

Mt. Equinox, VT – 2016 Gear Up For Lyme Bike Climb

Remarks of Pat Smith, President, Lyme Disease Association, Gear Up for Lyme (VT) 2016

Welcome & thanks to all of you who organized, participated, or supported the bikers in this race today and in the past 11 races, since the first in 2004. From 2004-2014, the Manchester Rotary has raised a total of more than \$71,000 for the LDA for its Lyme disease research programs.

The Manchester Rotary recognized the significance of Lyme in 2004, when only 50 cases were reported from Vermont by the Centers for Disease Control & Prevention (CDC). In 2014, 599 cases were reported, which ranked Vermont #13 nationwide in case numbers. CDC says only 10% of cases are reported, so VT had about 6,000 cases in 2014.

The US total was 33,461 cases, times 10, 334,000+ cases. We have to wait for the official CDC 2015 numbers in about 2 weeks to see if the upward trend continues in VT and nationwide. For the 10 year period from 2005-2014, Vermont ranked # 2 in the US in Lyme disease incidence with 70.5 cases/100,000 population. (Overall US 2014 incidence is 7.9). LDA reports that 30% of Lyme cases are children 0-19 years old.

The Rotary raises both awareness & funds for Lyme by holding this benefit each year. LDA has used those monies to help fund research projects including one supported right here in VT at Lyndon State College, research published in the 2013 journal, Northeastern Naturalist. Dr. Alan Geise & others found *B. burgdorferi*, the bacteria that causes Lyme, in 8.9% of adult black-legged ticks they collected along the CT River in VT. The LDA has also used the monies for research coast-to-coast

including for the Columbia Lyme & Tick-Borne Diseases Research Center in NY, a center partially endowed by LDA, which focuses on chronic Lyme disease. We have provided millions of dollars trying to move the field of Lyme & tick-borne diseases forward and research we supported has been published in 39 peer-reviewed journals to date.

The LDA has many other programs including its annual Lyme & Tick-Borne Diseases continuing medical education conferences for physicians and researchers for which the public is also invited to register, jointly provided by Columbia University. This year, it's being held October 15, 16 in St. Paul Minnesota. It features current research that could alter the field. The Keynote speaker, Dr. Moir from Harvard will present his breaking results on Beta Amyloid, Alzheimer's and Lyme Disease. This will be followed by a talk by Dr. Miklossy, International Alzheimer Research Center, reviewing evidence suggesting a link between spirochetal infection and Alzheimer's disease.

The current Lyme tests are highly inaccurate, but new technologies (proteomics and nanotechnology) for improved Lyme tests has led to development of a nanotrap, presented by Dr. Luchini, George Mason University. A new species of *Borrelia* was recently discovered to cause Lyme in the US; this will be discussed by Dr. Pritt from the Mayo Clinic. Dr. Zhang from Johns Hopkins will discuss new in vitro antibiotic strategies to eradicate "*Borrelia* persists," that offer promise for more effective interventions for human Lyme disease. Dr. Aucott from Hopkins will present new findings regarding the human immune response in Lyme disease.

In the area of prevention, a novel mouse vaccine under development will be discussed by Dr. Zatechka, US BIOLOGIC. Work so new it is generating discussions from scientists around the world on the impact it might have on ecology in general will be presented by Dr. Esvelt, from MIT Sculpting Evolution Lab, his talk will address Community-Guided

Ecological Immunization to Prevent Tick-Borne Disease using CRISPR technology. Other speakers will address other tick-borne diseases, neurologic, arthritic and cardiac Lyme disease, and the spread of the ticks that transmit Lyme to ~50% of the counties in the US.

Last year, the International Lyme & Associated Diseases Society, ILADS, doctors who believe in and treat chronic Lyme, published in peer review their new long-awaited clinical guidelines for treating chronic Lyme disease. Those have been published on the federal government's National Guidelines Clearing House. They allow for long-term antibiotic Lyme treatment, if necessary. So today, please help us celebrate these hard fought victories for Lyme patients by helping yourselves remain physically fit and at the same time, raising funds for Lyme disease research. Thanks to the Rotary and its President Susan Howard, and to all of you from the LDA and the Lyme Community.

