

# ILLUMINATE THE NIGHT:

Shine a Light on Sarcoidosis



An FSR Awareness Toolkit

## Illuminate the Night: Shine a Light on Sarcoidosis

The Foundation for Sarcoidosis Research has been an integral part of the movement to pave a brighter path for all those touched by sarcoidosis. Their annual Seek Answers. Inspire Results. campaign has been extremely effective in promoting general awareness about sarcoidosis, however, it is vital that the campaign conveys the seriousness of this disease. In the campaign’s fifth year, we seek to do more **to counter the false beliefs that sarcoidosis is not a serious diagnosis, that current therapies work, and that the complaints of sarcoidosis patients are unfounded or exaggerated. We strive to be part of the solution. One such initiative launched within the broader Seek Answers. Inspire Results. campaign this year is *Illuminate the Night: Shine a Light on Sarcoidosis.***

Volunteers around the globe are rallying together to paint their towns purple to promote awareness for sarcoidosis on April 13, 2019, World Sarcoidosis Day. Please join our growing list of partners who will illuminate landmarks, buildings, and businesses purple in support of patients living with this rare disease. **Illuminate the Night: Shine a Light on Sarcoidosis** will raise awareness about sarcoidosis and ignite a movement to help patients everywhere!

### How do I join the movement?

This toolkit outlines the project and provides tools you can use to approach building managers, your workplace, government leaders, and others to request that they help us shine a light on sarcoidosis.

#### Make a Plan

What are the buildings in your town that light up for other causes? Is there a prominent landmark or building in your state/skyline that could easily be lit up purple for a day? Can you purchase purple flood lights? Think about the possibilities for lighting up your home or local businesses! Find a friend and start brainstorming before you sit down to do your research online, by email, and phone.

Building Name and Location (City, State)	Building Contact Name	Phone	Email

## Make Contact

Once you identify some promising potential partners, make contact using our template letters and scripts in this toolkit. Also consider printing the flyer and going there in person to ask who is the best person to help with a lighting request. Be prepared with your 1 minute pitch about sarcoidosis and why it would be so meaningful for them to support you by honoring this request. Emphasize our other lighting partners around the globe and that this movement is intended to have global reach and that all lighting partners will be featured in our outreach efforts, including a press release. See “Who are Our Lighting Partners?” for more information.

Once you make contact, be sure to note the person’s name and contact information that helps you with your request! We will ask you to provide those so we can invite them to be a lighting partner every year with this initiative.

## Make it Count

You are our eyes and ears in your local community! If you don’t tell us about a lighting partner, it’s unlikely that we will find out about it. Please follow these steps to ensure we can recognize the lighting partners you identify on our website and in the press release.

1. Go to [www.stopsarcoidosis.org/litforsarc](http://www.stopsarcoidosis.org/litforsarc) and complete the short form for EACH lighting partner you identify. We’ll need you to provide the building/landmark name, web address where you originally made your request, if applicable, address, and contact information for the person/people who championed your request.
2. Follow up with your lighting partner by April 10, 2019 to confirm participation
3. On April 13, 2019, plan to take a photo of your hometown landmark and submit it via the form on our website at [www.stopsarcoidosis.org/litforsarc](http://www.stopsarcoidosis.org/litforsarc). You can also join the movement on social media by sharing your photo with #litforsarc.
4. Say thanks! Reach out to the people who helped shine a light on sarcoidosis and thank them for their participation in Illuminate the Night: Shine a Light on Sarcoidosis. Be sure to share any press that came from the event so they can see how their effort was part of a bigger movement.

We hope this inaugural year of this initiative ignites a movement that will only grow in future years. Thank you for joining us in shining a light and igniting hope for those touched by sarcoidosis everywhere.

## Who are our lighting partners?

**Our first lighting partner in 2019 is One World Trade Center in New York City!** Will your city join them shining a light on sarcoidosis? A growing list is joining them and will be available on our website at [www.stopsarcoidosis.org/litforsarc](http://www.stopsarcoidosis.org/litforsarc) as we approach April. Our goal is to see at least 100 buildings across the globe #litforsarc on April 13, 2019 and to have at least one lighting partner in each of the 50 states and the District of Columbia.

## About the Awareness Campaign

The Foundation for Sarcoidosis Research and the [American Lung Association](#) have teamed up for the fifth annual **Seek Answers. Inspire Results.** campaign to coincide with April for Sarcoidosis Awareness Month.

**Seek Answers. Inspire Results.** is a national awareness campaign encouraging people living with sarcoidosis to take a proactive role in their treatment plan. It also aims to provide resources for anyone looking for answers about sarcoidosis, whether they are a patient still awaiting a diagnosis, a chronic sufferer of the disease, someone looking to understand the experiences of their loved one, or just a member of the general public.

The campaign offers educational resources about sarcoidosis, as well as in-person and online opportunities to connect with healthcare providers experienced in the diagnosis and management of sarcoidosis. It will also encourage people to increase public awareness for this disease by equipping patients with resources to spark conversations in their own communities and harness the power of social media throughout the month of April.

