DYSAUTONOMIA
SUPPORT NETWORK

Ehlers-Danlos Syndrome Proclamation and Advocacy Toolkit

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How to Request a Proclamation for Ehlers-Danlos Syndrome Awareness Month in May

Having your hometown, county, city or state declare May as Ehlers-Danlos Syndrome Awareness Month is much simpler than you may think. It requires your town, county or city council and state governor to pass a non-binding resolution. Begin the process in February or soon after to coordinate with your state or local government officials. DSN will walk you through the simple step-by-step process:

Getting Started

1. Email Dysautonomia Support Network at advocacy@dysautonomiasupport.org to let us know which town, city, county, and/or state government you plan to ask for a proclamation from. This will help us update/maintain our list, so volunteers are not working on proclamations for the same locations. If there is another volunteer already working on the local or state government you want to target, we can connect you to increase awareness efforts in your area or work on different local government proclamations.

***2.* Check the "DSN State Contacts for Proclamations" to determine how to submit for requests for your state.**
Requests for statewide proclamations are made to the governor of that state. For many proclamations at the state level, all that is required is simply asking for a proclamation, many by filling out a form online. This DSN document includes links to the Governor's office in each state, instructions to submit the proclamations and the time frame you need to submit the proclamation application.

***3.* Research your hometown and county elected officials.** To ask for instructions on how to obtain a proclamation from a town, city, or county, you can start by contacting the clerk from your local government. This could include the Board of Commissioners or Board of Supervisors (whichever is applicable in your area). You can visit the website for your local town, city, or county to find the phone number for the appropriate office. The letter template and proclamation that are enclosed in this packet can be used in all types of local governments.

4. Ask your hometown and county officials if they will help you obtain a proclamation recognizing May as Ehlers-Danlos Syndrome Awareness Month.
When calling, be prepared to provide information about the impact of Ehlers-Danlos Syndromes in your community if possible, and even if you or a loved one happen to have it and you are willing to share this information

See the Top 10 Ehlers-Danlos Syndromes Facts within this kit to help you be prepared.

Questions you can ask the person on the phone:

- Will you be able to help me obtain a proclamation in early May for Ehlers-Danlos Syndromes Awareness Month?
- What is the process for me to be successful in time, to be granted a proclamation this year?
- Will you allow me to submit a sample proclamation?
- How should I submit the proclamation request: hard copy, electronic version, or both?
- Will there be a proclamation signing ceremony/proclamation reading ceremony or how will the proclamation be delivered?
- Do you have a dedicated contact within the press so as to allow for media coverage of the proclamation?

5. Prepare the required documents to request the proclamation.
You can use this sample cover letter and customize with personal details and a paragraph about your personal story with Ehlers-Danlos Syndromes.

If your local or state government will allow you to submit an example of a proclamation, we have provided one, you can use this sample proclamation.

6. Submit your cover letter and draft proclamation to the state or local government office in the format required by that office.
Politeness and persistence will pay off. Follow up on the status of your proclamation request a week to ten business days after submission.

7. Picking up the Proclamation
If you are going to pick up the signed proclamation, make an appointment to pick it up once it is officially signed. Dress professionally when you visit a government office and advocate for Ehlers-Danlos Syndromes patients in your area. If your elected official allowed you to schedule a proclamation signing ceremony you may have the opportunity to be called up to speak and or take photos with the elected officials. Remember to take and submit photos for a local newspaper on Ehlers-Danlos

Syndromes awareness! If you do not live close enough or would otherwise be unable to go, especially for a state ceremony, please contact advocacy@dysautonomiasupport.org so that we can work with your state chapter volunteers to find out who will be able to attend.

Ask the government or elected officials if they will post about Ehlers-Danlos Syndrome Awareness Month and direct people to the Dysautonomia Support Network website, www.dysautonomiasupport.org, for more information on their social media accounts, such as Twitter, Facebook, or Instagram.

Ask if the public affairs office can help you get the photo of the proclamation ceremony with an article about Ehlers-Danlos Syndromes printed in the local newspaper to help raise awareness. For more helpful tips about requesting media coverage and using social media to increase awareness about Ehlers-Danlos Syndromes, check out our guide on How to Request Media Coverage.
You can use this -Sample Press Release- and customize with details about you and and your local proclamation.

8. Share your experience with Dysautonomia Support Network.
Email pictures of the proclamation ceremony, photo or scans of the proclamation document, and links to any media stories about your state or local proclamation to advocacy@dysautonomiasupport.org. Let us know who is in the photos (please have everyone fill out this photography release form) and where the ceremony took place. We will share your accomplishment on our Facebook page. Each time one of us achieves an awareness proclamation, it inspires other patients and caregivers to do the same in their hometown!