Mt. Equinox, VT – Gear Up For Lyme Bike Climb

Remarks of Pat Smith, President, Lyme Disease Association, Gear Up for Lyme (VT) 2014

Welcome and thanks to all of you who participated, organized or supported the bikers in this race today and the past 10 years. Since the first race in 2004, the Manchester Rotary has raised a total of more than \$71,000 for the LDA for its Lyme disease programs. I am so sorry not to be here with you today and glad that Dr. Woolrich-Holzman is able to relay this information to you. I am not present today primarily because

of a tremendous fight I have been a part of for 30 years, Lyme disease advocacy. The past 6 weeks, there has been a little known battle taking place between Lyme advocates and Washington DC. There was a bill in Congress for more than a decade which was good for patients, which would have created a federal advisory committee for Lyme. For political reasons, the bill was scrapped by Congress and a new damaging one proposed earlier this year. LDA met in DC to change that bill into something that was protective for Lyme patients. After negotiations, all parties agreed to bill passage. The day of the vote, a half hour before, a new totally different substitute bill dangerous to patients was proposed and voted out of the House Health Subcommittee. That was June 19. Since then, the LDA with help from its associated groups, led a nationwide effort to again remake the bill. We were successful in getting 154 groups signed onto a letter sent to each of the 54 members of the Energy & Commerce Committee. It contained what we as a Lyme community needed in a bill to not oppose it. They would hear the bad bill next and we needed to influence them not to accept that bill. Numbers talk, and they were impressed with our group numbers and the rationale we presented.

For me, the past 6 weeks have been dedicated to the passage effort, day and night. If you are frustrated watching on TV how Washington acts, you would be horrified at what occurs to just get a working group with federal agencies, patients and advocates, physicians who treat Lyme and researchers who understand it at the same table to provide information into the development of a federal research agenda. Other diseases have had these working groups established for years. On the morning of July 30, I watched on line with bated breath while the entire Committee of 54 went through the same process which had killed our bill in the smaller subcommittee. This time, the same dissenters spoke, but the bill went through with a voice vote. It still has a long way to go, beginning with a trip to the House floor for a vote after Congress' summer

recess is over. If the bill makes it through there, it then must go to the Senate. We have to be vigilant throughout the entire process to ensure no changes are slipped into the bill.

This effort has been repeated by many in states across the country, including Vermont this year, getting legislation passed to protect physicians treating Lyme disease. One might think that fighting a disease is done in the laboratory, and that is usually true; however, with Lyme disease, much of the fighting is done in the political arena, to get the disease accepted, to allow treatment. The fact that the CDC announced last year that 300,000 new cases of Lyme occurred in 2013 and that there are more than 15 tick-borne diseases now in the US, would seem to spur government to be more rather than less proactive against the disease. Unfortunately, there are powerful vested interest who have the time, money, and people fighting against patients' getting diagnosis and appropriate treatment.

Besides the Lyme bill passage out of Committee, another positive for patients happened this week. The International Lyme & Associated Diseases Society, ILADS, doctors who believe in and treat chronic Lyme, published in peer review their new long-awaited clinical guidelines for treating chronic disease. So today, please help us celebrate these hard fought victories for Lyme patients by helping yourselves remain physically fit and at the same time, raising funds for Lyme disease research. Thanks to the Rotary, the Holzmans, and to you from the LDA and the Lyme Community..

