

25th ANNIVERSARY ISSUE: Part I

THE LYME TIMES

Volume 26 • Number 1 • 2014

The Journal of LymeDisease.org



THE EARLY YEARS



We advocate nationally for quality accessible healthcare for patients with Lyme and other tick-borne diseases. We are committed to shaping health policy through advocacy, legal and ethical analysis, education, physician training and medical research.

We communicate our message in print and online. We connect and educate the patient community through networking and state online support groups. We take the pulse of the Lyme community through patient surveys.

We analyze and archive information in our quarterly journal, *The Lyme Times*, and maintain an educational website at lymedisease.org. We publish regularly in peer-reviewed medical and health policy publications.

Online Support Groups

Participate in education and advocacy activities in your state. Learn about local resources and receive technical support for your efforts. Exchange information and patient support conveniently from your home. To find your own online state-based group, go to: [health.groups.yahoo.com/group/\(yourstatename\)lyme](http://health.groups.yahoo.com/group/(yourstatename)lyme).

Website

Visit our extensive educational website at lymedisease.org. Discover the basics at Lyme 101, read news and analysis, and check the events calendar. Sign up for our free email newsletter.

Facebook

Keep on top of developing news and share your own experiences and opinions by joining the conversation on our Facebook page: facebook.com/lymedisease.org.

Twitter

Receive our tweets on your phone or computer. Follow us at twitter.com/lymenews.

Join the Effort

Participate in the Lyme community and make our collective voices even stronger. Visit us at lymedisease.org or complete the membership form in this issue.

FRONT COVER: The first issue of *The Lyme Times* was distributed in 1989 by Phyllis Mervine. This collage of cover art represents the last 25 years of the only national journal dedicated to informing the Lyme community and the public about Lyme and tick-borne diseases.

Graphic Collage by MicheleLottDesign.com

25th Anniversary Issue



LymeDisease.org is grateful for the special support of the following sponsors:

Jill & Ira Auerbach
Sandy Berenbaum, LCSW, BCD
Dolly Curtis
Marcia Datson
Brian Fallon, MD
Ken & Kerry Fordyce
Suzanne MacDonald Fratus
In Memory of Paul E. Lavoie, MD
Georgia Lyme Disease Association
Thora Graves
Bob Lane, PhD
LDA of Southeastern Pennsylvania
Lyme Disease Association
Lyme Research Alliance
Alan MacDonald, MD
MaineLyme
Minnesota Lyme Association
Rene Rothstein
Ginger Savely, DNP, MEd, FNP-BC
Cynthia Sawtell
Laura & Dan Sawyer
Leo Shea, III, PhD
Virginia T. Sherr, MD
Patty and Harold Smith, MD
Sheila M. Statlender, PhD
Suzanne L. Stuttmann
Beatrice Szantyr, MD
Texas Lyme Disease Association
Janet Thietje

THE LYME TIMES

Volume 26
Number 1
2014



Photo: Phyllis Mervine

Phyllis Mervine and her family 1981

FEATURES

2 | EDITORIAL

In the beginning, ...
by Phyllis Mervine

3 | INTERVIEW

Phyllis Mervine
Starting with five volunteers,
Mervine built LDo into a widely
recognized advocacy nonprofit.
by R. Timothy Haley

6 | ADVOCATES IN ACTION

The First Decade

The unabashed history of
grassroots LD advocacy is
a tale of vision and fortitude.
by Phyllis Mervine

11 | The Denialists

Resistance to emerging information has plagued
patient care since Lyme was first identified.

18 | The Pioneers

Early advocates faced the challenge and entered
unchartered territory on behalf of patients.

Polly Murray
Willy Burgdorfer
Paul Lavoie
Paul Duray
John Drulle
Ken Liegner
Ed Masters
Charles Ray Jones
Joseph J. Burrascano, Jr.
James H. Oliver, Jr.
Robert Lane

10 | ADVOCATES IN ACTION

Activism Comes of Age
Author recounts early efforts
that changed the Lyme debate.
by Jeannine Phillips

12 | THE EARLY DAYS

Ukiah volunteers were once the
only source of patient support.
by Thora Graves

LymeDisease.org launched
as a patient advocacy group
in Northern California
by Nancy Brown

Finding our way as a
fledgling organization
built lifetime bonds.
by Linda Hildebrand



California patients gathered in
Marin County, CA, dressed in green
for the 2007 Human Race.



Phyllis Mervine, Lorraine Johnson, Dorothy Leland,
Cynthia Sawtell and Pam Cocks in Washington, DC at
the first LDo patient advocacy workshop in 2009.



Andy Abrahams Wilson, producer
of *Under Our Skin*, filming at the
LDo protest at IDSA 2013 SF.

In the beginning ...

Before 1977 my dream was to have a large family by adopting a lot of children – maybe a dozen! – but then a tiny tick bit me and I became profoundly sick. After 10 years of undiagnosed illness, I realized that dream was dead. As treatment finally restored my health, I discovered a new mission in life – to inform, support, share and empower people with tick-borne diseases. I created *The Lyme Times* and was swept along in the current of the pain and desperation I found across the country. I wanted to help in a bigger way. A nonprofit was the next logical step. I found people who shared my dream and wanted to help. We weren't always sure where we should go, but we didn't let that stop us.



I have many people to thank for their early involvement and support. The woman who helped me get diagnosed; my vet who introduced me to the doctor who saved my life and became my mentor as I took those tentative first steps. I'm grateful to the neighbor who organized a fundraiser when our fledgling organization was broke and to our board members and others who came to countless meetings with ideas and support and encouragement. From the lady who gave us our first computer, to the researchers who joined us for dinner while they were dragging our property for ticks, to the doctors and scientists who volunteered as speakers at our conferences – I remember them all with gratitude.

It has been a privilege to work with so many generous, smart and dedicated people. So much to do but what fun we had! I feel proud and amazed to see what *LymeDisease.org* has become. Not that our job is complete, but my dream has come true.

So this year we are celebrating our 25th year as an advocacy organization by publishing several special anniversary issues of *The Lyme Times*. In this first volume we reminisce about the earliest days of patient advocacy. We have been laughing over old photos and remembering classic moments. I wish there were room to tell you more stories, and hope you enjoy the ones we chose. We wanted this volume to capture our community's history and accomplishments so our readers may better understand our past, what the issues were, and what we still need to do to reach our goal of a better quality of life and effective treatment options for patients suffering from tick-borne diseases. They say those who forget history are condemned to repeat it. We definitely want to move forward.

The Lyme world has become a complex, contentious and fast-moving place. We can only hope that people will focus – as *LymeDisease.org* has always done and will continue to do – on the important work of trying to make a positive difference in the lives of patients. Let us know if you want to get more involved.

Phyllis Mervine

THE LYME TIMES

www.lymedisease.org

2014 VOL. 26, NO. 1

Published quarterly for members by LymeDisease.org

www.lymedisease.org

Library of Congress No. 92-595999

ISSN No. 1552-7506

TLT Production

Editor in Chief: Phyllis Mervine, EdM

Managing Editor: Pam Cocks, MPH, MLS

Contributing Editor:

R. Timothy Haley, MA

Mental Health Editor:

Sandy Berenbaum, LCSW, BCD

Online Editor: Dorothy Kupcha Leland

Graphic Design: Michele D. Lott

Production Design: Jay Gamel

LymeDisease.org

Executive Director: Lorraine Johnson, JD, MBA

President: Phyllis Mervine, EdM

VP Education & Outreach: Dorothy Kupcha Leland

Sr. VP and Secretary: Barbara Barsocchini, MBA

Treasurer: Mitch Hoggard

Membership and Publications: JoAnne Vidal

Please visit www.lymedisease.org. Write us at P.O. Box 1352 Chico, CA 95927. Phone 530.570.1811. Email jvidal@lymedisease.org. Please contact us for written permission to duplicate or reprint any portion of *The Lyme Times*.

DISCLAIMER

Articles in *The Lyme Times* are not intended as legal or medical advice regarding the treatment of any symptoms or disease. Advice of your healthcare provider should be obtained before pursuing any course of treatment. *The Lyme Times* makes no express or implied warranties as to the efficacy or safety of any treatment and disclaims all liability for use of any such treatment. Opinions expressed in articles are those of the authors alone and not necessarily those of *The Lyme Times* or LymeDisease.org.

**LymeDisease.org is a
501(c)(3) organization.**

© Copyright 2014 LymeDisease.org

INTERVIEW: Phyllis Mervine, EdM

Starting with five volunteers, Mervine built LDo into a powerful nonprofit

By R. Timothy Haley

When I was asked to interview the person who has been the driving force behind *The Lyme Times* (TLT) for the last quarter century, I thought it should be someone who had worked with Phyllis Mervine from the beginning. That turns out to be a short list. While encouraged by others, she, more than any other, is responsible for launching and sustaining TLT.

I first came to admire this little periodical in the early 90's, not only for its information that I could not seem to get anywhere else but for the reassurance it gave me that I was not alone, that there were many others out there fighting Lyme disease and the medical establishment. Besides, being a Lyme patient myself, I was looking for answers about an illness most doctors said I couldn't have.

Roll the presses

From the beginning, Phyllis Mervine was writer, editor, and layout person. "I had no idea how to lay out a paper," Phyllis said. The first issues had an oversized, pixelated graphic of the culprit tick that got my attention.

I remember trying to read the scientific research when I was really sick and falling asleep. Then I would read *The Lyme Times*, which began to clarify the medical controversy for me. Whenever I picked it up, I learned something new.

Phyllis doesn't claim any journalistic background. "It would have been a lot easier if I had actually worked on a paper – any paper – before," she said. She was a creative elementary school teacher out of Tufts University before moving west to San Francisco in the 60's.

By the early 70's she and her husband, Fred, became part of the back-to-the-land movement and bought property in northern California where they began building their own house. With their three children, they quickly acquired a horse, chickens and some goats, and started a huge garden. Then in 1977, Phyllis's life took a turn when she had a horrific summer flu. Five months pregnant, "I was flat on my back for a week,"

she said.

A few weeks later her knee swelled up and a doctor sent her to physical therapy. After the birth of her child, she didn't bounce back. She felt exhausted and developed excruciating neck spasms. Even her beautiful waist-long hair became too much to deal with so one day she took the scissors and cut it all off.

Her mother realized something was seriously wrong and insisted that she see a doctor. Lyme had not been discovered yet, and her tests came back normal. Acupuncture helped with the pain but otherwise Phyllis was desperately sick. With the daily malaise and profound fatigue, she had a hard time caring for her baby and three older children. A rheumatologist finally diagnosed her with an autoimmune arthritis and recommended non-steroidal anti-inflammatories. They hurt her stomach and didn't help much.

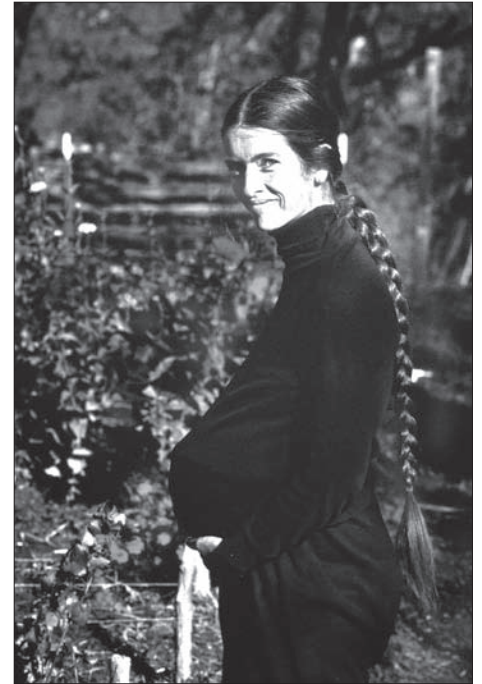
Serendipity

By 1987 she and Fred had one more child, a total of five, assorted animals and a large vegetable garden to tend and still no diagnosis. Her arthritis was crippling; she had tinnitus, deafness and attacks of vertigo; she developed severe food allergies; she felt tired and sick all the time. She remembers telling someone at one of her son's soccer games, "I don't think I'm going to live very long." She was in her early forties.

Her luck changed in 1987 when she took a pottery class with a neighbor who had herself been diagnosed with Lyme. Week after week as Phyllis dragged herself into the studio, the friend would nag, "I'm sure you have Lyme disease – you should get tested." She wouldn't give up.

Phyllis finally took her advice. Although the test was positive for Lyme, she was given only three weeks of antibiotics. Absolutely nothing changed. "By that time – after ten years – I wasn't expecting anything good to happen," Phyllis said, "and it didn't." But a chance meeting shortly afterward with a veterinarian friend did turn the tide. He had cared for the Mervine's animals but had moved to U.C. Davis where he was studying

Lyme in horses. He put her in touch with a doctor – Paul Lavoie – at what is now California Pacific Medical Center in San Francisco; luckily for Phyllis he was working on human beings with Lyme.



In the summer of 1977, Phyllis Mervine, pregnant with her fourth child, was bitten by a tick. 2011. P. Mervine photo

"I got the last appointment of the day, about four o'clock," Phyllis said, "and was still there at seven. It was incredible. He thought Lyme was like syphilis and so he asked interesting questions like, is your hair falling out? It was, but no one had asked me before. He seemed very confident, and I felt like I was finally coming home."

Dr. Lavoie put Phyllis on high-dose penicillin and three months later it dawned on her that she no longer had that terrible malaise and toxic feeling in her body, she said.

Lavoie warned that she might have to be treated for a year. The year came and went and she was still not well, so he continued the antibiotics. Three years later she had reclaimed her life and was able to plan more than one day at a time.

Continued on next page

Birth of a publication

Meanwhile, the county hospital in her town opened a Lyme clinic and Phyllis became the coordinator a couple of days a



For several months after Phyllis' baby was born, he seemed fine except he was unable to open his eyes all the way. An LLMD later looking at the photo thought it might be a partial bilateral Bell's palsy.

week. While working the phones in these pre-internet days, she soon learned that many Lyme support groups were sprouting up all over the United States.

She got the idea for *The Lyme Times* while at the clinic. Her husband's business partner came up with the name, and the county printed and paid for the first few issues. The first issue in 1989 was two legal-size sheets folded in half into a little booklet which she created on a Mac plus at her husband's office. Although she knew "absolutely nothing" about journalism, let alone layout and design, they distributed 2000 copies with the county's help.

"Besides educating people, we wanted to bring them together and empower them," she said. "We thought people could use *The Lyme Times* as a platform." They hoped that by publishing stories about awareness projects, others might be inspired to do the same despite their illness, she added.

From the first issue, there were always ar-

ticles from laypeople, doctors, researchers, clinicians or people with expertise related to Lyme. There were conference reports, support group lists, a calendar, and people to contact. As *The Lyme Times* continued to grow, Phyllis made a point always to include a patient story, "because ultimately, patients are central to what we are trying to do," she said.

Talking to people across the country about Lyme, she got the idea to put a "phone tree" into the paper. There were volunteers willing to share information about Lyme or just help a nervous patient wherever they were. The phone tree continued for two years until there were too many names to publish, Phyllis said.

Before long the newsletter had grown to a 32-page journal listing 25 support groups in Maryland, Michigan, New York, Pennsylvania, and Wisconsin as well as California. And Phyllis had been invited to be a member of California's Ad Hoc Lyme Disease Committee.

