



May/June 2014 Newsletter

Letter from the Editor

As many of you know, May is Lyme Disease Awareness month. But if you're one of the numerous people who experience fatigue or brain fog or migrating pain on a daily basis, you'd probably just as soon forget about Lyme & Company altogether, writing your experience off as a bad dream, rather than spreading knowledge of these body-wrecking buggers.

But with knowledge comes responsibility. Even when neighbors keep glancing at our pants tucked into our socks when we're outside or our friends think we're somewhat paranoid about not going anywhere near piles of leaf litter, we have the responsibility to share the knowledge of how and why everyone needs to protect themselves against tick-borne illness.

That's one of the aims of this newsletter, to spread the news - good and bad - so we're able to push back against this epidemic. This month, you won't want to miss the upcoming Lyme Seminar and Health Fair where you'll hear from three dedicated healthcare practitioners - and one journalist - all with in-depth perspectives on Lyme disease.



Poughkeepsie Journal investigative reporter and honoree,
Mary Beth Pfeiffer

Introducing our "Courage in Journalism" Recipient Mary Beth

I look forward to seeing you on May 13th.

Janet M. Jemmott

**LYME DISEASE:
BODY, MIND & SPIRIT**

Patient Seminar & Health Fair

Tuesday, May 13
Health Fair: 6 p.m. – 9:30 p.m.
Speakers: 7 p.m. - 9:30 p.m.

KEYNOTE SPEAKERS
Robert Bransfield, MD
Steven Phillips, MD
Sandy Berenbaum, LCSW

HONORING Mary Beth Pfeiffer *Poughkeepsie Journal* (NY)
Courage in Journalism Award

Western Connecticut State University
West Side Campus Student Center
(43 Lake Ave. Extension Danbury, CT 06810)

Presented by: The Ridgefield Lyme Disease Task Force
Jennifer@lymeconnection.org or www.facebook.com/RidgefieldLymeResource

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Join us on Tuesday, May 13 for an information-packed day of learning and Lyme disease connections. ***Lyme Disease: Body, Mind and Spirit*** is the theme for our 8th annual Lyme Awareness Month seminar and health fair. Free and open to all, this patient-focused event will once again be held in the WestConn Westside Student Center ballroom. Speakers include former ILADS president and local Lyme disease physician Steven Phillips, MD; former ILADS president, psychiatrist and psycho-pharmacologist Robert Bransfield, MD; and Lyme-literate mental

Pfeiffer

Mary Beth Pfeiffer is an investigative reporter working for the *Poughkeepsie Journal*, a newspaper covering the Mid-Hudson River Valley and surrounds. From 2002 to 2006, Dutchess County had the highest rates per capita in the nation. In August of 2012, Mary Beth Pfeiffer began a series of pieces called “No Small Thing,” exploring tick-borne illness. She interviewed patients, politicians, policy makers, and physicians. She read scores of scientific studies and then synthesized what she found into an extraordinary series of articles. Far-reaching and in-depth, her coverage of tick-borne disease is illuminating – even for those of us who follow news about Lyme disease. Recently, she received an award from the New York News Publishers Association, for “Distinguished Investigative Reporting.” The New York State Associated Press also awarded first place for continuing coverage to “No Small Thing”. She’s also won the hearts of countless Lyme patients for elucidating both the political battles over appropriate Lyme treatment and the heart-rending struggles of so many patients who just want to get well. Her coverage has prompted numerous letters to the editor by patients, by a CDC official, and by researchers and physicians who work in the trenches helping the uncounted number of people with persistent symptoms of tick-borne disease. Her coverage of the politics, the policy, and the current scientific evidence is the most comprehensive and balanced news coverage currently found in a news journal. While Ms. Pfeiffer has moved on to other vital topics, the *Poughkeepsie Journal* continues to cover the ongoing story of Lyme and other tick-transmitted diseases.

Recently, I spoke with Mary Beth Pfeiffer.

JMJ: First of all, thank you for your series “No Small Thing.” As a Lyme patient, I so appreciated your taking

health practitioner Sandy Berenbaum, LCSW, BCD.

Presentations will begin with the Ridgefield Lyme Disease Taks Force's first "Courage in Journalism Award" being given to *Poughkeepsie Journal* (NY) investigative reporter Mary Beth Pfeiffer for her nationally-recognized landmark series of articles about tick-borne diseases. In addition, Dr. William Lee Cowden of NutraMedix will conduct a free afternoon session from 1 p.m. - 4 p.m. in the same location.