Mt. Equinox, VT – Gear Up For Lyme Bike Climb

Remarks of Pat Smith, President, Lyme Disease Association, Gear Up for Lyme (VT) 2013

Welcome and thanks to all of you who participated, organized or supported the bikers in this race today and the past 9 years. Since the first race in 2004, the Manchester Rotary has raised a total of more than \$66,000 for the LDA for its Lyme disease programs. Those monies have been used for research efforts at the Columbia Lyme Disease Research Center in NY, a center endowed by the LDA and its CT affiliate, LRA, and LDA/Rotary monies have also been used to support research right here in VT at Lyndon State College. That research was published earlier this year in the Journal Northeastern Naturalist. Dr. Alan Geise & others found that *B. burgdorferi*, the bacteria that causes Lyme, in 8.9% of adult black-legged ticks they collected along the CT River in VT.

So it's no surprise then that in 2011, according to the Centers for Disease Control & Prevention, CDC, 623 cases of Lyme were reported in VT, which ranked 13th in case numbers nationwide. Since cases are under reported by ten, 6,230 cases probably occurred in VT in 2011 alone. The US had 33,097 reported cases, or 330,970 actual cases that same year. Astoundingly, in 2011, VT ranked number two in incidence of Lyme disease in the US with, 76 cases/100,000 of population.

Thanks to advocates within Vermont, legislators here have begun to address the issue. H-123, "An Act Relating to Lyme Disease and Other Tick-Borne Illnesses," was introduced in Jan. 2013 into the VT House and referred to the Committee on Health Care. It permits doctors to prescribe long-term antibiotics for Lyme disease and it also requires insurers to cover such treatment. In February 2013, S-0112, a bill similar to the House bill, was introduced in the VT Senate, and it

remains in the Health and Welfare Committee. No action has been taken to date on either bill.

Cases elsewhere in the Northeast are rising. This year, the state of Maine, which ranked 11th in 2011, passed a bill addressing Lyme disease which states that doctors must provide a copy of the Lyme test results to patients, and that Lyme disease may be difficult to diagnose and treat; and some patients do not respond to usual antibiotic treatment, and doctors do treat longer term and it is sometimes helpful, but there can be problems with long term treatment. A negative test does not rule out Lyme disease. Additionally, the bill also the state of Maine will post a number of sites for Lyme information including the Lyme Disease Association website.

Now it is known that bacteria similar to the Lyme bacteria called *Borrelia miyamotoi* are also being found in ticks in the US. This strain of the bacteria has produced disease in other countries and appears to be doing the same in the US. This bacteria just adds to the many other tick-borne organisms that people can now become infected with from a tick bite, producing diseases including: babesiosis, ehrlichiosis, anaplasmosis, bartonellosis, tularemia, RMSF, and STARI. The list is growing, and few research dollars are being given to halt the spread of these diseases, many of which are now worldwide, with Lyme itself found in 65 countries.

LDA continues its mission against these diseases. I just returned from a trip to Ft. Collins, CO, the home of the Vector-Borne Disease Division of the CDC, where we discussed the impact of Lyme on people nationwide and the need for more research. To date, LDA has awarded more than 94 research grants, and research funded by LDA has been acknowledged in 31 medical journals. It has provided more than 80 educational grants and helped more than 230 children without insurance to get diagnosed or begin treatment. The Manchester Rotary has become a partner in that effort by hosting this annual Gear Up Bike Climb, and donating a portion of the funds to LDA for its

mission. Everyone should be concerned about the spread of tick-borne diseases, and our children ages 5-14 remain at the highest risk for infection from the Lyme bacteria. Thanks again to the Rotary, the Holzmans, and you for your generosity. Together, we can make a difference.

Mt. Equinox, VT – Gear Up For Lyme Bike Climb

Remarks of Pat Smith, President, Lyme Disease Association to Gear Up for Lyme (VT) 2012

I regret that my schedule has prevented my attendance at Gear Up for Lyme and have asked Dr. Stephanie Woolwich-Holzman to speak on behalf of the Lyme Disease Association (LDA) at this inspiring event dedicated in part to ending the spread of Lyme disease which has swept across the world, now found in approximately 65 countries.

