RESOURCE GUIDE FOR COMMUNITY & ADVOCACY

COMPANION TO THE GREAT IMITATOR

Whether you have Lyme Disease, know someone with Lyme, or just want to help Lyme patients, you can make a difference to a community in need. We have compiled basic steps you can take with whatever energy, time and resources you may have.

IMPORTANT NOTES:

Take care of yourself.

Whether you are a patient, caregiver, doctor, or loved one, your health and wellbeing hold priority over any advocacy. As the saying goes: you can't pour from an empty cup.

Start small. It's

better to approach one action that feels achievable than become overwhelmed trying to juggle twenty at once!







Join a group

- There are many groups available for you to join, whether it's a one-time thing for you or long-term involvement. It's important and immensely helpful to find a support system of people who understand what you're going through
 - Examples: (San Diego Lyme Alliance Empowerment Circle, Generation Lyme, BIPOC Chronic Illness)

Join The Great Imitator movement

- Watch the play and invite friends to join you!
- Host a performance or reading in your community
 - This can include medical schools, health centers, nonprofits, and universities
- <u>Subscribe</u> to learn about performances and opportunities to become involved



Write to your state representatives

 If you want a service to simplify this process, consider <u>Advocacy Express</u>

Follow the <u>Center for Lyme Action (CLA)</u>, the leading group advocating for federal funding

Support single-issue groups that interest you

• Example; Mothers Against Lyme (advocacy and education about congenital and childhood Lyme)

Engage in thoughtful conversations with friends and family about the realities of Lyme disease



Support the scientific process

- Add your data to MyLymeData
- Donate samples to a biobank
 - See here for a list of collection sites



Donate to an organization whose cause speaks to your interests

- Examples:
 - Research, advocacy, education, awareness, communitybuilding:
 - Bay Area Lyme (research)
 - LymeDisease.org (policy advocacy)
 - Project Lyme (research, education, advocacy, community)
 - Lyme Disease Challenge (awareness)
 - Treatment Grants:
 - Ride Out Lyme (adults over 26)
 - LymeLight Foundation (ages 25 and under)
 - LivLyme Foundation (ages 21 and under)
- Donate time by volunteering at an organization of your choosing



Spread the word on social media

Share your story

- Consider seeking an outlet where you feel comfortable sharing your Lyme disease experience. However small or large, there are many platforms where you can share
 - Example: <u>Generation Lyme</u>

Share The Great Imitator

- Post your reflections, share what you learned, and invite people to check it out for themselves!
 - Tag <u>@greatimitatorplay</u> and use #thegreatimitator and #lymediseaseawareness

Share this guide

- Post what actions you intend to take and invite friends to join you
 - Tag <u>@greatimitatorplay</u> and use #lymeactionguide and #lymediseaseawareness



Advocacy, Research, and Educational Developments

- Stay up-to-date with <u>ILADS</u>, a nonprofit, multidisciplinary medical society dedicated to the appropriate diagnosis and treatment of Lyme and associated diseases
- Subscribe to informational newsletters from organizations that regularly share the latest in Lyme disease research, education, and awareness
 - Examples: <u>Bay Area Lyme</u>, <u>LymeDisease.org</u>, <u>Project Lyme</u>

Community news

- Subscribe to newsletters and social media platforms of the communities of your choice to stay connected with Lyme patients in your area and around the world
 - Examples: The Great Imitator, Generation Lyme

Keep learning

- There are multiple ways to learn about Lyme disease –
 everything from the science behind it to the experience of
 having it from a variety of books, documentaries, podcasts,
 and social media accounts
 - Example Podcasts: <u>The Generation Lyme Podcast</u>, <u>Lyme 360°</u>, <u>Tick Bootcamp</u>, <u>Ticktective</u>, <u>The Tick Chicks</u>, <u>In It Together by Ride Out Lyme</u> (not all episodes focus on Lyme, but they are closely connected to our community)

To find a Lyme organization in your area, <u>click here</u>.

If you want your Lyme resource and/or organization to be included in this guide, email Patricia at <u>inthelymelightmonologues@gmail.com</u> or DM <u>@greatimitatorplay</u>.

**Please note the list of nonprofits and media is in no way comprehensive and that this guide is not sponsored by any nonprofit organization or media outlet. It's a working list meant to be added to and customized by each individual who reads it.