

2024 GUIDE TO OBTAINING LUPUS AWARENESS MONTH PROCLAMATIONS

Help Us Solve The Cruel Mystery LUPUSTM



Lupus Awareness Month Proclamation Guide

A great way to engage lupus advocates and your local elected officials is by obtaining proclamations during Lupus Awareness Month each May, and this document will provide a stepby-step guide on how to obtain proclamations. Please keep in mind this guide does include an option for an in-person ceremony for the signing of the proclamation, but we recognize that this may not be possible. If an in-person ceremony is not possible or not something your participants are comfortable with, the entire process can take place digitally.

- 1. **Determine what kind of proclamation you are seeking.** This campaign should target state and local officials, **not federal officials**. Any state or local governing body could issue a proclamation of this kind a proclamation at the state level would need to be adopted by the state government, while a more local proclamation could be acquired from a mayor, city council, etc.
- 2. **Identify your local elected officials**. Using your address, <u>identify your state elected</u> <u>officials</u> and decide who you will ask to assist you in this campaign. Once you've identified your state or local targets, use their website to figure out the best way to contact them.
- 3. **Send them a written request.** Provide your elected officials with some background information on lupus and why this proclamation would be so important to you and to the lupus community. Remember that elected officials are more likely to respond if you are part of their constituency, so make sure to include that you are part of the geographical area that they represent. **Sample request email included below

Follow-up as necessary. If you do not hear back from the office within a week, reach back out to the office to confirm it was received. You can also call the office and request a response or speak directly to someone in the office about the request.

- 4. **Finalize the proclamation text.** Once you have secured an elected official for the proclamation, invite the office to make any changes they see fit, i.e. adding local information about the toll of lupus.
- 5. **Arrange the ceremony**. When speaking to the elected official's office, request a brief ceremony for presenting the proclamation. Keep in mind that this ceremony is

contingent on the availability of the elected official. It does not need to be a long ceremony, but an opportunity for you to thank the elected official and for them to speak briefly about lupus and their connection to it. If digital, the ceremony can be recorded and shared on social media.

- 6. Capitalize on publicity opportunities. Contact the LFA's Advocacy Department to obtain a press release specifically for your proclamation. We also encourage you to take a photo of the proclamation with the elected official and the other attendees, or record and screenshot the digital ceremony to be used on social media (with the permission of the elected official).
- 7. **Maintain the relationship**. Following the ceremony, be sure to email your elected official and thank them for their support. Maintain the relationship by inviting them to future lupus events, especially those in their local area, and keeping them updated on lupus policy issues and the region's work throughout the year.

FORMAL REQUEST LETTER (ATTACH TO EMAIL)

DATE, 2024

<MEMBER NAME> <MEMBER POSITION> <MEMBER ADDRESS LINE 1> <MEMBER ADDRESS LINE 2>



Dear <MEMBER NAME>,

On behalf of your constituents with lupus and the Lupus Foundation of America, we would like to request your support during Lupus Awareness Month this May. **By enacting a proclamation that designates May as Lupus Awareness Month and participating in a ceremony (either digitally or in-person) to present the proclamation, you would be participating in our nationwide campaign to enact such proclamations and raise awareness about the devastating effects of lupus among the lawmakers and citizens of <STATE>.**

Lupus is an unpredictable and misunderstood autoimmune disease that ravages different parts of the body, including the heart, lungs, kidneys, joints, and skin. It is difficult to diagnose, hard to live with, and a challenge to treat. Symptoms are heterogeneous both across the overall population with the disease and across individual patients' lifetimes. Common symptoms include extreme fatigue, joint and muscle pain, rashes, photosensitivity, organ inflammation, and, in many advanced stages of the disease, kidney damage or failure.

Estimates suggest that at least 1.5 million Americans are living with lupus. Although the disease does impact men and children, 90% of people diagnosed with lupus are women, with 80% of new diagnoses made during childbearing years. Lupus also disproportionately impacts women of color, who are twice as likely to develop the disease as Caucasian women.

The Lupus Foundation of America (LFA) is the largest publicly supported lupus organization devoted to solving the mystery of lupus, one of the world's cruelest, most unpredictable and devastating diseases. Through a comprehensive program of research, education, support services and advocacy, we lead the fight to improve the quality of life for all people affected by lupus. LFA has a strong commitment to advancing lupus research for both adult and pediatric populations and does this through a variety of methods including funding research, building collaborative research partnerships, and advocating for increased federal research funding.

<Use this space to expand on some of the work your region/state is doing>

The proclamation itself is attached below for your review. We look forward to working collaboratively with you and your colleagues to continue to support people with lupus in the state and create a world without lupus. If you are interested in participating in this campaign, please let me know and we can connect on next steps and logistics. Sincerely, **<YOUR NAME>**

SAMPLE PROCLAMATION TEXT

Whereas, lupus is an unpredictable and misunderstood autoimmune disease that can cause severe damage to the tissue and organs in the body and, in some cases, death; and

Whereas, more than five million people worldwide suffer the devastating effects of this cruel and mysterious disease and each year over a hundred thousand young women, men and children around the world are newly diagnosed with lupus, the great majority of whom are women of childbearing age; and

Whereas, medical research efforts into lupus and the discovery of safer, more effective treatments for lupus patients are under-funded in comparison with diseases of comparable magnitude and severity; and

Whereas, many physicians worldwide are unaware of symptoms and health effects of lupus, causing people with lupus to suffer for many years before they obtain a correct diagnosis and medical treatment; and

Whereas, there is a deep, unmet need worldwide to educate and support individuals and families affected by lupus; and

Whereas, there is an urgent need to increase awareness in communities across the U.S. and the globe of the debilitating impact of lupus;

Now, Therefore, Be It Resolved that the Month of May is hereby designated as Lupus Awareness Month, where the lupus community comes together to call for increases in public and private sector funding for medical research on lupus, targeted education programs for health professionals, patients and the public, and recognition of lupus as a significant public health issue.

Proclaimed This Day, XX XX, XXXX