Birth of an organization

Meeting with Karen Forschner in Connecticut, they agreed that Phyllis should form the West Coast Lyme Disease Network, a chapter of the Forshner's Lyme Borreliosis Foundation. But the association didn't work out, so she continued on her own.

Meanwhile, things were falling apart at the county hospital. Other local doctors complained about the Lyme clinic, arguing that those doctors at the clinic didn't know any more about Lyme than they did. One of the last projects Phyllis did there was to put on a medical conference – on Mother's Day 1990. Assisted by Paul Lavoie, she invited Joseph Burrascano and John Drulle from the East Coast, along with a "token Yalie," Rob Schoen, to balance the program. Over 100 people attended and everyone thought it a great success. It was the first of what became annual conferences around the state.

Eventually the clinic closed, Phyllis lost her job, and patients who had flocked there had to go elsewhere.

As she confided in Isis Coble, her friend and occasional co-worker at the clinic, Phyllis realized that she didn't want to stop what she was doing. If she didn't want to continue doing everything by herself, Isis advised, she had to ask for help. So at the

next Lyme group meeting in Santa Rosa, she asked for volunteers, and four people raised their hands. They became the nucleus of a new organization they named the Lyme Disease Resource Center. LDRC grew into CALDA and is now *LymeDisease.org*.

With her increasing awareness of the problem of Lyme in her area, Phyllis conducted a phone survey around her rural neighborhood. She was surprised and excited when Dr. Lavoie said it could be the basis for a research study.

Subsequently, joining forces with U.C. Berkeley entomologist Bob Lane and the



Sequoia Greenfield "diagnosed" Phyllis with Lyme disease after seeing her drag week after week into a pottery class they took together.

vet who had steered her to Lavoie, they collected ticks and mice and tested volunteer community members. A quarter of the residents turned out to be positive for Lyme. Based on physical findings, Dr. Lavoie estimated that a third of them probably had the disease.

The initial study was published in a medical journal, and Dr. Lane's team continued their tick surveys for many years, publishing multiple papers and making new discoveries about tick-borne diseases in Northern California.

Becoming "real"

The directors of the newly formed organization focused on education and patient support. In this interview, Phyllis explained how she has always believed people

should try to improve their own situation, rather than wait for someone else to rescue them. “The LDRC decided we’d be the organization that encouraged everyone else, instead of competing with them,” she said. Sometimes *The Lyme Times* was so focused on reports of activities elsewhere that they forgot to cover their own news.

A new board member with an MBA was able to get the organization a 501.C.3 non-profit status. She urged them to make themselves into a brand and organize, but it was too much too soon for the others. Meetings began to peter out. “I felt like Pinocchio when he wanted to become a ‘real’ boy, and I began to ask myself, how does this get to be a ‘real’ organization? I really didn’t have a clue,” she said. “I had never been on any board before, and I never wanted to be president of anything.”

Often Phyllis felt like giving up. Her main encouragement was letters from readers like “*The Lyme Times* is a lifesaver, and I read it from cover to cover the minute it comes.”

“I’ve always responded to people in need and that has kept me going,” she said. “I believe if I can help people, I should.”

She is forever grateful to Paul Lavoie, who could have been condescending about her early efforts to make sense of complex medical issues but instead helped and encouraged her. Although it was a steep learning curve, she said, she gradually learned to read “medicalese.” She attended Lyme conferences whenever possible, while she and Linda Hildebrand, her chief partner, continued to organize their own conference almost every year. In 1997 Jean Hubbard joined the team, serving for several years as associate editor of *The Lyme Times*. “Jean was an excellent writer, and I still remember the fun we had passing the editorial back and forth until we got it just right,” Phyllis reminisced.

Finance was not their strong suit. They did no fundraising apart from membership subscriptions and gave many issues away, especially to support groups. The organization hit a low spot in 1997 when they ran out of funds. Putting out an appeal, people responded generously. One of Phyllis’s neighbors put on a fundraising event. “We got over the hump and we’ve been going ever since,” Phyllis said.

Expanding sphere of influence

Early in 2001 the National Institutes of Health (NIH) invited Phyllis to serve on the advisory panel for the Klempner study, which was investigating extended use of antibiotics on a group of very ill Lyme patients. NIH held only two meetings in Bethesda before terminating the study early. They rushed to break the news that antibiotics did not help and insurance companies immediately seized the opportunity to deny reimbursement for anything more than short-term care.

“The other patient on the committee and I felt used and disgusted by the way it came down,” Phyllis said. “The study wasn’t even designed to prove what they said it did.” The experience taught her a tough lesson about collaborating with government agencies and self-serving researchers. “I had always thought doctors and scientists were unimpeachable. The scales fell from my eyes,” she said. “It was very disillusioning.”

But there were successes, too. In 2001 Herb Dorken, PhD, became the nonprofit’s volunteer legislative advocate. A retired career lobbyist, Dorken successfully shepherded several pieces of legislation, including a doctor protection bill. “He was a real bulldog in Sacramento,” Phyllis remembers. “People allied with the State Health Department lobbied against and defeated his bill to reform the Lyme Disease Advisory Committee. Herb’s response was, ‘If they didn’t like that one, wait till they see next year’s version.’ He never gave up.” Ill health finally forced him to retire for good, and he died in 2012 at the age of 85.

Turning the corner

In 2003 Lorraine Johnson joined the CALDA board. A Lyme patient and lawyer with an MBA, she quickly became involved

and immersed herself in learning more about the disease and the politics. Soon she started to take more and more responsibility for running the organization, serving as the editor-in-chief of *The Lyme Times*. Lorraine is now the CEO of *LymeDisease.org*. Phyllis feels Lorraine, more than anyone else, has helped the organization turn the corner and become the internationally recognized or-



Phyllis Mervine receives a Jefferson Award in 2012.

ganization that it is today.

Phyllis savors victories – a recent one in particular. After two years of research and preparation, Lorraine convinced Connecticut Attorney General Blumenthal that the Infectious Diseases Society of America (IDSA) was engaging in anticompetitive behavior by trying to drive International Lyme and Associated Diseases Society (ILADS) doctors out of business. When Blumenthal launched his civil investigation of the IDSA in 2006, the medical community was shocked because a medical society had never before been investigated. Blumenthal’s office uncovered undisclosed financial interests held by several of the most powerful IDSA panelists. He also found that the IDSA’s guideline process was seriously flawed.

While the IDSA agreed to review their guidelines, their panel stood behind their positions. All was not lost, however, as a light had been shined on their practices and had opened the Lyme debate. “Before this the IDSA had never thought we were even worth a response,” Phyllis said. “Now they

See PHYLIS, next page

The First Decade

The unabashed history of a grassroots advocacy effort tells a tale of vision and fortitude

By Phyllis Mervine, EdM

When Pam Weintaub was writing her book, *Cure Unknown*, she borrowed my precious archival stack of old *Lyme Times* to make sure she got her history straight. In preparing this story, I went to the same source. *The Lyme Times* is actually the only long-term written record of happenings in the Lyme community since the first patients joined together to form support groups and non-profits.

Of course, many people – including this writer – were sick with Lyme disease before the 1982 discovery of the causative spirochete, but up till that time, no one knew they had a treatable illness. But in the eighties, more and more people were diagnosed – mostly on the East Coast where the first support groups began.

Betty Gross's Lyme Disease Support Group in Westchester County, NY, laid claim to being the oldest group. In addition to meeting regularly, they published a simple newsletter of clippings and stories, which they sent around the country. This was before the Internet, and everyone was hungry for information.

Early pioneers

By 1987, the medical community was starting to realize the seriousness of the epidemic and organized a meeting in Tarrytown, NY. Tom and Karen Forschner, whose baby son had been infected with Lyme before he was born, were inspired to establish the Lyme Borreliosis Foundation (they later changed the name to Lyme Disease Foundation – LDF). Working from their home in Hartford, CT, they were soon overwhelmed by inquiries and requests. An epidemic was exploding around them.

Lyme was happening on the West Coast, too. The first case in California had been diagnosed in 1983. Several children in my neighborhood developed swollen knees. After my own diagnosis I started a simple newsletter – *The Lyme Times* – on two sheets



U.C. Berkeley entomologist Robert Lane, Ross Ritter, PA, and CDPH Senior Public Health Biologist Jim Clover were speakers at LDRC's first conference in 1990.

of legal-sized paper folded in half. Along with four volunteers from a local support group, we formed the Lyme Disease Resource Center (LDRC) in 1989 – Thora Graves, a fellow patient; Mark and Melanie McDougall, whose young daughter had Lyme; and Linda Hildebrand, another patient. None of us had any experience setting up an organization but didn't let that stop us.

Our stated mission was education and support, but our underlying goal was to empower patients and to bring people together. From the beginning, *The Lyme Times* reported news from people and groups all over the country; in fact, we were so focused on other groups that we often forgot to report our own news.

Organization was not our strong suit. We sometimes went

Phyllis, from page 5

couldn't afford to ignore us anymore."

In 2012 Phyllis was surprised and touched when she received a Jefferson Award for her volunteer efforts. "My friend Suzanne Smith wrote an over-the-top letter recommending me. It was embarrassing but very special," Phyllis said. She still puts in many hours each week on her Lyme work, juggling other responsibilities, including her seven grandchildren.

Looking back

While she feels the organization got off to a slow start and wishes she could have done more, Phyllis appreciates the sustained effort required just to keep it going. "Many, many people contributed hours and hours to the cause. We had a lot of dreams

and then there were the practicalities," she said. "We have always been short-handed, but the teamwork has been remarkable."

Phyllis remains disappointed that so-called "experts" in the field of Lyme disease hold on so stubbornly to the idea that there is no such thing as chronic or persistent Lyme after antibiotic treatment. She feels sad this position is only delaying solutions for patients. She understands that some doctors and researchers have staked their professional reputations on this view but wonders how they sleep at night when there is so much scientific evidence of persistence. She suspects that for some, their position has become an article of faith rather than a rational stand.

Over time Phyllis has become increasingly philosophical and content to have fought on the right side, even if they haven't won yet. One of her favorite quotes is by Nobel Prize-winning German physicist Max Planck: "A new scientific truth does not triumph by convincing its opponents and making them see the light, but rather because its opponents eventually die, and a new generation grows up that is familiar with it."

Phyllis told me she had hoped she would have worked her way out of a job by now. "I never thought when I started that it would go on this long. But since we haven't won justice for patients yet, we can't stop fighting. There is too much at stake."

months without a board meeting, but we managed to put on annual medical conferences and patient forums around California. We also produced *The Lyme Times* fairly regularly and it soon had a national following. People told us they read it from cover to cover as soon as it arrived. One patient wrote us, "*The Lyme Times* is my bible."

We were a bootstrap organization. We educated ourselves and met other movers and shakers by attending the LDF's annual medical conferences. Our own first symposium was held at a winery, a beautiful garden setting used for weddings. The tiny white folding chairs were more suitable for an hour-long wedding than for an all-day medical meeting, but the weather was perfect, the food exceptional and people were good sports. Our faculty included Joe Burrascano and John Drulle, who flew out from the East Coast on their own dime. Other speakers were CDPH Senior Public Health Biologist Jim Clover who liked to travel around California collecting ticks; UC Berkeley entomologist Robert Lane, who was studying ticks and wildlife in my back yard; Ross Ritter, a Physician's Assistant and Jim Katzel, MD, who treated Lyme in a nearby rural clinic. My own physician, Paul Lavoie, chaired the meeting.

Soon U.C. Berkeley graduate Jeannie Salmon joined our cause and guided us through the application for IRS non-profit status. Linda became what we called my "partner in Lyme," and together we ran the organization. By 1990 *The Lyme Times* reported there were eight support groups in Wisconsin, seven in California, and a few in several other states, including Maryland, Missouri, Michigan, Nebraska, and Pennsylvania. We published a list of six newsletters besides *The Lyme Times*, which by then we had transformed into a 32-page newsprint journal. Betty Gross, founder of one of the nation's first support groups in Westchester, NY, called *The Lyme Times* the "Tiffany's" of Lyme newsletters.

NJ and NY mobilize

Lyme hit New Jersey hard, and patients there organized early. In 1991, 40 members of the NJ Lyme Disease Coalition (NJLDC) met with the NJ governor and helped pass legislation to put warning signs in parks, among other things. This was another first. The Coalition was also instrumental in obtaining an hour-long special on television. In New York, the National Lyme Community Research Initiative (NLCRI), dedicated itself to finding a cure. Their initial plan was to conduct clinical trials. In 1992, *The Lyme Times* listed 62 support groups in 18 states.

The spectrum of Lyme disease was enlarging, and if doctors didn't know it, patients did. Recognizing this gap, our LDRC group held another medical conference in Ukiah, CA. The newly formed Lyme Disease Coalition of Minnesota organized a meeting at which Columbia University researcher Brian Fallon told more than 170 medical professionals that 47% of 193 seropositive patients had been misdiagnosed as having psychiatric problems before being diagnosed with Lyme disease. Seventy-five percent had symptoms of major depression. For people who believed Lyme consisted mainly of a rash and a swollen knee, this was eye-opening. Six other physicians and researchers, including Willy Burgdorfer, gave talks. Patient groups were taking the lead in educating healthcare providers.



Linda Hildebrand, Phyllis Mervine, and Jeannie Salmon, a recent business school graduate, worked together to achieve nonprofit status for LDRC.

State legislative action

Politically, we were all growing. With help from an assemblywoman, the Lyme Disease Association of New Jersey (LDANJ) pushed their legislature to pass a bill requiring Lyme education for teachers and health professionals in endemic areas. LDANJ started to organize professional seminars to allow school districts to meet the requirements of the law.

All this activity was encouraging, but as New York patient Richard Lynch, a director of NLCRI, reminded the patient community, "We are no nearer to a cure for chronic Lyme than we were five years ago."

"Although these research efforts are unquestionably of great importance, we must keep in mind that they have nothing to do with what we already-infected Lyme patients need most: research into the etiology of chronic Lyme, and ultimately a silver bullet cure."

Lynch called on patients to up the ante, to prompt Congress to convene hearings on the issue of persistent infection after "appropriate" treatment. He urged people to write to the National Institutes of Health (NIH) demanding that they commit more resources to finding a cure. He proposed a nationwide committee to address the problem that "no coherent message is being put forward by those of us in contact with the media."

The Internet

The Lyme world changed dramatically when Lehigh University student Marc Gabriel created the Lyme Disease Electronic Mail Network, working with others at the Lyme Disease Network of New Jersey (LDNNJ), especially Bill and Carol Stolow. "I did it because I'm tired of seeing people suffer the consequences of ignorance," Marc said. He was overwhelmed by the huge response to his free, periodic electronic newsletter. Another group lobbied to create a public "usenet" site where people could talk with each other.

Continued on next page



Pat Smith, third from left, was chair of the NJ Lyme Committee, a political action group, when she participated in a Lyme candlelight vigil in Trenton, NJ, in 1992. *Ken Fordyce photo*

Patients and groups started to connect as never before. The Stolows set up an interactive site – LymeNet – that has thousands of users today. Soon websites were added to the mix – first the LDF and then LDRC. The first efforts were primitive but advocates quickly learned how to use the new tools.

