

Hundreds Hike & Ride on the Hook for Lyme Disease Research & Awareness

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Press Release

For Immediate Release

Hundreds Hike & Ride on the Hook for Lyme Disease Research & Awareness

Weather Cooperates for 1st NJ Lyme Awareness Walk/Ride by national Lyme Disease Association

Monmouth County, May 12, 2008—Over 230 people came to raise funds for a disease that is newly infecting tens of thousands of New Jersey residents every year, Lyme disease. The participants came not only from Monmouth County but also from all over the state and from other states such as Pennsylvania and New York. They came as patients and as families and friends of patients to lend support to the NJ-based national Lyme Disease Association (LDA) for its first bike ride and walk, **Spotlight on Lyme**, held May 18 on scenic Sandy Hook.

Sandy Hook, a Peninsula bounded by the Atlantic Ocean to the East and Sandy Hook Bay to the West, is part of the Gateway National Parks Recreation Area. Bikers and walkers were treated on Sunday to the natural sand dunes which border the Atlantic Ocean and a spectacular view of the New York Skyline visible only on a clear day which Sunday was. Bright green shirts, symbolic of Lyme disease, with a lighthouse image spotlighting a tick, dotted the area under sunny skies, as the 50+ bikers rode 15 miles and the 150 walkers went 3 miles, some participants with canes and in wheel chairs due to the devastating effects of their Lyme disease.

Said Tinton Falls resident Joan Wire whose son participated in the walk in his wheel chair: “Lyme is a multi-

systemic disease, the effects of which are not well publicized in New Jersey, so people are unaware of its debilitating nature. Today's walk helped to change that picture by showing the victims of Lyme are everywhere in New Jersey and nationwide, and they are fighting for their very lives."

Many children registered for the event— appropriate since children are at the highest risk of acquiring Lyme disease. They were able to participate in games and face painting and snack on donated food throughout the event. DJ, Dru, donated his services, playing music for the crowd. LDA President Pat Smith gave a brief talk before the event, wearing a different green tee shirt sporting the Minnesota Lyme Action Support Group Lyme Walk, which took place the day prior, sponsored by the by the LDA affiliate there. Ms. Smith mentioned that Lyme is a worldwide problem found in 65 countries and is in all 50 states here. Lyme walks are happening nationwide, one held for LDA in Maine and an upcoming one in Corning, New York by the LDA Chapter there. She also mentioned the need for passage of the federal Lyme bill (Smith NJ-4), bottled up in the House Health Subcommittee by Congressman Frank Pallone (NJ-6)—a bill which provides much needed Lyme research monies.

Walk Chairman Kim Cronin, Little Silver, was happy with Sunday's turnout. She said: "We have opened the door for creating awareness here in Monmouth County and in New Jersey. Now is the time for that awareness, since so many more ticks carrying so many more diseases are biting us and our children. Our government has not taken a lead in awareness, so it is necessary for organizations like LDA who depend upon volunteers to become the leaders in this area." When asked during the height of the event if she would chair another walk next year, she replied with a grin, "I am not sure now is a good time to ask." Later however, she was seen reviewing paperwork for the 2009 walk/ride.

New Jersey ranks third in CDC reported Lyme case numbers nationwide, with Monmouth County 2nd in cases in the State. NJ also has one of the highest incidences in the country for babesiosis, a malaria-like illness transmitted by the same deer tick that transmits Lyme disease. The deer tick is now joined by the more fast and aggressive Lone Star tick which is spreading STARI (Southern tick-associated rash illness), a Lyme-like disease with no viable test, and also other diseases.

Many New Jerseyans currently suffer from co-infections, more than one tick-borne disease at the same time. Additional tick-borne diseases prevalent in NJ and the Northeast include anaplasmosis, ehrlichiosis, Rocky Mountain spotted fever, tularemia, tick paralysis and tick-borne Bartonella. Often these residents are unaware they have Lyme disease, since they may be misdiagnosed with MS, ALS, chronic fatigue, fibromyalgia, lupus, Alzheimer's and sometimes, even autism.

According to LDA President Pat Smith, a Wall Township resident, "This walk was so well run and so necessary to Lyme disease here. We used to host many events in NJ in the 90s, but the lack of interest by government officials over time led to a lack of coverage and lack of interest by people. This event shows

people's hunger for knowledge and research for a cure— Lyme disease has become a household word, yet government is still ignoring the rising numbers and ailing patients. It's a travesty leading to people becoming much sicker than necessary if they were educated about the disease."