Over 2011-2012, the LDA gave a grant entitled “Black-Legged Tick Population Dynamics and Lyme Prevalence in Vermont,” to a researcher at Lyndon State College in VT to help determine the geographical spread of the deer tick in Vermont with tick collection from South to North.

Evidence from other research and CDC Lyme disease reported case numbers is showing that the black legged (deer) tick populations are moving northward in the US. In 1990, Vermont had 11 reported cases of Lyme disease and the US had 7,943 reported cases. In 2010, the Centers for Disease Control & Prevention reported 356 cases of Lyme in Vermont. Contiguous neighbor states reported increasing numbers in 2010: New Hampshire 1,339; Massachusetts 3,263 and New York 3,425.

Ten times more cases occur than are reported, meaning 3,560 new cases in Vermont and 301,580 in the US in 2010. LDA did an analysis of 2010 CDC case numbers showing that 34% of Lyme cases come from states across the US other than the 9 states in the

Northeast. The numbers show that VT had 1% of the total national numbers. See www.LymeDiseaseAssociation.org for the graph.

Finally legislators are beginning to take notice. In May, Congressman Chris Gibson (NY) held a forum in NY to discuss plans for Lyme disease, having speakers and discussion panels. I sat on several of those panels. In July, US Senator Jack Reid of Rhode Island held a press gathering there which included federal officials to discuss Lyme disease. Last week, US Senator Richard Blumenthal (CT) held a state meeting on Lyme disease.

On July 17, 2012, US Congressman Christopher Smith (NJ) held the first ever hearing on Lyme disease in the US House in the Foreign Affairs Committee: Africa, Global Health & Human Rights Subcommittee. Testimony on Lyme brought out the global spread, the animal studies which show persistent infection after treatment for Lyme, the problems of diagnosis and treatment by treating physicians, and my testimony which included the country-wide spread with the impact on patients and treating physicians. A patient who has recovered with long-term treatment discussed his journey and a representative from the UK discussed the mounting problems of Lyme in Europe. The hearing video and written testimonies are available on the LDA website.

The Lyme Disease Association is an all volunteer national non profit working hard on behalf of patients to raise monies for educational programs and brochure distribution, ~ 2 million pieces of literature to date, to raise monies for uninsured children through the LymeAid 4 Kids fund, which has disbursed close to a quarter of a million dollars nationwide to date and to raise monies for research.

Research funded by LDA has been acknowledged in 25 medical journals and LDA helped establish an endowed research center for chronic Lyme at Columbia University to help find better diagnostics and a cure for Lyme disease. The Manchester Rotary has become a partner in that effort by hosting this annual Gear Up Bike Climb, and donating a portion of the funds to LDA for its mission. Everyone should be concerned about the spread of tick-borne diseases, especially those who are at high risk through their occupation or outdoor recreational pursuits. Your participation here helps you maintain health and helps provide answers to questions about Lyme disease. Kudos to the Manchester Rotary for organizing an outstanding event and to those who devoted their time to staffing it and to the Holzmanns. Thanks to you all for your continued participation. Together, we can conquer Lyme disease.

Click here for more information about Gear Up For Lyme

Bryant University, RI – Mental Health Practitioners Conference

I regret that I was unable to attend in person today for this very important conference, [*The Impact of Lyme Disease on the Brain: Implications for Mental Health Practitioners*](#). I welcome you here today to the conference on behalf of the Lyme Disease Association, LDA, and I thank you, especially the speakers, for your participation. LDA RI Chapter Chair, Julie Merolla, has done a wonderful job organizing this conference, and I thank her and the Chapter for continuing to educate medical professionals on Lyme disease and for conveying my message today.

As many of you know, Lyme disease is found 65 countries worldwide and has been reported in all 50 states. According to the Centers for Disease Control & Prevention, CDC, there were 30,158 total reported cases of Lyme disease in the US in 2010, and if 10% only are reported, that means 301, 580 new cases occurred in 2010 alone. To find out more about the numbers, go to the LDA website and download free its colorful US maps on Lyme disease numbers and incidence by state.

