

Lyme Bytes

Awareness • Prevention • Advocacy **September 2018**

A Newsletter from PA Lyme Resource Network



A little bit of Hollywood comes to Pennsylvania with *the little things*

PA Lyme Resource and Drexel University College of Medicine are delighted to bring the little things, a live multimedia theater piece written by actor/filmmaker Jeremy Davidson and directed by film and Broadway star Mary Stuart Masterson, to the Kaleidoscope Performing Arts Center at Ursinus College in Collegeville, PA on October 13, 2018.

The production, from Storyhorse Documentary Theater, is the work of both Jeremy and Mary Stuart. With a personalized approach to storytelling, *the little things* is helping make a major impact on the regional arts and entertainment landscape.

In this special issue of *Lyme Bytes*, we'll have an exclusive conversation with both **Jeremy Davidson** and **Mary Stuart Masterson**. We'll also get peek at an excerpt from award-winning author **Mary Beth Pfeiffer's** new book on climate change and Lyme, as well as hear from our own PA state tick expert, **Nicole Chinnici** with her latest "tick talk."

The goal of this event is to make this invisible disease visible. Visit www.palyme.org/the-little-things/ to get your tickets today. Early bird tickets end as of September 30 and tickets are selling fast! ■

save the date

the little things • October 13, 2018

A PREMIER THEATRICAL DOCUDRAMA ABOUT ONE FAMILY'S BATTLE WITH LYME DISEASE

@ The Kaleidoscope Performing Arts Center, Ursinus College
Pre-show: 5 pm • Show: 6:30 pm • VIP Reception: 9 pm

Visit or www.palyme.org for more information.










presented by Storyhorse Documentary Theater
written by Jeremy Davidson • directed by Mary Stuart Masterson



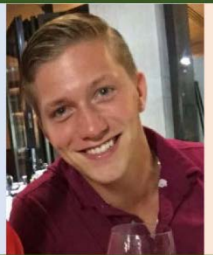
the little things tells the intimate story of a family who lost a son to Lyme disease. This event is presented in memory of **KEVIN FUREY, JEFF NATICCHIA & PETE SMITH** all from eastern PA, who lost their lives to Lyme disease in 2017.

a benefit event sponsored by



the little things award-winning cast includes **Kathryn Erbe** from NBC's *Law & Order: Criminal Intent* and HBO's *Oz*; **Frankie Faison** from the HBO's *The Wire*; and recent Julliard graduate **Toney Goins** and SUNY Purchase grad **Malik Reed**.

This event is presented in memory of (l to r) **KEVIN FUREY, JEFF NATICCHIA & PETE SMITH.**



What's the Story Behind Storyhorse? An exclusive interview with Mary Stuart Masterson

Q: What prompted you/interested you in starting Storyhorse?

MSM: We've always lived a bit of a gypsy life, moving job to job, town to town. And though we feel fortunate to be a part of the television and film world, people do pass in and out of your life and move on to other jobs quickly. When we had kids, we felt a desire to belong to a community, grow roots to a single place, and to contribute work to that place. Storyhorse is our effort to do that. Wendell Berry, the great writer, philosopher and farmer, talks about the importance of listening to our neighbors' stories and the spiritual disconnect that happens if you don't work where you live. We've experienced that disconnect and wanted to attach ourselves to local stories.

Q: Is there any special meaning to the name "Storyhorse?"

MSM: We tossed around a lot of ideas...there is an Irish saying - "What's the story, Horse?" Which essentially means, "What's up?" We like the simplicity of that. And also since the nature of Storyhorse is to gather stories from around the Hudson Valley...we like to imagine ourselves riding around on a horse to collect these stories - instead of our minivan :)

Q: How would you describe the format of Storyhorse's form of theatre? How does this form of theatre differ from traditional theater?

MSM: We look at our form of storytelling almost as a concert-play. We build the narrative from transcribed conversations, then build a projection and sound design and then bring actors on board to read the stories directly to a live audience. The design doesn't tell the story in as much as it helps give an emotional framework to the words. In some ways, the stories could probably live as well as a podcast - but we think there is real power in *live* storytelling. Where we all meditate at the same time on the same words. And if the words carry truth - as the Elone's story does - it can be bring us together in a positive way.