9. Be sure to thank everyone who has helped you to this point by sending emails or even mailing cards.
Thank You for all your hard work and persistence. It has paid off as we raise awareness about Ehlers-Danlos Syndromes and advocate for the people who live with it!

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State Contacts for Proclamation Requests

Are you asking your state or local governments to make a proclamation, such as a resolution, to support Ehlers-Danlos Syndromes Awareness Month?

Each U.S. state requires a state resident to submit a request before a proclamation is issued. Many states accept online submissions. For more tips on applying to your state or local government for a proclamation, view the DSN document How to Obtain a Proclamation.

The following is a list of U.S. state online proclamation request form links and deadlines:

State Online Form Link	**How many weeks in advance do you need to submit?**	**Notes**
Alabama	30 days	Fill out online form.
Alaska	4-6 weeks	
Arizona	6 weeks	
Arkansas	30 days	Organizations limited to 2 proclamation requests annually, proclamations should “not take sides in matters of political, ideological, or religious controversy, or individual convictions.”
California	Not specified	Contact Governor’s office for more information.

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Colorado	4 weeks	Contact Governor’s office for more information.
Connecticut	4 weeks	Fill out online form.
Delaware	3 weeks	Contact Governor's Communication Team if accompanied by press release.
Florida	4-6 weeks	
Georgia	45 days	Fill out online form. Only one request per organization per year.
Hawaii	4 weeks	Not more than 3 months prior
Idaho	3 weeks	Fill out form online. Can request a signing ceremony.
Illinois	4 weeks	2 proclamations per organization within the same calendar year
Indiana	6-8 weeks	Must be submitted by online form. No fax or mailing.
Iowa	6 weeks	Must be submitted by online form. No fax, calls or mailing. Indicate on form if you want a formal signing.

Kansas	6-8 weeks	Submit online or in mail. Include proclamation draft. Can request signing ceremony.
Kentucky	–	
Louisiana	2 weeks	Proclamation limited to 200 words, contact advocacy@dysautonomiasupport.org for proclamation template. No more than 45 days prior.
Maine	45 days	Cannot re-publish proclamation without consent from Governor
Maryland	8 weeks	In-person pick up not possible. Proclamations will be mailed
Massachusetts	20 days	Do not submit more than 30 days in advance. Request online or by mail.
Michigan	4 weeks	
Minnesota	20 days	No Proclamation form call Governor’s office and inquire.
Mississippi	Not specified	Contact for more information.
Missouri	3 weeks	Select Proclamation Request in subject.

Montana	–	Call and inquire.
Nebraska	At least 30 days	Submit by online form
Nevada	4 weeks	Mail or fax request.
New Hampshire	30 days	Use online for by following link.
New Jersey	Not specified	Scroll to and select “Request Proclamation” under Email Topic
New Mexico	4 weeks	Contact by online form or call for information
New York	Not specified	Or call 1-518-474-8390 between 9am-5pm
North Carolina	6 weeks	Fill out form online
North Dakota	6-8 weeks	Or call: 701-328-2200
Ohio	30 days	Call (614) 466-3555 or e-mail: Scroll to “Requesting Proclamations”

Oklahoma	Not specified	Proclamations are handled by the Oklahoma Secretary of State. No form available online, call (405) 522-4565 or email executivelegislative@sos.ok.gov
Oregon	30 days	State specific template. Contact advocacy@dysautonomissupport.org for template. Then send proclamation template by email to: gov.proclamations@oregon.gov
Pennsylvania	6-8 weeks	Contact the Governor's office
Rhode Island	45 days	Contact the Governor's office and upload proclamation document.
South Carolina	30 days	Email or call for more information.
South Dakota	3 weeks	Fill out form, attach proclamation, select want a response
Tennessee	3 weeks	300-350 words max. Fill out form online.
Texas	3 weeks	Click "I need assistance" and select complete required fields. Under issue click "Ceremonial item request."
Utah	6 weeks	Must be submitted online
Vermont	4-6 weeks	Fill out online form.

Virginia	45 days	No more than 120 days prior. Must use online form. Must get approval from Governor for press release. Only one request per organization per year.
Washington	30 days	Single page 12 pt font.
West Virginia	30 days	Will need to submit via online and copy and paste “whereas” statements into the form.
Wisconsin	4 weeks	Call 608-266-1212 for more information
Wyoming	2 weeks	Can mail, hand deliver or Email request to ruth.critchfield@wyo.gov. Multiple requests from same organization may not be honored.