The evening starts at 6:00 p.m. with a Lyme-focused health fair featuring tick-control products and services, Lyme-literate providers, laboratories and other ancillary professionals who support the Lyme patient community. Speaker presentations run from 7:00 p.m. to 9:30 p.m. The Student Center is located at 43 Lake Ave. Extension in Danbury, CT. Event sponsors include BugBeWear.com, IGeneX, Inc., Master Supplements, My Health 1st Urgent Care, NutraMedix and Select TCS Tick Control System.

For additional information, visit our Facebook page at:

www.facebook.com/RidgefieldLymeResource

May 13 Health Fair and Seminar Schedule

1 to 4 p.m. Eva Sapi and Dr. W.Lee Cowden

6 to 7 p.m. Health Fair

7 to 9:30 p.m. Speaker's Presentations

Support Groups

Lyme Connection offers free monthly support groups in Ridgefield for Lyme disease patients and their loved ones.

on the topic.

MBP: I have heard from many people in the community out there, which is quite large . . .

JMJ: . . . and growing.

MBP: Yes, that's really what inspired me to keep going. The more I wrote about it, the more I learned what a huge problem Lyme disease is and how many people are affected by lingering Lyme disease symptoms.

JMJ: Are you still writing about Lyme disease?

At the moment, I'm doing something else. As an investigative reporter I do have to explore other areas. I just finished a story that was published in late February on the growing suicide rates in our area and nationwide, and from there I'll be doing a piece shortly on overdose deaths related to prescription drug abuse, which seems to be leading many people to heroin abuse. That's a big project. I certainly do expect that I'll be writing about Lyme disease again since it's such a serious ongoing problem and there will be emerging developments in terms of research and the potential for persistence and chronic Lyme disease.

JMJ: What are you seeing in the research on Lyme that's new?

MBP: The research about persistence and the research methods being used to see whether Lyme persists or not, namely xenodiagnoses: "Clean" ticks, which are free of Lyme disease, are allowed to feed on mice, animals, and people that have been infected with Lyme and treated with antibiotics. What we seem to be seeing, at least in mice, is that the clean ticks are showing up to some extent infected with the Lyme spirochete, which seems to suggest that the pathogen can persist after standard antibiotic treatment. We're waiting at this point for Dr. Hu's research to be completed to see if that holds up in human beings as well. So that's one avenue of research.

There was a study recently published about Lyme

Evening Support Group

Day: Second Thursday of every month

Time: 5– 7:00 p.m.

Location: 2nd Floor Board Room, RVNA offices, 90 East Ridge, Ridgefield

Description: Free meetings offering speakers and discussion

Contact: Jennifer at 203-241-2400 or Jennifer@lymeconnection.org

Daytime Support Group

Day: Second Friday of every month

Time: 1:30 p.m. to 3:00 p.m.

Location: 2nd Floor Board Room, RVNA offices, 90 East Ridge, Ridgefield

Description: Focus on supportive strategies for coping with chronic illness and developing overall wellness practices.

Contact: Jennifer at 203-241-2400 or email

Jennifer@lymeconnection.org to register.

Young Adult Support Group

The Young Adult Support Group is presently on hold while we redesign the format to better meet the needs of patients and their families. For an update, email Ctyouthlyme@gmail.com.

disease and the potential for sexual transmission. I haven't looked into how that study's been received, but it certainly piques my curiosity.

There was a survey published that Lorraine Johnson was involved with about the quality of life of people believed to have chronic Lyme. They continue to have debilitating symptoms and other negative effects in terms of productivity and lost ability to function (1).
JMJ: That was sobering because it indicated that chronic Lyme patients have greater disability than other people with chronic disease, including congestive heart failure.

MBP: It really makes you question what's going on here. What Lorraine Johnson found in her research and survey is all part and parcel of why I got into this, that is, the experience of people who have had Lyme disease is a testament to the fact that something greater is going on than science or the medical community seems to acknowledge or at least seems to have discovered the truth behind.

In my interviews I came across so many people who have/had lingering symptoms after treatment, or who had longer than recommended antibiotic treatment and who got better, at least temporarily or at least while they were on antibiotics. Some of them recovered completely after they were on longer courses. The question is why? What is happening there? Are the antibiotics controlling the pathogens or do the antibiotics have some other palliative or anti-inflammatory effect? There's something going on besides what science knows at this point. There are many, many questions.

JMJ: Have you seen changes in the media's coverage of tick-borne disease since you started writing about it?

MBP: Yes, I thought I was seeing a shift. The article in the New Yorker was certainly softer in its tone about Lyme disease and about admitting that there are some unknowns. The Boston Globe article played it down the



Congratulations to 4th Grade student Caroline Tucker of Danbury, CT for winning the BLAST/Western CT Health Network 2014 Lyme disease prevention poster contest. Participants were asked to design a poster highlighting one of the five BLAST safety tips. Caroline's happy pup has owners who treat their pet with veterinarian-recommended products to repel ticks and avoid disease. Thank you to all of the students who participated and are helping us spread the BLAST message.