Q: What is your goal with Storyhorse and the stories you choose to share with the public in this format?

MSM: Our goal has always been simply to lift up important and inspiring voices from the Hudson Valley. These pieces take a long time to develop...and it's certainly not a commercial venture...so you either work in the theater because you can't help yourself...or you don't work in the theater. But we feel invigorated working on these stories and particularly honored when we get to share them for important organizations like PA Lyme Resource Network or the National Young Farmers Association (for whom we produced a farm piece called *Good Dirt*).

Q: I believe I read that you and a child/ren experienced tick bites and treatment for Lyme. Did this occur before or after you produced *the little things*? If produced before the tick bites, how do you think knowing about the dangers of ticks and tick-borne disease prior to this experience helped you with the ordeal?

MSM: I started to notice symptoms right around the time we were preparing the first production. And I was hyper-aware, because of our relationship to the Elone's and also having met Dr. Richard Horowitz, (who did the talkback for our first production). But we are also parents of four young children, so it was difficult to know if some of my symptoms were due to parental exhaustion and general stress. Thankfully we had access to a smart and helpful doctor.

Q: What would you share with other parents about tick awareness/prevention in light of your experience?

MSM: Well, we're not experts on Lyme and would never pretend to be. That's why we always follow with a talkback with researchers and Lyme literate doctors - to answer questions and give a broader context to the Elone's story. But we do think knowledge is power and to seek out Lyme literate doctors. ■

www.storyhorsetheater.org



Giving Life to "the little things"

An exclusive interview with Jeremy Davidson

Q: What interested you in the story of Joseph Elone?
How did you hear about his story?

JD: When we moved to the Hudson Valley in New York State, we thought the best way to learn about the issues facing our community were to simply try and reach out to the people who likely knew the most about them. Lyme Disease is an epidemic where we live. And as we were trying to learn about what to do as parents of four small children, we came across the Elone family's story. I should probably say - *what the media presented as their story*. We wrote them a letter and they were incredibly generous to open their life to us in such a brave and intimate way.

Q: What was the experience like interviewing the family and then writing the story? What was the hardest aspect about it? What surprised you the most?

JD: Well, first off - Ben, Diane and Emmanuel are truly remarkable people. That was evident the moment we walked into their home. They have a strength and spirit and humor and intellectual vigor about them that is a genuine treasure to be around. More than any work we did on this - I think *who they are ... and how they share who they are ...is what makes the little things so worthwhile*.

At our first meeting, we didn't record the conversation. We just wanted them to ask us questions about our work, and then once we left...to have a chance to think about whether they would be comfortable opening their life up publicly this way. After that initial conversation, they called us and invited us back the next day. I guess we recorded about 15 hours of conversation with them over a few months and then spent awhile transcribing and shaping those conversations into a narrative that could live in this format.

It became clear to us immediately that *the little things* was not really about Joe's death. It would be about his life. They allowed us access to something much bigger, I think. And kind of magical. Hopefully who Joe was and who the Elone's are will inspire people the way they have us.

Q: Personally, how did hearing their story impact you knowing that you were living/raising a family in a highly tick-endemic area?

JD: Well, we try to be as vigilant as we can. But I also try to manage my anxiety so that my kids aren't overwhelmed by fear all the time. About a month after we produced *the little things* my son and wife both were showing symptoms of Lyme and I'm not sure we would have taken them in were we not as aware. Fortunately, their treatment seems to have worked and they haven't had a recurrence. We live in a time where stories and videos about tragedy are in front of us all the time. I don't want to add to people's fears. And that's not what this story is. We chose to tell this story in the theater because it gives us a chance to gather and reflect on the same story and that itself feels resilient and healing to me.

Q: Before you wrote the story, what was your perception about ticks? Since writing the story, how has your perception about ticks changed?

