

# DISCUSSION GUIDE

*Under Our Skin*  
&  
*Under Our Skin 2: Emergence*

A Production of  
OPEN EYE PICTURES

A Film by  
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[www.UnderOurSkin.com](http://www.UnderOurSkin.com)

## THE FILMS

***Under Our Skin*** (103 minutes) and the sequel ***Under Our Skin 2: Emergence*** (59 minutes) follow the stories of several individuals with Lyme disease and the doctors that treat them. Through the trials and tribulations of patients and treating physicians, viewers soon learn that Lyme is not a typical disease.

In seeking to understand why incidents of Lyme disease are underreported and why patients are so often misdiagnosed or simply dismissed, the ***Under Our Skin*** documentary series exposes a complex story of politics and conflicts of interest among researchers, insurance companies, and “Big Pharma.” Lyme physicians who successfully treat patients with “unproven” protocols are threatened with sanctions by state medical boards. Patients are left untreated and the disease continues to spread.

These films provide a penetrating view into the science and politics of one of the most prevalent, misunderstood and controversial illnesses of our time. It invites viewers into the heroic lives of people struggling with the disease and into the complex web at the intersection of science, medicine and money.

## TOPICS

*NB: While this discussion guide was designed for use with UNDER OUR SKIN, the topics and questions are relevant to and amplified by the sequel EMERGENCE.*

- Lyme disease and other tick-borne diseases
- Public health policy
- The role money and funding play in medical research, publishing and policy and public perception
- Medical ethics, including researchers’ financial conflicts of interest
- The privatization of medical research, including the effects of current patent policy
- The role of insurance companies in defining disease
- The role of major pharmaceutical companies in setting or limiting medical research agendas
- The role of medical organizations and state medical boards in establishing accepted medical practice
- The line between malpractice and unconventional practice
- Growing resistance to antibiotics and control of antibiotic supply
- The link between disease and environmental problems such as climate change
- Patient rights and physician rights
- The psychological impact of living with a chronic debilitating disease

## **DISCUSSION PROMPTS**

### **General**

- List the three most surprising things you learned in the film(s). How has what you learned influenced your thinking about Lyme disease or the people who live with Lyme? How might you act on what you learned?
- How did the films change or enlarge your perspective on the health care system and your trust in it?
- What moments or scenes did you find inspiring? What inspired you about them?
- What moments or scenes did you find disturbing? What disturbed you about them?
- If you could ask anyone in the films a question, who would you ask, what, and why?

### **Understanding the Basics of Lyme Disease**

- What did you learn about...
  1. the consequences of late diagnosis?
  2. mistaken beliefs about where Lyme outbreaks occur?
  3. the consequences of misdiagnosis and the duration of Lyme treatment?
  4. how people who have Lyme disease look?
  5. the relationship between miscarriage and Lyme disease?
  6. the relationship between Lyme and other neurologic degenerative diseases?
  7. congenital transmission of Lyme disease?
  8. the consequences of misdiagnosing Lyme as a psychiatric disorder?
  9. the debate whether chronic Lyme disease really exists?
- What do you wish more people knew about Lyme disease? What misconceptions would you want to correct? How can you help people become better informed?
- Based on what you learned from the film, respond to each of the following claims made by physicians who support the IDSA Lyme guidelines:
  1. Dr. Eugene Shapiro:
    - “There has not been one documented case of congenital Lyme disease.”
    - “The only way that Lyme disease is transmitted is through the bite of an ixodes tick.”

2. Dr. Lawrence Zemel:
    - "...long-term antibiotics as the right treatment has never been shown in any double-blind, controlled, randomized trial."
    - "If I was to ask whether Lyme disease could be fatal, I would say not in my experience and not suggested by any of the existing literature."
  3. Dr. Gary Wormser:
    - "There's no evidence that I can find to support the concept that there is a chronic *Borrelia* infection after treatment. That kind of situation has been referred to as "Post-Lyme Syndrome. Those symptoms may be due to the aches and pains of daily living."
- Discuss the medical implications of the following hypotheses:
    1. Dr. Horowitz's suggested that "years ago the patients were only getting pure Lyme disease...What we're now seeing is these ticks are containing multiple organisms...the immune system gets overwhelmed."
    2. Dr. MacDonald's discovered the Lyme DNA in seven out of ten brains of people who died from Alzheimer's.
    3. Dr. MacDonald's discovered a colony of Lyme bacteria protected by a biofilm.
  - Dr. Burrascano suggests that if Lyme disease were found to be a sexually transmitted disease, "it would change the landscape of the whole argument."
  - According to the film, in many cases Lyme disease may be mistakenly diagnosed as fibromyalgia, chronic fatigue, lupus, rheumatoid arthritis, Parkinsons, ALS, autism, attention disorders, and multiple sclerosis. What do these illnesses have in common with Lyme disease?
  - What is the basis for Dr. MacDonald's hypothesis that there is a link between Lyme disease and neurodegenerative diseases? What are the implications of such a link? What are the difficulties in proving it?