Congress gets involved

In 1993, the year JAMA published Lyme guru Allen Steere's notorious over-diagnosis paper, Lynch's idea of a Congressional hearing materialized. Unfortunately, Lyme advocates at the LDNNJ didn't find out about it until the last minute. To their horror, Steere was to be keynote speaker with no opposing view. Patient advocates frantically conducted an intense telephone campaign.

Within two days over 2,000 calls, letters and faxes from support groups across the country flooded congressional offices. As a result, committee chairman Edward Kennedy agreed to include speakers who believed in the existence of chronic, persistent infection, and personally invited Lyme disease patient advocate Dr. Joe Burrascano.

Senator Kennedy asked the LDF to submit a proposal to the hearing. In their

submission they elaborated on issues such as insurance company denials; the "narrow, falsely restrictive and misleading surveillance case definition;" under-reporting; and conflicts of interest. We published the full text in *The Lyme Times* #11. It is sobering and sad to see how many of the points they made then remain current today.

At this hearing Burrascano gave his famous speech suggesting that the government was carrying out another Tuskegee experiment on Lyme patients. He accused a "core group of university-based Lyme disease researchers and physicians ... of adhering to outdated, self-serving views and attempting to personally discredit those whose opinions differ from their own."

Evan White, a teenager disabled by Lyme, testified (his mother interpreting because he could barely speak). Steere told a reporter that he had never seen a case like it. A legislator was heard to remark, "It seems that our two speakers [Burrascano and Steere] don't agree." Soon after, the N.Y. Office of Professional Medical Conduct (OPMC) launched an attack on Burrascano that cost him thousands of hours and tens of thousands of dollars to defend. The Lyme Wars had begun.

Existing groups didn't seem to be winning. The battle had become personal, and some people were still trying to create a more perfect patient organization. The Lyme Disease Association of the United States (LDAUS) was Ohio attorney Janice Beers' attempt to bring unity to the many diverse groups springing up across the country. Beers set up a democratically representative infrastructure with state groups combining into districts, and each district electing a member to the board of trustees. LDAUS started a newsletter in 1994 and planned the first general assembly in 1995. By 1996 LDAUS was doomed to failure as Beers became too ill to run it.

Our adversaries were not sitting idly by. Vaccine trials were under way. A group of academicians and researchers formed the American Lyme Disease Foundation (ALDF), an IDSA front group. Patients believed they chose their name to deliberately deflect attention from the Forscher's "real" Lyme Disease Foundation. ALDF was pro-vaccine and had the support of the Centers for Disease Control (CDC).

Gaining ground

At the same time there were hopeful signs. The New Jersey Lyme Disease Coalition was raising thousand of dollars for research, Ohio had a Lyme Disease Association. The Greater Cleveland LD Support Group appeared on an educational TV show and arranged a forum for legislators. In what would have been the first doctor protection bill, the Georgia Lyme Disease Association tried to pass the "Access to Medical Treatment Act," permitting healthcare practitioners to provide any method of treatment that fell within their scope of practice, as long as it would not endanger the patient. The bill sought to restrict medical boards from prosecuting providers solely because of unapproved treatment protocols; it did not pass. In Minnesota, the Dept. of Health Services asked advocates to develop and disseminate clinical guidelines for diagnosis and treatment, and the Minnesota Coalition stepped up to the plate.

Increasingly, however, Lyme practitioners were being targeted by medical boards. By 1995, Michigan support groups were organized enough to rally to support one of their doctors who had been targeted



Ted Kennedy talks to Evan White, who was so disabled by Lyme that he could barely speak, during the Senate hearing in 2003. Evan's mother, Ruchana, interpreted for her son. *R. White photo*

by the medical board for over-diagnosis and over-treatment. Although the trial judge exonerated the doctor, the medical board voted to disregard the court's decision and to impose sanctions anyway. The groups raised thousands of dollars for the doctor's defense fund and submitted an *amicus* brief to the court.

More than 100 physicians came to hear Dr. Burrascano at a seminar organized by the Cape Cod Lyme Disease Awareness Association. The same group, led by John Coughlan, later pushed for important revisions to the state's Lyme reporting form.

Science and the press

Over the next few years, scientists announced the discovery of at least four new *Borrelia* genospecies, and the NIH awarded a \$4 million grant to Mark Klempner for a clinical treatment trial. I was invited to serve as a patient representative on the Advisory Panel. The experience opened my eyes to the deceptive practices of the academic research community and their allies in government. The research trial was ended before enrollment was completed, but that didn't stop the NIH from trumpeting unsupported conclusions that would effectively deny extended treatment to Lyme patients. All the major media outlets ran the NIH Clinical Alert headline, "Chronic Lyme Disease Symptoms Not Helped by Intensive Antibiotic Treatment."

St. Martin's Press published Polly Murray's book, *The Widening Circle*, in 1996, and attorney Ira Mauer won a medical malpractice case for a client who was harmed because she was not informed of a positive Lyme test. New support groups sprang up in Alabama, Arizona, and Nevada. Recognition of Lyme was spreading along with the disease.

National efforts build

In spite of all the efforts and impact of support groups and medical conferences, people still felt the lack of an all-inclusive national group to unite patients. The Lyme Alliance of South Central Michigan decided to go national as Lyme Alliance. They called on patients to vote for their top issues, and recruited board members from across the country.

By 1998, many groups offered educational videos and tapes. The Lyme Disease Foundation produced award-winning videos for children. The LDA of New Jersey videoed IGenEX Labs president Nick Harris talking about testing. The Ohio LDA sold tapes of its successful 1997 conference.

Not everyone worked with a group. Dolly Curtis, a Connecticut entrepreneur, sold videos of her interviews with Lyme experts and played them on public TV. Steve Nostrum, founder of Lyme *Borrelia* Out-Reach in Massachusetts, had been providing referrals and counseling since 1987. He hosted and produced a monthly cable program on Lyme and sold the videotapes to support his nonprofit.

Eleven groups published newsletters, including one in Australia and one in Germany. New support groups started up in Connecticut, Louisiana and Pennsylvania.

Enter the vaccine

When the FDA approved the LymeRix vaccine in 1998, it invigorated advocacy efforts by the Lyme community. The LDF and

Continued on next page



Advocate Ken Fordyce and Lyme pediatric neurologist Dorothy Pietrucha celebrate at an early "Masquerade" fundraiser for New Jersey Lyme Disease Association, which later became the national LDA. Ken's wife, Kerry, was president of the organization before Pat Smith was invited to take over. *Ken Fordyce photo*

LDANJ worked with Congressman Chris Smith (R-NJ) for several months drafting the first federal Lyme bill. Congress did not pass the bill that year or in the next ten years that Cong. Smith introduced it. We collaborated with the Lyme Alliance's national drive to collect 50,000 signatures on a petition to support the bill and send letters and limes to President Clinton. LDANJ awarded a record \$60,000 in grants to researchers.

Seasoned advocates had done their homework and were on the warpath. LDANJ president Pat Smith minced no words in a speech in June 1998. Indignantly, she told a group of legislators that school physicians were preventing children from receiving proper accommodations under the federal disability law. "I have witnessed outright emotional cruelty in meetings with school personnel when a child's plight is not believed and the parent is brutally questioned in an accusatory fashion," Smith said. She was appalled at how much money her school district was spending on special accommodations for children disabled by Lyme.

LDF's Karen Forschner delivered strong testimony in February 1999 at CT Attorney General Blumenthal's hearing on insurance coverage. "Lyme costs society over one billion dollars per year," Forschner said, citing a survey of 1,000 patients done by LDF, Society of Actuaries, and the Stern School of Business.

"Early diagnosis and treatment decreases insurer costs. Insureds diagnosed in less than seven months needed an average of three doctors to get diagnosed and cost about \$35,000. Insureds taking 7-12 months needed an average of five doctors

to get diagnosed and cost \$68,000. Insureds taking over 12 months to get diagnosed needed an average of seven doctors and had an average cost of \$92,000."

At the same hearing, the audience gave Lyme specialist Steven Phillips, MD, a standing ovation for his presentation on persistent infection.

the surveillance case definition, the two-tier testing protocol, insurance denials ... patient advocates were having to juggle many sophisticated concepts and deal with the personal ravages of Lyme disease at the same time. The opposition was powerful and digging in, but patients were learning, too, and becoming better organized for the battle.

It is now 25 years since a small group of amateurs started the Lyme Disease Resource Center. We have earned our spurs. Today, *Lyme-Disease.org* publishes a respected journal, funds research, organizes meetings and workshops, and runs a nationwide network of state groups connecting thousands of patients. We maintain a popular website, several blogs and a presence on Facebook and Twitter. And we continue to organize and support patient protests - the heart of our original advocacy efforts.

With similar dedication, there are numerous other patient support and advocacy groups doing good work, as well as informative online groups and blogs. Despite the continuing struggle, much has been accomplished. Collectively we've raised

public awareness immensely - a critical task that must continue. We've passed important laws, participated in powerful protests, lobbied and educated Congress, organized patient and professional conferences, published books and articles, and much more. It's time to look back and recognize all the people who began the march, because we all are riding on their shoulders and building upon their successes.



Law helps kids handicapped with Lyme - page 19

the **Lyme Times**

Vol. 3 No. 1 SUMMER 1992

Insurance companies cutting off benefits to Lymies

New Jersey - The March 22, 1992 Star Ledger (New Jersey) reported that some major insurance companies in that state are limiting payments for intravenous antibiotics, cutting off payments for treatment that exceeds thirty days. Nine complaints have been received so far by the state Insurance Department. Seven involve Prudential Insurance Co. and two involve Blue Cross and Blue Shield. Insurance officials base their policy on expert medical opinion that a 30-day course of antibiotics is generally sufficient. Actua Insurance Company reviews requests for treatments beyond 30 days but does not automatically reject claims.

Lyme disease patients are caught in the middle of the debate among physicians who advocate a month of treatment and those who advocate a longer course. Some doctors cite the relapses and continuing symptoms of

See Insurance on page 23

Inside:
Pediatric articles.
Children with Lyme
present special
problems.

Lyme disease cost to society comparable to cost of AIDS

Delaying diagnosis and treatment raises the price tag

by Babette Kiesel

Stanford, Connecticut - The 1992 State of the Art Conference on Lyme Boreliosis was held in Stamford, Connecticut, on April 10 and 11. Irwin Vanderhoof, PhD, FSA, CLU, Society of Actuaries, Stern School, New York University, reported on the financial cost to society of Lyme boreliosis. He observed that the "cost to treat Lyme disease escalates in direct proportion to the length of time to diagnose.... Six months or less up to \$40,000; seven to twelve months - \$80,000; over one year - \$125,000... Average cost per difficult case, per

patient - \$90,000, which is about the same as for the average AIDS patient's treatment.... 60% of Lyme disease cases were diagnosed by family practitioners," he stated. "20% of the people in the study lost their jobs, and a similar percentage reported that they lost significant time from school." He warned that the CDC reporting criteria result in serious under-reporting nationwide. Some physicians declare that it is not reportable, or that they "don't report too many."

See Conference on page 35

New tick species confirmed to carry Lyme

Researchers suspect more tick species guilty of spreading Lyme disease

St. Louis, Missouri - Researchers at St. Louis University have identified the *Borrelia burgdorferi* organism, the bacterium that causes Lyme disease, in two more species of ticks - the lone star tick and American dog tick. They are conducting tests to determine whether these ticks will be efficient transmitters of the disease.

If this proves true, it would expand the list of proven Lyme disease transmitters to include tick species covering nearly the entire United States.

See Lone Star on page 30

Doctors were finally beginning to organize themselves as well. In 1999 a group of doctors and scientists gathered in Boston and formed the International Lyme and Associated Diseases Society (ILADS).

The past as prologue

Ten years after the first advocacy groups had been formed, the Lyme Wars were becoming more intense. The vaccine,

Lyme Denialists

Resistance to emerging medical and scientific information has plagued patient care since Lyme was first identified in Lyme, CT

Douglas Dodge, a Yale graduate who lived in Connecticut, had a big beef with his *alma mater*. He blamed Yale Medical School for his wife's chronic illness and premature death when doctors refused to treat her despite positive tests for Lyme disease. An early Lyme activist, he set up a website called LymeTruth and began collecting public statements by "denialists" - those professionals who persistently have resisted the emerging science about tick-borne diseases. *The Lyme Times* has built upon Dodge's collection to capture the flavor of the misguided opinions of those who have resisted the evidence.

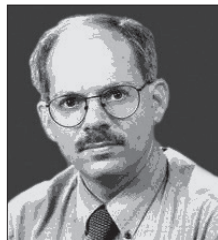
Phillip Baker, PhD



Executive Director, American Lyme Disease Foundation. NIH Lyme Program Officer (now retired)

I'll certainly miss all of you people [CDC colleagues] - the scientists but not the Lyme loonies. (2007)

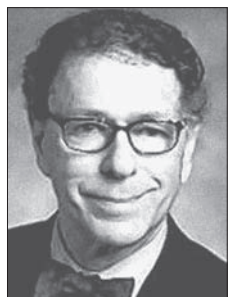
Steven M. Ostroff, MD



Former CDC associate director, testified before the 2010 IOM Committee on LD

Lyme is a Yuppie disease that only rich suburbanites get. (1997)

Stephen E. Malawista, MD



Professor of Medicine and one of two researchers who identified LD in 1975

Lyme disease has become a magnet for people who do not feel well. No one doubts that they are suffering. The question is whether they are suffering from Lyme disease. There is a difference between hope or belief and hard clinical evidence. A danger is that some other condition will be ignored while the possibility of Lyme disease, however remote, is being endlessly pursued. (1998)

Leonard H. Sigal, MD



Rheumatologist at Robert Wood Johnson Medical School, NJ.

Lyme disease, although a problem, is not nearly as big a problem as most people think. The bigger epidemic is Lyme anxiety. Even if you get the disease, it is easily treatable and curable. (2001)

Edward McSweegan



NIH Health science administration, microbiology and infectious diseases; former NIH Lyme Program officer (fired).

What we have here is a war. Actually a disinformation war...The Lymeans and their parasitic [doctors] have been at this for a long time. (2007)

Allen C. Steere, MD



A Yale rheumatologist, he identified the first cases of LD in 1977 as "Lyme arthritis."

We remain skeptical that antibiotic therapy helps. (1997)

There is more fiction to Lyme disease than fact, and only experts like myself know how to tell the two apart. (1998)

I suppose Lyme disease is one of the few diseases that some people want to have because it's defined. I think it's very difficult to have something that is not well understood. (1999)

David Weld

Executive director of the American Lyme Disease Foundation (ALDF), not to be confused with the Lyme Disease Foundation (LDF).

Lyme is a socially acceptable disease. You can talk about it at any cocktail party. (2005)

The Early Days

Ukiah volunteers were once the only source of patient support

By Thora Graves



Thora Graves, a volunteer at Lyme events, was one of LDRC's original board members in 1989.

I first met Phyllis Mervine in late 1988. Someone wrote to me about a Lyme disease support group at the Mendocino Community Hospital in Ukiah. In those days there was no Internet, cell phones, facebook, etc. All of us had to search hard to find others suffering from this new mysterious disease.

Phyllis was working at the hospital clinic when she started a newsletter called the Lyme Times in 1989. We could not wait for the next edition. It was our only means

of getting the latest information. The local libraries did not have information back then like they have now.