JD: While I'm extremely aware now how prevalent it is ...and how desperate people are for help...I'm also more aware of all the good people - scientists and doctors - doing research and thinking deeply about this problem. So, I feel hopeful.

Q: With each production of the little things, what do you see as striking/surprising the audience the most?

JD: We've been fortunate to hear the story with several different casts. But what comes through each time is the deeply honest way this family shares their life. I hope people feel like they are in the Elone's living room with them. It's extremely tender.

Q: Aside from people learning about the dangers of Lyme, what other aspects do you hope people walk away with after seeing the little things? I

JD: I think most people who attend this will already be fairly aware of Lyme. I recognize it's not an easy story to choose to come out and hear. But I hope people find it hopeful in some ways. And empowers them to love a little bigger. I know the Elone's helped us to do that. ■

In Remembrance...

There's an average of 300,000 new cases of Lyme disease every year, with 112,000 in PA annually. This disease is invisible, unfortunately, and the deaths of those from Lyme have gone unnoticed in the greater public as well...until now. We are honored to memorialize the three men, all Eastern PA residents who lost their battle with Lyme and tick-borne diseases in 2017. This event will make these invisible losses, **VISIBLE**, commemorating their lives, and raising much needed funding for PA Lyme to continue public awareness and prevention work.



Kevin Furey October 9, 1987 - October 8, 2017

Kevin was smart, tall & handsome, with a gift for making friends. A day short of his 30th birthday, Kevin lost his 10+ year battle with tick-borne diseases...Lyme disease, Bartonella, Babesia, Ehrlichia and Anaplasma.

Kevin's life wasn't what we dreamed for him. Instead of a wonderful happy life, he was debilitated, bed-ridden with pain, fatigue, brain fog, confusion, digestive problems, depression and anxiety. Twice in grade school and, again, in high school, Kevin was diagnosed with Lyme disease. He was given the "guideline-recommended" 2 weeks of antibiotics. In high school, Kevin had the stretch mark-like Bartonella rash and developed shortness of breath, for which a well-regarded pulmonologist ran numerous tests, but never tested for tick-borne diseases. At age 20, an infectious disease doctor, after 28 days of IV antibiotics, declared Kevin "cured" of Lyme, pronouncing no evidence of Bartonella.

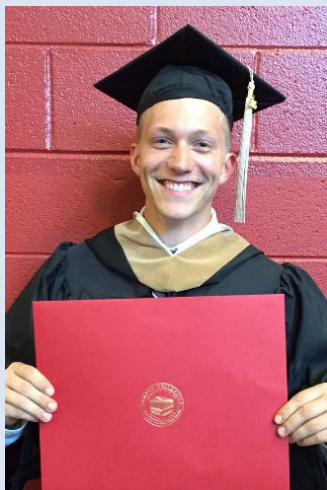
We were clueless, believing Lyme was like a cold or the flu. The Lyme, Bartonella & Babesia were never properly treated despite numerous doctor visits across many different disciplines. The medical community's denial and disagreement as to diagnosis and treatment left us unsure and on our own as to what could really help. We tried many things—expensive clinics and many treatments—some helping, and some not. We were left seeking solutions with little available in the way of proven medical solutions... ultimately not getting the results that could help Kevin.

Jeff Naticchia August 12, 1966 - July 27, 2017

Jeff was a fun-loving, easy-going caring man who could always make people laugh with his dry sense of humor. He loved music, the outdoors and spending time with friends and family. Jeff had an infectious personality and made a lasting impression on those that knew him. In July 2017, Jeff's life tragically ended, shortly before his 51st birthday, leaving behind his wife and two children.

Jeff was a healthy, strong man who had recently begun exercising and walking in the state park near their home. He developed a fever and drenching sweats which led him to Urgent Care, where he was diagnosed with a kidney infection. He was not asked if he had a recent tick bite. Still not feeling well after several days and looking jaundiced, Jeff went to the ER and was admitted to the hospital. In a matter of 1 day, his health quickly deteriorated, progressing to organ failure and he was put on life support. It took the doctors 5 days to diagnose him with a tick-borne disease called Babesia. Even though it was summer, and peak tick-bite season, and he had experienced exposure risk, tick-borne diseases were not considered. Those 5 days proved to be too late. Jeff passed away 5 days after being admitted.

