



Lessons Learned from Lyme Disease

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Today's Presentation

- Lyme disease's lessons for Long COVID
- The context of Lyme's controversy
- Explanation of research

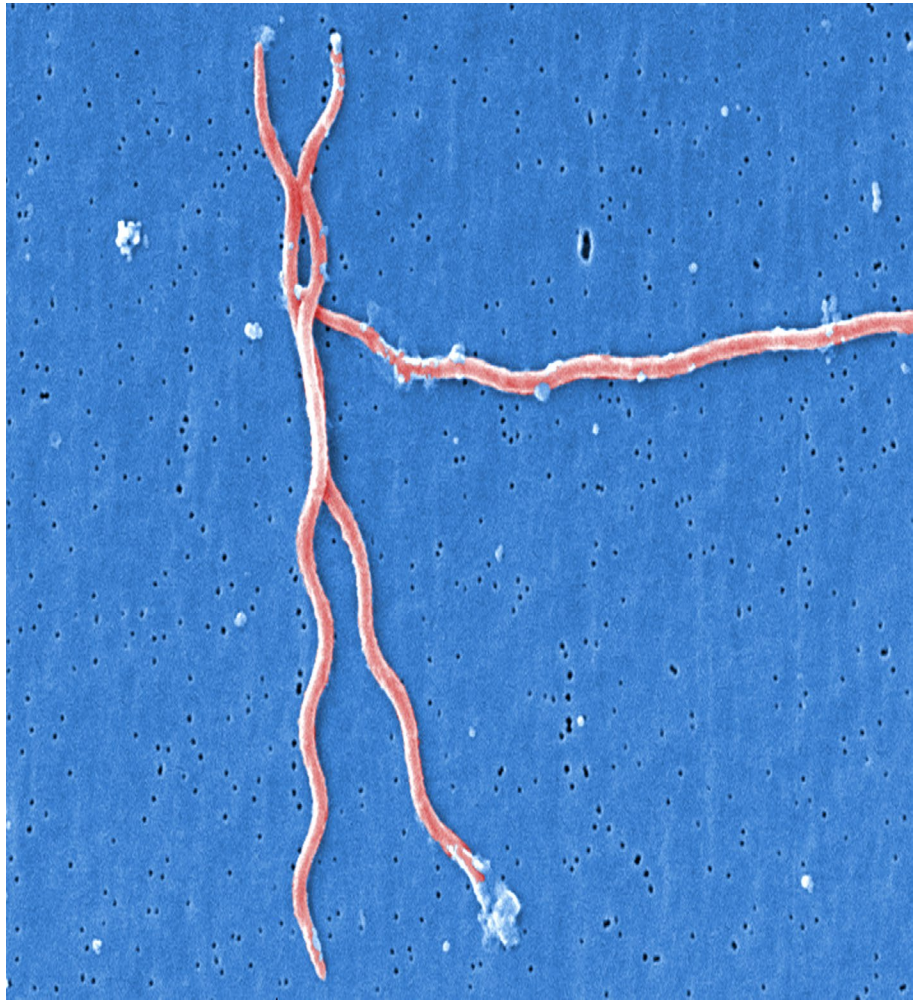
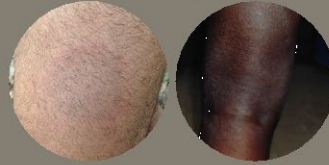


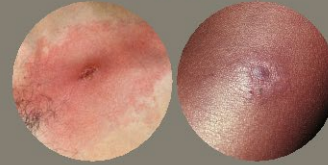
Photo courtesy: California Department of Public Health

The Many Forms of Lyme Disease Rashes (Erythema Migrans)

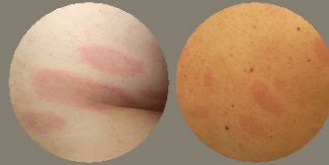
Faint colors and borders



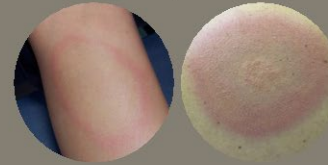
Crusted centers



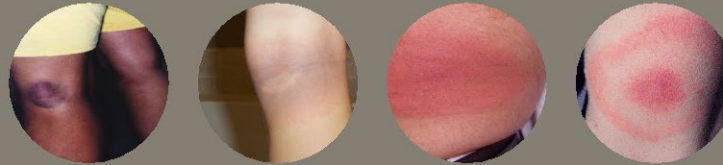
More than one rash



Different shapes and colors



Appearing anywhere on the body



Most people with Lyme disease develop an erythema migrans rash at the site of the tick bite. The rash usually expands slowly over several days reaching up to 12 inches or more (30 cm) across. **However, not all rashes are a sign of Lyme disease.** The redness in the picture to the left is caused by irritation to the tick bite — not a tickborne infection.

