

# 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.

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# 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](http://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](http://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.

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# Remarks from LDA & TFL to Lyme Community

**April 30, 2007 A Dream to Reality**

**Lyme & Tick-Borne Diseases Research Center at Columbia University Medical Center!**

**LDA & TFL say: Thank You, Lyme Disease Community, For Your Support!**

The Lyme Disease Association and Time For Lyme want to thank the Lyme community for helping to make this dream of a research center a reality. All of us have fought long and hard, together, to establish credibility for chronic Lyme disease. Now, one of the most prestigious institutions in the world, Columbia University Medical Center, has established a research center to study chronic Lyme disease.

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# Congressman Smith's Letter

# Christopher

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

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## **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.

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# 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](#)

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## Columbia TBD Research Center – Support Letters

Lincoln Almond – Governor of Rhode Island

Michael R. Bloomberg – Mayor of New York City, New York

Richard Blumenthal – Attorney General of Connecticut

Howard Dean, M.D. – Governor of Vermont

Christopher J. Dodd – US Senator, CT

Brian A Fallon, M.D., M.P.H. – Columbia University  
Gerald D. Fischbach, M.D. – Columbia University  
Serphin R. Maltese – Senator of Queens County, New York  
Mary McDonnell – Actor, National Spokesperson for the Lyme Disease Association, Inc.  
James E. McGreevey – Governor of New Jersey  
Amedeo C. Merolla – Brigadier General (Ret.) AUS  
George E. Pataki – Governor of New York  
Joseph R. Pitts – US Congressman, PA  
John G. Rowland – Governor of Connecticut  
Christopher H. Smith – US Congressman, NJ  
Remarks of Pat Smith – President of the Lyme Disease Association, Inc

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## **What is the Columbia TBD Research Center all About?**

### **Who will head the Center and advise it?**

The Director of the Center will be Dr. Brian Fallon, Associate Professor of Clinical Psychiatry, Columbia University College of Physicians & Surgeons.

The Scientific Advisory Board for the Columbia Lyme and Tick-Borne Diseases Research Center brings together internationally-renowned scientists, including Dr. Claire Fraser (led the team that mapped the *Borrelia* Genome), Dr. Janis Weis (pathogenesis of Lyme arthritis), Dr. John Mann (translational neuroscience), Dr. Steven Schutzer (novel diagnostic tests), Dr. Ian Lipkin (foreign pathogen identification), Dr. Jorge Benach (*Borrelia* and Coinfections),

Dr. Scott Hammer (infectious disease), Dr. Diego Cadavid (neuropathology and neurology), Dr. Ronald Van Heertum (neuroimaging), and Dr. Aaron Mitchell (molecular pathogenesis).

### **What is the Center?**

The Lyme and Tick-Borne Diseases Research Center will use the vast resources of Columbia University in New York 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.

The clinical and research mission includes studies of new diagnostic tests, clinical phenomenology, immunopathogenesis, co-infections, genetic markers of vulnerability, functional and structural brain imaging, neuropathology of post-mortem brains, and well-controlled studies of new treatments. This Center, the first such facility in the world devoted to chronic Lyme disease, 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.

### **Where will the Center be located?**

The Center will use existing space within Columbia University Medical Center.

When will the Center officially open?

April 30, 2007, opening ceremonies.

### **Why is the Center needed?**

While much is known about early Lyme disease, relatively little is known about chronic Lyme disease, despite its rising prevalence and disabling effects. These effects may include arthritis, cognitive loss, peripheral neuropathies, and debilitating fatigue. Sometimes, LD 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.

### **How was the Center established?**

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.

LDA's Literati with Lyme, a group of authors and others in the publishing field, helped in the fundraising effort (Amy Tan, Meg Cabot, Rebecca Wells, Jordan Fisher Smith, E. Jean Carol, Jennifer Weis) as did LDA's National Spokesperson, two time Oscar-nominated actor, Mary McDonnell, currently starring in the Peabody Award TV series, BattleStar Galactica. Many other professionals and corporations contributed their efforts to help the LDA & TFL establish the Center.

### **Quotes on the Center Opening**

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." © Rebecca Wells 2007

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## Actress Mary McDonnell Dances with Lyme Fundraiser

***✖ New York Governors Office and Celebrities Take on Debilitating Disease***

Oct 18, 2002 – Oscar-nominated Actress Mary McDonnell will serve as honorary chairperson of a benefit dinner to raise money to create the first Lyme disease research center of its kind in the United States at Columbia University. The Time for Lyme benefit dinner, which is open to the public, will be emceed by NBC's Chuck Scarborough and actress Jayne Atkinson, who stars on Broadway in the production of Our Town with Paul Newman. Funds raised at the event also will be directed at Lyme disease education, prevention, and other types of research programs.