Jeff's heartbroken family wants to raise awareness for these diseases, which can be treatable if caught early. They are fighting to bring education to the public and to the healthcare professionals so that these diseases can be identified **EARLY** and treated promptly.



Pete Smith January 24, 1992 July 2, 2017

Peter Smith was the first of six children, four brothers and a sister who loved him dearly, and looked up to him. He was homeschooled until ninth-grade, and then played football and volleyball for Quakertown High. He had an adventurous spirit and was the life of many parties. His contagious smile put you at ease. After graduating from Temple University in 2015, he worked as an auditor for KPMG. He travelled to Nepal utilizing his construction skills to do humanitarian work.

On June 5, 2017 he went to the ER due to fever, nausea, vomiting, skin rash and body aches. He tested negative for Lyme and was told he had a virus. Benadryl was recommended. He was granted permission to travel out of state for training. His symptoms got worse and upon his return went to the same ER on June 20 with full-blown hives on his entire body, plus the previous complaints. He was given the same explanation.

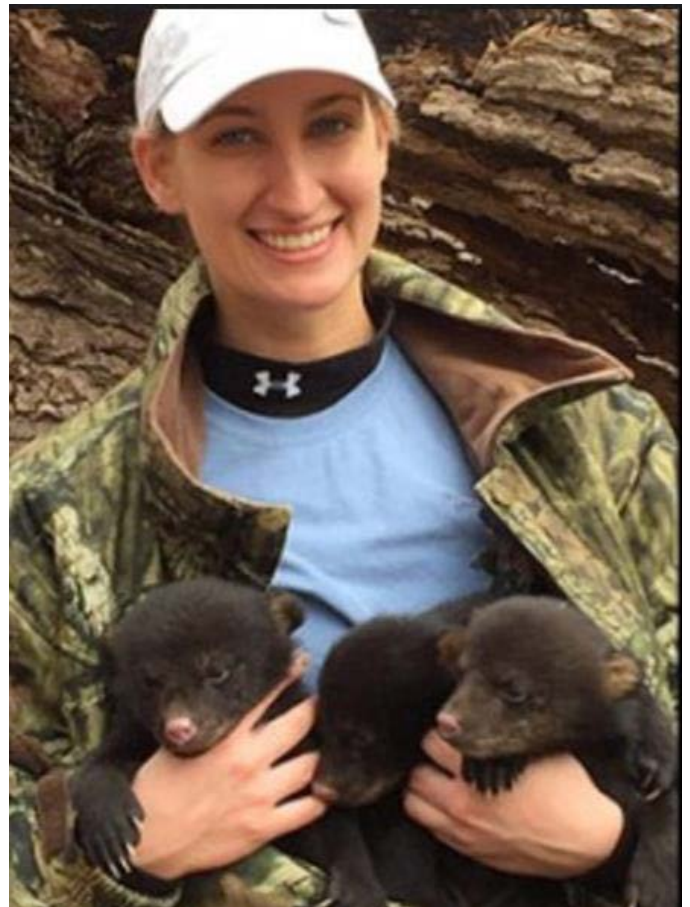
Upon awakening five days later, he called 911 struggling with dizziness, shortness of breath, and consciousness. He was taken to a different hospital with 3rd degree heart block, given a semi-permanent pacemaker for three days, and released on the fourth day with 1st degree heart block and a positive Lyme test, for which he was sent home with oral antibiotics.

His mother and brother drove him to PA, where he collapsed after climbing a flight of stairs three days after discharge. "No one dies from Lyme disease," his parents were told. The truth is, many people die from it due to misdiagnoses or, as in Pete's case, too late a diagnosis and with a "he'll be OK attitude" and a lack of serious attention. Healthcare professionals and the public must be made aware of this silent killer.

