

## Background

Marfan syndrome is a potentially life-threatening connective tissue condition that affects the heart and blood vessels, eyes, bones and joints, lungs, and other parts of the body. The most dangerous part of the condition is the impact on the aorta, the large artery that takes blood away from the heart. In affected people, the aorta is prone to enlarge and can tear or rupture, causing sudden early death. That's why early diagnosis and treatment are so critical. More than 200,000 people in the U.S. have Marfan and related conditions, but experts say that half are not diagnosed. Awareness saves lives.

## Description

Awareness of Marfan syndrome and related disorders leads to early diagnosis, treatment, and an extended lifespan. February is Marfan Awareness Month, a time when The Marfan Foundation and all those in the Marfan community focus on raising awareness of Marfan syndrome and the signs of Marfan so that people can seek a life-saving diagnosis and treatment if they suspect that they, or a loved one, might be affected.

## How to Ask for a Proclamation

1. Find out to whom the request should be sent for processing. It can be your governor, city mayor, or county commissioner. Calls can identify the correct office, which often has standard procedures for issuance of official proclamations.
2. Invite the official to present the proclamation at a public event that offers press coverage. This may be more difficult (and in some cases, unsafe) during the COVID-19 pandemic, so you may consider asking them to take a picture with the proclamation and send it to you for social media or post it online themselves.
3. If the governing body you are requesting the proclamation from does not have a policy limiting the number of proclamations, they should not be hard to get. Getting an official to attend an event or participate online can be trickier, so if it doesn't work the first year, don't be discouraged!
4. Use the letter on page two as a sample letter to send to your representative. **If you need to tailor this letter to include your specific story to encourage your representative, do so!**
5. Your representative may ask for a sample proclamation to use. If so, provide them with the sample on page three.
6. After your event or receipt of a proclamation for Marfan Awareness Month, send a thank-you email or letter to the official who issued the proclamation!
7. Email us a picture! We want to share all proclamations we've received on social media.

### A Letter Requesting a Proclamation

Dear \_\_\_\_\_,

On behalf of myself and others affected by Marfan syndrome, I am writing to request that February be proclaimed as Marfan Awareness Month in the (county/city/state of \_\_\_\_\_)

Marfan syndrome is a potentially life-threatening connective tissue condition that affects the heart and blood vessels, eyes, bones and joints, lungs, and other parts of the body. The most dangerous part of the condition is the impact on the aorta, the large artery that takes blood away from the heart. In affected people, the aorta is prone to enlarge and can tear or rupture, causing sudden early death. That's why early diagnosis and treatment are so critical. More than 200,000 people in the U.S. have Marfan and related conditions, but experts say that half are not diagnosed. Awareness saves lives.

The Marfan Foundation's mission is to save lives and improve the quality of life for people living with Marfan syndrome and related conditions. The Foundation pursues the most innovative research and ensures that it receives proper funding. creates an informed public and educated patient community, and also keeps the medical community up-to-date to increase early diagnosis and ensure life-saving treatment. In addition, the Foundation provides relentless support to families, caregivers, and healthcare providers.

In recognition of the importance of and the threats it imposes on the lives of our citizens, we ask that the (county/city/state of \_\_\_\_\_) issue a proclamation for Marfan Syndrome Awareness Month, declaring it as the month of February.

We look forward to working with your office on this journey in representing the (county/city/state of \_\_\_\_\_) in this important global campaign. Thank you for your consideration.

Sincerely,

**Draft Copy 1**

In Recognition of Marfan Awareness in [State]

Marfan syndrome is a life-threatening genetic condition, and an early, accurate diagnosis is essential, not only for people with Marfan syndrome but also for those with a related condition. Knowing the signs of these conditions can save lives. Approximately 200,000 people in the U.S. have these conditions. Only with an accurate diagnosis and treatment can affected people live a full life span. Otherwise, they are at risk of an early sudden death due to a tear in their aorta, the large blood vessel that takes blood away from the heart.

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February is Marfan Awareness Month. Throughout the month, The Marfan Foundation and all those with Marfan syndrome and their families are focused on raising awareness about the signs of Marfan syndrome so that people who might be affected but do not know can get a life-saving diagnosis and treatment.

The State of [State] commends The Marfan Foundation for its commitments to individuals living with Marfan syndrome and related disorders, and their families, and extends best wishes for a successful month of increasing awareness and saving lives.

**Draft Copy 2 - A Proclamation**

**Whereas**, Marfan syndrome is a life-threatening genetic connective tissue condition that can involve many parts of the body including the heart and blood vessels, eyes, bones and joints, and lungs; demonstrated by varying degrees of disability, pain, muscular skeletal issues, often resulting in a lifelong series of multi-system health-related maladies; and

**Whereas**, It is estimated that 1 in 5,000 individuals worldwide are born with Marfan syndrome, regardless of race, gender, ethnicity; and

**Whereas**, the number and severity of symptoms associated with Marfan syndrome differ greatly among individuals even among members of the same family; and

**Whereas**, all expressions of Marfan syndrome are life-long, incurable, and potentially debilitating. Because it is a life-threatening genetic condition, timely diagnosis and treatment is essential; and

**Whereas**, Marfan syndrome is often misdiagnosed and may be an under-diagnosed condition; and

**Whereas**, through public awareness, the State of [STATE] seeks to raise awareness of Marfan syndrome in order to properly diagnose and treat individuals affected by this condition.

Now, Therefore, I, NAME, Governor of STATE, do hereby proclaim The Month of February 2023, to be,

MARFAN SYNDROME AWARENESS MONTH