Once I met Phyllis and saw her strength and determination to get the word out about this new disease, I decided to join the mission to help educate the public, medical professionals, politicians, etc., about this mysterious new disease.

In 1989 some of us helped Phyllis form the Lyme Disease Resource Center (LDRC). It was greatly needed. So many people were

LymeDisease.org launched as a patient advocacy group in Northern California

By Nancy Brown

The sidebar box on the 7" x 8 1/2" newsprint eight-page booklet read: *The Lyme Times is the publication of the Lyme Disease Network, founded in 1989 for the purpose of education and patient support.*

The newsletter was launched on a shoestring budget from donations received from a few individuals. Members of that initial group, including Phyllis Mervine, Linda Hildebrand and Thora Graves, were personally fighting their own battle against Lyme disease. Phyllis, still a champion and activist to this day, was the original editor. Some of the authors for those first editions were Isis Coble, Vicky Womack, James Katzel, MD, Ray Wiser, MD, Valerie Novak, MD, and Richard Williams.

Soon after, the Lyme Disease Resource Center (LDRC) was officially organized and received nonprofit status from the IRS. *The Lyme Times* continued to be published under its banner. Board meetings were held in private homes, in hospital meeting rooms, or restaurants – anywhere someone had a network that could be



Thora Graves, second from left, attended the book signing event LDRC held for author Polly Murray (seated left) with Rene Landis and IGenEX president Nick Harris (right) during the International Conference for Lyme Borreliosis in San Francisco in 1996.

desperate for information and support. After a while, groups were formed so patients could support each other. It has never been an easy time. We all thought for sure there would be a cure for us. For some, maybe there has but for so many others there has not.

For many years *The Lyme Times* has been the most valued information available for the Lyme community. The LDRC became CALDA (California Lyme Disease Association) and eventually *LymeDisease.org*. A lot has happened in the past 25 years, and without Phyllis and her continued devotion to fighting for the cause we would not be as far along as we are. We must keep up the fight.



Pharmacist Mitch Hoggard and Ray Stricker, MD, share a joke at the 2003 conference in Ukiah. Both currently serve on the LDo board of directors.



LDo president Phyllis Mervine, Columbia Univ. Lyme Research Center director Brian Fallon, LDo treasurer Nancy Brown, and Mountain View Lyme disease support group director Karen Chew pose for a photo after the LDo's 2000 San Francisco patient/medical conference at which Fallon was a keynote speaker.

tapped. Directors were volunteers from all parts of California and Nevada, some driving long hours in spite of illness to conduct business.

Early on, the group organized physician and patient symposiums featuring such speakers as Paul Lavoie, MD, John Drulle, MD, Joseph Burrascano, MD, Robert Lane, PhD, and many other physicians and researchers working on the front line on behalf of Lyme

disease patients. If energy or experience was lacking for those organizing the events, perseverance and devotion to the cause carried them through.

Patients and support groups were brought together and given a broader voice in a common cause through the LDRC and *The Lyme Times*. People who previously had felt isolated in their battle against a terrible disease were given hope. When the controversies started raging in the medical community about diagnosis and treatment, the LDRC stood alongside other organizations nationwide to fight for patients and physicians who were caught in the middle.

The LDRC evolved into CALDA (California Lyme Disease Association). Lorraine Johnson grew the organization and inspired an even higher level of activism. Over the years there has been a long list of people who have contributed expertise, energy and financial support. But it is certain that the dogged determination, dedication and perseverance of those early pioneers in the Lyme Disease Resource Center set the foundation and direction for the organization to grow and evolve into what it is today: *LymeDisease.org*.

Despite the name changes, this organization has always been about people – patients, their families, physicians and researchers. My association as director went from 1990 to 2002. Although some of the memories have gone rather hazy, it is fun to remember the original group, in particular Phyllis Mervine (first and foremost, of course!), Linda Hildebrand, Thora Graves, Jean Hubbard, Karen Chew, Walt Prehn, Bob Lane, Mitch Hoggard, Barbara Barsocchini, Stephanie Propp, Ray Stricker, Marilyn Barkley, Rene Rothstein, Lorraine Johnson, and Nick Harris.

Finding our way as a fledgling organization built lifetime bonds

By Linda Hildebrand

Phyllis Mervine and I first met at a Spring 1990 meeting when the Lyme Disease Resource Center (LDRC) was formed. Phyllis was elected president and continued as the editor of *The Lyme Times*. At that time, only a few printed issues had been produced with limited distribution.

Phyllis was also busy working at a Mendocino County Lyme clinic and in the midst of organizing the first medical conference to be held on the West Coast. I was elected treasurer, as there were only a handful of us who had any energy to devote to this project. I had been sick almost three years, had undergone treatment in 1989, but had been unable to return to work. I was eager to feel that I was contributing to what I expected would be a short-term project. At that point, I had only attended a handful of support group meetings, so my knowledge of Lyme was limited.

We held the first LDRC medical conference on May 12, 1990 in Hopland, CA, with a public forum following. Phyllis had done most of the symposium organization on her own, but there still was a lot of last minute activity. She had forgotten the programs, so had to run back to her office to fetch them, a 45-minute roundtrip. Meanwhile Dr. Lavoie sent me hunting for flowers to give her – a serious challenge amid the Mothers' Day rush. But all went well and both events had full capacity attendance.

During the pre-Internet decade, the all-volunteer LDRC operated on a shoe-string with much on-the-job training required.

We were like sponges, always studying and taking in information. Phyllis and I relied on each other greatly for encouragement and support. We were fortunate to have the assistance of many sci-

Continued on next page



San Francisco physician Paul Lavoie, chairman of the first LDRC conference on Mother's Day 1990, presented Phyllis Mervine with a bouquet of red roses. *M. MacDougal photo*

entific and medical professionals, as well as support from the community and patients throughout the U.S. Because of her vast knowledge and professionalism, Phyllis was repeatedly asked to serve on various state and national governmental Lyme disease committees.

Producing The Lyme Times

To produce the earlier Lyme Times editions, Phyllis had to make frequent one-hour round trips from home to get computer time, working on computers at her husband's office and at the local environmental center. Later we were able to purchase a couple of computers for LDRC, but still encountered glitches along the way. Phyllis' home power sources were hydro and solar power. During a Winter 1992 drought, there were times when the Mervines didn't have enough water or sunlight for their computer to power up. This situation was not amusing at the time but now is laughable.

Phone calls, faxes and mailing costs were extremely high in those years. Mail turnaround could also greatly delay work on any project. But gas was relatively cheap and our time was free. We met frequently with average two-hour round trips to swap floppy disks and review hard-copy work. Because we needed to lower production and mailing costs, we switched to a newsprint layout after studying many newsletters, publications and font books. We used that updated version for a number of years. I am thrilled to see how *The Lyme Times* has morphed over time to the current journal complete with cover.

Spreading the word

The 1990's was an exciting and energizing time. Besides production of *The Lyme Times*, the LDRC held regional medical conferences and many public forums. We undertook numerous other educational programs, including hospital grand rounds and employee safety programs. Support group leaders from throughout the country participated in trainings that we organized and facilitated.

In 1996, the chairman of the VII International Conference on Lyme Borreliosis in San Francisco asked us to organize the medical continuing education component. During that conference, the LDRC held a wine-tasting reception for author Polly Murray, the Connecticut mother who in 1975 first brought the "mysterious illness" to the attention of public health and medical professionals. Efforts by people like Polly Murray, support group leaders like Betty Gross, Westchester County, NY, Thora Graves, Sonoma, CA, Linda Goffinet, Stanford, CA, Betty Owens, Santa Rosa, CA and many others provided me with ongoing inspiration. It is rewarding to see that the nationwide network we all struggled to support back then is now achievable through the use of the Web.

A final reflection

My LDRC experience dramatically changed my life for the better. We formed lasting relationships. While some of the same individuals who were around 25 years ago are still involved in Lyme advocacy and education, that number has dwindled. Only a few have plodded on year after year. Phyllis Mervine is one of those individuals. It is my greatest hope that soon there will



LDRC's "Meet the Author" reception, held for Polly Murray during June, 1996, VII International Conference on Lyme Borreliosis. L to R: LDRC board member Jim Katzel, MD; Linda Hildebrand; and Betty Gross, founder of Westchester County (NY) Lyme Disease Support Group.

no longer be the need for all of her efforts. I don't want to get another call in 2039! But I do continue to look for ways to contribute in this new technologically-driven era.

Advice? If you, a family member or friend has energy and time to volunteer, please look for ways to help. You can do this at a local, state or national level. Finally, donations are needed to fund research and advocacy. Contribute if you can.

HEALDSBURG PRINTING, INC.
NEWSPAPERS - TABLOIDS - ADVERTISING CIRCULARS
CATALOGS - MAGAZINES - DIRECT MAIL

**Northern Sonoma County's
premier publication printer,
offers our congratulations to
The Lyme Times
&
LymeDisease.org
on their 25th Anniversary**

THE PIONEERS

Our Pioneers

More than twenty-five years have passed since Polly Murray reported the Lyme epidemic and Willy Burgdorfer discovered the Lyme spirochete. All these pioneers entered uncharted territory and opened the way for many more to follow. They had to be enterprising, courageous, persistent, curious and open-minded. Lyme disease fascinated and challenged them. They brought their clinical acumen and scientific training to bear and refused to give up. They all cared deeply about patients. We owe them our respect and thanks.

Polly Murray



Lyme, CT, housewife Polly Murray, shown here at a Lyme conference, wrote a book about her experiences that lead to the discovery of Lyme disease. *Ken Leigner photo.*

When artist Polly Murray and her family became sick back in the early 1970s, there was no name for the multifaceted illness that afflicted her and many of her neighbors. In 1975, after years of being misdiagnosed, misunderstood, and dismissed by doctors, she was finally able to persuade the public health authorities to check out the situation in her town of Lyme, Connecticut. They sent Allen Steere, MD, then at Yale University, to investigate. With Steere's work, a description of a new tick-borne infection he called "Lyme arthritis" began to emerge. The causative organism was discovered 1982 by Willy Burgdorfer, PhD, a scientist with the National Institutes of Health (NIH), after which the bacterium is named.

Eventually, Polly Murray came forward to tell the world about the spirochetal illness that was discovered thanks to her powers of observation, intelligence, and persistence. St. Martin's Press published her book in 1996: *The Widening Circle: A Lyme Disease Pioneer Tells Her Story*.

For many suffering from Lyme disease, *The Widening Circle* offered hope. With new viruses and diseases arising every day, Murray's story remains an example of how one person can influence the medical community - to force them to pay attention. In the end, Polly made a huge difference to the developing story of Lyme disease.

Willy Burgdorfer, MD, PhD

By Phyllis Mervine

When *LymeDisease.org* gave Willy Burgdorfer a Community Service Award in 2008, we wanted to recognize his leadership and research. We knew the wily spirochete might have remained undetected much longer if not for the unique skills and experience Willy brought to the task. We also wanted to appreciate his compassion. He has been known to talk with patients who call his listed Montana phone number at wee hours of the night.

Willy was thrilled when we invited him to San Francisco to take part in our Lyme Action Program. ILADS also stepped up to the plate, shared expenses with us, and honored Willy with a special video and ceremony. Willy later told me it was the highlight of his career.

In 1993 the editors of *Clinics in Dermatology* asked him to write an article about his 1981 discovery. He decided the story should "reflect my education, training, and research interest that provided the background needed for a discovery variously described as 'a scientific breakthrough,' 'serendipity,' or even 'an accident.'"

In 1946, Willy was a graduate student in Switzerland when his professor handed him a "glass dish filled with light brown soil from an incubator." The sand contained ticks from the Congo infected with



LymeDisease.org President Phyllis Mervine (L) and Executive Director Lorraine Johnson (R) present Lyme spirochete discoverer Willy Burgdorfer their 2008 Community Service Award for "leadership and dedication to reducing human suffering from Lyme disease through research, discovery, and compassion."

relapsing fever spirochetes. "Over the next three years, I dissected thousands of tick," Willy wrote. He figured out the complex life and transmission cycle of the African spirochetes.

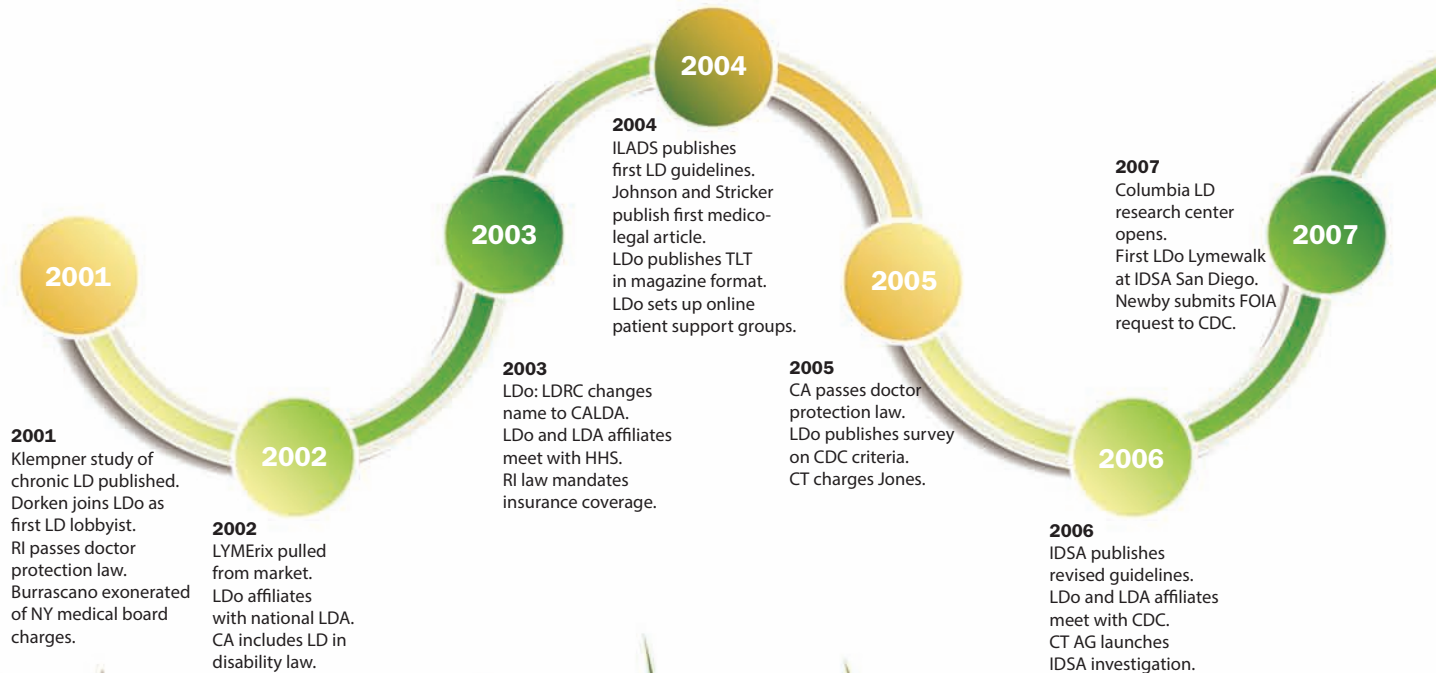
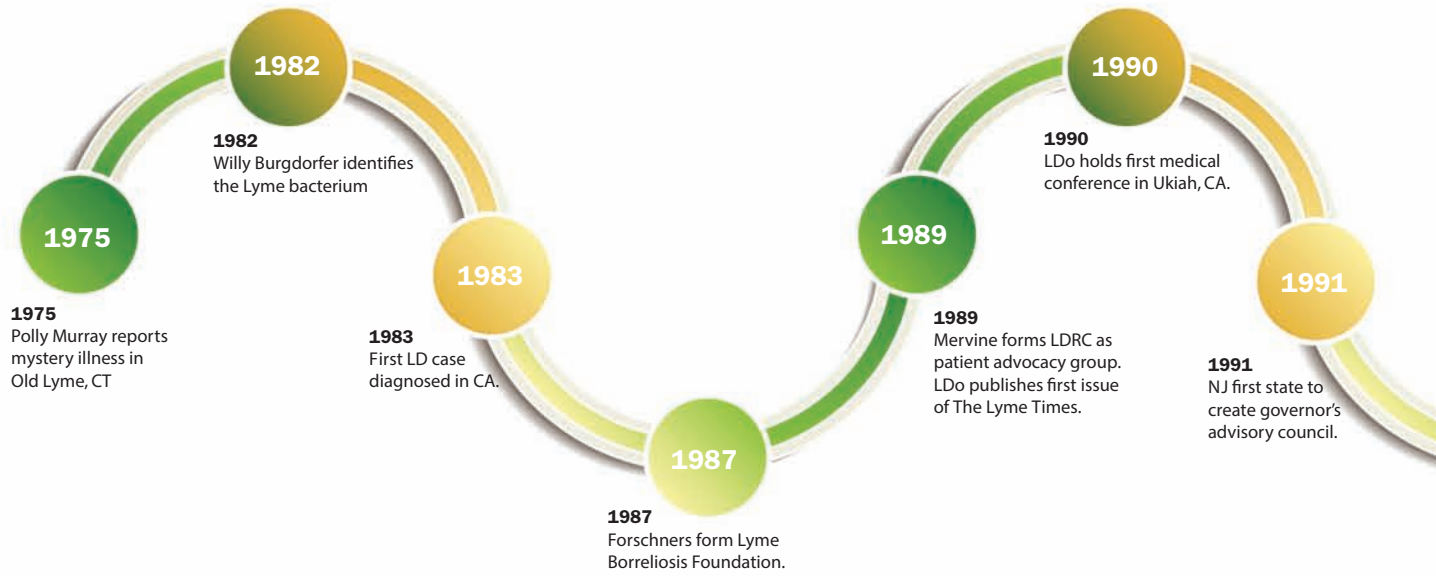
His professor also required his doctoral candidates to have a thorough knowledge of the "voluminous" literature on relapsing fevers, thus Willy learned of the "speculative claim" by European dermatologists that a type of rash was caused by a spirochete associated with a tick. In 1949 he also heard a speech by Hellerstrom reporting that the rash could be successfully treated with penicillin. No one at the time really believed that spirochetes were involved.