Top 10 Ehlers-Danlos Syndromes Facts

1. Ehlers-Danlos Syndromes (EDS) are a group of 13 different inherited connective tissue disorders.There is no cure for EDS. Treatment is based on symptom management and improving quality of life.$_1$
2. EDS is characterized by joint hypermobility, skin hyperextensibility, and tissue fragility.$_1$
3. Most, if not all types of EDS are caused by alterations in fibrillar collagen genes or genes that encode collagen modifiers. Collagen, is a protein that is found in connective tissue. Connective tissue helps provide strength and elasticity in the body. $_1$
4. The Beighton Score is the most recognized tool to assess for generalized joint hypermobility. Generally a score of greater than or equal to 5 points out of 9 can indicate hypermobile EDS.$_1$
5. Those with hypermobile EDS (hEDS) can have gastrointestinal symptoms such as nausea, vomiting, abdominal pain, feeling full after eating, irritable bowel-like symptoms, constipation, and diarrhea.$_{2-6}$
6. Those with EDS can also have symptoms of autonomic dysfunction such as presyncope, lightheadedness, dizziness, fainting, palpitations, chest pain, neuropathies, and impaired peripheral vasoregulation.$_{7-9}$
7. A large survey of those with EDS found that 98% of patients experience chronic musculoskeletal pain. 85% of patients reported that the pain can change in severity over time but is continuously present.$_{10}$
8. Those with vascular EDS (vEDS) can have ruptures of arteries and other tissues and spontaneous pneumothorax resulting in medical emergencies. They need to have emergency plans in place.$_1$
9. Mast Cell dysregulation has been implicated in connective tissue disorders, including EDS resulting in varied symptoms of allergic reaction ranging from flushing and itching all the way to life threatening anaphylaxis.$_{11}$
10. Some people have what is known as the “trifecta” where they have Ehlers-Danlos Syndrome, Mast Cell Activation Disorder, and Postural Orthostatic Tachycardia Syndrome (POTS), a form of dysautonomia. Researchers may have found a genetic explanation linking them all, the alpha tryptase gene.$_{12}$

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Sample letter- be sure to personalize the letter and change the highlighted portions to fit who you are requesting the proclamation from.

DATE

The Honorable John (or Jane) Jones
Governor of _______________
State Capitol Address
City, State, Zip code

Dear Governor Jones**,**

As a concerned resident of [STATE/COUNTY/Town] and a patient with a condition called Ehlers-Danlos Syndrome, I am asking (STATE/COUNTY/TOWN) to help raise awareness for Ehlers-Danlos Syndromes and the impact it has on the lives of those affected by this condition by issuing a Proclamation declaring May to be Ehlers-Danlos Syndromes Awareness Month in (STATE/COUNTY/TOWN)**.**

Ehlers-Danlos Syndromes are a group of inherited connective tissue disorders that greatly affect the body in many ways. Connective tissues are found everywhere in the body. They are made up of strong proteins that allow for body tissue to be stretched, but not beyond its limit, and then return to a normal position and function. In Ehlers-Danlos Syndromes there are problems with the proteins of the connective tissue that can cause the tissues to be pulled beyond normal limits, causing damage.

There are thirteen different types of Ehlers-Danlos Syndrome, each with unique manifestations depending on the genetic cause. They can result in symptoms such as joint hypermobility, with joints that are loose and unstable, that can dislocate easily. Skin can also be hyperextensible causing it to be fragile, velvety and hyperelastic and resulting in bruises, scars and skin tears. Many with Ehlers-Danlos Syndrome also have musculoskeletal problems ranging from chronic, early onset, debilitating pain, scoliosis and poor muscle tone. Some with Ehlers-Danlos Syndrome also deal with comorbid conditions such as mast cell disorders and dysautonomia.

I am one of the 1:2,500-5,000 people worldwide that live with Ehlers-Danlos Syndrome.

TELL YOUR STORY HERE!
Include some of the following:
What Type Of Ehlers-Danlos Syndrome Do You Have?

What are your symptoms?
When Were You Diagnosed?
Where Have You Had to Go for Diagnosis or Treatment? Did You Travel Out of Your Area?
What have your struggles been?

You Want To Keep This Section To A Two Paragraph Description.
Less Is More. Keep It Simple.