## **Appreciating Medical Policy Issues**

### *The Big Picture*

- One of the subjects in the film states, "It is a national health crisis that is completely and totally being ignored and squashed. What is going on?" What do you think has prevented Lyme disease from becoming a national priority? What causes the misinformation about Lyme disease to persist?

- Who benefits from each of the following:
  1. The underreporting of Lyme disease cases
  2. The claim that Lyme disease exists only in the Northeast U.S.
  3. The IDSA policy that Lyme disease is easily and completely treatable with two to four weeks of antibiotics
  4. Limiting the diagnosis of Lyme only to those who had signs of a tick bite with a distinctive rash
  5. Sticking with existing tests for the disease even though about half will receive false negatives
  6. Challenging the licenses of Lyme-literate physicians like Dr. Jemsek or Dr. Jones
  
- What are the weaknesses in the U.S. approach to medical research and care? How would you change it?

### *The Influence of Corporate Money*

- Who funds the research being done on Lyme disease? How does the source of funds affect public interest? What rules (including laws governing patents), regulations, or ethical standards would you create to protect public interest?
  
- The 2006 Infectious Diseases Society of America (IDSA) Lyme treatment guidelines state that chronic Lyme disease doesn't exist, and that if symptoms remain after a two to four week dose of antibiotics, they are caused by something other than Lyme. What would happen if the IDSA validated claims of chronic long term lyme disease? What would be the impact on patients? On insurance companies? On the IDSA itself? Why might the IDSA be reticent about doing so?
  
- Jordan worries that his insurance is going to stop paying for his prolonged treatment with antibiotics. Do you think that Jordan's insurance company should be required to cover his costs? Why or why not? What are the pros and cons of insurance companies paying for treatment that is not recognized by medical societies like the IDSA.

### *Medical Boards & Licensing*

- If you had been on the board considering the suspension of the medical licenses of Dr. Jemsek or Dr. Jones, how would you have voted and why?
  
- In your view, what role should medical boards play in the relationship between informed patients and doctors who are not using standard protocols? How, if at all, should they protect patients from malpractice?

- Who should have final authority over what kind of treatment we are able to receive? The medical board, doctors, or the patient? What authority should each have?
- Dr. Burrascano stated that “the great majority of complaints don’t come from doctors or patients, but they come from insurance companies trying to get rid of doctors who cost them a lot of money.” In your view, how should medical boards treat claims that come from insurance companies?
- Dr. Lawrence Zemel argues that Lyme-literate physicians who base their diagnosis on clinical grounds alone rather than on lab data are “practicing medicine that is widely outside of the standards of medical care.” What should be the basis of those “standards of medical care”? Who should be responsible for setting them?
- How could the medical system ensure that there were no conflicts of interest? In your view, should the government require transparency in relation to who funds research and medical organizations (like IDSA)? Why or why not?

### *Diagnosis & Treatment*

How would you describe the two sides of the debate over chronic Lyme disease? What do they have in common?

- Several of the people in the film are treated with long-term antibiotics. Dr. Donta responds to concerns that such treatment will strengthen resistant bacteria noting that other infectious diseases that are treated for much longer than two to four weeks, including tuberculosis and HIV. He says, “We’re not talking about new concepts. We’re talking about concepts that have not been, for whatever reason, applied.” What do you think are the reasons that the concept of long-term drug therapy has been applied to other infectious diseases, but not to Lyme?
- Dr. Lawrence Zemel objects to Lyme-literate physicians basing a diagnosis on clinical grounds alone rather than on laboratory evidence. What are the comparative strengths and weaknesses of clinical observation and evidence from lab tests? What criteria would you use to distinguish between malpractice and unconventional practice?
- What are the benefits and drawbacks of a system in which only double-blind, randomized, controlled research studies are accepted as adequate scientific evidence for successful treatment? What would be included in your definition of acceptable scientific proof?

