



CHIARI MALFORMATION PROCLAMATION AND ADVOCACY TOOLKIT





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How to Request a Proclamation for Chiari Malformation Awareness Month in September

Having your hometown, county or state declare September as Chiari Malformation Awareness Month is much simpler than you may think. It requires your town or county council to pass a non-binding resolution. Begin the process in August, or earlier, to coordinate with your state or local government officials. Dysautonomia Support Network (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 a proclamation from. 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 with them to increase awareness efforts in your area or work on different local government proclamations.

2. Get contact information for your state by finding your state in our database.

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. See our [State Contacts for Proclamation Requests](#) to find 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 is 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 September as Chiari Malformation Awareness Month.

When calling, be prepared to provide information about the impact of Chiari Malformation in your community if possible.

See [Top 10 facts about Chiari Malformation](#) here 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 September for Chiari Malformation Awareness Month?

What is the process for me to be successful 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?

May I schedule a proclamation signing ceremony?

5. Prepare the required documents to request the proclamation.

You can use this [Chiari Malformation proclamation letter request](#) and customize with personal details and a paragraph about your personal story with Chiari Malformation.

If your local or state government will allow you to submit a template of a proclamation, we have provided one, you can use this Chiari Malformation awareness [proclamation template](#).

6. Submit your proclamation letter request and draft proclamation awareness template to the state or local government office in the format required by that office.

Being polite and persistence will pay off, follow up on the status of your proclamation request a week to ten business days after submission.

7. Make an appointment to pick up the proclamation once it is officially signed.

Dress professionally when you visit a government office and advocate for Chiari Malformation patients in your area. If your elected official allowed you to schedule a proclamation signing ceremony you may have the opportunity to be called upon to speak and take photos with the elected officials. Remember to take and submit photos for a local newspaper on Chiari Malformation 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 someone who will be able to attend on your behalf.

Ask the government or elected officials if they will post about the Chiari Malformation Awareness Month proclamation and direct people to 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 Chiari Malformation 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 Chiari Malformation, check out our guide on [How to Request Media Coverage](#). You can use this [sample press release form](#) and customize with details about you 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.

Most importantly, we thank *YOU* for all your hard work and persistence. It has paid off as we raise awareness about Chiari Malformation and advocate for the people who live with it!

State Contacts for Proclamation Requests

Each U.S. state and the District of Columbia require 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.
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	30 days	
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	Fill out online form or mail to address on Contact Us page.
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	45 day min or 6 months max	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@dysautonomiasupport.org for template. Then send proclamation template by email to: gov.proclamations@oregon.gov
Pennsylvania	Not specified	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.
Washington D.C.	At least 2 weeks	Fill out form online

How to Address Public Officials

When writing our public officials, it is important that we show them the respect due to their office and address them correctly. Here is a brief chart to help you find the correct way to signify the public official on letter address, letter greeting, and spoken greeting.

Person	Letter Address	Letter Greeting	Spoken Greeting
President of the United States	The President The White House 1600 Pennsylvania Ave NW Washington, DC 20500	Dear Mr. (or Madam) President	Mr. (or Madam) President
Vice President	The White House Office of the Vice President 1600 Pennsylvania Avenue, N.W. Washington, DC 20500	Dear Mr. (or Madam) Vice President	Mr. (or Madam) Vice President
Former President	The Honorable First Name Last Name Current address	Dear. Mr (Mrs., or Ms). Last name	Mr (Mrs., or Ms). Last name
Cabinet Member	The Honorable First Name Last Name The Secretary of _____ or The Attorney General	Dear Mr. (or Madam) Secretary	Mr. (or Madam) Secretary
United States Senator	The Honorable First Name Last Name United States Senate Washington, D.C. 20510	Dear Senator Last Name	Senator Last name
Speaker of the House	The Honorable First Name Last name Speaker of the House of Representatives United States House of Representatives Washington, DC 20515	Dear Mr. (or Madam) Speaker	Mr (or Madam) Speaker
United States	The Honorable First	Dear Mr. (or Mrs.,	Mr. (or Mrs., Ms.)



Representative	Name Last Name United States House of Representatives Washington, DC 20515	Ms.) Last Name	Last Name
Governor	The Honorable First Name Last Name Governor of _____ State Capitol Address	Dear Governor Last Name	Governor or Governor Last Name
State Legislators	The Honorable First Name Last Name Address	Dear Mr. (or Mrs., Ms.) Last Name	Mr. (or Mrs., Ms.) Last Name
Mayor	The Honorable First Name Last Name; Mayor of _____ City Hall Address	Dear Mayor Last Name	Mayor Last Name; Mr (or Madam) Mayor; Your Honor

Top 10 facts about Chiari Malformation

1. Chiari Malformations (CM) are most commonly caused by structural defects during fetal development, often caused by a genetic mutation or maternal diet lacking in vitamins or nutrients. It is believed that CM affects 1:1000 births. With recent increases in the use of imaging studies, that number is expected to be greater.(2) Chiari malformations affect individuals of every race and ethnicity, although it is thought to affect more women than men (3)
2. Chiari Malformations (CM) can be acquired, also called secondary CM. This is caused from tumors, or excessive loss of spinal fluid.(1)
3. Chiari Malformations are categorized as Type I, II, III, IV, and 0 depending on the amount of cerebellar tonsils that have been pushed into the spinal canal. (1)
4. Chiari Malformations affect the area in the skull where the brain and spinal cord connect. The malformations are thought to be present at birth (congenital), however, many do not show symptoms until adulthood (3)
5. The specific part of the brain affected is the cerebellar tonsils, small peg-like structures at the base of the cerebellum. The cerebellum is the area of the brain that controls balance, posture and voluntary movements. (3)
6. With increased pressure, this causes the cerebellar tonsils to descend in to the foramen magnum, the hole in the base of the skull, which causes blockage in the proper flow of cerebrospinal fluid (CSF) (3)
7. Specific symptoms occur in different combinations and reflect the area of damage in the cerebellum, brainstem, spinal cord, and cranial nerves (3)
8. The most common symptom is headaches in the back of the head (occipital headaches). Other common symptoms are: double vision, sensitivity to light, blurred vision, dizziness, ringing in the ears, poor

coordination and balance, muscle weakness, difficulty swallowing or speaking, palpitations. (3)