ABOUT THE LYME DISEASE ASSOCIATION (LDA): —The Lyme Disease Association (LDA) is a national volunteer nonprofit based in Monmouth & Ocean Counties that devotes ninety-eight percent of its funds to programs—funding research, education, prevention and patient support. LDA has funded research projects coast to coast—some of which have 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 and Time for Lyme, its Connecticut affiliate, raised funds and collaborated with Columbia University to open an endowed Lyme disease research center there in New York in 2007. LDA also has a fund for children with no insurance initiated by internationally acclaimed author Amy Tan. Go to www.LymeDiseaseAssociation.org.

Lyme Disease Association (LDA) Announces Lyme Walk/Ride on Sandy Hook

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Lyme Disease Association (LDA) Announces Lyme Walk/Ride on Sandy Hook

Lyme & Other Tick-Borne Diseases Continue to Rise in NJ

Wall Township, May 12, 2008—The NJ-based national Lyme Disease Association (LDA) announces it is hosting a bike ride and a walk, **Spotlight on Lyme**, on May 18 in Monmouth County New Jersey. Participants have a choice of a 3 mile walk or 15 mile bike ride taking place on Sandy Hook to raise funds for the LDA for research to fight this debilitating disease and to raise awareness. New Jersey is third in the nation in CDC reported Lyme disease case numbers and Monmouth County ranks 2nd in case numbers in New Jersey.

Walk Chairman Kim Cronin, Little Silver, says: “We need much more awareness about Lyme disease all over New Jersey but particularly in the Jersey Shore area. Little is being done to prepare the public and our kids about how to prevent a tick bite, what to do when you are bitten, and what to do after you have Lyme disease. Little monies are being spent on Lyme education or research, so we need to focus on the disease and on raising funds to spotlight prevention and a cure. “

NJ has one of the highest incidences in the country for babesiosis, which is a malaria-like illness transmitted by the same deer tick that causes Lyme disease. Deer ticks are being joined by more aggressive Lone Star ticks which are spreading STARI, a Lyme-like illness with no viable test, and also other diseases. Additional tick-borne diseases prevalent in the Northeast include anaplasmosis, ehrlichiosis, Rocky Mountain spotted fever, tularemia, tick paralysis and tick-borne Bartonella.

Special attention needs to be paid to tick-borne diseases in children, since age groups 5-9 and 10-14 years are at highest risk of acquiring Lyme disease. Unfortunately, too many people are unaware that Lyme disease can interfere with the learning process—neurologic Lyme can even cause a drop in IQ for some students, which can usually be rectified with treatment. Since the disease is often misdiagnosed or has a delayed diagnosis, Lyme disease can attack every system in the body and produce cardiac, neurologic, musculo-skeletal, ophthalmologic, and psychiatric manifestations.

According to LDA President Pat Smith, “Chronic Lyme disease is often misdiagnosed as MS, ALS, chronic fatigue, fibromyalgia, lupus, Alzheimer’s and sometimes even autism. Patient organizations such as LDA are

providing some of the only monies for research into chronic Lyme disease. Government has ignored the plight of these very sick patients, and more research needs to be done to answer the tough questions, such as why some people do not get totally better.” HR 741, the Lyme bill, which would provide needed federal research funds, is stuck in the US House of Representatives Energy & Commerce Health Subcommittee.

ABOUT THE WALK & RIDE: The event will be held on Sandy Hook Gateway National Park, New Jersey-Beach Area E Sunday, May 18, 2008, 9am check-in, Rain or Shine. Registration for adults is \$25 and for children 13 and under is \$15. Credit card registration can be done online through 6pm May 14 (www.LymeDiseaseAssociation.org) and registrations after that time will then be accepted the day of the event, by cash and check only. Games, DJ, face painting, prizes and food will be a part of the event festivities. Helmets are required and a waiver needs to be signed prior to participating in the event. Children 13 & under must be accompanied by an adult.

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Lyme Disease Physicians and Patients Expose Research Group's Ploy to Silence Them

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Lyme Disease Physicians and Patients Expose Research Group's Ploy to Silence Them

Already caught up in an anti-trust investigation, IDSA opposes research bill in order to maintain monopoly over Lyme diagnosis and treatment options

Washington, DC – Physicians specializing in treating chronic Lyme disease and a national coalition of Lyme disease patients and their families today accused a medical research group of trying to exercise monopoly control over research on Lyme and tick-borne diseases.