## What is Sarcoidosis?

Sarcoidosis (SAR-COY-DOE-SIS) is an inflammatory disease that can occur in any demographic regardless of age, gender or race, however, it often strikes people with a wide array of mysterious symptoms in the prime of their lives between 20-40 years of age. It occurs when an individual's immune system goes into overdrive and they develop granulomas, tiny clumps of inflammatory cells, in one or more organ of their body. When too many of these clumps form, they can interfere with an organ's function and lead to permanent damage. The cause of this disease is unknown.

While the organs involved and progression of the disease vary widely, 90% of patients have lung involvement. Spontaneous remission is common, however, 30-40% of patients develop major organ involvement which can lead to organ failure and death. Others face reduced quality of life due to the symptoms of the disease which include chronic pain and uncontrollable fatigue and/or side effects from treatment. Despite progress in research, sarcoidosis remains hard to diagnose with few reliable treatment options and no known cure.

## Focus on Advanced

There is a tendency among doctors, researchers, and advocates to speak of sarcoidosis as a disease that is not serious or one that resolves. Statements such as, "*with good medical care, most cases of sarcoidosis are controlled*" can be misleading and harmful; they convey a message that if patients are proactive, they will go into remission or be able to easily manage the disease. Furthermore, it reinforces the beliefs among many clinicians that it's

appropriate to diagnose patients with sarcoidosis and declare it to be “*good news.*” This is especially problematic for patients who will go on to suffer from advanced sarcoidosis.

FSR is has always been committed to finding a cure for this disease and to improving care for sarcoidosis patients. However, if we continue to be complacent with the use of messaging that guides patients towards a place of complacency and comfort as opposed to one of empowerment and proactiveness, we are perpetuating the problem. **We refuse to uphold the false beliefs that sarcoidosis is not a serious diagnosis, that current therapies work, and that the complaints of sarcoidosis patients are unfounded or exaggerated. We will always strive to be part of the solution.**

While the Seek Answers. Inspire Results. campaign has been extremely effective in promoting general awareness about sarcoidosis, it has not consistently conveyed the seriousness of this disease. The Illuminate the Night: Shine a Light on Sarcoidosis initiative is just one of the ways in which FSR seeks to shed a light on this rare disease.

# One World Trade Center in NYC is lighting up purple for World Sarcoidosis Day

## *How will you raise awareness?*

Volunteers around the globe are rallying together to paint their towns purple to promote awareness for sarcoidosis on April 13, 2019. Please join our growing list of partners who will illuminate landmarks purple in support of patients living with this rare disease. **Illuminate the Night: Shine a Light on Sarcoidosis** will raise awareness about sarcoidosis and ignite a movement to help patients everywhere!

### **What is Sarcoidosis?**

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Learn more and join the fight for awareness at [www.stopsarcoidosis.org](http://www.stopsarcoidosis.org).

**#LitforSarc**

*Sample letter requesting proclamation and illumination support*

Dear \_\_\_\_\_(Governor's Name),

My name is \_\_\_\_\_ and I am a (sarcoidosis patient and) volunteer for the Foundation for Sarcoidosis Research. As one of your constituents in \_\_\_\_\_(HOME STATE), I hope you will help me by:

1. Lighting the Capitol building or other state landmark purple on April 13th, World Sarcoidosis Day
2. Recognizing April 2019 as Sarcoidosis Awareness Month with a proclamation

Our goal is to see at least one building/landmark in each state lit up purple on World Sarcoidosis Day in support of FSR's *Illuminate the Night: Shine a Light on Sarcoidosis* initiative. Seeing the (State Name) Capitol or (other monument – customize as appropriate) lit up alongside our growing list of partners which includes One World Trade Center in New York City would be extremely meaningful for me and sarcoidosis warriors. A flyer with more information is attached.

Furthermore, I would greatly appreciate you showing your support for those touched by sarcoidosis in \_\_\_\_ (state name) by issuing a proclamation recognizing April 2019 as Sarcoidosis Awareness Month. We greatly need more awareness for sarcoidosis as it has no known cause, few reliable treatment options, and no known cure. By issuing a proclamation, you will put our state on the map in this national campaign and ensure those constituents whose lives have been touched by this disease feel seen and heard. I'm happy to provide language which might be helpful in drafting a proclamation.

(Include short story about sarcoidosis and how it affects your lives/the lives of other individuals in your home state, what their support would mean to you.)

I appreciate your consideration. and look forward to working with your office on this important endeavor.

All the best,

(Name)

(Contact Information)

*Illumination Support Letter*

Dear Building Manager/Mayor/Governor \_\_\_\_\_:

On behalf of the Foundation for Sarcoidosis Research (FSR), I invite you to join a global initiative by lighting up (Building/Monument/Business Name) purple on April 13, 2019 in recognition of World Sarcoidosis Day.

Volunteers around the globe are rallying together to paint their towns purple to promote awareness for sarcoidosis, an inflammatory disease with no known cause, few reliable treatment options, and no known cure. You can help by joining our growing list of lighting partners which includes One World Trade Center in NYC. Lighting partners in the **Illuminate the Night: Shine a Light on Sarcoidosis** initiative will be featured on FSR's website, a press release, and in worldwide communications celebrating the movement.

Our goal is to see at least one building/landmark in each state lit up purple on World Sarcoidosis Day and I appreciate any help you can provide in ensuring \_\_\_\_ (building/landmark/state/city name) on the (map/list of partners.) A flyer with more information is attached.

Thank you for your consideration.

Sincerely,

(Signature and title)

(Contact information)