

## Sample Letter Requesting a Proclamation

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

On behalf of people affected by Marfan syndrome, <<OR INSERT PERSONAL SENTENCE OR TWO i.e. “like me, like my <<family member>>” etc.>> I am writing to request that February be proclaimed as Marfan Syndrome 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, joints, lungs, and other parts of the body. 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 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. The Marfan Foundation’s mission is to save lives and improve the quality of life for people with Marfan syndrome and related conditions.

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.

Thank you for your consideration.

Sincerely,

\_\_\_\_\_

EXAMPLE: Letter of Proclamation

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. 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 commitment to individuals living with Marfan syndrome and related conditions, and their families, and extends best wishes for a successful month of increasing awareness and saving lives.

EXAMPLE- 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 are 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