally signed bookmark included from the author and benefit the work of LDA at the same time.

Literati with Lyme Book Sale:
Buy books with signed bookmarks from the authors. Support LDA’s Lyme disease research and education efforts!

Amy Tan

{simplecaddy code=AmyTan}
Jordan Fisher Smith

{simplecaddy code=FisherSmith}

Meg Cabot:

{simplecaddy code=MebCabot1}

{simplecaddy code=MegCabot2}

{simplecaddy code=MegCabot3}

{simplecaddy code=MegCabot4}

{simplecaddy code=MegCabot5}

{simplecaddy code=MebCabot6}
Who Is Literati With Lyme

For the first time, four nationally acclaimed authors and an executive editor are sharing the stage with two prominent medical authorities on Lyme for a firsthand account of the disease and its impact on peoples’ lives and livelihoods. Thursday, May 19, 2005, 7-10PM, the Lyme Disease Association (LDA) will host Literati with Lyme, a fundraising event at New York University, entitled “Writer’s Block of the Worst Kind.” The event is featuring Literati who have all had Lyme disease: Amy Tan (The Joy Luck Club and movie); Meg Cabot (The Princess Diaries series and movies); E Jean Carroll (advice columnist for Elle Magazine); Jordan Fisher Smith (Nature Noir: A Park Ranger’s Patrol in the Sierra); and Jennifer Weis (executive editor St. Martin’s Press).

Amy Tan
NY Times bestselling author, Internationally acclaimed, Joy Luck Club (made into a movie), Kitchen God’s Wife, Hundred Secret Senses, Bonesetter’s Daughter, and Opposite of Fate, which contains a chapter on her own Lyme disease http://www.AmyTan.net

Meg Cabot
Meg Cabot #1 New York Times best selling author whose works
include The Princess Diaries series, which were made into two hit movies http://www.megcabot.com

E Jean Carroll
Internationally known Elle Magazine advice columnist (Ask E Jean); author whose works include Hunter, Mr. Right, Right Now; Emmy nominated writer for Saturday Night Live; and co-founder of www.Greatboyfriends.com http://www.ejeanlive.com

Jordan Fisher Smith
Author whose new book, Nature Noir: A Park Ranger’s Patrol in the Sierra, sold out its first printing in a month, includes a chapter on his own Lyme disease http://www.naturenoir.com

Jennifer Weis
Executive Editor St. Martin’s Press

Ms. Weis was editor for Pat Weintraubs book “Cure Unknown, Inside the Lyme“

Rebecca Wells

Joined the Literati at a later date. She is a New York Times

visit the Literati website http://www.Lymeliterati.org

---

What is Literati With Lyme

Literati with Lyme is an effort by nationally-known authors, publishers, editors, literary agents, other publishing professionals, and the national non-profit Lyme Disease Association to raise awareness of this growing infectious disease threat and to raise research funds for a cure. Literati with Lyme is supported by Columbia University Medical Center, Houghton Mifflin, Milkweed Editions, Penguin Group (USA) Inc., IGeneX Labs, the DEET Education Program, and a growing list of others.

Literati with Lyme is the brainchild of Amy Tan, author of The Joy Luck Club, The Bonesetter’s Daughter, and The Opposite of Fate; Jordan Fisher Smith, author of Nature Noir: A Park Ranger’s Patrol in the Sierra; and Pat Smith, President of the Lyme Disease Association, Inc. They are joined by Meg Cabot, bestselling author of The Princess Diaries, E. Jean Carroll, best-selling author, advice columnist for Elle Magazine and Emmy nominated writer for Saturday Night Live, and executive editor Jennifer Weis of St. Martin’s Press

Literati with Lyme will feature two days of events in Manhattan during Lyme Awareness Month in May of 2005.

On May 18, 2005, a private press breakfast will be held at Columbia University. Featured will be Amy Tan, Meg Cabot, Jordan Fisher Smith, Pat Smith, and Brian Fallon, M.D.,
Associate Professor, Clinical Psychiatry, Columbia University Medical Center (CUMC); Director, Lyme Disease Center, CUMC & NY State Psychiatric Institute.

That evening, there will be a by-invitation-only reception for major Literati with Lyme donors (over $200) at the Manhattan home of Amy Tan. Other guests at the reception will include prominent Lyme researchers and clinicians.

On May 19, 2005, Literati with Lyme will host an evening fundraising event for the public ($20) at New York University entitled “Writer’s Block of the Worst Kind,” featuring authors Tan, Cabot, Carroll and Smith and executive editor Weis in conversation with doctors Fallon and Joseph Burrascano. The authors, who have all had Lyme, will discuss how the disease affected their lives and books. Fallon and Burrascano will discuss the physiological causes of the authors’ often frustrating and sometimes hair-raising experiences with the disease. Public question and answer period will follow. The Expository Writing Department and The School of Social Work are NYU co-sponsors with Dr Dean Ornish underwriting the auditorium.

Literati with Lyme has selected Manhattan because it is the traditional home of American publishing and is located in a state that often reports the highest number of Lyme cases.

Lyme is now the most common vector-borne disease in America. Although sometimes associated only with fatigue, vague, flu-like symptoms, and joint aches, Lyme often invades the central nervous system, in some cases causing crippling disability and occasionally, even death.

The publishing industry is proud of its two centuries of service as a conduit of information to the American public. Its authors are welcomed into millions of homes as trusted friends. The authors and publishing professionals of Literati with Lyme are now reaching out to the public to discuss simple
strategies to prevent, recognize, and secure early treatment for this infection. By doing so, they will share the dignity of their profession and their ability to verbalize their experiences with thousands of Lyme disease victims who suffer in silence.

Donations to Lyme Disease Association’s Literati with Lyme are tax-deductible to the full extent of the law and will go to the Lyme Disease Association to support its public education and research efforts on causes and cures of Lyme disease, including the proposed center at Columbia University Medical Center. Go to https://lymediseaseassociation.org

Visit Literati Lyme Website