The CDC announced that Lyme disease cases tripled from 1992 to 2009. In spite of that statistic and the debilitating nature of Lyme, the federal government expends very little monies on Lyme disease research. Due to huge fiscal problems in general in the US, it is safe to assume funding will not increase in the near future. Thus, organizations like the LDA are left to try and fund cutting edge research projects to answer questions about Lyme disease. I am pleased to announce that by the end of 2010, the LDA surpassed \$5 million raised for research and education over its lifetime. Since LDA is an all volunteer national organization with little overhead and no paid employees, most of those monies have gone directly to education and research projects and to patient support.

In two weeks, LDA is hosting its 12th annual scientific and medical conference for doctors and health care providers with its joint sponsor, Columbia University, to be held in Philadelphia October 1 & 2. 13.25 category 1 CME credits are offered for attendees. The public is also invited to register. Details are on the LDA website, LymeDiseaseAssociation.org.

The LDA has been successful in having research it has supported published in scientific peer reviewed publications. The findings can be and have been used to move the Lyme disease field forward. LDA was acknowledged as a funder in three new scientific research publications in 2010 and two to date in 2011, bringing the total to 22 journal publications for LDA funded research including *Neurology*, *Proceedings of National Academy of Science*, *JAMA*, *Journal of Clinical Microbiology*, *Infection*, *Psychiatric Clinics of North America*, *Journal of Psychiatry & Clinical Neuroscience*, *Journal of International Neuropsychological Society*, and *Archives of General Psychiatry*.

LDA and Time for Lyme, one of its affiliates, endowed a research center for chronic Lyme disease at Columbia University under Director Dr. Brain Fallon, who is also a Professor of Clinical Psychiatry at Columbia and Director of the Center for the Study of Neuroinflammatory Disorders & Biobehavioral Medicine. The Center has just announced the purchase of a special freezer for the creation of a tissue bank, funded by LDA.

Lyme research has shown that the Lyme bacteria can enter the central nervous system in less than 24 hours after a tick bite, and it can cause psychiatric and neurologic manifestations as well as arthritic, cardiac, and eye problems. It may be misdiagnosed as MS, ALS, chronic fatigue, fibromyalgia, lupus, Alzheimer's, even autism. Studies have shown people with Lyme can be as sick as those with congestive heart failure. Unfortunately, children 5-14 are at the greatest risk of acquiring the disease.

With that in mind, LDA continues to fund its LymeAid 4 Kid program for children without insurance coverage for Lyme—LDA has already awarded more than \$205,000 for the program. The Association also has printed brochures offered for free on its website, *LymeR Primer*, which is the basics of tick-borne diseases; *The ABCs of Lyme Disease* written especially for parents and educators, which provides a more detailed description of what happens to children with Lyme; and a tick bookmark and a tick card which both provide tick identification, removal and prevention facts. It also

has a separate section on the website with articles on Lyme in the Schools and Kids and includes a prevention PowerPoint which can be used from the site in the classroom

Also posted on its website are a new prevention video and an interactive video game geared for children, developed in a partnership with University of Medicine & Dentistry of NJ through an Environmental Protection Agency, EPA, grant. LDA is a partner with the EPA's PESP program for Lyme prevention, and I co-chaired a section of FDA's prevention conference in Virginia in March 2011 with the CDC on community programs.

The LDA has been invited to brief officials at all levels of government, local, county, state, and federal. Officials in Pennsylvania have invited us in to present to insurance companies, legislative committees, and bill hearings. In Rhode Island, we spoke at the bill signing in the capital several years ago at the request of the then governor, spoke in New Hampshire a few years ago at the Governor's request, spoke before the Maryland Delegates legislative committee, in New York with Governor's office, Commissioner of Health, at county levels, and local; in Connecticut and New Jersey at many levels, in Minnesota, Florida, Georgia, Tennessee, and other areas. CDC invited me to Ft. Collins, CO, where I briefed the Vector-Borne Diseases Division on the programs provided by LDA and the problems facing patients.