To read more about the BLAST program, go to:
www.ridgefieldct.org/content/46/6311/6347/8975.aspx

Protect your Pets!

If you have a dog or outdoor cat, you may have noticed that they're already re-entering the house with ticks clinging to them. Ticks that haven't yet been embedded are known as roaming ticks, and they pose a risk to everyone in your household.

The best way to deal with roaming ticks is to repel them before they have the opportunity to hitchhike a ride into your home. Below are some examples of products used on dogs. The visual came from a webinar by the University of Rhode Island Tick Encounter Resource Center (TERC). You can find them on Facebook or online at:

middle but was more in line with traditional reporting, but it did acknowledge there are unknowns. Again, it wasn't so quick to dismiss them and say that the suspicions of people who believe that they have chronic Lyme are unfounded. In the past, those complaints of the people with lingering Lyme symptoms have been all too readily dismissed. I'm seeing slight changes in the reporting. I haven't seen a great deal of reporting and I think it needs more attention in the media; that's something I'd like to see. And the fact that there isn't a great deal of reporting out there seems to reinforce that for the most part the media is really accepting of the medical wisdom, such as it is.

JMJ: I went to a lecture by Dr. Brian Fallon (Columbia University) last week and he presented the information about the xenodiagnostics, and I thought: How can the NIH and the CDC continue to hold the old line after we see this? What do you think it might take for either of those entities to say that borrelia can survive antibiotic therapy?

MBP: I think it will take a number of studies that will keep reinforcing the same finding. I have asked the NIH and the CDC about the findings of Clark, that there is indeed Lyme disease in Florida and Georgia. Dr. Clark's studies seem to be very compelling in terms of the frequency the Lyme pathogen was found and the various methods that identified the Lyme pathogen in people and in ticks(2). And the answer that I got was: "Yes, well, but we need more studies." Because there are other studies that say quite the opposite. They tell me there's other research that shows the opposite. Science is slow to move, I think, and in the case of Lyme disease, the scientific "truths" are very well entrenched. There is that school of thought that is perpetuated by CDC and NIH officials and people in the IDSA, and they have the megaphone right now.

JMJ: Some of the states in the Northeast have moved

www.tickencounter.org and www.Facebook.com/TickEncounter

Even with a tick collar or treatment, you may find live ticks on your pet. After they've been out and about, make sure you carefully check them and remove any that you find. If you'd like to identify the tick and the stage in its life cycle it's in, go to the website listed above. Talk to your veterinarian about which products are appropriate for your pets.



There are lots of pet products available! Maybe you're already using one of them?

Tick preventative pet products	Whole body protection	Also kills	Also kills or repels	Also kills fleas	Applied via attachment	Water resistant	Safe for cats	Safe for pregnant females
Centinel (Top Spot) NexGard NexGard Chewable	✓	✓		✓	✓	✓		✓
W Advantix II Advantix II Advantix II (Chewable)	✓	✓	✓	✓		✓		✓**
Advantix II Advantix II Advantix II (Chewable)	✓			✓		✓	✓	✓
Frontline Plus Frontline Plus Frontline Plus (Chewable)	✓	✓		✓		✓	✓	✓
Bravecto Bravecto Bravecto (Chewable)		✓	✓			✓		

http://www.TickEncounter.org/prevention/tick_control



Low-Down on Lyme at Ridgefield Library

Join us for the latest news on Lyme on Tuesday June 10, 2014, at 7 p.m. at the Ridgefield Library

We'll turn to Lyme treating physicians Dr. Kenneth Liegner and Dr. Steven Phillips, along with Joann Petrini, PhD, MPH from the Western

to provide some protection for doctors who provide long-term treatment. What's happening in New York right now?

MBP: There are bills pending in the New York State legislature to protect physicians who treat outside of IDSA guidelines, also to require that insurance companies pay for that care, but there is resistance to adopting such a law.

JMJ: So even within the legislature there's resistance?

MBP: Yes, it hasn't moved yet. I haven't updated myself within the last couple of months as to where it was, but it was proposed several years ago – 2005 may have been the first time it was proposed. I think there is a little bit more incentive now to move it along. The Lyme community has really organized itself and it has the ear of certain legislators, so I think there's more hope that it will pass. I have heard comments by certain legislators who are leery of taking away the power of medical regulators in legislating medicine essentially.

JMJ: You don't sound too optimistic.

