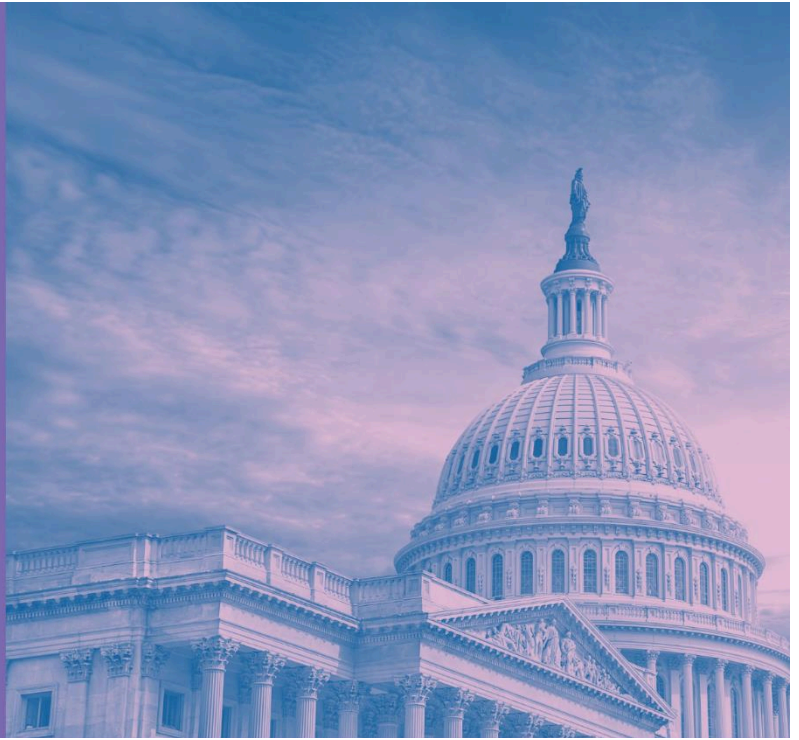




FOUNDATION FOR
SARCOIDOSIS RESEARCH
Proclamation Toolkit
Making Your Voice Heard



The Foundation for Sarcoidosis Research (FSR) is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support. Since its establishment in 2000, FSR has fostered over \$5 million in sarcoidosis-specific research efforts.



Securing a Proclamation for Sarcoidosis Awareness Month

City and state proclamations are an excellent way to increase awareness for sarcoidosis! And getting a proclamation is much easier than one might imagine.

Where to Begin

- Find the names and contact information of your elected officials.
 - Visit your town/city's website first. Learn about your elected officials and to which communities/committees they belong.
 - If there is a councilman/woman specifically designated to your community, contact them first. If not, decide who will be the best advocate for your cause.
 - Determine if there is an application process for proclamations
 - Is the application online? Do you submit the request by mail?
 - What is the timeline for securing a proclamation?
- Contact the office of your elected officials. Inquire about the process of obtaining a proclamation, if the information wasn't available online.
 - Know in advance what it is that you want. See page 2 for a sample letter of request and page 3 for a sample proclamation.
 - Make it your own! The only reason your official will care and act is if you speak to why you care about the cause! They'll care too because you are their constituent.
- Request a meeting to discuss your request in more detail. The more personalized your approach, the more likely the official will act to make a proclamation a reality.

Preparing to Meet an Official

- Get to know the government official and/or aide/person you're going to meet
 - To what committees do they belong?
 - How have they voted on issues concerning health care and advocacy?
 - Look for connections you may have with them. Where are they from? Where did they go to school? What issues do they care about?
 - Thank them for something they did or voted on.
 - Determine what district to which you belong and/or whether you're one of their constituents. If so, be prepared to mention it in the meeting.
- Go in knowing exactly what you want to say and be prepared to explain yourself. Make sure that you mention:
 - April is Sarcoidosis Awareness Month
 - Brief overview of sarcoidosis and why you want to raise awareness. This is a great opportunity to tell your story and share how sarcoidosis affects other citizens in your community!
 - Prepare questions. How will the proclamation be officially presented? Would they be willing to present it at a local event? At a support group meeting? With a press release?
- Bring printed materials with you, when possible. Email info@stop sarcoidosis.org to request materials and information by mail.
 - Direct the officials to FSR's website to learn more information.
- Dress professionally and arrive 10 minutes early