"We're very disappointed," said Pat Smith, president of the national Lyme Disease Association (LDA), responding to a letter to Congress by the Infectious Diseases Society of America (IDSA) that seeks to deny patients a voice regarding the research needed to better understand the disease.

Lyme disease is a serious bacterial infection that develops from the bite of an infected tick. The disease is often misdiagnosed or goes untreated, causing many patients to suffer persistent health problems, including neurological disorders, crippling muscle and joint pain, disabling fatigue, psychological disorders, and even death. Even when Lyme disease is caught early and treated with a short course of antibiotics, the debilitating symptoms can persist and require additional longer-term treatment.

In March, IDSA wrote Congress attacking the Lyme and Tick-

Borne Disease Prevention, Education and Research Act of 2007, introduced by Chris Smith (R-NJ) and Bart Stupak (D-MI) in the House, and Christopher Dodd (D-CT), Charles Schumer (D-NY) and Chuck Hagel (R-NE) in the Senate. The broadly supported bipartisan bill calls for acceleration of Lyme disease research and creates a new federal advisory committee made up of the full range of scientific viewpoints on Lyme, including a seat for patient advocacy groups.

The IDSA is currently under investigation by the Connecticut Attorney General for abuse of monopoly power and exclusionary conduct in formulating its Lyme disease guidelines, which were developed by a panel that held significant commercial interests in diagnostic tests, vaccines, and consulting arrangements. In its letter to Congress opposing the Lyme Bill, the IDSA failed to mention this ongoing investigation.

IDSA researchers have virtually controlled Lyme disease research for the past 30 years amidst ongoing controversy surrounding its guidelines, which deny patients the right to treatment options and undermine the ability of physicians to use their clinical discretion in treating patients. IDSA provides private health insurance companies with the basis for denying long-term treatment for chronic Lyme disease.

The California Lyme Disease Association (CALDA), national Lyme Disease Association (LDA) and Time for Lyme (TFL) are non-profit organizations that were founded by individuals who had personal experience with Lyme disease, in order to address the lack of research, education and support services available for this newly emerging infection.

Lyme Disease Association & Mercy Hospital Announce Lyme Disease Forum

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Lyme Disease Association & Mercy Hospital Announce Lyme Disease Forum

Local University Student Gives Back to Community after delayed diagnosis changes life

Scranton, Pennsylvania, March 10, 2008—The national Lyme Disease Association (LDA) announces a free public forum to be held at Mercy Hospital on March 31, 2008, 7-10PM, on Lyme and other tick-borne diseases. Featured speakers include Dr. Richard Horowitz, Hyde Park New York, who will discuss the diagnosis and treatment of Lyme disease; and Patricia Smith, Wall Township New Jersey, President of the Lyme Disease Association, who will present the spread of tick-borne diseases and the problems faced by patients.

Lyme is the most prevalent vector-borne disease in the country, and it has been joined by other emerging co-infections in the Northeast including babesiosis, anaplasmosis/ ehrlichiosis, and tick-borne Bartonella, transmitted by the bite of the same deer ticks that carry the Lyme disease bacteria. Pennsylvania has consistently ranked number 2 nationwide in reported case numbers of Lyme disease. The NE District in Pennsylvania, which includes Lackawanna County, ranks third of 6 districts in 2006 case numbers and 3rd in incidence over 5 years.

This forum was developed in conjunction with Heather Okun, Marywood student, as part of her professional

program at Marywood University. After suffering a tick-bite as a teen, she developed severe cognitive problems that dropped her grades while in high school; yet, she remained undiagnosed for Lyme disease for two years. Heather had intended to become a veterinarian. Subsequent to treatment and then a relapse, however, she was seen by a physician's office that employed physician's assistants (PA). Then and there, she decided that she would study to become a PA. Heather, who, is on the verge of graduation, will also be a conference speaker. She says, "It seems appropriate that for my professional contribution which is required for graduation, I tell my story and educate others about this disease that changed my life."

