

Williamsport, PA – Public Presentation at the YMCA

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Williamsport PA Opening

January 15, 2005

Lyme disease has not been taken seriously, and has never received monies or recognition commensurate with its status as the most prevalent vector-borne disease in this country today and the most prevalent vector-borne bacterial disease in the world. This is one of the reasons the Lyme Disease Association decided to become a national umbrella organization with a number of Lyme groups across the country joining as affiliates. The need to do this is pressing, since anywhere from 220-240,000 Americans develop new cases of Lyme disease each year. This number is based upon the CDC's own statistics which indicate only 1/10th of actual cases meeting the CDC criteria are reported. The LDA has been raising monies for Lyme disease, and has raised over \$2 million toward research, education, prevention, and patient support. Since LDA is all-volunteer, it is noteworthy that over 98% of those monies go directly to programs. The LDA and its affiliates have together raised over \$4 million for Lyme disease research education & prevention.

We have funded research projects from coast to coast and were very excited with the publications of one of our projects in Sept 2004 in The Proceedings of the National Academy of Science, Wei-Gang Qiu et al on the rapid exchange of genetic material among different strains of Borrelia, which presents a finding which can have a significant impact on the diagnosis, treatment, and prevention of Lyme disease. These newly published results come from the LDA funded research, principal investigator, Dr Steven Schutzer, which mapped the genomes of two different strains of borrelia and compared it with the B31 strain, which was already mapped. Renowned genome experts including Dr Claire Fraser from The Institute of Genomic Research (TIGR), where the human genome & B31 were mapped in the past, and Dr. Sherwood Casjens from University of Utah School of Medicine took part in the study. The Lyme Disease Association & its CT affiliate, Time for Lyme, are partnering with Columbia University to open an endowed research center for chronic Lyme disease which will house dedicated researchers to study Lyme disease. By summer, we anticipate that half the monies \$1.5M will be raised for the center, the first of its kind in the world. Meanwhile, Columbia University Medical Center has announced the opening of a Lyme and Tick-Borne Disease Evaluation Service at Columbia, directed by Brian Fallon, MD, which focuses on patients who are still

experiencing symptoms after being diagnosed and treated for Lyme disease and patients who have unexplained psychiatric symptoms that may be due to Lyme or other tick-borne diseases. The goal is to provide a comprehensive evaluation, seeking to also rule out other disorders that may cause the multi-systemic symptoms. Also, Dr Fallon announced at the joint LDA/Columbia conference in November in Rye, NY, the results of his \$4.7 NIH-funded study. Patients with chronic Lyme disease retreated with 10 weeks of intravenous antibiotics showed significant

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improvement in cognition and other symptoms. This finding represents a huge step forward in the battle against chronic Lyme disease. He is working on the publication of that material now. The LDA's DVD from the conference should be ready in February. Check our website then.

LDA has just published a unique resource book called Lyme Disease Update

Science, Policy & Law, which presents a digest of the peer-reviewed literature supporting chronic Lyme disease and also gives a state-by-state breakdown of actions taken by individuals and groups to help Lyme patients and physicians. It also has a section on the types of legal cases pertinent to Lyme patients. Written by Marcus Cohen, a columnist for the Townsend Letter for Physicians and Patients, the Foreword is by Dr. Fallon of Columbia and the Preface by New York Time's best-selling author, Amy Tan. It is a resource suited

for physicians who need "evidence" before they will treat chronic disease and for patients who need to provide insurance documentation.

LDA has just released the first of its kind publication, a book for children 8-12 who have Lyme disease! Lyme Disease Is No Fun: Let's Get Well! written by Mary Wall MEd, CCLS, a Columbia graduate student, and edited by Colleen M. Smith, a peer-review medical journal production editor! each has battled Lyme disease.

At the Philadelphia 2003 conference, LDA established LymeAid 4 Kids for anyone under 21 with no Lyme disease insurance coverage. Any physician nationwide can apply for his/her patients! up to \$1,000 per child for diagnosis and treatment.

Amy Tan is supporting the fund. You can find information on the fund on LDA's newly revamped website: LymeDiseaseAssociation.org

In February, 2004, International Lyme & Associated Diseases Society (ILADS), a professional medical society, published Evidence Based Guidelines for the Management of Lyme Disease in the peer-review journal Expert Review of Antiinfective Therapy. The first guidelines to include the management of chronic Lyme disease, they have been accepted for listing on the National Guideline Clearinghouse™ (NGC™), a public resource for evidence-based clinical practice guidelines. NGC is an initiative of the Agency for Healthcare Research and Quality (AHRQ), US Department of Health and Human Services. Four weeks ago, ILADS

held its annual meeting and received CME accreditation from the Westchester Academy of Medicine. The Society is growing by leaps and bounds. It is a place for physicians to share their knowledge of tick-borne diseases' diagnosis and treatment for the benefit of all.

In another vein, Lorraine Johnson, JD, MBA, executive director of California Lyme Disease Association, an LDA affiliate, and Ray Stricker, MD, president elect of

ILADS, published *The Treatment of Lyme Disease: A Medicolegal Assessment*

in the peer reviewed journal *Ex. Rev. Anti-Infect. Ther.* 2(4),(2004). The authors

discuss the medical basis for diagnostic and therapeutic uncertainty in Lyme

disease, the issues regarding the legal standard of care that apply to treating

physicians and insurers, the role of evidence-based medicine, patient autonomy,

patient preference, and informed consent in Lyme disease.

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School Leader, the official publication of New Jersey School Boards Association,

published my article titled *Effects of Lyme Disease on Students, Schools, and*

School Policy in the Sept/Oct 2004 issue. Full text is on LDA's website.

The Lyme community has fought and made inroads in some significant legislative

battles. In RI, the legislature passed the doctor protection bill and mandatory

insurance coverage for patients although that insurance bill had a sunset

provision. The NY Assembly & Senate passed OPMC reform legislation which

gives doctors who are brought up on charges some due process rights they have not had, including introduction of scientific literature. Unfortunately, Gov Pataki vetoed the bill. We are working with some legislators there to see what can be done this year. In Pennsylvania in 2003, the House passing a bill to protect physicians' right to treat and mandatory insurance coverage combined. The senate did not have an opportunity to take up the bill before the session ended. Thanks to House Majority Administrator Merle Phillips for that bill. CA held a senate hearing on Lyme disease last year and our CA affiliate, CALDA, presented significant testimony there. Right now LDA is working with a senator in NH on a resolution there and may be going to DC to meet with several US Senators soon on the issue of Lyme disease. We are also working in one state with the medical board on the doctor issue. In Dec, LDA met with Gov. Codey's office in NJ to discuss the insurance bill now introduced in both houses. In May, LDA is hosting an event called Literati with Lyme which will feature author Amy Tan (Joy Luck Club), Meg Cabbott (Princess Diaries), and Jordan Fisher-Smith (about to be released Nature Noir). Held in NY, there will be a major press conference at Columbia, a fundraiser in Manhattan, and a panel discussion at NYU with major authors and doctors on the problems these authors face in their work because of Lyme disease. The focus will be to raise the credibility of Lyme

disease as well as to raise funds.

The next portion of my talk will deal with Lyme disease itself.