The official newsletter of LymeConnection.org

NOV/DEC 2013

A Message From

Jennifer Reid & Karen Gaudian

Introducing Your New Resource—*Lyme Connection*

The Ridgefield Lyme Disease Task Force is pleased to introduce our first issue of *Lyme Connection*, a new bimonthly newsletter for the Lyme disease community. Throughout the past 10 years, the Task Force has focused on bringing Lyme patients the information they need to live the healthiest lives possible. Many of you have been part of our seminars, workshops, health fairs, support groups, and other special events. Every time we sponsor a learning opportunity, we are filled with respect for the resilience of Lyme disease patients in the face of what are often daunting obstacles.

As fellow patients, we clearly remember our own sense of relief at finding the help we needed. That first support group meeting where we realized there were other patients experiencing the same symptoms and confusion. That first doctor visit where we knew this physician understood Lyme disease and took us seriously. That first moment when the symptoms started to lift and we recognized ourselves again.

For many Lyme disease patients, finding those successful firsts can be a long and arduous journey through misdiagnoses, denial, and tremendous self-doubt. The one comment we hear far too often at support groups is: “It took us too long to find you.”

That’s why, when writer and editor Janet Jemmott offered to create a newsletter for us focusing on connecting patients with providers and programs that could help them recover their health, we couldn’t believe our good fortune. Our hope is that *Lyme Connection* will prove to be a valuable resource for patients with tick-borne illnesses. Most importantly, we want patients to know early on in their journey that there is hope and they are not alone.

In this issue, we welcome back Dr. Steven Phillips, thank two professionals who are helping students with Lyme disease succeed at school, and we invite all caregivers to a free day of healing at the beautiful Leir Retreat Center in Ridgefield. We look forward to your ideas, suggestions, and support for this new venture in the months to come.

Jennifer Reid & Karen Gaudian
Co-Chairs
Ridgefield Lyme Disease Task Force

Healing Day for Caregivers

Refresh, Reflect, Rejuvenate
Monday, November 18th from 11:00 am—3:30 pm at the Leir Retreat Center,

Ridgefield, CT

The Ridgefield Lyme Disease Task Force, Ridgefield Visiting Nurse Association, and Integrative Health Coach Christel Autuori invite you to join us for this special retreat designed to support everyone caring for someone they love. Join us for lunch and a relaxing afternoon filled with new friends and refreshing ideas:

Stretching/Gentle Yoga, by Christel Autuori, RDH, RYT, MA
Lighten Your Load, presented by Laura Switzer, LCSW, RVNA
The Health Benefits of Tea, by the Bigelow Tea Company
How to Eat Right on a Busy Schedule, by Sandra Novella, MS, RD
Tools/Techniques to Help You Care for Yourself so You Can
Care for Others, by Christel Autuori, Integrative Health Coach
HeartMath stress reduction with Reiki Master/Teacher Ellie Kirk

Free of Charge
RSVP to RVNA at 203-438-5555 by November 6. Registration is required. Seating is limited to 35 guests.

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Ridgefield Lyme Disease Support Groups

Evening Support Group: Second Thursday of each month, 5:00—7:00 pm
2013 Dates: November 14, December 12
Free, drop-in group for patients and caregivers
Location: RVNA offices, 2nd floor, 90 East Ridge, Ridgefield

Daytime Support Group: Second Friday of each Month, 1:30—3:00 pm

2013 Dates: November 8, December 13
Free, drop-in group focusing on skills for coping with chronic illness
Location: RVNA offices, 2nd floor, 90 East Ridge, Ridgefield

Young Adult Support Group: Second Saturday of the Month, 11:00 am—1 pm
2013 Dates: November 9, December 14
Free drop-in group for patients ages 14 to 30
Location: Annex Building adjacent to the Yanity Gym, 66 Prospect St., Ridgefield
CTYouthlyme@gmail.com

Thank you to Michele Isenberg, Ed.M., and Sandy Berenbaum, LCSW, BCD
The Young Adult Support Group hosted two professionals dedicated to helping Lyme afflicted students succeed in school. Michele Isenberg spoke during the August 10th meeting, answering questions and providing advice on educational accommodations for high school and college. Sandy Berenbaum met with the group on October 12, also offering advice on educational issues as well as information on Lyme disease and mental health. Members found both speakers' suggestions extremely helpful, as school can be daunting for students with Lyme. We are so grateful to both of them for giving group members a clearer understanding of the learning tools and services available to them.