Meeting with the Official

- Relax! They work for you!
 - Mention your district and/or whether you're a constituent
 - Eye contact shows confidence and shows you are passionate about your cause.
 - Share your story and those of other patients in your community!
 - Answer questions and discuss your points in detail. If there's a question to which you don't know the answer, tell the official you'll find out and follow up with them.
- At the end of the meeting, thank them for their time and for listening.
- Ask the official when you can follow up with them about securing the proclamation.
- Always follow up a meeting with a letter thanking them again for their time. Call their office after the agreed upon amount of time if you don't hear back.

When a Proclamation is Issued

- Call the office and thank them.
- Ask for the date when the proclamation will be signed. Find out who you may contact in the office to follow up on the process.
- Once you have a date for the proclamation signing, confirm the number of guests who can attend. The office may ask you to submit a list of guests in advance of the presentation.
- Ask about how the office plans to publicize the signing.
 - Offer to support their efforts by preparing a press release and sharing it with local newspapers, radio, and TV stations.
 - Notify physicians and hospitals that treat sarcoidosis patients.
- Take photos! Share your photos on social media, with local media, and with the Foundation of Sarcoidosis Research at info@stop sarcoidosis.org. We will feature them on our website and in social media.

Once you've received a proclamation from your town/city, you can move to the next government level!

- For a city proclamation, start with the mayor's office.
- For a proclamation signed by city councils or state assemblies, start by contacting the office of the chairperson or president.
- For a state proclamation, start with the governor's office.



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Sample Proclamation Request Letter

Dear Mayor/Governor/Councilmember _____:

On behalf of the Foundation for Sarcoidosis Research, I am writing to request your proclamation of the month of April as Sarcoidosis Awareness Month in the city/state of _____.

Sarcoidosis is a systemic, inflammatory disease that can affect almost any organ in the body. It occurs when a person's immune system overreacts resulting in the formation of granulomas, microscopic clumps of inflammatory cells. Patients can experience a wide range of debilitating symptoms which can lead to death - the cause remains unknown.

Sarcoidosis Awareness Month offers a rare opportunity to focus attention on this devastating illness.

(Briefly discuss why you care and local activities/support for sarcoidosis)

In recognition of sarcoidosis and 175,000 patients suffering across the United States, we ask that the city/state of _____ issue a proclamation for Sarcoidosis Awareness Month. We would be particularly honored to have you present this proclamation at (describe the event at which you would like the proclamation read).

More information and sample language that might be helpful in drafting a proclamation, is attached. We look forward to working with your office on this important endeavor and in representing our city/state in this major international campaign.

Thank you for your consideration.

Sincerely,

[Signature and title]



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Sample Proclamation:

Whereas, sarcoidosis is a potentially debilitating and deadly multi-organ, inflammatory disease, estimated to affecting 175,000 people in the United States with no known cause, cure, or reliable treatments to slow or halt the progression of chronic cases;

Whereas, the signs and symptoms of sarcoidosis vary widely depending on the person and organs affected and can include debilitating fatigue; shortness of breath; difficulties with balance and coordination; irregular heartbeat; visual problems, including blindness; pain affecting joints and muscles; weakness or numbness of limbs; skin rash and discoloration; mood disorders such as depression and anxiety; organ failure; and sleep difficulties;

Whereas, Sarcoidosis can affect people of any age, race, or gender, but is most common among adults between the ages of 20 and 40 and 3.8-fold higher in African Americans than in whites;

Whereas, sarcoidosis is a diagnosis of exclusion as there is no objective test or biomarker; numerous diagnostic tests and ongoing clinical observation and/or management lends to high economic burden of this disease, including great costs to patients and family members;

Whereas, volunteers, researchers, caregivers, and medical professionals are working to improve the quality of life and prognosis of persons living with sarcoidosis and their families and more research is needed to find more effective treatments and improve care for those living with the disease today;

Now, therefore, I, _____, do hereby proclaim April as Sarcoidosis Awareness Month. In Witness Whereof, I have hereunto set my hand and caused the Great Seal of _____ to be affixed.

Done at _____ in the _____ this _____ day of _____ in the Year of Our Lord two thousand _____.