Although there is no cure for Ehlers-Danlos Syndromes, increased public and physician awareness and research offer hope for greater understanding, faster diagnosis, improved quality of medical care, and improved quality of life for patients and their families.

I have attached a sample proclamation along with some additional information on Ehlers-Danlos Syndromes. The proclamation was drafted by Dysautonomia Support Network, a 501(c)(3) non-profit that is dedicated to improving the lives of individuals affected by dysautonomia and its related conditions, Ehlers-Danlos Syndrome, being one of them. Dysautonomia Support Network provides support, resources, education, advocacy, and awareness to patients, family, caregivers, and providers. More information about Ehlers-Danlos Syndrome and Dysautonomia Support Network can be obtained at www.dysautonomiasupport.org.

Please let me know if your office is able to help us raise awareness of Ehlers-Danlos Syndromes by issuing the attached proclamation declaring May to be Ehlers-Danlos Syndromes Awareness Month in (STATE/COUNTY/TOWN). If possible, we would like to have you present the proclamation publicly. If there is any other information you need or if you have any questions, please feel free to contact me at (YOUR PHONE NUMBER)

Respectfully,

YOUR NAME
Address
City, State Zipcode
YOUR EMAIL ADDRESS
YOUR PHONE NUMBER

A PROCLAMATION FOR EHLERS-DANLOS SYNDROME AWARENESS MONTH

WHEREAS, Ehlers-Danlos Syndromes are a group of genetic connective tissue disorders which are characterized by joint hypermobility (looseness, instability, and dislocation of joints), skin hyperextensibility (fragile and often velvety, hyperelastic skin that bruises, scars, and tears easily), tissue fragility (arterial, intestinal, uterine fragility or rupture), and musculoskeletal problems (chronic, early onset, debilitating musculoskeletal pain, scoliosis and scleral fragility, poor muscle tone); and

WHEREAS, there are 13 different types of Ehlers-Danlos Syndrome that are characterized by distinctive features and it is estimated that the prevalence of all types of Ehlers-Danlos Syndromes is 1 in 2,500 to 1 in 5,000 people worldwide; and

WHEREAS, there is no cure for Ehlers-Danlos Syndromes, but an early and accurate diagnosis can help provide the opportunity for the patient and medical team to know what complications and symptoms might arise and can intervene earlier so as to improve symptom management and quality of life; and

WHEREAS, Ehlers-Danlos Syndromes have been frequently misdiagnosed or underdiagnosed for decades resulting in greater discomfort and disability and ongoing research is building a better understanding of the many forms of Ehlers-Danlos Syndrome, offering new hope; and

WHEREAS, Dysautonomia Support Network, a 501(c)(3) non-profit organization that advocates on behalf of patients living with Ehlers-Danlos Syndromes and other related disorders, encourages communities to celebrate Ehlers-Danlos Syndrome Awareness Month each May; and

WHEREAS, we seek to recognize the contributions of the professional medical community, patients, and family members who are working to educate our citizenry about Ehlers-Danlos Syndrome in ____.

NOW, THEREFORE, I, ____, ____________________________ of _______________________________, do hereby proclaim the month of May as Ehlers-Danlos Syndrome Awareness Month throughout ____________________________

OBTAINING MEDIA COVERAGE

How to Request Media Coverage

Publicity helps your community to become more aware of Ehlers-Danlos Syndromes and its related conditions. This also demonstrates to your local government officials you are grateful to them and the proclamation they took time passing is already being used in action.

1. Develop a list of local media contacts to be used to publicize the proclamation once it is signed.

2. Once you know the proclamation will be signed, send out a press release. Include in the release that a resolution to observe May as Ehlers-Danlos Syndrome Awareness Month passed and Dysautonomia Support Network proposed it. It is a good idea to recognize the public official who signed the proclamation and mention any other individuals who were instrumental in its passage. You can customize this sample press release and submit it to local papers.

3. Include a photo of your group representatives with the public officials or you speaking to the group.

Media Guide

May is right around the corner and that means Ehlers-Danlos Syndrome Awareness Month is coming! You should consider how to maximize the impact of your proclamation and other Ehlers-Danlos Syndrome activities through media outreach. Here are a few ideas that could help get the word out about your event or tell your whole state about your accomplishments in raising awareness!

- **Contact your local newspaper or radio station**

Local papers love to publish stories about people in the area doing something for a good cause. Write a letter to the editor and share your story; they might just feature your event in the next issue. Radio stations also report on local happenings and could become interested in your story.