Lyme can cause neurological, arthritic and severe joint problems. An estimated 90 percent of the cases of Lyme go unreported. Actress McDonnell embraced the needs of Lyme patients after her cousin's husband died. McDonnell's family learned he died of Lyme only after his death. "If physicians were better educated to identify Lyme, he may have lived. We need to raise money to help the thousands out there still

suffering when they don't have to," says McDonnell.

The benefit begins at 6 p.m. on Friday, October 18, at Manhattan's Sky Club, which is located at 200 Park Ave. on the 56th floor, and includes a cocktail reception, live and silent auctions, and live entertainment. The Lyme disease Association (LDA) and the Greenwich Lyme Disease Task Force (GLDTF) are sponsoring the event and already have donated \$700,000 to Columbia University, but \$3 million is needed to make the center fully operational. New York Governor George E. Pataki also is supporting the benefit. And honorary committee members for the benefit include: Jayni and Chevy Chase, Tommy Hilfiger, Sonia and Paul Tudor Jones, Magee Hickey, and Ellen and Chuck Scarborough.

Brian Fallon, MD, associate professor of clinical psychiatry and director of the current Lyme Disease Program at New York Psychiatric Institute, will be the Center's director. He is considered by many to be the leading expert on neuropsychiatric manifestations of Lyme disease.

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# **Fundraiser with Mary McDonnell**

September 25, 2002

The Lyme Disease Association and the Greenwich Lyme Disease Task Force are hosting Time for Lyme in New York on October 18 at Manhattan's Sky Club at 200 Park Ave. on the 56th floor. The event will raise funds for Lyme disease research and education, and will consist of a cocktail reception, live and silent auctions, and live entertainment. Over five hundred people from the Tri-State area are expected to attend the benefit. Lyme Disease Association spokesperson and Event Honorary Chair,

Mary McDonnell (Oscar-nominated actress in *Dances With Wolves*) will appear at the event. Honorary Committee members include Jayni and Chevy Chase, Tommy Hilfiger, Sonia and Paul Tudor Jones, Magee Hickey and Ellen and Chuck Scarborough.

According to the Centers for Disease Control, Lyme disease is the fastest growing infectious disease in the United States after HIV, and the nation's number one vector-borne disease. The national Lyme Disease Association (LDA) and its affiliate the Greenwich Lyme Disease Task Force (GLDTF) want to see that change, and are fighting to find an accurate test to determine active infection and, eventually, a cure for Lyme and other tick-borne illness.

Children are at greatest risk for contracting Lyme disease as they often play in and around tick infested areas. Symptoms of Lyme can include nausea, extreme fatigue, joint pain, cardiac issues, severe headache and a general inability to lead a normal life. Diagnosis is difficult because current blood tests are often inaccurate, and the multi-systemic nature of the disease leads to difficulty in diagnosis.

"The lack of a sensitive diagnostic test to confirm active infection is the key problem in the field of Lyme disease treatment," said Dr. Brian Fallon, Associate Professor in the Department of Psychiatry at Columbia University and a well-known authority on the neurological manifestations of disseminated Lyme disease. "The absence of such a test leaves doctors in the uncomfortable quandary of not knowing what treatment to choose, and places patients at risk for developing a more entrenched illness."

Lyme disease is caused by the bacterium *Borrelia burgdorferi*, and is transmitted through the bite of an infected tick. According to the CDC's latest statistics, cases of Lyme disease reported to the agency increased eight percent in 1999-2000, but many experts, including the International Lyme and Associated Disease Society (ILADS), believe that Lyme

disease is underreported by tenfold due to lack of knowledge about the disease and stringent reporting criteria.

"More than 160,000 people are infected each year, and the one-size-fits-all approach for treatment that many doctors use is often inappropriate," said LDA President and ILADS Board of Directors member Pat Smith.

The Greenwich Lyme Disease Task Force and the Lyme Disease Association have agreed to partner with Columbia Presbyterian Medical Center of New York, and are working to open the Columbia Lyme Disease Research Center, the first of its kind in the nation. The Center, under the direction of Dr. Fallon, will conduct research on Lyme and other tick-borne diseases, and will treat patients. The GLDTF and the LDA are endowing the Center, and \$3 million is required to make the Center operational. Substantial private and corporate donations are needed to fund this research effort, which will be a primary focus of Time for Lyme in New York. Funds raised at the benefit will also be directed at Lyme disease education and prevention awareness.

"I have seen first hand the suffering that comes from Lyme infection," said event co-chair Dana McAvity of the GLDTF. "Those of us who have suffered with Lyme and all those who may be infected in the future need this Center. Time for Lyme in New York is an important first step in getting the funding. It should be a wonderful evening."

The Greenwich Lyme Disease Task Force and the Lyme Disease Association are non-profit organizations. Tickets for the benefit begin at \$250 per ticket, and are tax deductible to the extent allowed by law.