Heather's experience with her Lyme disease not being recognized, is not an uncommon one, especially in children. They are a special concern, because age groups 5-14 years are at highest risk of acquiring Lyme disease. Unfortunately, too many people are unaware that Lyme disease can interfere with the learning process and that many students require special accommodations in the classroom as a result. And since the disease is often misdiagnosed or diagnosed months or years after infection, Lyme disease can cause numerous ongoing physical problems involving the cardiac, neurologic, and musculo-skeletal systems, and it can manifest as psychiatric problems. Neurologic Lyme can even cause a drop in IQ for some students, which can usually be rectified with treatment.

Says LDA President Patricia V. Smith, "LDA has been happy to work with Heather and with Mercy Hospital to provide this forum in an area where Lyme and other tick-borne diseases are too often overlooked as a diagnosis. Awareness is certainly the key to prevention of this disease, and more research needs to be done to answer the tough questions, such as why some people do not get totally better."

ABOUT THE LYME DISEASE ASSOCIATION (LDA): –The Lyme Disease Association (LDA) is a national volunteer run nonprofit that devotes ninety-six 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 and Time for Lyme, its Greenwich, Connecticut affiliate, collaborated to raise funds to open in 2007 the Lyme & Tick-Borne Diseases Research Center at Columbia University in New York which will coordinate research projects from across the country. LDA is currently planning its 9th fully CME accredited medical conference for physicians on Lyme and other tick-borne diseases to be held in San Francisco in October 2008. Go to LymeDiseaseAssociation.org.

National Association Announces Eastern Connecticut Lyme Chapter

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PRESS RELEASE FOR IMMEDIATE RELEASE

National Association Announces Eastern Connecticut Lyme Chapter

Eastern counties high in disease, low in awareness, says new LDA chapter chair

NORWICH, CONNECTICUT, November 26, 2007—The national Lyme Disease Association (LDA) announces the formation of the Lyme Disease Association, Eastern Connecticut Chapter (LDAECC), bringing the current total of LDA-associated organizations nationwide to 31.

LDAECC's formation was initiated by a family personally affected by Lyme disease who is deeply concerned by the prevalence of this disease. Commenting on the formation, the new Chapter Chair, Kimberlee Pappa, of Sprague, Connecticut said, "As a businesswoman, every day I speak to people who have been affected by Lyme, and they are all reaching out for help and information. I want to be a resource for them."

Lyme is the most prevalent vector-borne disease in the country, and it has been joined by other emerging co-infections in the Northeast including babesiosis, anaplasmosis (formerly ehrlichiosis), and tick-borne Bartonella, transmitted by the bite of the same deer ticks that carry the Lyme disease bacteria. Tolland County's number of Lyme disease cases has increased by 95% from 2004 to 2006, with a corresponding 75% increase in New London County's numbers.

Children are a special concern because age groups 5-14 years are at highest risk of acquiring Lyme disease. The Pappa Family has 2 children suffering from Lyme disease and therefore is aware of the learning difficulties caused by it. Unfortunately, too many parents are unaware that Lyme disease can interfere with the learning process and that many students require special accommodations in the classroom as a result. Lyme disease can cause numerous ongoing physical problems involving the cardiac, neurologic, and musculo-skeletal systems, especially if treatment is delayed or incomplete, and it can manifest as psychiatric problems. Neurologic Lyme can even cause a drop in IQ for some students, which can usually be rectified with treatment.

Says LDA President Patricia V. Smith, "I am delighted to announce the creation of this chapter, LDA's 8th chapter, in an area which contains some of the highest Lyme disease occurrences in the country. Awareness is certainly the key to prevention of this disease, and more research needs to be done to answer the tough questions, such as why some people do not get totally better." To that end, LDA and Time for Lyme, its Greenwich, Connecticut affiliate, collaborated to raise funds

to open in 2007 the Lyme & Tick-Borne Diseases Research Center at Columbia University in New York.

The LDAECC will work to further the LDA's mission of education, prevention, research, and patient support. LDAECC is looking for volunteers and support. Contact Kimberlee at easternctlda@yahoo.com

ABOUT THE LYME DISEASE ASSOCIATION (LDA): LDA is a 501(c) 3 non-profit organization which has developed and presented many programs for children in the schools, for scouts, and to help children obtain diagnosis and treatment if they lack medical insurance for Lyme disease through the LymeAid 4 Kids fund. You can find out more information about both Lyme disease, including the numbers, and impact upon students (visit the Lyme in the Schools Section), and information on the Lyme Disease Association by visiting its website at www.LymeDiseaseAssociation.org.

**Nationally Recognized Speaker
to Address Lyme Case
Increases & Controversy**