- **Send out a notice on social media**

Do you use Facebook, Twitter, Instagram, Tumblr, or any other social media sites? If so, take a moment and post a little something about your accomplishments. Blogs are also another great way to share with the world. Several patients have very successful blogs that have been featured in a number of newsletter and websites. Don't worry, it's not bragging!

- **Use Ehlers-Danlos Syndromes hashtags:**

#EDS #EhlersDanlos #EhlersDanlosAwareness #myEDSstory #myHSDstory #myAwarenessStory #ZebraStrong

- **Share your story with us media@dysautonomiasupport.org**

We love hearing about what our patient advocates are doing! Send us your story and we can feature it on our social media sites, www.dysautonomiasupport.org, *https://www.facebook.com/DysautonomiaSupportNetwork*, or in our newsletter. If you want to share with members directly, send us a message on Facebook and we will post for you! Please remember to include the Adult Photography Release For more ideas on amplifying your voice, or to get involved, contact the
Advocacy Team at advocacy@dysautonomiasupport.org.

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Sample Press Release

Contact: John Doe
Phone: XXX XXX XXXX
Email: jdoe@gmail.com

Mayor *[insert name of your mayor or other public official]* Declares May "Ehlers-Danlos Syndrome Awareness Month"

[Insert City, State, Date] — *[insert City and Mayor's name]* has proclaimed May 2019 "Ehlers-Danlos Syndrome Awareness Month". Ehlers-Danlos Syndromes are a group of genetic connective tissue disorders. They are estimated to impact 1:2,500-5,000 people worldwide. There are currently 13 different kinds of Ehlers-Danlos Syndrome, each with different symptom manifestations. In general, those with Ehlers-Danlos Syndrome are affected by joint hypermobility resulting in joint instability and dislocations. Skin can also be very thin, velvety, fragile and hyperextensible resulting in easy bruising, scarring, and tearing. Individuals also can deal with chronic, early onset debilitating musculoskeletal pain. Ehlers-Danlos Syndromes can also occur frequently with other comorbid conditions such as dysautonomia and mast cell disorders. There is currently no cure, but ongoing research is offering hope for better understanding and new treatment options.

"We appreciate Mayor *[name]*'s help in raising awareness for Ehlers-Danlos Syndromes," said [*insert your name*], member of the DSN [*insert your state*] Chapter Support Group. "This recognition is important to me because *[explain why this matters to you in a few short sentences.]*

[*Insert your name*], who lives in *[town, state]*, was diagnosed in *[year]* when [he/she] was *[age]*. "I appreciate that our support group not only offers resources and support for dysautonomia, but also Ehlers-Danlos Syndromes and other conditions that often occur together. We can be incredibly complex patients, and having others who truly understand helps me feel that I am not alone." Or insert other such quote

[Insert information for your DSN support group: contact information, Facebook link]

The Dysautonomia Support Network increases confidence and independence in its members by supplying them the tools, support, education, and resources they need to adapt to life with chronic illnesses while challenging themselves to set new goals despite their physical limitations.

XXX

ABOUT THE DYSAUTONOMIA SUPPORT NETWORK
DSN is a U.S. based, 501 (C) (3) non-profit, organization providing support, resources, education and advocacy for patients affected by the many forms of Dysautonomia and related conditions such as Connective Tissue Disorders, Mast Cell Activation Disorders, Chiari Malformation and Gastric Motility Disorders. Founded in 2012 as Dysautonomia Divas, the organization now runs over 50 groups online and has chapters in all 50 United States and supports patients globally.

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Adult Photography Release

I hereby authorize the Dysautonomia Support Network, hereafter referred to as "DSN," to publish photographs taken of me, and my likeness, for use in the DSN's print, online, and video-based educational, awareness, and fundraising materials, as well as other DSN publications. I understand that my name will not be used in association with said photographs without my consent.

I hereby release and hold harmless DSN from any reasonable expectation of privacy or confidentiality associated with the images specified above.

I further acknowledge that my participation is voluntary and that I will not receive financial compensation of any type associated with the taking or publication of these photographs or participation in DSN materials or other DSN publications. I acknowledge and agree that publication of said photos confers no rights of ownership or royalties whatsoever.

I hereby release DSN, its contractors, its employees, its volunteers, and any third parties involved in the creation or publication of DSN's materials, from liability for any claims by me or any third party in connection with my participation.

Authorization

Printed Name: ____

Signature: ____

Date: ____________

Street Address: ____

City: ________________________ State: _____ Zip: ____________

Learn more about Dysautonomia @ www.DysautonomiaSupport.org