LDA has set up Congressional briefings in DC for doctors to speak with US Senate and House Committees several times, has been instrumental in getting appropriations for Lyme disease research in 2010 at the federal level—research looking at better testing methods, and monies for a conference on Lyme disease through the National Institutes of Health, NIH, which was carried out by the Institute of Medicine in 2010. LDA and two of its affiliates, Time for Lyme (CT) and the California Lyme Disease Association, were successful in having patient perspectives on research funding priorities published in the Congressional Record last year, when it was read into the Record on the floor by Congressman Christopher Smith, NJ, Co-Chair of the US House Lyme Disease Caucus, sponsor of the House Lyme bill, HR 2557.

In 2002, Rhode Island's Congressman James Langevin co-hosted a Lyme disease seminar, where I received a Certificate of Special Congressional Recognition for speaking. He has been a supporter of all of our Lyme efforts in Rhode Island and in DC, and we thank him for that support.

Like in many areas affecting public health, Lyme disease advocacy is important. It is especially important in Lyme because it is so poorly defined, underfunded, and lacks a gold standard test. Patients often find themselves without jobs, unable to attend school, losing their homes, and even experiencing a break up of their family. They have few resources, few doctors willing to diagnose and treat them, and they experience a systems' wide assault from Lyme disease. When these situations occur, they turn to officials for help. Those officials turn to organizations such as LDA and the network of 43 organizations nationwide that LDA has pulled together, to try and understand the damage Lyme has caused and to find out how they can best serve their constituents. Education is the key to the disease and officials need to be educated by patients and by Lyme organizations, often working together for the public good, and often supporting legislative remedies.

The Lyme Disease Association supports science through research, education and advocacy, a powerful combination needed to unlock the secrets of *Borrelia burgdorferi*, the spirochete that causes Lyme disease.

Thank you.

Mt. Equinox, VT – Gear Up For Lyme Bike Climb

Remarks of Pat Smith, President, Lyme Disease Association to Gear Up for Lyme (VT) 2011

I am sorry not be able to be with you this year at Gear Up for Lyme, as I have been since its inception. I have asked Dr. Stephanie Holzman to speak on behalf of the Lyme Disease Association at this inspiring event dedicated in part to ending the plague of Lyme disease which has swept across the US unabated since the first case was recognized in 1975, about 36 years ago.

In 1990, Vermont had 11 reported cases of Lyme disease and the US had 7,943 reported cases. In 2009, the Centers for Disease Control & Prevention reported 408 cases of Lyme in Vermont and 38,468 in the US. Lyme is underreported by a factor of 10, meaning Vermont cases were over 4,000 and the US cases were almost 400,000 in 2009.

Yet the government has not proposed any plan to deal with the rising case numbers, nor have they been willing to expend monies to solve the problem. The same tests that were used when case reporting began are still used to determine who has the disease—tests which utilize antiquated technology when cutting edge technology is being used in other diseases. Current testing is less than 50% accurate and people can test negative with the current blood test and still have the disease. The problem is, doctors are diagnosing based on the faulty tests, and insurance companies will generally only pay for treatment based on the tests.

We have patients across the country, across the world, who are falling through the cracks. They are sick. They have no place to get diagnosed and treated. They are out of work, out of school. No one will help them.

The Lyme Disease Association is an all volunteer national non profit that is working hard on behalf of patients. We work to raise monies for educational programs and brochure distribution—we have distributed almost 2 million pieces of literature to date—we help children to get diagnosed and treated through LymeAid 4 Kids, which has currently disbursed close to \$200,000 nationwide for children without insurance coverage for Lyme—and we raise monies for research.

