

A Division of The Marfan Foundation

Background

Local (city, county) proclamations are a great way to secure local government recognition of a program- and getting a proclamation is much easier than it may seem! Proclamations “proclaim” a specific day, week, or month, as the program you are asking to declare. A written proclamation is a kind of merit from an official for a program, and is great for promoting it year after year. Most proclamations will have a shelf-life, so this is a great activity that can be done every year.

Awareness of VEDS leads to early diagnosis, which is important for treatment and care. October is VEDS Action Month, a time when The VEDS Movement and the community focus on raising awareness of VEDS and the signs so people can seek diagnosis and treatment if they suspect they may 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 VEDS Action Month, send a thank-you email or letter to the official who issued the proclamation!
7. If you receive a proclamation letter, post a picture of it online and tag us @VEDSMovement to let us know!
8. You can also use a proclamation to direct media attention to VEDS. Check with your local news or radio station.

Be sure to let us know if you receive a proclamation letter from your representative by emailing us or tagging us online @VEDSMovement!

Date

Dear (local representative)

On behalf of myself and others affected by Vascular Ehlers-Danlos Syndrome (VEDS), I am writing to request that October be proclaimed as VEDS Action Month in the (county/city of _____)

Vascular Ehlers-Danlos Syndrome is estimated to affect approximately 1 in 50,000 individuals of all sexes, races, and ethnicities, but because it is rare, many people do not know they have it. This can place people at risk in an emergency, when knowledge of the condition and emergencies associated with it are critical.

Characteristics that affect some people, but not all, are fragile, translucent skin, characteristic (but subtle) facial appearances, early-onset varicose veins, easy or unexplained bruising, hypermobility of some of the joints, and premature skin aging. Regardless of the presence or lack of these outward signs, all individuals with VEDS are prone to spontaneous arterial and aortic dissections, bowel perforations, lung collapse, bleeding lungs, hollow organ rupture, and other life-threatening emergencies. VEDS is a genetic condition, which means it can be passed on in families, even though about half of the people diagnosed are the first in their families with the condition. Each child of an affected parent then has a 50% chance of inheriting it. Unfortunately, there is no proven treatment to prevent the life-threatening emergencies that are associated with this condition.

Our mission is to give hope to all those whose lives are affected by VEDS. The focus of the month will include physician education initiatives, research initiatives, awareness and fundraising campaigns, advocacy for those living with the condition, and community-building for all of those affected by VEDS. In the effort to raise awareness of VEDS, this Action Month could spark a worldwide consideration for the future of medical research in curing or preventing the severe emergencies and symptoms associated with VEDS, giving hope for a longer, better life for those diagnosed.

[The VEDS Movement](#), a division of [The Marfan Foundation](#), is launching the second annual VEDS Action Month this year by providing resources to educate healthcare professionals, medical students, supporters, and all who suffer from the condition, and building the community of those affected. The Movement's mission is to save lives and improve the quality of life of those affected by Vascular Ehlers-Danlos Syndrome.

In recognition of the importance of the VEDS and the threats it imposes on the lives of our citizens, we ask that the (county/city of _____) issue a proclamation for VEDS Action Month, declaring it as the month of October.

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

Sincerely,

Proclamation

By: _____

A proclamation declaring October 2021 as Vascular Ehlers-Danlos Syndrome Action Month, and directing distribution.

WHEREAS, Vascular Ehlers-Danlos Syndrome (VEDS) is a life-threatening genetic connective tissue condition that can cause spontaneous life-threatening emergencies of the blood vessels and hollow organs, can cause varying degrees of disability, pain, and muscular skeletal issues, and can result in life-long health challenges and early death;

WHEREAS, it is estimated that 1 in 50,000 individuals worldwide are born with VEDS,

WHEREAS, VEDS is a lifelong, incurable, potentially debilitating, and life-threatening genetic condition, and timely diagnosis and life style modifications are essential,

WHEREAS, VEDS is often misdiagnosed and underdiagnosed,

WHEREAS, VEDS is frequently mistaken for other forms of Ehlers-Danlos Syndrome, some of which do not carry the same risks for life-threatening emergencies,

WHEREAS, through public awareness, the state/county of _____ seeks to raise awareness of VEDS in order to properly diagnosis and care for individuals affected by VEDS,

and WHEREAS, further medical research and awareness can provide hope for a treatment and a cure for VEDS.

NOW, THEREFORE, I, _____, do proclaim the Month of October, 2021, to be VEDS Action Month,

AND urge all citizens of _____ to participate fittingly in its observance,

AND direct a copy of this proclamation be sent to The VEDS Movement, a division of The Marfan Foundation.

Signed by: _____