Fast forward to 1981. Willy, looking for Rocky Mountain spotted fever *rickettsiae* with his NY colleague Jorge Benach, dissected several hundred *Dermacentor* ticks from Long Island, NY. Not finding any *rickettsiae*, they decided to check another species of tick, *Ixodes scapularis*. Benach provided 44 more ticks. Again, there were no *rickettsiae*, but in two ticks Willy noticed "poorly stained, rather long, irregularly coiled spirochetes." In a 2007 interview with *Under Our Skin* director Andy Wilson, Willy describes the moment of discovery.

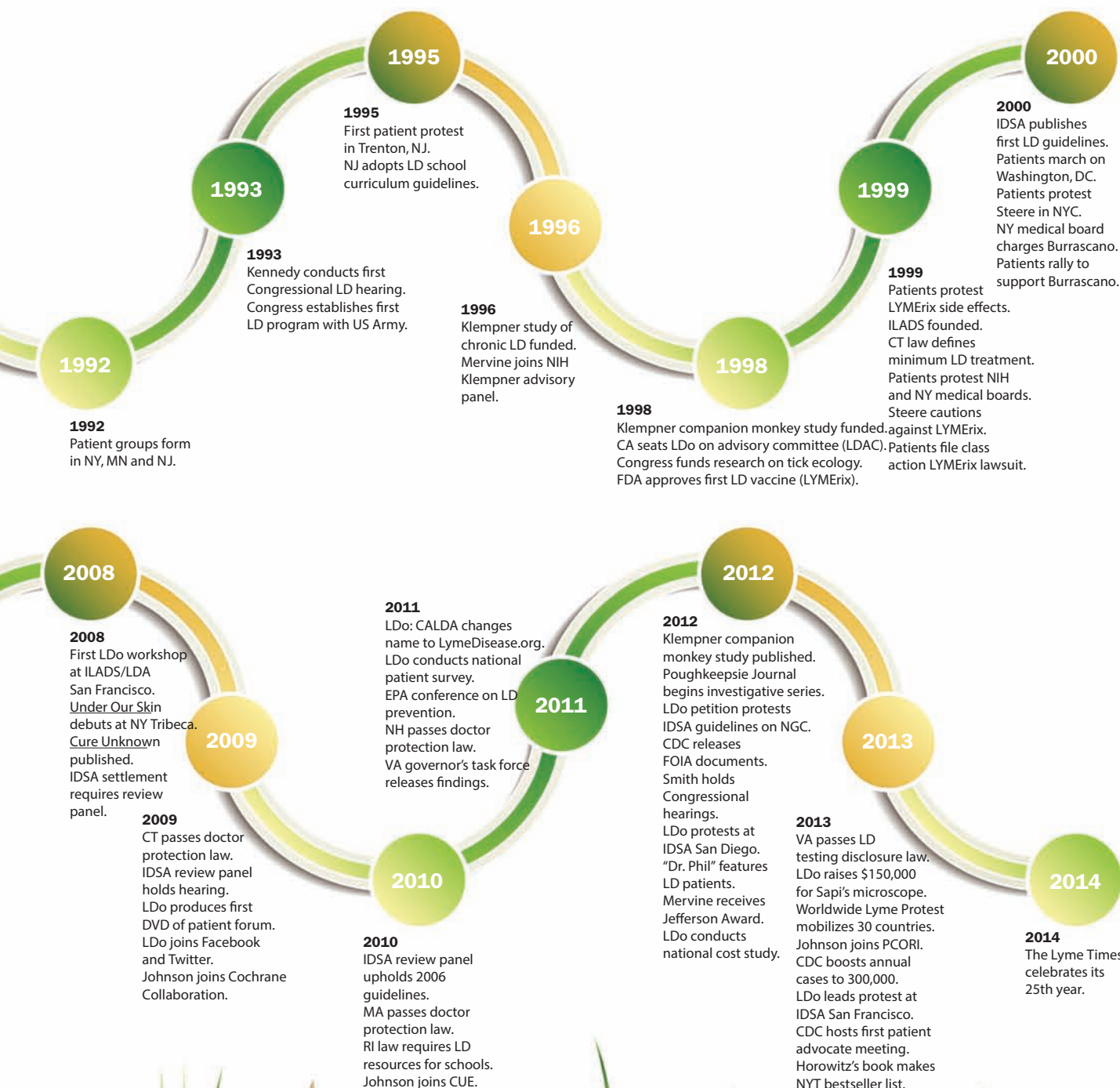
I remember that time quite well.... But it was not an "Aha" [moment]. It was a "What in the hell? What's in that smear?" And then my work [on relapsing fever]

Continued on page 18

TIMELINE OF LYME HISTORY:



The Lyme Times and LymeDisease.org 1975-2014



THE PIONEERS

as a Swiss student came back. [I said to myself], "Willy, these are spirochetes!" The slide showed long slender forms, a little bit curved, and they were only in the mid-part of the tick. Nowhere else. There were so many people who said, "That is impossible Willie. You can't get spirochetes out of hard-bodied ticks." [But from my work on] relapsing fever ticks from Africa, I knew what a spirochete looked like. The Belgian Congo and Kenya are hot spots for relapsing fever. Even Livingston [the African explorer and Scottish missionary] was exposed, and he called it "tick fever."

Willy says he remembered Hellerstrom's paper and couldn't help thinking that he had found "the long-sought causative agent of *erythema migrans* and possibly also of Lyme disease."

Within weeks, Alan Barbour was culturing the spirochetes, and European researchers were looking for spirochetes in European ticks. Spirochetes were found in ticks in California and Oregon. There are now over 10,000 publications on Lyme disease listed on the National Library of Medicine website. The spirochete was eventually named for the man who discovered it though he has said he has never been sure if he is happy about it.

Paul Lavoie, MD

By Suzanne Fratus

When I first met Paul Lavoie, I thought he had to be a nut. How could a tick bite 30 years earlier still be causing such serious health issues for me? Little did I know that I had just met one of the most influential persons in my life.

The first year and a half of treatments was miserable. Each change of medication knocked me down again and again. I almost quit. Although those around me could see definite improvement in my functioning, I became discouraged and feared that my quality of life might never again be worth the effort I had to expend daily just to live. Sure, after treatment I could get up from a chair and walk down a flight of stairs on my own. But when I compared where I was with other 35-year old women, my life was

From The Lyme Times #12, April 1994

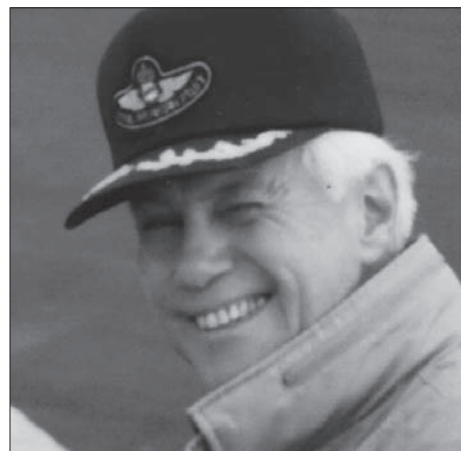
Dr. Lavoie was a specialist in rheumatology and internal medicine in private practice in San Francisco since 1973. He held several medical teaching appointments, including Clinical Professor of Medicine at UCSF. An active board participant of national, state, and local organizations, he was a Founding Fellow of the American Rheumatology Association.

In 1977, Dr. Lavoie diagnosed the first two cases of Lyme disease in the far-western United States. He subsequently played a major role in both the treatment and research of Lyme disease, often bridging the gap between the clinician and the bio-medical community. He treated hundreds of patients with Lyme disease, and contributed 25 published papers on aspects ranging from laboratory diagnosis to clinical approaches. Lecturing widely, he participated in special Lyme disease conferences at both the NIH and CDC.

still a train wreck.

I thanked Paul for his efforts and told him that I was going to quit taking the Lyme medication because I wasn't making progress fast enough. I was sure that there must be other disease processes going on. Paul took time to explain how the various medications could only interfere with the bacteria when it was replicating, and since Lyme was a very slow replicator it took long than other diseases. In the end he left the decision up to me. I decided to stick with oral antibiotics - to give it more time. That decision saved my life.

Gradually, even I could see there was undeniable progress. In the meantime I read everything I could



Paul Lavoie diagnosed the first case of Lyme disease on the West Coast. A pioneer physician, veteran pilot, amateur singer and generous mentor, he died of pancreatic cancer in 1993 at the age of 60.

JP Lavoie photo

get my hands on about *Borellia*. Soon my one hour appointment with Paul became mini lessons in Lyme and other tick-borne diseases. I was excited to exchanged names and numbers with other patients in the waiting room. I began to interview them in depth about their health histories and treatment plans..

"This can't all be Lyme disease." I said to Paul. "There's more here," he told me as he launched into a quick lecture on co-infections.

Paul was getting heat from the local rheumatologists and the pressure was on.



Suzanne Fratus, who has written her personal recollection of Dr. Lavoie, seated with IGeneX president Nick Harris at a Lyme conference in 2008.

THE PIONEERS

But as an old fighter pilot he never let them see him flinch. Quiet time was spent with friends, flying, skiing, and volunteering with the Air National Guard locating downed pilots.

I remember the day he told me he had pancreatic cancer. I had been teasing him about gaining some weight in his diaphragm area. He said simply, "I have some bad news." And he sat down on the stool and stared at me with his steely blue eyes. He did not have to say another word. I knew.

"Cancer? I asked".

"Yes."

"What kind?"

"Pancreatic"

The silence between us hit like a stone.

"That is 98 percent fatal, isn't it?"

"Last time I checked," he replied.

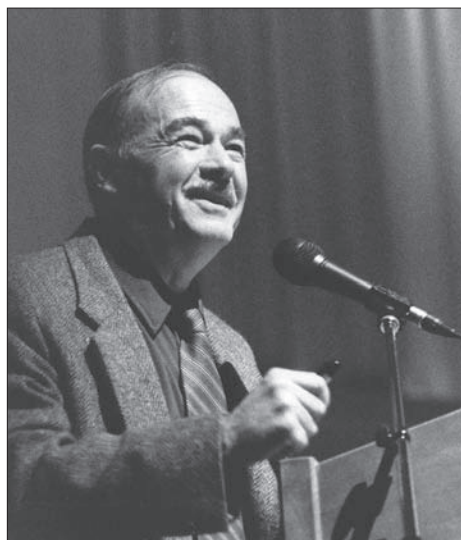
"Damn, damn, damn ... I'm gonna miss you." (And I do miss him every day.)

He beat the politics out of me and showed me how to work with others. He taught me the value of learning medical history. He showed me how seemingly small discoveries and random acts of kindness can change our world.

Paul Duray

By Alan B. MacDonald, MD

Excerpted from The Lyme Times 24-3 2012



Paul Duray spoke at the 1999 Lyme forum at Bard College, NY. *Ken Liegner photo.*

Paul was a friend to the entire Lyme community. He gave selflessly of his keen intellect, laboratory adroitness, good humor and fellowship.

Credentialed as a hospital pathologist, his job was to diagnose [benign versus malignant] in all medical specialties. He was at home in the surgical suite, the microbiology lab, the hematology division, the clinical chemistry lab and the blood bank.

Paul was a developer of the "Lyme focused Autopsy." He was the official pathologist in residence for Dr. Allen C. Steere. Many challenging cases came to him from all over the world. He was a superb diplomat - at the same time a member in good standing of the IDSA and a friend to every member of the ILADS community.

He was recognized as a national authority on malignant melanoma, and this was sought after by the National Institutes of Health (NIH), where he served his country as a researcher. Recruited as the Director of Laboratories of the prestigious Fox Chase Cancer Center in Pennsylvania, he was also a valued member and leader in pathology practice in the Veteran's Administration Hospital system.

But Paul's skills as a flight surgeon were his contribution to many volunteers who served their country by wearing the uniform of military service.

Paul's earliest memories of the Pearl Harbor attack (which he survived at the age of four) taught him courage under fire. He continued to serve his country courageously at 68 years of age with three tours of service in the Medical Corps in Iraq. In lieu of flowers, Paul requested that donations be made to the Wounded Warrior Project.

Paul loved to discuss all things cultural, especially opera, and was indeed a renaissance man, a man for all seasons, a man of character whom all could admire and strive to emulate.

We miss you, Paul. God Bless you.

