

QUICK GUIDE SERIES

for Rare Disease

A Global Genes Quick Guide is a resource for advocates focused on pressing topics causing challenges in their lives and communities.

Quick Guide to Securing a State Proclamation for Rare Disease Awareness

For rare disease advocates in the United States, pursuing a state proclamation can be a powerful and accessible way to raise awareness and build momentum for future advocacy. Whether you're seeking recognition for a rare disease awareness day, week, or month, a proclamation from your state legislature or Governor can elevate visibility, attract media attention, and serve as a strategic first step toward deeper legislative engagement. And the best part? It's often more achievable than you might expect.

Thanks to Barby Ingle, a dedicated member of our Global Advocacy Alliance Leadership Council, we're able to provide you with a practical template to help secure a proclamation in your home state—and in any other state where you have an advocate willing to champion the cause locally. This tool empowers you to extend your impact beyond borders by activating your network and raising awareness in multiple communities.



"Proclamations are like fireworks: they can shine brightly or fade into smoke. When you receive yours, share it with the media and include personal stories that resonate. Use it to boost awareness, which can enhance understanding and research of your rare disease. Let your words inspire action!"

- Barby Ingle
Global Genes Global Advocacy Alliance Leadership Council, Board of Directors, International Pain Foundation

"Be prepared as much as you can when submitting a proclamation to provide statistics on *why* your proclamation should be approved. This isn't always something that's required but each city or state's criteria for approvals can differ. Reaching out to patient and health organizations can be helpful in gathering statistics and even partnering on the proclamation request. If your proclamation is denied, follow up with their office to inquire why. Sometimes even with a denial, a reconsideration can be requested."

- Jenny Jones, Rare Disease Advocate & Children's Book Author



After you complete the required form you'll need to craft the language you hope will be adopted as a proclamation by your legislature or governor. The key is crafting your WHEREAS statements to match your own rare disease.



"As someone who has successfully secured city and state proclamations in Nevada for over seven years, I recommend clearly explaining the cause or individual being honored and why recognition is meaningful to your city or state. State proclamations often require formal 'Whereas' language, so be sure to follow that format—many examples can be found online. City-level requests are typically less formal and can be made through a mayor, city councilmember, or equivalent, depending on your state."

– Georgene Glass, Founder of Dreamsickle Kids Foundation & RDAC Vice Chair, Nevada

Below is sample verbiage from Barby Ingle for requesting a proclamation for chronic pain awareness. You'll need to change each of these and any dates, statistics, the state named and the governor named to fit your own rare disease.

SAMPLE PROCLAMATION LANGUAGE

EXAMPLE: SEPTEMBER 2025 AS PAIN AWARENESS MONTH

WHEREAS, over 2,354,000 Washingtonians suffer from chronic pain, enduring debilitating conditions such as chronic lower back pain, diabetic peripheral neuropathy, fibromyalgia, and arthritis, while many others experience acute pain from injuries, surgeries, or medical procedures; and

WHEREAS, significant barriers to adequate pain care persist for Washingtonians, with chronic pain patients frequently consulting multiple healthcare providers and enduring years of untreated or mismanaged pain, and acute pain patients facing risks of inadequate treatment that may transition to chronic pain; and

WHEREAS, research demonstrates that improved treatment of acute pain can prevent its progression to chronic pain, yielding substantial savings by reducing workers' compensation costs, lost tax revenues, and the burden of opioid abuse and misuse, while better chronic pain management enhances patient outcomes and quality of life; and

WHEREAS, system and organizational barriers, including insurance reimbursement policies, obstruct patient-centered care for both chronic and acute pain patients, limiting access to timely and effective pain management; and

WHEREAS, increased awareness and education about the causes, consequences, management, and prevention of chronic and acute pain will empower patients, providers, and communities to support those affected, fostering a more compassionate and effective approach to pain care.

NOW, THEREFORE, BE IT RESOLVED, I, Governor Jay Inslee, Governor of the State of Washington, do hereby proclaim September 2025 as Pain Awareness Month, recognizing the urgent need to address both chronic and acute pain to improve the health and well-being of all Washingtonians.

You may decide to add more or fewer WHEREAS statements to reflect the needs in your rare disease community.

Additional Resources:

[How to Obtain a Proclamation or Resolution](#), while this .pdf guide is written for Ataxia it can be applied to other rare diseases as well.

[A Guide to Awareness Proclamations: What Are They and Why Do They Matter?](#) In this piece for [RareDisease.net](#) Global Genes contributor Jenny Jones walks you through how to get started and what to do after you succeed in getting a proclamation.

We are grateful to the [EveryLife Foundation for Rare Disease](#) for all their work leading the way on all aspects of legislative advocacy for people affected by rare diseases. Please consult their [resources](#) page and these related resources they offer:



[Fostering a Relationship with Your Members of Congress](#)
[Scheduling a Meeting with Your Legislator](#)
[Social Story on Meeting with Your Legislator](#)
[Sharing Your Story with Policymakers](#)

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