

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 https://recruit.cumc.columbia.edu/clinical_trial/1661# for this study

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.](#)

Fundraiser at Carmine's, NY

Columbia Lyme & Tick-Borne Diseases Research Center Fundraiser
– Order by Nov. 2

Come have dinner at Carmine's and see the new musical MEMPHIS with the Columbia Lyme Center on Thursday, November 19 in NYC. It's a hot show, lots of "bring it home and sing it" music, fabulous male and female leads. Limited seating. Tickets are \$375 per person (\$185 tax deductible) for dinner and prime orchestra seats. Print out the RSVP and mail to address provided.

Congressman Christopher Smith's Letter

Congress of the United States
House of Representatives

April 30, 2007

Committees:

Foreign Affairs

Africa and Global Health Subcommittee – Ranking Member

Western Hemisphere Subcommittee

Commission on Security and Cooperation in Europe – Ranking Member

Dean, New Jersey Delegation

Dear Friends,

I sincerely regret that I cannot be with you today as I have a

commitment in Washington related to my responsibilities as Ranking Member of the Foreign Affairs Subcommittee on Africa and Global Health.

I want to offer my most heartfelt congratulations to all of you on this truly great occasion in celebration of the opening of the Lyme & Tick-Born Diseases Research Center at Columbia University. As someone who has been aggressively advocating for Lyme disease patients and Lyme disease research since the early 1990's and who in that time has met with uncounted numbers of Lyme disease patients and their families, I am so grateful that this -the first in the world endowed research center for chronic Lyme disease -is opening. I am grateful because it finally brings hope to so many chronically suffering patients -hope in the very tangible and very impressive form of a research center at one of the most respected universities in the world and in the form of internationally-renowned and multi-disciplined scientists devoted to solving the mysteries of chronic Lyme disease.

In the first meeting I held in my office on Lyme disease in March 1992 with officials from the Centers for Disease Control and Prevention and the National Institutes of Health, Lyme patients, and now Lyme Disease Association President Pat Smith, I felt both saddened and challenged with how bleak the situation looked. After many years of advocacy, I hosted a meeting last year with Pat Smith and other advocates, where Dr. Brian Fallon sat across the table from CDC Director Gerberding to discuss some of his research findings regarding chronic Lyme, and I was gratified that we were indeed making progress. But today, we can all agree that it's a whole new ballgame, and I, like all of you, anxiously anticipate what the opening of this Chronic Lyme Research Center will mean for Lyme disease patients.

Let me join in offering my sincerest thanks to Pat Smith, President of the Lyme Disease Association, and to Diane Blanchard and Deb Siciliano, Co-Presidents of Time for Lyme,

Inc., for the unbelievable efforts and resources they have devoted to the development and opening of this Center. Let me say that it has been my pleasure to work with Pat for over 18 years, and recently with Diane and Deb who have been kind enough on many occasions to share their knowledge about Lyme disease issues with my staff. I'd also like to recognize and thank Dr. Brian Fallon, the Director of the Research Center that we celebrate today for being an indisputable champion of unearthing scientific truths about neurologic Lyme disease. Let me also thank the often unsung heroes, the Boards of Directors for both the Lyme Disease Association and Time for Lyme, Inc., and the many others nationwide who have contributed to this great accomplishment.

Finally, let me tell you that to aid the fight against Lyme disease, I have registered in the current Congress the Lyme Disease Caucus, which I am co-chairing with Representatives Bart Stupak of Michigan and Tim Holden of Pennsylvania. In January, I introduced HR 741, the "Lyme and Tick-Borne Diseases Prevention, Education, and Research Act of 2007," which provides an increase in total research, prevention, and education funding for Lyme and other tick-borne diseases of \$20 million per year over 5 years. The bill also establishes a Tick-Borne Diseases Advisory Committee designed to be a focus of communication and coordination among patient representatives, the scientific/medical community, and agencies. The Lyme community has been seeking this voice for a decade. We already have 69 co-sponsors on this bill and we're picking up steam. I am pushing hard for the Energy and Commerce Committee to hold a hearing on this bill.

Congratulations again on the opening of the Lyme & Tick-Borne Diseases Research Center at Columbia University. Let me assure you that I will remain committed to working in Congress to fight for Lyme disease patients and those dedicated individuals, like so many of you, devoted to helping them.