Michele is the founder and CEO of Wise Learning, with locations in Ridgefield, Fairfield, Stamford and Madison. Her website can be found at:
www.wiselearning.us
Sandy Berenbaum is a Lyme-literate psychotherapist who focuses on chronic tick-borne disease. She is a long-time ILADS member and the Children's & Mental Health Editor for *The Lyme Times*.
Check out her website at: www.lymefamilies.com

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Dr. Steven Phillips Resumes the Fight Against Lyme

Lyme disease patients were gratified to hear that Dr. Phillips reopened his practice on September 1, which he had shuttered in June of 2011 due to a serious medical problem. This past September, over fifty attendees gathered at the Ridgefield RVNA to welcome him back and ask questions.

Dr. Phillips has been a proponent of treating stubborn cases of Lyme disease with longer, more intensive courses of antibiotics. His long list of accomplishments include being well published in the medical literature on the topic of Lyme disease; giving numerous testimonies in Connecticut, New York, and Rhode Island as a Lyme disease expert; and being a past president of The International Lyme and Associated Diseases Society (ILADS). He has extensive experience not only in the management of Lyme disease, but also with its other associated vector-borne infections. An internationally known physician and researcher, he has treated patients from over twenty countries. Dr. Phillips has said that while incapacitated, he time spent a great deal of time reading and researching, and he returns to work with an open mind and an increased empathy for patients.

Recently, he spoke with the editor about his approach to treating Lyme disease:
Can you tell me how you approach the diagnosis and treatment of Lyme and coinfections?
In order to make a diagnosis of Lyme and its associated diseases, you have to look for a progressive, multi-system illness. What are the pattern and the breadth of symptoms and how long have they been going on; these are the clinical clues. Then you look at the laboratory data. Just to rely on lab work is a nightmare because there is variability and lack of sensitivity across many domains. You also use ancillary tests for inflammation and disease: Sed Rate and CRP and various autoimmune markers that show up with Lyme and coinfections. An example of an immunologic marker would be the CD-57 natural killer assay. There are a lot of tests you can do besides simple antibody tests and PCRs, so if you can’t actually detect the presence of these infections, you can look for their weight, that is, the effects of the infections on the body.

If there are mixed test results but the clinical presentation suggests Lyme, what do you do?

If the clinical presentation is suspicious and I think the person has Lyme, the person deserves treatment. By and large, the drugs used are safer than many others used empirically by doctors. Given a risk-benefit analysis, something like doxycycline is a good equation. I will do an empirical trial – a therapeutic trial that helps in diagnosis. If a person responds dramatically to antibiotics, you have part of your answer.

What do you do when a patient doesn't respond to treatment with a Herxheimer reaction?
Again, you look at the breadth of the clinical symptoms. Babesia effects red blood cells, whereas Lyme effects many different types of cells. So, Babesia shouldn't be causing peripheral neuropathy or white spots on the brain. With Babesia, you shouldn't have cardiomyopathy. But, patients can have elevated liver enzymes and anemia and fever and muscle aches and generalized flu-like symptoms. Does the breadth of symptoms go outside of the spectrum of where say, Babesia and Ehrlichia might be? Babesia is isolated to red blood cells but Ehrlichia is isolated to white blood cells. Then you have Bartonella, which effects endothelial cells and white cells, and then there's Lyme, which effects any cell in the body. Lyme has the broadest clinical presentation of the infections we're discussing.

Has your approach to treating Lyme changed since you began your practice in 1996?
When I was first treating, I didn't think Bartonella was an issue. Some doctors only treat Bartonella if a patient has AIDS or is immune compromised. When you think about it - what is Lyme doing to your system? There is a measurable decrease in killer cell activity with Lyme and that contributes to the pathology.
Now I take Bartonella much more seriously. Also, when I was younger I

believed in treating patients maximally, blasting these infections hard. But a lot of people are very frail and can't tolerate this. Some Herxheimers can make people so sick they feel like they're dying. So now I slowly ramp up dosages.

Do you use any supportive therapies?
Previously I was a strictly allopathic doctor. But I was away from practice for a couple of years and since I couldn't do anything but read I've searched everything. Now I know more about alternative treatments. Actually, before I went out on disability I received funding and approval to study the effects of Rife machines on the body, specifically if they damage DNA, but I was having problems with my back by then and I had to close the study before it began. I've had about a hundred patients who have gotten profoundly better with Rife after they've reached maximum benefit from antibiotic therapy. You learn not to close your eyes to things. When things are happening in front of you, you can't deny it. You have to listen to the patient, that's the most important thing.

I heard that you had back problems:
I didn't officially have a diagnosis. I did everything... name a therapy and I did it. It's a very frustrating experience to go to thirty doctors and not get a single answer and to rely on your self.