To date LDA has raised over \$5 million for our efforts against tick-borne diseases. The Manchester Rotary has become a partner in that effort by hosting this annual Gear Up Bike Climb. LDA has opened a research center at Columbia University to help find better diagnostics and a cure for Lyme disease,

and funds from this event have gone to that cause. This year, Columbia announced the beginnings of a tissue bank, which LDA started by financing a special freezer. Gear Up monies were used toward that project.

Everyone here should be proud that they are contributing to get answers to a disease which is preventing many people from enjoying the great outdoors, a disease which is stealing childhood from our children, a disease which the medical and government establishment have chosen to ignore. Your participation here signifies continuing health, and all of us want that to continue, so we work together to be able to say in the near future, we have taken back the outdoors, they are ours again to enjoy without the threat of Lyme disease. Thank you.

Long Branch, NJ – LDA Spotlight On Lyme© Walk

I welcome you here today on behalf of the Lyme Disease Association for the 4th annual LDA Spotlight on Lyme 5k walk/run and thank you for your participation. As many of you know, Lyme disease is found 65 countries worldwide and has been reported in all 50 states. New Jersey ranked 4th in the US in 2009 with 4,973 reported cases, meaning there were 49,730 actual new Lyme cases in NJ in 2009. Monmouth County ranked fifth in the State in Lyme case numbers with 409 reported cases in 2009, meaning 4,090 actual cases that year in Monmouth County alone.

The Lyme bacteria can enter the central nervous system in less than 24 hours after a tick bite, and it can cause psychiatric and neurologic manifestations as well as arthritic, cardiac, and eye problems. It may be misdiagnosed as MS, ALS, chronic fatigue, fibromyalgia, lupus, Alzheimer's, even autism. Studies have shown people with Lyme can be as sick as those with congestive heart failure. Unfortunately,

children 5-14 are at the greatest risk of acquiring the disease.

The Centers for Disease Control & Prevention, CDC, just announced yesterday that Lyme disease cases tripled from 1992 to 2009. In spite of that statistic and the debilitating nature of Lyme, the federal government expends very little monies on Lyme disease research. Due to huge fiscal problems in general in the US, it is safe to assume funding will not increase in the near future. Thus organizations like the LDA are left to try and fund cutting edge research projects to answer questions about Lyme disease. I am pleased to announce that by the end of 2010, the LDA surpassed \$5 million raised for research over its lifetime. Since LDA is an all volunteer national organization with little overhead and no paid employees, most of those monies have gone directly to education and research projects and patient support.

LDA continues to fund its LymeAid 4 Kid program for children without insurance coverage for Lyme, and it just posted on its website a new prevention video and an interactive video game geared for children, developed in a partnership with UMDNJ. LDA is a partner with the Environmental Protection Agency's PESP program for Lyme prevention, and I co-chaired a section of FDA's prevention conference in Virginia in March. LDA is busy planning its 12th annual scientific and medical conference for doctors and health care providers with its joint sponsor Columbia University, to be held in Philadelphia October 1 & 2. The public is invited to register. Details will be on the LDA website www.LymeDiseaseAssociation.org soon.

The LDA has been successful in having research it has supported published in scientific peer reviewed publications, meaning that research LDA has supported has been validated by reviewers in the field of Lyme and tick-borne diseases, and it is now available to all researchers. The findings can be used to base new projects on, moving the Lyme disease field forward. In 2010, LDA was acknowledged in 3 new scientific research publications and so far in 2011, one new publication, bringing the total to 22 journal publications to date for LDA research.

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Bike Climb Up Equinox Manchester Rotary 2009 Pat Smith, President Lyme Disease Association, Inc.

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- Thanks to the Manchester Rotary !
- Thanks to you for being here today.
- Part of the team.
- Seeking a cure for Lyme disease !