Photo credits (from top, left to right): 1. Centers for Disease Control and Prevention; 2. Courtesy of Dr. Gary Wormser, New York Medical College; 3. iDermAtlas, Bernard Cohen. Used with permission; 4. Reprinted from Bhatia C, Shwartz RA. Lyme disease: Part 1. Advances and Perspectives. Am Acad Dermatol 2011;64:519-36, with permission from Elsevier; 5. iDermAtlas, Bernard Cohen. Used with permission; 6. Courtesy of Vermont Department of Health; 7. iDermAtlas, Taryn Holmes. Used with permission; 8. iDermAtlas, Vergera Salguero. Used with permission; 9. Courtesy of New York State Department of Health; 10. iDermAtlas, Robin Stevenson. Used with permission; 11. iDermAtlas, Allison Young. Used with permission; 12. Centers for Disease Control and Prevention, <http://phil.cdc.gov/phil>



Learn more about Lyme disease symptoms at
www.cdc.gov/lyme/signs_symptoms





ANNALS OF MEDICINE THE LYME WARS

The Lyme-disease infection rate is growing. So is the battle over how to treat it.

BY MICHAEL SPECTER



Kaleigh Ahern was twelve years old when a tick bit her. She noticed it "perched" on her shoulder when she was taking a shower one morning. "I thought it was your average, everyday bug," Ahern told me recently. But, when she tried to brush it off, the tick wouldn't budge. "The legs wiggled but it was embedded in my skin. I freaked out and started screaming," Kaleigh's mother, Holly Ahern, came running and removed it. "I took the kid and the tick to the doctor," she said. "I told him, Here is my kid, here is the tick, and there is the place where it was attached to her." That was in 2002. The Aherns live near Saratoga Springs, New York, where Lyme disease has been

endemic for years. The infection is transmitted by tick bites, so Ahern assumed that the doctor would prescribe a prophylactic dose of antibiotics. But he said that he wasn't going to treat it. "If a rash develops or she starts to have flu-like symptoms, bring her back," he told her. At the time, Ahern, an associate professor of microbiology at SUNY Adirondack, didn't know much about tick-borne illnesses. She took Kaleigh home and watched for the signature symptom of Lyme disease: a rash that begins with a bright-red bull's-eye around the tick bite.

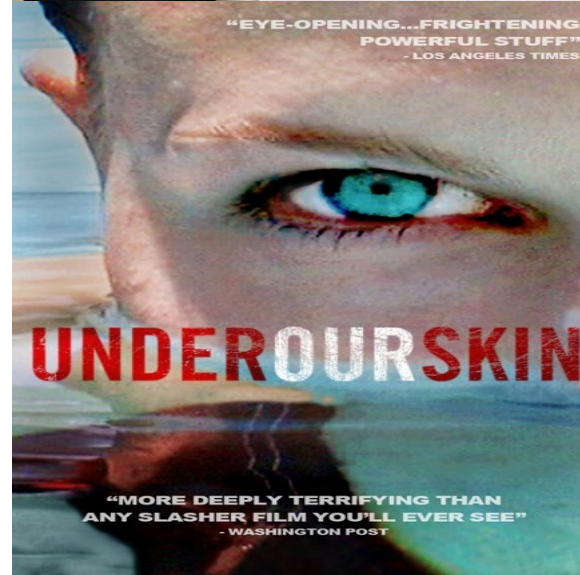
No rash developed, and Kaleigh was fine—strong enough to become an all-American swimmer both in high school

and at Union College. There were times during high school when she felt mentally hazy and not quite right physically, which she attributed to allergies or a teen-age bout of mononucleosis. But at the end of her freshman year in college she found herself crippled by anxiety, depression, and insomnia. She was beset by scaring headaches, her muscles often felt as though they were on fire, and her brain seemed wrapped in a dense fog. Kaleigh tested positive for Lyme disease. Like most physicians, her doctor followed the standard medical practice, endorsed by public-health officials throughout the United States, and prescribed a three-week course of antibiotics. "I was so happy to know what was wrong with me," Kaleigh said. "For a while, I didn't mind the pain."

The drugs didn't work, though. At her mother's insistence, the doctor extended the prescription three more weeks, but Kaleigh only got sicker. This brought the Aherns to a clinical impasse. The Centers for Disease Control and Prevention has established highly specific criteria for the diagnosis of Lyme disease: an acknowledged tick bite, the appearance of a bull's-eye rash, and, for those who don't live in a region where Lyme is common, laboratory evidence of infection. Most people who fit the profile respond well to antibiotics, even months or years after the initial infection. Many Lyme specialists, however, believe that short-term antibiotic therapy may suppress symptoms but rarely cures the disease. Kaleigh switched doctors and began a course of antibiotics that lasted eight more months.