It sounds a lot like what Lyme patients go through.
You get into the debate about what is subjective versus objective. Lyme causes so many subjective things. If you look at the ILADS guidelines on how to treat Lyme there aren't specifics.
On the flip side of the coin, there's a huge amount of these infections that are asymptomatic. For example in the Lyme vaccine study, they found that

11% of the people were asymptomatically infected; that's a lot. Do you treat these people? There are no guidelines as to what to do with people with a positive blood test who don't have any symptoms.

What can Lyme patients do to get the best care?
You have to be your own best advocate, and use common sense. If a doctor's using medical terms or words you can't understand, something's wrong there. If a doctor's condescending or says your symptoms are due to stress and this doesn't make sense to you, something's wrong there. I don't believe that stress would cause certain patterns we see with Lyme. For example, if someone's stressed out, they may have trouble with sleep. The patterns you see with sleep in Lyme is that patients fall asleep and then they wake up every hour and a half or so, sort of like you have a kind of nocturnal ADD - your mind is flitting from thing to thing. That's not the pattern you see with stress. If you're familiar with the patterns of these illnesses, it becomes pretty clear that Lyme is a distinct entity that we're dealing with.

Help us to help you: What should we bring to an appointment?
When a patient comes in, it's always good to have a written summary. If someone is having cognitive issues, a written summary will help them stay on track and stay focused. I'll have patients read the summary to me and they often fill in with more nuanced information or things they've forgotten. Everything can be important.

Will we continue to see more strains of tick-borne organisms?
I can't see why that wouldn't be the case. Technology has allowed us to identify new strains and technology will continue to improve. There's a huge diversity of life on the planet.

So is technology the way?
Technology is part of the way.

Dr. Phillips practices in Wilton, CT . He can be reached at 203-544-0005

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Lyme Connection is a bimonthly newsletter of the Ridgefield Lyme Disease Task Force

The Ridgefield Lyme Disease Task Force (RLDTF) was established in 2003 in response to growing concern about tick-borne diseases in our community. Since its inception, the task force has focused on preventing illness, supporting patients, advocacy and educating the community about all issues related to tick-borne diseases. Our mission is to alleviate the suffering caused by tick-borne diseases. Our vision: A world where tick-borne diseases are no longer a threat to health and well-being.

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BLAST educators Devin Norkowski and Socheata Lim visited Blue Jay Orchards in Bethel, CT to teach apple pickers how to protect themselves from ticks

Ongoing programs include:

BLAST Lyme Disease Prevention Program

BLAST is an acronym representing the five most effective ways to avoid tick-borne diseases. Partnering with the Ridgefield Health Department in 2008, the Task Force won a $50,000 Connecticut DPH grant to create a prevention and early symptom identification program. Look for the BLAST display and our devoted volunteers at health fairs and events throughout Connecticut. BLAST materials are available on the Town of Ridgefield website: http://www.ridgefieldct.org/content/46/6311/6347/8905.aspx

Support Groups
The RLDTF hosts three support groups: Thursday evening, Friday afternoon, and Saturday mid-day for young adults. A complete schedule is included in this newsletter.

Seminars
The RLDTF sponsors a Spring seminar and health fair at Western Connecticut State University in Danbury, CT each May. We look looking forward to hosting our eighth event in 2014.

This November, we Invite you to join us for our first Caregiver Retreat for parents and spouses balancing busy lives while caring for a Lyme patient. Complete information Is included in this newsletter. Seating is limited for this free event. Tickets will be issued on a first come, first served basis.

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Join Us:

The Ridgefield Lyme Disease Task Force meets on the second Thursday of each month, immediately following the evening support group. Everyone is invited to share your ideas or volunteer your time and talents. Join us at Tom Tom's Restaurant in Ridgefield. For more Information contact Karen Gaudian at karen@lymeconnection.org

BLAST Lyme Disease Prevention Program—Jennifer Reid 203-431-2745 or BLASTlyme@ridgefieldct.org
Support Groups, Jennifer Reid (Thurs. and Fri. groups)
jennifer@lymeconnection.org

Saturday Young Adult Group, Katy Reid, katy@lymeconnection.org
Newsletter, Janet Jemmott, janet@lymeconnection.org

We'd love to hear from you regarding topics of interest. This is a work in progress that will depend on community support. Donations can be made out to Friends of Ridgefield Community Programs—RLDTF, and mailed to Ridgefield Lyme Disease Task Force, 66 Prospect Street, Ridgefield, CT 06877

Jennifer J. Reid, *Publisher*, Janet M. Jemmott, *Editor*, Marta Willett, *Creative Director* from Studio23

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