- Lyme disease has increased in VT
- 1993 12 cases
- 2007 (138) 31% over 2006 (105)
- 2007 1050% over 1993 cases
- CDC says 10x reported cases 1380 cases/2007/VT !
- Nationally 2007 saw about 274, 440 new cases develop !
- Lyme now in 65 countries worldwide !
- Children 5-9 & 10-14 at greatest risk of acquiring the disease !
- One bite of the deer tick can cause Lyme & anaplasmosis babesiosis bartonellosis tularemia powassan encephalitis tick paralysis !
- One bite of the lone star tick can cause STARI ehrlichiosis RMSF tularemia tick paralysis !
- One bite of the American dog tick can cause RMSF ehrlichiosis tularemia tick paralysis !
- The tests for Lyme are unreliable, about 40-60% accuracy
 - o You can test negative and still have Lyme disease. o

Lyme is meant to be a clinical diagnosis made by a physician, with testing as an adjunct. ! Some tick-borne diseases can be transmitted through the blood supply, o Like babesiosis, a malaria like illness you can get from the deer tick o Lyme disease has not been shown to be transmitted through the blood supply, however, it can survive blood banking processing and o A recent CDC study showed it can be transmitted thru transfusion in mouse model o There is no screening for Lyme disease in the blood supply ! Tick-borne diseases are serious o Lyme can get into the brain less than 24 hrs after a tick bite o Lyme bacteria can cross the placenta and cause death of the fetus o Lyme can progress and cause severe arthritic, neurologic and psychiatric problems o Several TBDs have high fatality rates, especially if untreated !

The government is spending only 27.4M on Lyme disease 9that's CDC/NIH combined ! Bill HR 1179/S1352 100M/5 years o 76 House, 6 Senate Not one VT congressman or senator has signed o Pls go to LymeDiseaseAssociation.org get info, call your legislator today

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Bike Climb Up Equinox Manchester Rotary 2009

Pat Smith, President Lyme Disease Association, Inc.

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-

Long Branch, NJ – LDA

Spotlight On Lyme Walk

Too often today instead of spending time with our families having fun outdoors, we are spending time trying to protect them from the dangers which lurk not only in our public recreation areas but in our own backyards.

Our children 5-9 and 10-14 are at the highest risk of acquiring this disease which ravaged 274,440 new victims in 2007 alone, 31,340 of them new Jerseyians. NJ claims 12% of Lyme cases reported to the CDC nationally since 1990. Yet there is little to no awareness or monies expended on the disease in NJ or by the federal government. We have a bill in Congress which would provide \$100 million for Lyme disease research, education and prevention, yet despite the NJ statistics, a local NJ Congressman has not put the bill up for a hearing in the House Health Subcommittee.

We need to make Lyme disease something more than a disease we all hear about, read about, and view clips about on U tube, we need to take actions that will save people from suffering and death due to Lyme disease. Today's walk and run is one of the actions where we raise awareness about Lyme and raise funds to help research for a cure.

The Lyme disease Association has raised and distributed millions of dollars in its quest to get answers and has even with Time for Lyme, its Connecticut affiliate, endowed a research center at Columbia University in New York to perform cutting edge research such as the project published a week ago through the Center showing that patients with persistent Lyme encephalopathy do have objective abnormalities in functional brain activity, an important concrete finding.

LDA has been meeting and talking with CDC, NIH, EPA, US Army CHPPM, and other governmental officials to try to communicate the level of devastation Lyme disease is producing nationwide.

LDA's Spotlight on Lyme is an event which raises awareness, generates funding and shows that people in NJ are concerned about Lyme disease and want something to be done about it.

The effort here today was spearheaded by those who are intimately acquainted with Lyme disease, Committee Event Co-Chairs Kim Cronin, Alyssa Murray, and Joan Wire, whose lives and families have been significantly altered by Lyme disease. They have

spent countless hours putting together this event, and we are grateful to them and the organizing committee for their efforts. The Lyme Disease Association thanks all the sponsors for their generosity and all the participants for making this event a success.

Together, we will make a difference.