MBP: I really can't say. A good reporter needs to know what's going on now, and my information is a little dated. I think it's fair to say that there's probably as great a chance as there's been in the last few years because Lyme disease in New York is a high agenda item. The health department did get some additional funding this year. Our local legislators are really working hard on it, I think in part because we're paying a lot of attention to it - that helps.

JMJ: How or why did you become an investigative reporter? Is it your passion?

MBP: There's no doubt it's my passion. I've been a reporter for more than 30 years. For me, it's the highest and best form of reporting. Every news reporter ought to practice some variation of investigative reporting, even in breaking news, just by virtue of asking the right questions. But it is a very difficult form of reporting

CT Health Network Lyme Disease Registry for the most recent news about Lyme in our community. Bring your questions and engage in a lively, informative discussion.

The evening is sponsored by the Ridgefield Lyme Disease Task Force and Lyme Connection.

The Ridgefield Library is on 472 Main street. For directions, go to:

<http://www.ridgefieldlibrary.org/about/directions.shtml>

Words to note by investigative reporter Mary Beth Pfeiffer:

I'm comforted by the fact that everything I've written has been well documented, based on science, based on interviews with scientists, but also based on the experience of people out there, and I think that they really do deserve a place at the table and a voice in this process.

Check out our new website!

Live soon! Stay tuned.

<http://www.lymeconnection.org>

because it requires a “no stone unturned” philosophy and it does require a lot of time and you have to really figure out each topic as it comes to you and do the background reading. For example, for the piece I did on Lyme testing, I had to read about 25 scientific studies – very dry scientific studies. As someone who doesn't have a degree in biology or chemistry, I was a bit challenged by it. You work your way through those studies by talking to the experts who help you figure it out, by taking the time, and doing your homework. That said, I have to credit the *Poughkeepsie Journal* with giving me the time to do these kinds of pieces. A lot of papers will not free somebody up for the very extensive endeavors. It can be overwhelming. Every topic is new and every topic is huge, but this was worth the effort, based on the response that I got.

JMJ: Have you gotten any pushback from journalists, clinicians, or policy people on your Lyme series?

MBP: The CDC has disagreed with the approach we've taken, but has not been able to cite any inaccuracies at all. After my piece on chronic Lyme, Dr. Peterson (CDC) did write an Op-Ed where he reiterated what the current science – in his view – holds. There are some scientific studies that don't agree with the CDC's philosophy and policies. I haven't gotten push back from other journalists though I suspect there is a bit of skepticism, perhaps, about what I've written. I'm comforted by the fact that everything I've written has been well documented, based on science, based on interviews with scientists, but also based on the experience of people out there, and I think that they really do deserve a place at the table and a voice in this process.

JMJ: So you'll keep an eye on what's going on with Lyme moving forward. Is there anything you'd like to say that I haven't covered?

MBP: One thing you might want to tell your readers is that they should feel free and emboldened to contact

Dutchess County Legislative Tick Task Force Information Session

On Wednesday, May 14, Dr. Brian Fallon of Lyme and Tick-Borne Diseases Research at Columbia University and Dr. Rick Ostfeld of The Carey Institute's Center of Ecosystem Studies will be holding an information session at the Pleasant Valley Fire Department, 1618 Main Street, Pleasant Valley, NY 125569. Free and open to all.

For further information: [DutCoTickForumLink](#)

newspaper reporters, selectively. So, if they see a reporter that writes about health or who writes well and seems to take topics seriously, call them on the phone, write an email, and say, this is something that's really important to our community, take a look at it. Send a couple of links to my articles to the reporter and say this is how another newspaper has handled it. Another thing would be to include some statistics about the local area. You need a hook, a reason, and you might be able to give them a reason by showing them local statistics. That's really where a lot of stories do begin. If you can make it easy for a small, low-budget paper - give them some statistics, some quotes, some phone numbers of people to interview - you probably could get something published, especially with tick season right around the corner.

A link to the Poughkeepsie Journal articles on Lyme disease:

<http://www.poughkeepsiejournal.com/lyme>

1. Survey Results: Chronic Lyme Patients Suffer Poor Quality of Life and High Rates of Disability and Unemployment

http://lymedisease.org/news/lyme_disease_views/lyme-policy-wonk-survey-results-published-chronic-lyme-patients-suffer-poor-quality-of-life-and-high-rates-of-disability-and-unemployment.html

2. Geographic and genospecies distribution of *Borrelia burgdorferisensu lato* DNA detected in humans in the USA.

http://jmm.sgmjournals.org/content/63/Pt_5/674.abstract

Jennifer J. Reid, Publisher, Janet M. Jemmott, Editor

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Our Contact Information

Lyme Connection
66 Prospect Street
Ridgefield, CT 06877
203-241-2400

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