Ask the Experts: Tick Talk

Nicole Chinnici, MS, C.W.F.S.
Laboratory Director, Northeast
Wildlife DNA Laboratory, East
Stroudsburg University

ESU Wildlife
DNA Laboratory



Q: What can you share about the new longhorned Asian tick? What new diseases is it carrying?

A: The Longhorned tick has been identified on a white-tailed deer and through tick drags in PA. To date, no diseases have been found in these ticks.

Q: What prompted you to enter into the field of wildlife DNA? Was there any personal connection?

A: I have a passion for science and genetics. During my graduate studies, I was connected with Dr. Jane Huffman whom became my advisor and mentor. At that time, I began my research journey in wildlife genetics and zoonotic diseases.

Q: When you first started in this field, did you know anyone who had Lyme disease or tick-borne disease? What about now?

A: Yes, I knew of a few individuals with Lyme disease. As I have progressed into this field, I've met more and more people and began to encounter individuals exposed to other tick-borne diseases.

Q: What's changed since you started in this field?

A: A lot has changed since I started my research in 2013...we have identified new tick species in PA, documented the expansion of tick species into northern regions of the state, and have identified an increase in co-infections within the vector. We as researchers are just starting to peel back the layers of complexity within the vector.

Q: Prior to entering this field, did you think much about ticks? How has your attitude toward ticks changed since then?

A: I was aware of ticks and tick-borne diseases but not the complexity behind a bite. Efforts to understand these emerging diseases and spreading awareness to high-risk groups has become a priority as a researcher and professor. Knowledge is power, the more we know and understand, the more protection and education we can provide. ■

Nicole Chinnici will be answering audience questions with the other leading Lyme experts panel after the reading of *the little things*. Other panel members include:

- Mary Beth Pfeiffer, award-winning journalist and author of *Lyme: The First Epidemic of Climate Change*
- Julia Wagner, President, PA Lyme Resource Network
- Garth Ehrlich, Ph.D., Drexel University College of Medicine
- Dr. Marina Makous, who specializes in Lyme and tick-borne diseases
- Dr. Martin Mulders, a Chester County physician who focuses on Integrative Medicine
- Jeremy Davidson, writer of *the little things*
- Mary Stuart Masterson, producer of *the little things*

Lyme: The First Epidemic of Climate Change

by Mary Beth Pfeiffer

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<http://islandpress.org/book/lyme>

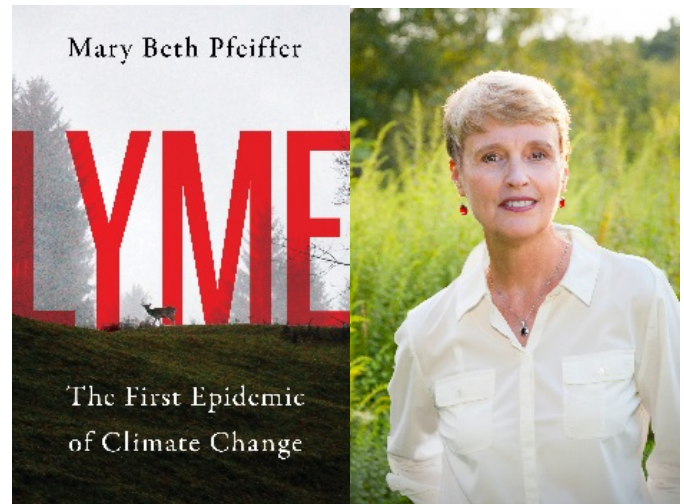
Introduction

On the day after Christmas in 2015, I took a walk with my thirty-year-old son in an old cornfield that long ago morphed, with changing patterns of agriculture, into a gently tended meadow we know well. This nine-acre patch of earth, across the dead-end lane from our home in upstate New York, has a rare and wonderful feature that we have worked, with the cooperation of neighbors, to sustain: a mowed trail around its perimeter that allows access even when summer mustard, milkweed, and goldenrod are four feet high and the blackberry brambles profuse.