Alan B. MacDonald, MD
November 6, 2012

John Drulle, MD

John Drulle, MD, of Jackson, NJ, was a pioneer in the management of Lyme and other tick-borne diseases. He was especially concerned about Lyme's effect on pregnant women and the fetus. This was his topic when he spoke at the first LDO conference in 1990.



John Drulle with his wife, Milo Eiras, at a NJLDA event in the early nineties. *John Drulle, MD Memorial Lyme Fund photo.*

According to the website devoted to raising money for a memorial fund bearing his name, Dr. Drulle's practice was patient-centered. "He would go so far as to pick up prescriptions and deliver them to a patient's house when they were too sick to do so themselves," the website states.

Drulle, a member of the Lyme Disease Association, was recalled for his powerful intellect in Pat Smith's memorial tribute to him.

"I called him for advice on LDA grants we were to review or scientific papers that were out there," she wrote. "It was then I realized his brilliance and his seemingly photographic memory. I called him once and cited a paper, and he informed me he had read X paper 20 years ago with some obscure citation in it that contradicted the paper I mentioned."

He helped to initiate the New Jersey Governor's Council on Lyme Disease. As Pat Smith notes, neither he nor she was invited back to the council after the first year. "We

Continued on page 20

THE PIONEERS

had done our jobs very effectively,” she said, “setting the health department on its ear.”

Drulle suffered from Lyme disease for 15 years and was only 56 when he died. He practiced medicine for 23 years, sharing a medical practice with his wife, Milo Eiras, until he became too ill to work.

In her tribute, Pat Smith describes lively arguments that used to occur between Drulle and his wife when they were discussing different approaches to treating a patient. She concludes, “At the LDA’s Lyme disease medical conference in NY, I could see him looking down during the annual John Drulle Memorial lecture whispering into the lecturer’s ear, ‘I don’t think that’s quite right, you should read page 14 of the paper published by Dr. such and such 10 years ago ... ? That’s the John Drulle we knew and loved.’”

Drulle was also a member of the International Lyme and Associated Diseases Society and a medical advisor to the Lyme Disease Foundation. He died of Lyme disease in 2003.

To read Pat Smith’s entire tribute, visit lymediseaseassociation.org and select Testimonies/Other.

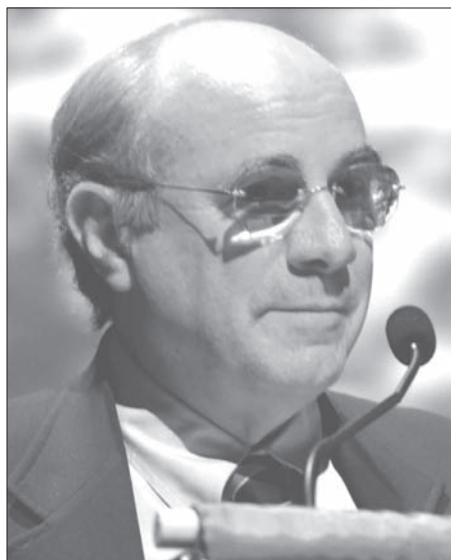
Ken Liegner, MD

By Stephan J. McLain, PhD

Excerpted from The Lyme Times #27, Winter 1999

The 1999 Distinguished Physician Award, which recognizes a physician for clinical excellence, leadership, compassion and dedication to the treatment of Lyme disease, has been awarded to Dr. Kenneth B. Liegner of Armonk, New York.

Dr. Liegner is an internist with a special interest in Lyme Borreliosis and related disorders. When he began his private practice in the mid-80s in Armonk, he observed that many of his patients with evidence of Lyme disease did not fit the pattern considered typical at that time. Some patients were seronegative by currently available tests, or did not have a fully developed immune response to the Lyme organism. Some patients did not improve on the recommended short course of oral antibiotics, or relapsed after cessation



Ken Liegner spoke at the 2012 congressional hearing at Skidmore College in NY.

Lyme Action Network photo

of treatment. This discrepancy between the diagnostic standards and treatment protocols of the time and what he was observing in his own patients led Dr. Liegner to question the conventional wisdom that Lyme disease is easy to diagnose and treat. By studying the literature, conferring with academic and clinical colleagues, and carefully observing his own patients, he has become one of the leading experts in Lyme disease. Sitting in Dr. Liegner’s waiting room, one is likely to meet patients who have traveled a great distance to consult with him about difficult cases. Dr. Liegner is notable for the thoroughness and rigor with which he approaches the evaluation of his patients. New patient visits allow sufficient time for a complete physical exam and a thorough history. He is an astute objective observer and keeps detailed written documentation of patient history and his clinical observations. Drawing on his comprehensive knowledge of tests for Lyme and other tick-borne diseases, he excels at obtaining objective evidence as part of the diagnostic process. He typically makes full use of the arsenal of available tests. In his treatment protocols, he practices scientific evidence-based medicine relying on both peer-reviewed medical literature and his personal contacts with other clinicians who

treat difficult cases. He is at the forefront of investigating new treatment protocols in a clinical setting.

Dr. Liegner has been a forceful advocate for patients in his public speaking engagements and regular participation in national meetings. He has attempted to “bridge the gap” that exists between academic researchers and clinicians by maintaining strong contacts with both groups, and by publishing regularly in peer-reviewed journals. His numerous publications are a remarkable achievement for a clinician with a busy private practice. His commentary article “Lyme Disease: The Sensible Pursuit Of Answers,” [J Clin Microbiol 1993 Aug;31(8):1961-3] is a compelling, well-documented paper arguing that the medical profession needs to consider the true complexity of this disease and the implications that complexity has on how patients should be treated. He is a co-author of a seminal paper on the neuropsychiatric manifestations of Lyme Borreliosis. Other publications include a well documented case study of the persistence of *Borrelia burgdorferi* infection despite extended oral antibiotic treatment, and a recently published set of case studies of antibiotic responsive patients where the differential diagnosis between Lyme disease and other neurological or autoimmune diseases was exceedingly difficult.

Congratulations Dr. Liegner, and thank you for your tireless efforts on behalf of Lyme patients. From my perspective as a patient, I wish that there were many more doctors of your caliber in Lyme country.

2011 — Lyme Times Vol. 23 No. 2

CALDA Changes Name and Logo

We’ve outgrown our name and our logo, but not our mission. The California Lyme Disease Association (CALDA) is now LymeDisease.org. That might sound familiar since it is our URL. Our new name reflects what we already do. We remain committed to empowering Lyme patients through advocacy, education and research.

THE PIONEERS

Ed Masters, MD

Excerpted from The Lyme Times #19, Winter 1997

In 1997 the Lyme Disease Resource Center (now LymeDisease.org), presented its Distinguished Physician Award to Edwin Masters of Cape Girardou, Missouri. The award recognizes a physician for clinical excellence, leadership, compassion and dedication to the treatment of Lyme disease.



Dr. Ed Masters of Missouri and author Polly Murray at the International Lyme Borreliosis Conference in San Francisco in 1996.

Dr. Masters was a familiar figure at Lyme disease conferences for many years, never failing to make the audience laugh while sharing his experiences of diagnosing and treating clinical Lyme disease in Missouri. In nominating letters he was termed “a remarkable gentleman” and “a gentleman and a scholar” who “has dedicated his practice to helping patients who had been incorrectly diagnosed after other physicians had refused to consider the possibility of Lyme disease.”

Another writer praised his “keen judgment” and “astonishing patience and persistence in declaring the existence of Lyme disease in Missouri despite the denial of government agencies determined to embarrass him and disprove his statements. He forged ahead fearlessly and calmly, never to be diverted from his deeply held conviction of the rightness of what his eyes told him.

The writer continued, “He showed strength of spirit in holding fast to the clear evidence repeatedly appearing before him and continued to meticulously record data which confirmed that undeniable [EM] rash in a variety of presentations..” eventually forcing the CDC to acknowledge the existence of Lyme or at

least a “Lyme-like” organism in Missouri.”

Dr. Masters was further praised for his compassion. “A more caring physician is difficult to envision, and his commitment to his patients, and his will to see them well again, have distinguished him ...”

Charles Ray Jones

By Sandy Berenbaum, LCSW, BCD

Excerpted from The Lyme Times #52, Summer 2008.

Reverend Martin Luther King once said, “The ultimate measure of a man is not where he stands in moments of comfort, but where he stands at times of challenge and discovery.”

I am privileged this evening to have the opportunity to say a few words in tribute to Dr. Charles Ray Jones – only a few words to acknowledge the immense appreciation we all feel for the compassionate and brilliant care Dr. Jones has given to over 11,000 children stricken with chronic tick-borne illness, children who have traveled from all over the world, from every continent, seeking his help.

Dr. Jones’ route to medicine began when he attended Boston University’s Divinity School in 1954, along with his classmate and friend, Martin Luther King. Together with others, they met weekly to discuss the value of a world community and civil rights. The seeds of Dr. Jones’ commitment to stand for what is right and

Continued on page 23



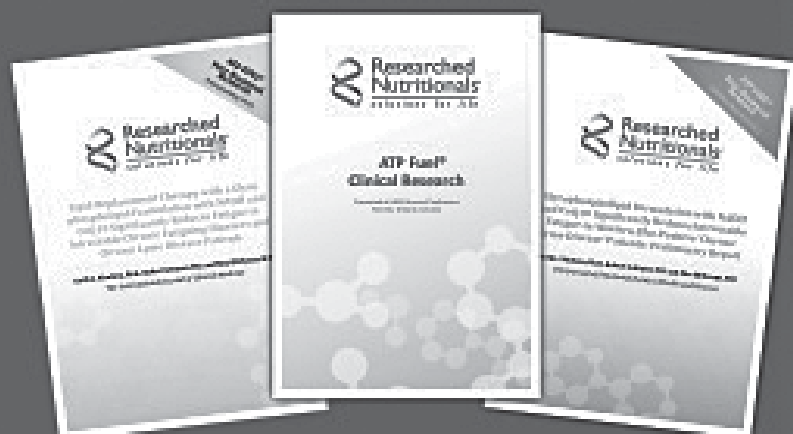
Dolly Curtis interviewed Dr. Jones about his experience treating children with Lyme disease for her radio show in 1999. A DVD of the show is available at dollycurtisinterviews.com. *Dolly Curtis photo*

Optimized Energy for Serious MITOCHONDRIAL NEEDS

ATP Fuel® starts with the base of our highly acclaimed NT Factor Energy™ phospholipid delivery system for mitochondrial membrane support. Stabilized NADH and CoEnzyme Q10 are incorporated to promote healthy Krebs output.

PEER-REVIEWED PUBLISHED RESEARCH

.....



PRESENTED at ILADS.

PUBLISHED in peer-reviewed *International Journal of Clinical Medicine*.

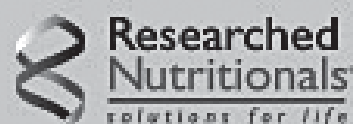
PUBLISHED in peer-reviewed *Journal of Functional Food in Health & Disease*.

.....



JOSEPH BURRASCANO JR., MD

"Due to the efficacy and the science behind the product, this is one of my favorites"



CALL FOR A FREE COPY OF OUR PUBLISHED RESEARCH

Toll Free: 800.755.3402 • Tel: 805.693.1802 • Fax: 805.693.1806

www.ResearchedNutritionals.com | Available only through healthcare professionals

*These statements have not been evaluated by the Food and Drug Administration. These products are not intended to diagnose, treat, cure or prevent any disease.

THE PIONEERS

just were certainly nourished there.

A career-turning point came when he paid a ministerial visit to an elderly woman in the hospital. She said, "Help me in a real way." At that moment, he realized that his ministry was the practice of medicine.

Dr. Jones is a man of great courage. While serving in the army, he risked court martial by leaving the base to march with his friend, Dr. King. He does not back down from taking a moral stand out of fear, pragmatism or to serve egotistical ends. He never has, and I'm sure he never will!

Dr. Jones has been treating children with Lyme disease since the mid '70s, even before researcher Willy Burgdorfer discovered the spirochete. He is often in his office seven days a week, caring for his young patients, at an age when many would have retired. (He is over 80.)

Science journalist Pam Weintraub quotes two of his colleagues in her excellent article about Dr. Jones in the Winter 2001 issue of *The Lyme Times*. One doctor is quoted as saying "I have had the chance to observe him examining patients, and he's a highly astute clinician. The way in which he interacts with children is absolutely wonderful." And in the words of another of his colleagues, "Dr. Jones is an international treasure – a courageous, selfless, inspirational and outstandingly gifted clinician who has helped thousands of the most severely ill children with Lyme disease from around the world to regain their health and their lives."

As many of you know, the CT Department of Public Health has brought Dr. Jones before the Medical Board, alleging that his practices violate the "standard of care". Even as they claim it is not about Lyme disease, they bring forth "expert witnesses" who are clearly connected with the IDSA attack on those who treat chronic Lyme. With the help of an outstanding legal team, headed by Attorney Elliott Pollack, Dr. Jones continues to defend his practices.

This struggle for the right of Dr. Jones to continue to practice is yours and mine. It is the struggle to preserve our right to choose from two approaches to care, to choose our doctors, should we or our family members

become ill with Lyme. It is the right to have available to us doctors who recognize chronic tick borne disease, and take on the diagnosis and treatment of those who are the most ill, and need the most comprehensive care. Our doctors around the country should be able to treat patients without fear of reprisals by any agency, insurance company, or licensing board.

Joseph J. Burrascano, Jr., MD

Excerpted from The Lyme Time #23, Winter 1998.



Joseph J. Burrascano, Jr, MD, has published LD guidelines based on his experience treating over 10,000 people with tick-borne diseases. *Burrascano photo*

Living and practicing medicine in the highly endemic eastern end of Long Island, Dr. Burrascano has been treating Lyme patients since the mid-1980s. He was one of the first physicians to recognize that Lyme disease could be chronic and to design a treatment program to address the problem of constant relapses after 10- to 14-day courses of antibiotics. He observed that many patients responded well to re-treatment and suspected that persistence of symptoms represented ongoing infection. A 1987 study confirmed his suspicions: 26 culture-positive patients who

were treated with ceftriaxone IV for two weeks were culture negative at the end of therapy but became culture-positive again within several weeks. This phenomenon has now been substantiated by other studies.

In his experience with thousands of patients, Dr. Burrascano has studied the effects of lengthened duration of treatment and established a direct relationship between duration and success, starting at 17% for one month of therapy and reaching a plateau at 67% at five months duration. He has participated in further studies of prolonged treatment, including one with the NIH utilizing the antigen detection method of Dorward, et al. *Borrelia burgdorferi* were recovered from body fluids of patients who had received months to years of antibiotic therapy.

"He has been on the front line for Lyme patients for years," says John Coughlan, president of the Cape Cod Lyme Disease Awareness Association and one of Dr. Burrascano's patients. "He's our Number One advocate. He has helped so many people, and he gets the worst of the worst, patients who have been to one doctor after another."

Coughlan has another reason to praise his doctor: Dr. Burrascano's trip to Massachusetts in 1996 "virtually woke up the entire Cape and islands when over 600 turned up for his lecture," he says. "It started to unravel the ignorance and the suppression of information that has been going on." Coughlan added they have run the tape of the lecture at least 1,000 times on local cable stations.