Sincerely,

Chris Smith
Member of Congress

LDA's Opening Remarks

LDA Remarks at Opening of Lyme & Tick-Borne Diseases Research Center at Columbia University

April 30, 2007 , Pat Smith, President, Lyme Disease Association, Inc.

Since the discovery of Lyme disease over 30 years ago in Connecticut, millions of people have acquired it in the United States alone, yet its sickest victims have been treated like Lepers, banished to a shadowy world where doctors are afraid to treat and where researchers on only one side of the controversy surrounding Lyme are usually funded. While battles rage, patients die—and doctors are targeted for treating, and children are taken away from parents whose only crime is having their children treated for Lyme disease.

This is the world many of us mothers faced at the turn of the century, when some impatient moms, who had originally met in 1998, took matters into their own hands. Diane Blanchard, Debbie Siciliano, and I, met and conceived of the idea of developing something at Columbia . An endowed chair morphed into a center, one to study chronic Lyme disease, one that would be cutting edge and be under the direction of Brian Fallon, a man whose research in neurologic Lyme disease was already acclaimed internationally.

So the journey began: three mothers, a researcher, and 2 attorneys spending hours in meetings hammering out what the center would be like, how the monies would be used, who would

guide the center. From the seed of the Center idea to the time of full funding, Lyme disease reported cases increased by almost 1/3, and our chronological ages increased by 7 years. One of us became a Center Director and may have acquired a few gray hairs in the process :), two of us became mothers of high schoolers, and one had her last child graduate from college and acquired the title of grandmother, a title that will be bestowed upon me two more times this summer. In hindsight, 7 years was the blink of an eye, but for suffering patients, it has been an eternity. These patients are why we are here today.

This center has been our dream, a dream that started with a strong partnership, a dream that required thousands of man hours, and woman hours, to bring it to fruition today in these hallowed halls of Columbia University Medical Center . As with most worthwhile things, the work was hard, frustrating, and seemed endless at times. But we had our dream, beyond that next mountain, we could see it- that nebulous concept of Center out there- shrouded in fog, one day giving us tantalizing glimpses of its potential, the next cruelly hiding its glorious nature from our view.

Today marks the beginning of a new era, one in which chronic Lyme disease will finally have its day in the sun, where its deadly secrets will be exposed for all to see. Like any commencement, today signifies the passing from one stage to the next: today from dream to reality, and tomorrow passing into the future reality where the work is already progressing toward the cure for chronic Lyme disease. When that cure happens, I will not be on this podium but dancing in the streets, with my partners, Di & Deb, who will probably be holding me upright by then.

At this time, I want to thank all of those esteemed scientists who have agreed to serve on the Center advisory board and everyone who has come today, especially the speakers and Dr. Ben Beard from the Centers for Disease Control & Prevention

who came all the way from Ft. Collins Colorado to share in our celebration today.

I thank all of those who have helped in this endeavor, an awesome effort, considering it has been done with all volunteers and both groups have scored other major accomplishments at this same time. We had total commitment from our attorneys (Phil Marella TFL, Jurij Mykolajtchuk, LDA), our boards (LDA board stand–Pam Lampe, Corey Lakin, Ruth Waddington, Kim Uffleman, Inge Querfeldt, Linda Davis, Joan Wire, Jeannine Phillips), and our advisory boards. I particularly want to acknowledge my Executive Vice President, Pam Lampe, whose hard work behind the scenes is only exceeded by the tons of emails and phone calls I made to her over time, demanding actions no real person could complete, yet she did.

I thank those who took time from their busy personal schedules to lend their support, like LDA's Literati with Lyme: Amy Tan, Meg Cabot, Jordan Fisher Smith, E. Jean Carroll, Jennifer Weis, and Rebecca Wells, and LDA's national spokesperson, Mary McDonnell who graciously joined us at the both the kickoff and the opening celebration today. Then we have LDA chapters, affiliates, & supporters nationwide, the doctors, researchers, and the patients, who laughed with us, cried with us, and worked with us.

I especially thank the donors, who without fan fare, have been so charitable to us, and without whose generosity, this dream could not have become reality. I must not forget our families who have been so emotionally supportive of us and forgiving of the time we have spent on this project –our children, who have been an inspiration to us.