The day was unusually balmy in the last week of a year that had gone down as the warmest in 135 years of weather history, followed only— but considerably—by the year before. The temperature had topped out at 55 degrees Fahrenheit that December 26th; it had reached into the mid-60s on Christmas and hit 72 in nearby Poughkeepsie the day before. For that time of year, daytime temperatures at or near freezing would have been far more typical here in the Hudson Valley, a hundred miles north of New York City. Instead, it had been so warm that forsythia buds had sprouted in one neighbor's garden; crocuses peaked through in another's.

When we came back from our short walk, we did what has become in New York State a routine practice from spring through fall, but not for winter. We checked the dogs for ticks. When we were done, we had picked twenty-one blacklegged ticks from the scruffs of our pups, each about the size of a small freckle, and all with one goal in mind: to latch onto a warm body and suck its blood.

When I moved to this rural county in upstate New York thirty years ago, such things did not happen. Ticks certainly did not show up in December, were indeed rare, and, if seen, were usually of the easier-to-spot dog tick variety, which infrequently carried Rocky Mountain spotted fever. They did not pack the potential arsenal of infection of the small, ubiquitous blacklegged ticks of today. Every year, the list of diseases found within this tick grows longer, including new bacterial, viral, and parasitic pathogens.



These infections have changed daily life in the county in which I live, and they have altered the course of many lives, particularly when they go unrecognized for weeks or months. Mention Lyme disease at a gathering here and nearly everyone has a story. The odd rash, fever, occasional palsy, meningitis, and joint pain of early stages. The sometimes-crippling arthritis, memory loss, depression, numbness, and fatigue of advanced disease.

Even the rare infection that can kill. In towns near me, Lyme carditis, in which the bacterium quickly cripples the heart, claimed a seventeen-year-old high school boy and a thirty-eight-year-old father of three within five months. A woman, who at ninety-one was an active gardener, died after being bitten by a tick and contracting another common tick-borne disease, babesiosis.

Blacklegged ticks have taken up residence in half of continental America's counties, spreading west, north, and south from the Connecticut town for which Lyme disease was named in the late 1970s, like some unchecked algal bloom. These eight-legged arachnids have turned childhood from a time to explore nature to a time to fear it. My seven-year-old grandson has been warned since he could walk: Don't brush up against the tall grasses at the edge of the trail. Don't venture into the weeds. Tuck socks into pants. Sit still for repellent. Check yourself, and remind Mommy to also.

Then, pray we see the tick, and pity the parent who doesn't know to look. Guidance counselors and teachers have told me of children, the most frequently infected, missing months, sometimes years, of school because the tick went unseen or the symptoms were misconstrued. But happenstance is not the only reason that cases are missed or treatment delayed, I have learned. Many patients have suffered needlessly, in the United States, Canada, England, France, Germany, and many other countries, because of how Lyme disease has been framed in American medical journals and treatment guidelines. This is an illness that has been minimized, underestimated, and politicized to the point that doctors fear treating it aggressively with a cheap, common drug: antibiotics.

I began to write about Lyme disease as an investigative reporter for a Dutchess County, New York, newspaper in 2012. I intended to write one or two stories about a prevalent local disease, focusing on its origins, growth, and management by health officials. But Lyme disease proved to be a story far beyond the parameters I'd envisioned. Over a period of four years, I studied the policies, paper trail, and scientific literature. I tested the postulates of patients and their advocates. Many of their assertions, I concluded, were true.

Decades-old testing protocols failed to diagnose many people with the disease. The risk of overtesting—and falsely diagnosing people with Lyme disease—was exaggerated at the expense of cases missed and symptoms dismissed. Official figures did not reflect the epidemic's scope and were soon revised tenfold. Human trials concluded that short-term antibiotics eradicated the bug, while animal and test-tube studies showed they didn't.