Patients appreciate Dr. Burrascano's openness about having had Lyme disease himself. "It makes him a role model for success as a Lyme patient," says one patient, "and it's reassuring. It's scary to be a Lyme patient." Others appreciate his tone of quiet confidence, of "absolute thoughtfulness and concern." "You feel such trust," says another. "He never jokes about it." Another important quality is never giving up on a patient. "If one thing

Continued on page 24

THE PIONEERS

doesn't work, you try something else." And Dr. Burrascano hired an insurance specialist to work as a mediator between patients and insurance companies, to help reduce the stress on sick patients. His understanding of the total Lyme situation is the ultimate in patient support.

Colleagues praise Dr. Burrascano for his courage in taking a stand and for being so persistent that his ideas are gaining acceptance. He has contributed to the medical literature and taken time to write up results and get them published. His Diagnostic and Treatment Guidelines were published in the 1997 Conn's Current Therapy and are widely distributed on the Internet and to local public health departments and physicians' offices where they are serving as guides to clinical practice. One colleague stated: "He has done more single-handedly on how to diagnose and treat than any other physician I can think of."

James H. Oliver, Jr., MD

Excerpted from The Lyme Times #19, Winter 1997.

Dr. James H. Oliver, Jr. has made major contributions to our understanding of Lyme disease, especially in the South. Callaway Professor of Biology and Director of the Institute of Arthropodology and Parasitology at Georgia Southern University, Oliver is "the world's most renowned researcher of Lyme disease vectors and the most-decorated professor in the history of Georgia Southern," according to their website. Oliver was instrumental in the permanent loan of the U.S. National Tick Collection from the Smithsonian Institution to a University research unit that bears his name, they say. It is the only national collection that is not in Washington, DC.

Oliver's discoveries have overturned the widely accepted dogmas that Lyme disease is exclusively an East Coast disease. By mating ticks from Massachusetts and Georgia, he proved that *Ixodes dammini*, a newly named species, was actually a variety of the long-identified black-legged tick, *Ixodes scapularis*, known in the U.S. since 1821. This finding undermined the conventional wisdom that Lyme disease was mainly a northeast phenomenon because of its association with *I. dammini* and had spread only recently to the South. The name "dammini" was dropped.

Oliver documented the heterogeneity of *Bb* in the South and suggested that the Lyme disease organism had been there for centuries, giving rise to many different strains over time. In 1993, Oliver and his colleagues isolated the Lyme spirochete from mice and ticks from Sapelo Island, Georgia. The same year, he and his colleagues confirmed that black-legged ticks occur widely in the eastern half of the U.S. Recent isolates from several southern states show that *Bb* is more widely distributed than previously realized, and the isolates are more heterogeneous



James Oliver, the world's most renowned researcher of Lyme disease vectors, is the most-decorated professor in the history of Georgia Southern University. He is custodian of the Smithsonian tick collection.
GSU photo

than northern varieties. He believes that *Bb* enzootic cycles appear to be more complex, and more tick species are identified as vectors of the spirochete in the southern states. Symptoms in infected patients may be different, as well.

Family physician Dr. Ed Masters (deceased), who practiced medicine in Missouri, understood the importance of Oliver's scientific contributions. For years Masters has battled with the Centers for Disease Control for recognition of Lyme disease in the south, where many of his patients met the clinical case definition. He worked with Oliver in identifying Missouri tick-borne diseases, and considered him a "scientist's scientist."

"If ever the phrase 'a gentleman and a scholar' were appropriate, it would be in describing Dr. Oliver," Masters wrote for the *Lyme Times*. "In my opinion, he is open-minded, smart, meticulous, and does not have an agenda. He lets the facts speak for themselves. He understands that absence of proof is not proof of absence and does not prejudge the evidence. When the conventional wisdom was that there was absolutely no *Bb* in Missouri, he simply said, 'Let's take a look,' and now has many Missouri *Bb* isolates. He is more interested in discovering the truth than in protecting the conventional paradigm. It has been an honor for me to have been associated with him on some research projects."

THE PIONEERS

Robert Lane, PhD

The Lyme community is fortunate that U.C. Berkeley entomologist Robert Lane, has devoted his professional career to studying the ecology, epidemiology and prevention of tick-borne diseases (TBD). He has clarified the transmission cycles and figured out what behavioral and environmental factors increase risk.

An internationally recognized entomologist, Lane has published numerous articles in peer-reviewed medical journals. He is a top-rated NIH grantee. He has taught at UC Berkeley and conducted numerous field studies in California, training many students who now conduct research in other parts of the country.. He advises the California Dept. of Public Health and serves on the California LD Advisory Committee. He serves on the LDo Scientific Review Committee and was co-chairman of the 1997 LDo conference, "Tick-borne Diseases in the Western United States," as well as chairman of the 1998 International Conference on Lyme Borreliosis.

In 1984, Lane joined the faculty of UCB as a medical entomologist. He and his co-workers have investigated Colorado tick fever, human granulocytic anaplasmosis, relapsing fever, Rocky Mountain spotted fever, and tularemia. He has been active in many organizations such as the Society for Vector Ecology, and has received many awards and honors..

Since Lane retired from his Cal faculty position in 2010, he remained a professor in the graduate school while continuing his research. His more recent research investigated the role of over 50 bird species in the ecology of the LD spirochete in northwestern California, determining why southern California is less endemic than northern California, and which species or strains of LD-group spirochetes infect people and cause illness in Mendocino County, CA. He has studied the genetic diversity of LD spirochetes in ticks and small mammals in Alameda County, CA. Molecular studies yielded several species of spirochetes, two of which previously were



Entomologist Bob Lane spoke at the 2011 Lyme Disease Association conference.

unknown in North America. He found a link between that Sudden Oak Death and a reduced risk for LD in coastal California and Oregon woodlands.

Discoveries

In the designs for his many research projects, Lane has searched for a strategy for reducing human exposure to TBD agents. Several studies have highlighted the relationship of various LD spirochetes (and other emerging TBD agents in the bacterial genera *Anaplasma*, *Bartonella*, *Borrelia* and *Ehrlichia*) to their vectors and vertebrate hosts. The ability of ticks to acquire, maintain and transmit the LD spirochete, as well as the role of lizards, birds and mammals in perpetuating it, continue to be assessed. In northern California, he has studied biotic and abiotic factors that elevate the risk of human exposure to vector ticks in endemic areas, particularly in dense woodlands and mixed hardwood forests. These investigations seek to clarify factors that place humans at heightened risk of exposure to emerging TBD, and enable us to develop risk-assessment models for remote sensing and ground-truthing ecological studies.

LDo thanks Bob Lane for his leadership, dedication, professionalism and generosity in sharing his time and expertise with LDo for so many years.BOX if needed

Bob Lane speaks:

"After Dr. Willy Burgdorfer and colleagues published their epochal discovery of the LD spirochete (subsequently named *Borrelia burgdorferi* in his honor) in black-legged ticks from Shelter Island, New York in 1982, Willy invited me to join him in the inaugural tick-LD spirochete survey in western North America. This collaboration led to the discovery that the western black-legged tick (*Ixodes pacificus*) is the primary carrier of *B. burgdorferi* in the Far West. Willy generously taught me laboratory techniques essential for investigating tick-pathogen-host interrelationships, which enabled me to establish my own LD research program at U.C. Berkeley in 1984."

2012 The Lyme Times Vol.24 No.2

From Phyllis Mervine's editorial

Birthdays, especially advanced ones, have a way of making us look back. So do certain other events – like my Jefferson Award for public service for my Lyme work. It was hard to believe I had put in 25 years of patient advocacy – a career that before Lyme I had never envisioned for myself.

Sometimes I look through stacks of old Lyme Times and am amazed. I remember what a bootstrap operation we had. How my colleague Linda and I used to put our heads down on our desks, we felt so ill. But at the same time we were driven by the enormous need people had for information and for a connection. This was before the Internet. People depended on *The Lyme Times* as their link to the wider community, and we tried to provide that.

I never dreamed I would be doing this 25 years later, or indeed, that it would still be so sorely needed. When will the NIH and CDC step up to their responsibility as guardians of the public health? Soon, I hope.

Lyme Advocacy Comes of Age

Author recounts early activism that changed the Lyme debate

By Jeannine Phillips

Editor's note. The following is excerpted from a piece by Jeannine Phillips that recounts the history of Lyme advocacy over the last couple of decades. Part 2 will appear in the next issue of The Lyme Times.

Lyme Advocacy across the U.S. reflects the Japanese Kaizen philosophy of Buddhist origin – Good Change – which teaches that many small changes add up to continuous improvement. Thus it has been with Lyme disease advocacy – many small efforts increasingly over time adding up to continuous improvement and public awareness.

Building a case

Lyme patients first realized what they were up against when the organizers of the Fifth International Conference on Lyme Borreliosis, scheduled for May 1992 in Crystal City, VA, excluded the contributions of several well-known Lyme-treating doctors. Because the conference was publicly funded by the CDC, advocates were able to convince their congressmen to pressure the organizing committee.

In 1993, Senator Edward Kennedy heard a prominent New York physician testify in Senate hearings in Washington, DC, about problems facing physicians who were treating Lyme.

A few state health departments have now begun to investigate in a very threatening way physicians who have more liberal views on Lyme disease diagnosis and treatment than they do. And, indeed, I have to confess that today I feel I am taking a personal risk – a large one –



The author wore a tick costume for the 2000 March on Washington.

because I am stating these views publicly.

The doctor who testified – Joe Burrascano – was later charged by the New York Office of Professional Medical Conduct (OPMC).

In April 1995, in Vancouver, Diane Kindree, president of the Lyme Borreliosis Society, was distressed that the Eighth Annual Scientific Conference on Lyme Disease, sponsored by the Lyme Disease Foundation, was essentially ignored by most Canadian physicians. She noted that “many patients have been misdiagnosed, mis-

treated or untreated and are now chronically disabled.” Audience members related medical treatment denial, ignorance of physicians and refusal of authorities to consider funding research into the prevalence of infected ticks in British Columbia and other Canadian provinces.

In the beginning ...

The first serious “demonstration” by Lyme disease advocates took place in October 1995, at the Trenton office of the New Jersey Board of Medical Examiners. Billed as a protest march, patients gathered under a “Tick Bite Fight” banner to express their concerns over the lack of attention to Lyme disease. And so it began.

A year later, Allen Steere, MD, aggressive proponent of the “over-diagnosed, over-treated” perspective on LD, spoke at Seattle’s Swedish Hospital. Local patients – including members of the NW Lyme Disease Support Network – organized a protest and attempted to distribute literature rebutting Steere’s position, including documented benefits of longer, more aggressive treatment. Four activists were ejected by the hospital.

On May 21, 1997, patients held a peaceful “Ticked Off” rally at Yale’s 10th Annual Lyme disease symposium. Yale had been Steere’s base of operations during his early work in Old Lyme, CT; had hosted LD conferences since 1983; and had established a Lyme clinic. Much of the early Lyme research was done at Yale. Advocates identified Yale as the source of their problems obtaining proper diagnosis and treatment. Wearing lime-green shirts, protesters passed out literature



Joseph Burrascano, Jr, MD, who treated hundreds of patients in highly endemic Long Island, NY, speaks at the first LDRC medical conference in 1990. In 1993 he testified at Sen. Kennedy’s Lyme hearing.



Security was tight during the patient protest in Bethesda as NIH honored Lyme researcher Allen Steere. *J. Phillips photo*

highlighting the high number of Lyme cases that had been under-diagnosed, misdiagnosed and under-treated, resulting in needless expense, pain and suffering for patients. Some 60 patients – many of whom identified themselves as chronic Lyme disease patients – protested the quality of information being dispensed to health professionals by Yale University.

A year later, 1998, patients rallied again outside Yale's 11th Annual Lyme Disease Symposium, providing educational materials and answering questions. The Yale Medicine Alumni Bulletin noted the protesters' objections to improper diagnosis and treatment of tick-borne illness by their clinicians and researchers. Protesters who were "ticked off" at Yale physicians accused them of minimizing the severity and frequency of the illness, leaving too many patients undiagnosed and untreated because of the Yale protocol.

Finally, in 1999, Yale organizers cancelled the 12th annual symposium. According to the Hartford Courant, "The sessions [had] attracted protesters from among Lyme disease activists [who] believe that Lyme disease – especially the long-term illness – is more common than do some physicians associated with Yale and other academic medical centers."

The shot heard 'round the world

Frustration levels were high when the Lyme community received word that Allen Steere had been selected to give the National Institutes of Health (NIH) Director's 1999 Second Astute Clinician Lecture in November. Established to honor a scientist who has has opened an important new avenue of research.

Since the lecture series was open to the public, dozens of patients – enraged at what they thought was a misplaced honor – gathered at the NIH campus in Bethesda, Maryland, in November 1999. Hundreds of others from across the nation supported this action, their names prominently displayed on signs.

They were outraged that NIH was bestowing such status on a researcher whose parochial viewpoint had hindered the understanding of what was increasingly being seen as chronic Lyme disease. They objected to Steere's disregard for patient realities

and his narrow viewpoint that ignored a growing body of scientific evidence. Many patients believed that Steere's position allowed insurance companies to decline coverage and medical boards to prosecute treating physicians.

The protesters listened peacefully to Steere's lecture and lodged a few questions before organizers unexpectedly terminated the session. The Boston Herald covered the protest, and hundreds of patients sent them their stories of living with Lyme. These heartfelt and searing accounts created more than 250 printed pages of public testimony. The Lyme community had discovered itself, flexed its muscle, and felt its power. And it was not about to sit back down quietly.

The NIH protest had become "the shot heard 'round the world." The national Lyme community had begun to connect.

New York City

When the OPMC revoked the medical license of Perry Orens later that same month "after forty years of unblemished medical practice," critics claimed it was because he treated his Lyme patients until they were well. Over 120 determined Lyme patients from Northeastern, Midwestern and Southern states came together in Manhattan in December 1999 to object to the action and to ongoing investigations and harassment of Lyme physicians. A massive national call-in occurred simultaneously with the protest.



Albert Eichelberger, wearing a TOFU T-shirt, and his sister Dorothy Rew, both Lyme patients, listen to country Western stars perform at the 2001 LYME AID event in Gettysburg. *Vicki Karam Smith photo*

The rising tide of activism

With the NIH rally, patients recognized that a national movement was building. Knowing how patients had to travel across state lines for treatment, they understood that resistance from some academic researchers and harassment of physicians were affecting patient care in many states.

Targeting Lyme doctors in any single state constituted a threat to the wider Lyme community. Cooperation across state lines was clearly required. Patient participation gained momentum, and as advocacy planning took form, their eye turned to a national event in Washington, D.C.

Continued on page 30



Physician Directed. Patient Specific.

**HomeCare
Solutions**

- ◆ **Lyme-Literate Pharmacy** Established in 1990
- ◆ Home Care Infusion:
Specializing in IV Antibiotic Therapy
- ◆ Personalized Compounded Therapies for Lyme Patients
- ◆ Holds Contracts with Most Insurance Providers
- ◆ Ships Directly to Patients Overnight via FedEx
- ◆ Licensed in Over 40 states
- ◆ Avid Supporter of *The Lyme Times* for 8 Years
- ◆ State of the Art Lab Renovated in 2012
Prescribers are Welcome to Tour Lab
<http://www.qmedrx.com/video/>



ACHC Accredited



TICK & INSECT REPELLENT CLOTHING

BugBeWear.com



- Factory Bonded ODORLESS Finish
- Long Lasting – 70 Washes
- Shirts, Jeans, Socks, Hats & More

Items For Men, Women, Boys & Girls

“Stop the Bite” Convenient protection that lasts as long as your day.