I thank the Columbia team, Dean of the Medical School, Dr. Lee Goldman; Dr Jeffrey Lieberman, Chair of Department of Psychiatry; and former Dean Dr. Gerald Fischbach, supportive since the Center's inception, and of course, Dr. Brian Fallon,

whom I first met in 1993 when he gave a talk in a church basement in NJ for us. Rumor has it, he still gives the same talk today, and I guess we'll find out later in the program. He has probably breathed a huge sigh of relief thinking he is now able to leave behind these three moms who have run him ragged for many years and be able to close himself into his lab, roll up his sleeves, and get to work. Little does he know, however, that relief is short-lived—we moms will be outside that lab door, peering in, banging on the glass for his attention, until he and the other Center researchers find that definitive test and ultimately, a cure for chronic Lyme disease.

Last, but never least, I thank my partners and dear friends, Deb & Di, for their shared vision, their leadership, their dedication, and their camaraderie. United, we stood, and united, we stand. Surely, a Lyme Disease Research Center built on that kind of foundation shall be nothing but successful.

Thank you.

Author Rebecca Wells Speaks out on Columbia Research Center

April 30, 2007

Author Rebecca Wells on Lyme disease and the opening of the Lyme & Tick-Borne Diseases Research Center at Columbia University (5 minute video, the first two black screens have no sound)

View with: [RealPlayer](#)

View with: [Windows Media Player](#)

Quotes from Opening Day

QUOTES ON THE OPENING OF THE LYME & TICK-BORNE DISEASES RESEARCH CENTER AT COLUMBIA UNIVERSITY

Pat Smith, LDA President

“This is a banner day for everyone connected to Lyme disease and those at risk for tick-borne diseases. Columbia University now houses a premier center which will focus efforts on a definitive Lyme test, chronic Lyme disease, tissue studies, and even tick pathogens. The unsettled science which has clouded diagnosis and treatment will be closely examined in an environment where researchers are interested in discovering the truth about Lyme disease.”

Brian Fallon, MD, Director, Lyme & Tick-Borne Diseases Research Center

Benefits accrue exponentially when scientists from multiple disciplines apply their specific expertise to solve complex problems. This is what is so tremendously valuable about this new Lyme and Tick-Borne Diseases Research Center at Columbia, as the solutions to fundamental diagnostic and treatment questions require the coordinated effort of highly skilled scientists using the latest in biotechnology that only a university-based center can provide.

Amy Tan, Author

My deep gratitude to all those whose commitment helped create this world-class

center for Lyme disease research. For many of us, it is also a center for hope. We now know there is support

for the best minds in science and medicine to work toward more accurate diagnosis and more effective treatment of a widespread and devastating disease

Rebecca Wells, Author

Sometimes when I am weak, lying in bed, I think of those with Lyme who cannot turn from side to side and I give thanks. Sometimes when I am, strong and can exercise a bit, I think of those who cannot walk, and I give thanks. Gratitude is what keeps me going.

I have great gratitude for the opening of this Center. I pray that the research done here will be blessed with good work, work that gives those of us suffering with Lyme hope and healing, work that flows from the minds and hearts and bodies of those doing the research into the bodies, hearts, and minds of we who daily do our best to claw our way, in darkness, out of the trenches of Lyme. I pray that the work that this Center grows will help soften the world that Lyme patients live in, and widens our world with the healing power of knowledge.

In our shared longing for knowledge, all of us— those who live with Lyme; those who work to heal; those who work to shed light on the labyrinthine passages of this disease through research; and those, who with their activism, move us forward, will, create a force field so strong that no shape-shifting spirochete can stop it. We shall walk hand in hand, and make it clear to the unknowing, and those who know, but turn their heads in greedy denial that we will no longer let Lyme flourish in darkness. The light we shine shall be a healing light. The movement from ignorance to knowledge will be felt in the bones of those who cannot turn over in bed, who cannot walk. Knowledge is power, and real power remembers the weak, the ill, and the forgotten. We shall not forget anyone who

suffers. The search is a brave one, and will touch us all.

LDA Press Release on Center Opening

Contact: Pat Smith, Lyme Disease Association, Inc.

email: Lymeliter@aol.com or 888-366-6611

For Immediate Release

A FIRST! LYME & TICK-BORNE DISEASES RESEARCH CENTER OPENS AT COLUMBIA THROUGH PARTNERSHIP WITH LYME DISEASE ASSOCIATION & TIME FOR LYME

Author Amy Tan calls it “Center for Hope” for patients

Wall Township, NJ, April 2007 – In a move that coincides with scientific concern worldwide over global warming and the resultant increase in the range and numbers of ticks and tick-borne diseases, Columbia University Medical Center is opening the first endowed research center for chronic Lyme disease in the world on April 30. The Lyme & Tick-Borne Diseases Research Center in New York will use its vast resources to bring together various disciplines from within and outside of the University to address fundamental clinical and basic science questions that plague adults and children affected by Lyme disease.