There was no change. Furthermore, there is no evidence that prolonged antibiotic therapy helps patients with Lyme disease, so insurance companies almost never pay for it. "I realized that my parents were shovelling thousands of dollars into these antibiotics," she said. "After the oral approach failed, I was recommended to go onto I.V. treatment, but I had had enough." Kaleigh's condition had become so grave that she withdrew from school. "I would have episodes where I would just lie on the ground writhing. And my parents could do nothing but watch. I wish they had taken videos and put them online, so people would know."

Kaleigh turned to alternative treat-



The disease is carried by the black-legged tick, now found as far south as Florida.

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PHOTOGRAPH BY KENJI AOKI

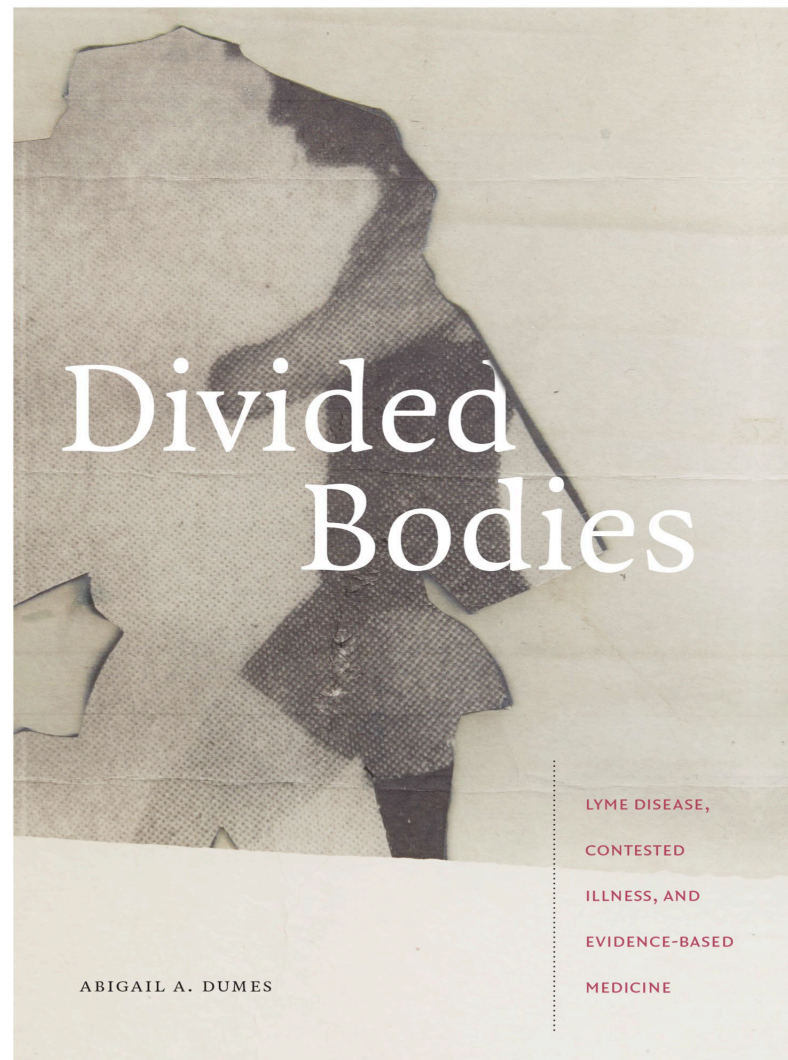
Lyme's Two Standards of Care

“Mainstream”

- *Erythema migrans*/antibody test
- 10-28 days of antibiotics
- Infectious Diseases Society of America (IDSA) and the CDC
- Chronic Lyme disease= medically unexplained illness

“Lyme Literate”

- Range of symptoms with or without antibody test
- Extended antibiotics
- International Lyme and Associated Diseases Society (ILADS)
- Chronic Lyme disease= biologically substantiated



- Contested illness= any condition whose biological basis is disputed.
- Diagnostic importance of signs over symptoms in conventional medicine.
- The shift to evidence-based medicine in the late 1980s and early 1990s reinforced contested illnesses as “medically unexplained.”

Five Lessons from Lyme Disease

- Bring divided stakeholders face-to-face
- Keep an eye on how evidence is used
- Language matters
- Incorporate social science into medical education
- “Acknowledge uncertainty” and lead with empathy and humility