- When the doctor told Mandy, “You’re an attractive girl and obviously you don’t feel like you’re getting enough attention,” what assumptions did he express? What role do you think Mandy’s gender, appearance, and age may have played?

### *Bioethics*

- In the film, Kris Newby points to the deregulation of medicine and the newfound ability on the part of governmental agencies and research universities to patent live organisms as the beginning of what became an “Oklahoma land grab” to profit from future vaccines and test kits using patented biological markers. What is the impact of patenting organisms and parts of organisms, like proteins of the Lyme spirochete? Discuss the ethics and outcomes of governmental agencies (like the CDC and NIH) and academic institutions partnering with private corporations in the pursuit of profit.
- In the film, IDSA physicians point to the dangers of long-term antibiotic use, citing the generally accepted belief that overuse of antibiotics is contributing to drug resistant bacteria and a “super bug” scenario. Lyme-literate physicians believe that the risks are outweighed by the Hippocratic oath to help their patients. Discuss this dilemma and the ethics involved. Where do you stand on the issue? What would you want for you or your family?
- What should citizens be told about health threats? On what basis would you draw the line between providing actionable information and providing so much information that people only become paranoid? How do we manage the need to feel safe in our world with the level of threat that exists?
- What other bioethical issues are raised in the film or as a result of watching the film?

### **Exploring the Relationship between Nature and Society**

Jordan Fisher Smith notes that, “While many species are dying out, viruses and bacteria are finding new opportunities. Warming climates, jet travel, and human expansion into wildlife habitats are favoring diseases that jump from animals to people, diseases we’re not prepared for.” Can you think of any other evidence of this? What can be done about it? Who is responsible for protecting people from these kinds of environmental threats?

- What impact does the prevalence and severity of tick-borne diseases have on your feelings about being outside and of nature as a whole? How does that feeling affect your life?
- What would have to be different in order for society as a whole to reduce the likelihood of more diseases like Lyme to emerge? What can you do about it?
- How might our notions of our separateness from nature have helped foster an environment in which Lyme disease could flourish?

### **Personal Reflections**

- Have you or anyone you know experienced Lyme disease? How has your experience been like or different from the experiences of the people featured in the film?
- If you don't have Lyme, what experiences have you had that help you understand or identify with someone living with the disease?
- Knowing what you now know about the disease, how would you respond if you discovered you had it? How would you respond if you discovered somebody you know has it?
- How does what you learned in the film affect the way you view some of the hot-button topics of the day, including health care for all, insurance reform, conflicts of interest in science, Western vs. integrative medicine, antibiotic resistance, and climate change?
- Who in the film did you relate to the most and why? Who did you admire the most and why?
- As you go through a day, imagine that a significant number of the people you meet have a chronic, debilitating, and invisible disease—and either they don't know it, or they don't know that you know they have it. How does that affect you?
- Think of a time when you weren't taken seriously, told that "nothing is wrong with you" or "it is all in your head"? What did it feel like? What did you do? Think of a time when you doubted that somebody who claimed to be sick was actually sick? If so, how did that affect your relationship with him/her?

- As is evident in the film, for many people with Lyme disease the battle to regain health takes years. In your view, what specific things help people persist in the face of such a challenge?
- If you had the disease, what kind of support do you imagine you would want? If you knew somebody with the disease, how would you want to support them?

### **Taking Action**

- Brainstorm what actions you could take in your community that would improve medical care for people with Lyme. Pick the top three you are most likely to do and do at least one.
- Investigate how your health care provider would respond to a potential case of Lyme disease. You (or someone you know) might call your health care provider (anonymously if you like) and tell them that you think you have Lyme disease. Find out how they respond, what treatment they offer, and what they suggest. Use what you learn as the basis for a conversation with your provider, to make a decision about whether or not to find another provider, or to share information about your provider with others in your community.
- If you are insured, make sure you know whether or not your policy would include your preferred treatment in the event that you were diagnosed with Lyme disease. Convene a meeting of extended family members, co-workers, or members of a club, church, civic group, etc. to compare health insurance policies. If you think changes need to be made in coverage for Lyme disease, contact the insurance company as a group (not as individuals who might put their coverage at risk by speaking up). You might request the change or offer to begin a dialogue by asking to meet with a representative who is empowered to grant your request for change.
- Start or join an online community to advocate for recognition of and better treatment for chronic Lyme disease.  
*See the Resources page of [www.underourskin.com](http://www.underourskin.com)*