SELECT TCS

TICK CONTROL SYSTEM™



TICK BOX TECHNOLOGY CORPORATION

www.tickboxtcs.com

“We Stop Lyme Disease Where It Starts”®

Tick Box Technology Corporation 1 Testa Place Norwalk, Ct. 06854

Congratulations
to *The Lyme Times* and *LymeDisease.org*
for 25 years of advocacy on
behalf of Lyme patients

Steven J. Harris, MD
Mischa Grieder, ND
Jennifer Sugden, ND
Yvonne Sorenson, PA-C



PACIFIC FRONTIER
M E D I C A L

The new millenium

Ventura, CA

Patients confronted Steere again in January 2000. Advocates scheduled a patient support meeting to coincide with his appearance at the Gordon Research Conference in Ventura, CA. Although guards prevented patient activists from interacting with attendees, information was distributed to the public – even taped inside restrooms and elevators. Steere left by a back door.

Gettysburg, PA

As Spring approached, the Gettysburg Lyme disease community was getting "Ticked Off and Fed Up" (TOFU). They rallied in April to protest doctor harassment and most particularly to support Joseph Burrascano, Jr., MD. Under fire from the New York OPMC, doctors Burrascano and Orens headlined the event.

"The Second Battle of Gettysburg" - this time in Lincoln Square - included speeches by Pat Smith, Orens and other Lyme community notables amidst the cheering of over 150 advocates. Attendees were encouraged by newspapers and TV coverage including DATELINE. Joseph Burrascano, Nick Harris, and Harold Smith presented an educational symposium.

Buoyed by the event, attendees experienced a burgeoning sense of community. Harassment of Lyme physicians was unacceptable. More latitude in research and treatment must be allowed. Accurate statistics and tests were essential to defining the growing national threat.

Washington, D.C.

A May March on Washington (MOW) drew hundreds of patients. Parading in front of the Capitol building in the "Senate Swamp," patients called attention to the Lyme Disease Initiative (Bills HR-2790, S-1905) languishing in committee. Lyme disease quilt squares from the Gettysburg rally and hundreds of green ribbons were displayed.

Along with Senators Dodd and Santorum, Representatives Smith and Pittco called for an investigation by the Government Accounting Office (GAO) into how Lyme disease funds were being spent, inspired by reports of misused funds, conflicts of interests, harassment and retal-

Cyclorama Center ruling not based on merit, advocates say — Page A3

Bermudian's disci indicates some ir

SERIALS DOCUMENTS DIV 200 W WASHINGTON ST GETTYSBURG PA 17325-1400

Squires finally meet match — Page B1

MUSSELMAN LIBRARY
MAR 16 2000

GETTYSBURG TIMES

VOL. 98, NO. 65
GETTYSBURG, PA, MARCH 16, 2000
Section A 35c

THURSDAY
Good Morning

WEATHER

Cloudy with showers likely by afternoon. A thunderstorm is also possible. High 55 to 60. Chance of rain 70 percent.

Tonight, colder with periods of rain, possibly mixing with snow by dawn. Low in the lower 30s.

Friday, cooler with scattered rain or snow showers. High around 40.

Saturday, partly cloudy. Low around 20. High around 40.

Sunday, mostly cloudy. Low in the 20s. High in the mid 40s.

NEWSWATCH

Dow soars

NEW YORK (AP) — The Dow Jones industrial average soared more than 300 points Wednesday as investors who sold off technology stocks this week put their money back into the long-forgotten industrial sector.

The Dow rose 320.17, or by 3.3 percent, to close at 10,131.41.

It was the fourth-biggest point gain ever for the Dow, but wasn't close to a record in percentage terms. The blue chip index rose as much as 368.96 points before slipping back a bit.

Meanwhile, investors continued shedding technology shares. The Nasdaq composite index fell 124.01 to close at 4,582.02, bringing its loss for the past three days to 465 points, or 9.2 percent.

The Standard & Poor's 500 rose 33.00 to 1,392.15 and the Russell 2000 index of smaller companies fell 14.11 to 505.86.

"What a ride day," said Vernon Winters, chief investment officer at Mellon Private Asset Management. "A lot of money managers have been forced to sell blue chips to buy technology stocks, and today, they're reversing course."

So much damage has already been done in these old economy stocks," said Arthur Hogan, chief market analyst at Jefferies & Co.

LYME DISEASE

Frustration of finding treatment adds to pain for sufferers

County names Larry Martick its head mosquito hunter

BY JOHN MESSIKER
Times Staff Writer

West Nile virus killed seven people in New York and 82 more people were diagnosed with West Nile encephalitis last summer. State and county officials are taking steps to ensure the zone is not repeated in the commonwealth this year.

"We need someone who's going to be out in the field," Commissioner Tom Collins said following the Wednesday morning commissioners meeting. "The disease is potentially deadly. It's spread by mosquitoes and there is fear it may spread into the state."

The county commissioners have appointed Larry Martick, county Conservation District manager, as the county's liaison with the state Department of Environmental Protection as the department begins planning a response to a potential outbreak of the deadly virus.

Although the virus has not yet been seen in the commonwealth, it was found in August in Burlington County, N.J., just across the state line from Philadelphia.

"If it comes into Pennsylvania, it would actually be coming with birds," said DEP spokeswoman April Hutcheson, adding, "Mosquitoes can fly only about 150 yards."

The virus is spread when a Northern House mosquito drinks blood from a bird, then flies to another bird — or human — spreading the virus as it takes another drink. Hutcheson said other breeds of mosquito are not known to be carriers of the West Nile virus.

(See MOSQUITO HUNTER, Page A9)

"I'm basically scared to death that there's not going to be anyone to help me."

—Rebecca Peake, Bannockville

The girl called to schedule an appointment to begin IV therapy on a Monday morning and the next day, she was informed that her doctor was no longer practicing medicine. He was one of 16 Lyme disease specialists in New York who are having their licenses revoked for prescribing long-term antibiotics.

Other Lyme specialists in New Jersey, Michigan and "countless" have had their licenses revoked as well.

Many Lyme patients living and coping with the disease in Adams County travel hundreds of miles each month to seek out these itinerant physicians.

"We're all traveling to New York because our doctors don't know enough about Lyme disease," Teresa Peake said. Her daughter is one of four.

(See LYME on Page A5)



Photo courtesy of Vicki Karam Smith

From left, Lovette Mott, Dr. Harold Smith and Vicki Karam Smith display the 2 x 2-foot quilt squares made by some of the local Gettysburg Lyme Disease Support Group members. Many more quilts will be on display at the rally April 8. The quilts are designed and made by each individual dealing with the effects of Lyme. Dr. Smith was an emergency room physician who had to stop practicing due to the devastating effects of Lyme disease. He will also be speaking at the symposium at The Gettysburg Hospital.

Gettysburg citizens added to nation's 'Wall of Echoes'

A Pennsylvania newspaper headlines efforts by local citizens to draw attention to the Lyme epidemic by displaying quilts at their Gettysburg rally.

iation in the conduct of the federal government's Lyme disease programs. Representatives of the Lyme Disease Association (LDA) and the Lyme Disease Foundation (LDF) spoke about the state of research and treatment, announcing support for pending bills and the GAO investigation. Patient advocates visited their Representatives and Senators.

New York, NY

Activism continued as over 300 people converged in June at the Hotel Pierre for an early evening "Vigil" objecting to the honoring of Steere at a gala sponsored by the American Lyme Disease Foundation (ALDF). Perceived as an unwelcome influence on Lyme disease research and treatment, the ALDF event attracted protesters from throughout the Eastern Seaboard and as far away as Kansas and California.

Protest signs highlighted Steere's "over-

diagnosed/overtreated" Lyme philosophy. Patients chanted "Steer clear of Steere" and sang "We Shall Overcome (Lyme disease)." Their public letter to Steere (endorsed by 784 patients who could not attend) supported the message that under-diagnosis, underfunding, under-reporting and doctor harassment would no longer be ignored. TV cameras from Dateline, Fox and ABC were rolling as journalists interviewed patients, activists, and Lyme community leaders at the rally. Lyme activism had finally garnered media attention.

Philadelphia, PA

The emphasis on public events continued to provide an opportunity to present a broader view of Lyme disease. Activists protested the 35th Annual Scientific meeting of the American College of Rheumatology in November. The slogan: "Science Shows A Different Point of View On Lyme Disease." They offered health pro-

professionals a broader perspective and painted Steere as "Wrong.... Because of the Science." Public materials supported persistent Lyme disease and the need for a wider latitude in treatment. Steere, scheduled to present a two-day course, had tried unsuccessfully to stop the demonstration. In the end, he cancelled the second day's class

New York City

Several hundred patients and physicians traveled to Manhattan in November to support Burrascano. The OPMC had been looking into his records ever since 1993 when he testified before a Senate sub-committee on Lyme disease. An international figure who had freely shared his treatment observations, Burrascano published in medical journals, made appearances throughout the world in an unceasing attempt to define a more accurate picture of the disease

as experienced by treating physicians who saw real patients on a continuing basis. Now facing disciplinary action and potential loss of license, Burrascano presented a threat to the powers-that-be.

Patients rallied at the Plaza Hotel, arriving in chartered buses and planes from as far away as Virginia, Maryland, Florida, Michigan, Texas, California and the Eastern Seaboard. Extensive press coverage included articles in *The New York Times*, *Southampton Press* (NY), *York Dispatch* (PA), *Easthampton Star* (NY), *Easthampton Independent* (NY), and the *Boston Herald* (MA).

As *The New York Times* reported, protesters also objected to some 50 treating physicians in several states having been investigated or disciplined; they explained the chilling effect such targeted actions were having on the willingness of other doctors to treat the disease.

Got Lyme? Join an Online Support Group

Want to learn more about Lyme disease?

Want to connect with other patients?

Your state online support group allows you to connect with other Lyme patients in your area - a virtual meeting place - a source of information and emotional support for people with tick-borne diseases.

For help finding your state support group, visit

lymedisease.org

Click on "Activism" and choose "Not in California"

Or visit your state site directly.

Enter your state name into the following url:

health.groups.yahoo.com/group/(YOURSTATENAME)Lyme

(all sites include a state name run together with "lyme")

e.g., Maryland: health.groups.yahoo.com/group/marylandlyme

In South Carolina, insert a hyphen between state name and Lyme:

(southcarolina-lyme)

For Washington DC, go to DCLyme



A national advocacy organization supporting Lyme patients throughout the United States

Join LDo Today!

Become a member and make our voices even stronger

All members receive an annual subscription to

THE LYME TIMES

For 25 years, the only national journal covering Lyme and tick-borne diseases

YES! Please begin my 1-year membership in LDo

MEMBERSHIP CATEGORIES

- | | | |
|--|---|---|
| <input type="checkbox"/> \$35 Basic | <input type="checkbox"/> \$100 Sustaining | <input type="checkbox"/> \$500 Champion |
| <input type="checkbox"/> \$50 Supporting | <input type="checkbox"/> \$125 Masters Series | <input type="checkbox"/> \$1000+ Gold Circle |
| <input type="checkbox"/> \$75 Contributing | <input type="checkbox"/> \$250 Patron | <input type="checkbox"/> Add \$20 for International |

Members may order back issues and bulk orders at reduced prices

SPECIAL DVD OFFER

Join at the \$50 level and choose ONE DVD, choose TWO at the \$75 level, choose THREE at the \$100 level, or receive ALL FOUR at the \$125 level. Please send me the following DVD(s):

- ☐ **Dr. Burrascano** – Putting Lyme Behind You
- ☐ **Drs. Corson & Green** – Using Integrative Medicine to Heal from Lyme
- ☐ **Dr. Horowitz** – It's So Much More than Lyme Disease
- ☐ **Dr. Stricker** – Review of Lyme Disease Diagnosis & Treatment

☐ I include an additional \$ _____ tax-deductible contribution to the LDo Fund for education and research.

Name (print) _____ Email _____

Street Address _____

City _____ State _____ Zip Code _____ Phone _____

Help us save resources. Let us send renewal notices and payment receipts directly to your email account.

Your confidential information will be used for LDo membership purposes only.

- ☐ Bill my VISA or MasterCard _____ Expires _____ CSV _____
- ☐ Enclosed check payable to LymeDisease.org, PO Box 1352, Chico, CA 95927

or visit www.lymedisease.org to join online

Questions? Email: contact@lymedisease.org



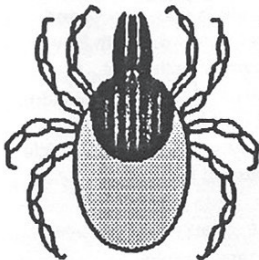
**Specializing in
Lyme Disease
and Associated
Tick-Borne Diseases
for Over 20 Years**



IGeneX Inc. 795/797 San Antonio Rd Palo Alto, CA 94303 800-832-3200

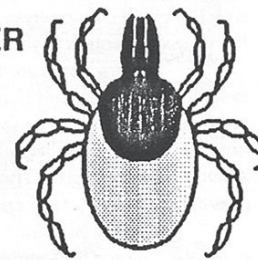
Features -- Telephone Tree -- News -- Opinion Column

THE LYME TIMES



THE LYME DISEASE NEWSLETTER
OF THE WEST COAST LYME DISEASE NETWORK
CHAPTER OF THE LYME BORRELIOSIS FOUNDATION

*"GOT A LEMON? MAKE LEMONADE!
GOT LYME? MAKE LYME-AID!"*



VOLUME 1, NUMBER 1

FALL, 1989

Introducing the Lyme Disease Newsletter

by Phyllis Mervine, Editor

We, members of the newly formed West Coast Lyme Disease Network, thought it was time to give ourselves a medium for communication, not only among ourselves, but with people all across the country and especially on the West Coast. The goals of this Newsletter are information, support, sharing, and empowerment. We hope to make this a quarterly publication. We were inspired by the recent fruitful efforts of our friends in Minnesota. and hope they will take it as a compliment that we utilize some of their ideas for features, which include: 1) reports of activities, meetings, slide shows, etc. 2) case studies 3) questions and answers about LD, ticks, etc. 4) articles by experts (if we can get any), 5) opinions, 6) telephone tree, and 7) you name it! We are all full of ideas on how to expand and improve our services to you and others. Our program exists to help you, and to help you to help others. It isn't any fun to have a chronic disease, but we sure do have fun working together. We invite you to join us. We welcome your participation on

any level, just let us know where you would like to fit in. If you are interested in receiving further issues of this Newsletter, and/or participating in other ways, please return the coupon on page 7.

The Lyme Times is the publication of the West Coast Lyme Disease Network, chapter of the Lyme Borrelia Foundation, a non-profit national organization founded in 1988 for the purpose of education, research, and patient support.

The Lyme Times is produced on a Macintosh Plus computer using Pagemaker 2.0 software.

The Lyme Times welcomes comments from its readers. Letters may be edited for brevity and clarity and should be addressed to:

Phyllis Mervine, Editor
The Lyme Times
P.O. Box 700
Talmage, CA 95481