And then there was the politics of Lyme disease. Doctors who prescribed repeated courses of antibiotics—standard in other diseases—faced professional disciplinary charges, huge legal fees, and sometimes suspension or loss of their licenses. Research was discredited, ignored, or relegated to second-tier journals when it challenged prevailing dogma. Scientists who were invested in a benign view of Lyme disease used access to elite journals to uphold the status quo. And little money was available for treatment trials because the medical system purported to have the answers to Lyme disease care.

And yet, some 10 to 20 percent of people infected annually with Lyme disease, estimated at 380,000 Americans in 2015, have symptoms that linger months and sometimes years after treatment. ■

Get your tickets today!

<https://www.eventbrite.com/e/the-little-things-tickets-48999731516>

Discounted early bird tickets extended through
September 30, 2018!

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NOTE: The information provided in this newsletter is not meant to diagnose or provide specific treatment guidelines or recommendations for Lyme disease or other tick-borne illnesses. There are inherent dangers in treating yourself for any health condition, and PA Lyme Resource Network does not endorse or condone such action. Please discuss all therapies you desire to use with your personal physician or other health care practitioner and receive and follow their medical direction.

About PA Lyme

PA Lyme Resource Network is a 501(c)(3) non-profit organization chartered for charitable and educational purposes. It was founded in 2012 by individuals personally affected by Lyme/tick-borne diseases and compelled to change the circumstance for others.

Pennsylvania is #1 in the U.S. in reported cases of Lyme disease, with cases increasing each year. The need for PA Lyme Resource Network's mission of Lyme awareness, education, advocacy and patient support has never been more important. Visit www.palyme.org to learn more about our advocacy, education and prevention efforts.

Our Regional Support Groups

Southeast

Berks County, berkslyme@palyme.org

Bucks County, buckslyme@palyme.org

Delaware County, delcolyme@palyme.org

Lehigh Valley, lehighvalleylyme@palyme.org

Montgomery County, montcolyme@palyme.org

Greater Philadelphia Lymie Moms Social Group (Facebook)

Northeast

Bradford County, bradfordcountylyme@palyme.org

NEPA Region, NEPA@palyme.org

Southcentral

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Altoona Area, altoonalyme@palyme.org

Chambersburg, chambersburglyme@palyme.org

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Harrisburg Area, harrisburglyme@palyme.org

Lancaster County, lancasterlyme@palyme.org

York County, yorklyme@palyme.org

Northcentral

Tioga County, tiogacountylyme@palyme.org

Southwest

Butler County, butlerlyme@palyme.org




Pittsburgh Area, pittsburghlyme@palyme.org

Special Interest Groups

Lymie Moms Unite (Facebook)

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 PA Lyme Resource Network
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Dare 2 Help

Pennsylvania continues to be #1 in the U.S. in reported cases of Lyme disease...and cases increase each year. The need for PA Lyme's mission of Lyme awareness, education, advocacy and patient support has never been more important.



What You Can Do Today

1. **SHARE** this newsletter.
2. **PURCHASE** a ticket for this event.
3. **SPONSOR** this or another one of PA Lyme's events.
4. **BECOME** a PA Lyme Ambassador. You can become educated on the Dare program and do outreach/promote it in your community. Email info@palyme.org for information.
5. **VOLUNTEER** for your local support group or START a new local support group. We offer new groups a "Support Group in a Box" as well as ideas for meeting locations, meeting topics/speakers and more! Email info@palyme.org if you are interested in starting a new group.
6. **SHOP** on AmazonSmile <https://smile.amazon.com/> and select PA Lyme Resource Network (North Wales, PA) as your designated charity. Amazon will donate 0.5% of the purchase price from your eligible purchases to PA Lyme.
7. **DONATE** and ask other to make a tax-deductible donation as well. As a non-profit, we have very limited funding to run our DARE 2B Tick Aware program and other programs, and funding is always needed. You can name your donation in honor or in memory of someone as well. Donations can be made via check, mail to: 211 South Main Street, North Wales, PA 19454 or online: www.palyme.org.
8. **MATCH** your gift to PA Lyme with your employer's matching gift program.

Visit www.palyme.org to learn more about our advocacy, education and prevention efforts. ■