According to Brian A. Fallon, MD, the new center director, “Benefits accrue exponentially when scientists from multiple disciplines apply their specific expertise to solve complex problems. This is what is so tremendously valuable about this

new Lyme and Tick-Borne Diseases Research Center at Columbia, as the solutions to fundamental diagnostic and treatment questions require the coordinated effort of highly skilled scientists using the latest in biotechnology that only a university-based center can provide.” Dr. Fallon is also associate professor of psychiatry at Columbia University and director of the Lyme Disease Research Program, New York State Psychiatric Institute.

The Center’s clinical and research mission includes studies of new diagnostic tests, clinical phenomenology, immunopathogenesis, co-infections, genetic markers of vulnerability, brain imaging, neuropathology of post-mortem brains, well-controlled studies of new treatments and tick pathogens. This Center will serve as a national resource, providing pilot grants to researchers nation-wide and focusing the latest scientific technology on helping to resolve the problems of chronic Lyme disease.

As Lyme cases increase worldwide, so does the development of chronic disease which may result from a delayed diagnosis and delayed or inadequate treatment. While much is known about early Lyme disease, relatively little is known about chronic Lyme disease, despite its disabling effects, which may include arthritis, cognitive loss, peripheral neuropathies, and debilitating fatigue. Sometimes, Lyme may also cause strokes, blindness, severe psychiatric disorders, and multiple-sclerosis-like illnesses. Adults may become permanently disabled, and children may be home sick for months or years, missing the key academic and social influences so critical to healthy development.

Internationally acclaimed author (and Lyme patient) Amy Tan expresses “my deep gratitude to all those whose commitment helped create this world-class center for Lyme disease research. For many of us, it is also a center for hope. We now know there is support for the best minds in science and medicine to work toward more accurate diagnosis and more

effective treatment of a widespread and devastating disease.”

The national New Jersey-based Lyme Disease Association, Inc. (LDA) and Connecticut-based Time For Lyme (TFL) who are affiliated organizations, partnered with Columbia in the development of this center concept and devoted a large percent of their efforts and resources in the past 5 years to funding the endowment for the Center. People nationwide contributed to make this effort a success. Pat Smith, LDA President, said of the opening, “This is a banner day for everyone connected to Lyme disease and those at risk for tick-borne diseases. Columbia University now houses a premier center which will focus efforts on a definitive Lyme test, chronic Lyme disease, tissue studies, and even tick pathogens. The unsettled science which has clouded diagnosis and treatment will be closely examined in an environment where researchers are interested in discovering the truth about Lyme disease.”

About Lyme Disease Association—The Lyme Disease Association (LDA) is a national nonprofit all-volunteer organization that devotes ninety-eight percent of its funds to programs-funding research, education, prevention and patient support. LDA-funded research has been published in peer review including JAMA, Neurology, Infection, and the Proceedings of the National Academy of Science. Recognizing that the ability to find solutions involves a multi-disciplinary effort, the LDA has partnered with businesses, patient groups, celebrities, government, and the medical community to unlock the secrets of Lyme and other tick-borne diseases. LDA is currently planning its 8th fully CME accredited medical conference for physicians on Lyme and other tick-borne diseases. Go to LymeDiseaseAssociation.org.

About Time for Lyme—TFL, affiliate of Lyme Disease Association, is an organization dedicated to eliminating the devastating effects of Lyme and other tick-borne diseases. Its mission is to prevent the spread of disease, develop definitive diagnostic tools and effective treatments, and to

ultimately find a cure for tick-borne illness by supporting research, education, and the acquisition and dissemination of information. In addition, TFL advocates for Lyme disease sufferers and their families through support of legislative reform on the federal, state and local levels. For more information on TFL, please visit www.timeforlyme.org.

About Dr. Brian A. Fallon, MD, MPH—He is Associate Professor at Columbia University College of Physicians and Surgeons and director of the Lyme Disease Research Program at the New York State Psychiatric Institute. He graduated from Harvard, got his M.D. and a MPH from Columbia University College of Physicians and Surgeons. He has dozens of publications in the Lyme disease field and much of his work has been supported by NIH grants and has been acclaimed internationally.