9. Symptomatic Chiari malformations are most often treated, not cured, by a surgery called suboccipital craniotomy (decompression). This is where the opening at the base of the skull is widened to make room for better cerebrospinal fluid (CSF) flow. (3)
10. The diagnosis of Chiari Malformation doesn't mean life-long goals are out of the question. With a little creativity and support, your dreams are just as close as before. Claudia Martinez, a new graduate from McGovern Medical School, stated in the third year of medical school, "You may see a young woman who has overcome adversity with resilience, time and time again, but I hope you also see a woman who is only human, a woman with a disability and medical history neither she nor her doctors can change, a woman who is good enough to become a doctor, despite everything". (4)

References

- (1)*About Chiari Malformation*. (2016, April). Retrieved from Chiari & Syringomyelia Foundation:
https://csfinfo.org/files/8314/6170/0906/About_CM-web.pdf
- (2)*Chiari Malformation Fact Sheet*. (2019, May 13). Retrieved from National Institute of Neurological Disorders and Stroke:
<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Chiari-Malformation-Fact-Sheet>
- (3)*Chiari Malformations*. (2014). Retrieved from National Organization of Rare Disorders:
<https://rarediseases.org/rare-diseases/chiari-malformations/>
- (4)Martinez, C. (2018). The Patient Who is Studying to be a Doctor. *TMC News*.



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

YOUR ADDRESS

DATE

**NAME OF GOVERNMENT OFFICIAL
ADDRESS**

Dear _____,

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

Chiari Malformation is a congenital or acquired condition affecting the size and/or shape of the base of the skull. This causes pressure changes in the skull and pushes the cerebellar tonsils through the opening at the base of the skull. The herniation of these small parts of the brain can cause disruption in the flow of cerebrospinal fluid (CSF) and in turn, cause symptoms that range from mild to disabling. Some of the most common symptoms include: severe head and neck pain, vertigo, muscle weakness, balance problems, blurred or double vision, difficulty swallowing, and sleep apnea.

I am one of the one in 1,000 births with Chiari Malformation. Although, through recent increases in the use of imaging, these numbers are believed to be greater.

Although there is no cure for Chiari Malformation, 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 with Chiari Malformation and their families.

TELL YOUR STORY HERE!
Include Some of the Following:

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?



You want to keep this section to two or three paragraph description.

Less Is More. Keep It Simple.

I have attached a sample proclamation along with some additional information about Chiari Malformation. The proclamation was drafted by Dysautonomia Support Network, a 501(c)(3) nonprofit that is dedicated to improving the lives of individuals affected by dysautonomia and related conditions, including Chiari Malformation, through support, resources, education, advocacy, and awareness. Dysautonomia Support Network runs over 50 groups online and has chapters in all 50 states. They also offer service dog grants and educational scholarships to their members. If you are interested, you can learn more about Chiari Malformation and the Dysautonomia Support Network on their website, www.dysautonomiasupport.org.

Please let me know if your office is able to help us raise awareness of Chiari Malformation by issuing the attached proclamation declaring September to be Chiari Malformation Awareness Month in the (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



A PROCLAMATION FOR CHIARI MALFORMATION AWARENESS MONTH

WHEREAS, Chiari Malformation is a defect in the cerebellum, the part of the brain that controls balance and coordination, that creates pressure on the cerebellum and brain stem, restricting the normal flow of cerebral spinal fluid to and from the brain;

WHEREAS, Chiari Malformation is considered rare and may be understudied and underrepresented in the general population;

WHEREAS, it was believed that Chiari Malformation occurs in one in every 1,000 births, but the increased use of diagnostic imaging has shown that Chiari Malformation may be more common than originally estimated; affecting many people living in

_____;

WHEREAS, symptoms usually appear during adolescence or early adulthood and can include severe head and neck pain, vertigo, muscle weakness, balance problems, blurred or double vision, difficulty swallowing, and sleep apnea;

WHEREAS, the cause of Chiari Malformation is unknown; however, the National Institute of Neurological Disorders and Stroke of the National Institutes of Health believes that it is either a congenital condition caused by exposure to harmful substances during fetal development, or that can be a genetic condition, as it may appear in more than one family member;

WHEREAS, Dysautonomia Support Network, a 501(c)(3) non-profit organization that advocates on behalf of patients living with Chiari Malformation, encourages communities to celebrate Chiari Malformation Awareness Month each September;

WHEREAS, we seek to recognize the contributions of the professional medical community, patients, and family members who are working to educate our citizens about Chiari Malformation in _____.

NOW, THEREFORE, I, _____,
_____ of _____, **do hereby**
proclaim the month of September as
Chiari Malformation Awareness Month
Throughout _____

OBTAINING MEDIA COVERAGE





How to Request Media Coverage

Publicity helps your community to become more aware of Chiari Malformation. 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 telling your community that a resolution to observe September as Chiari Malformation Awareness Month passed, Dysautonomia Support Network proposed it, 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 form](#) 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

September is right around the corner and that means Chiari Malformation Awareness Month is coming; you should consider how to maximize the impact of your proclamation and other Chiari Malformation Awareness 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 happening 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 Dysautonomia hashtags:**

#ChiariMalformation #DSN #ChiariMalformationAwareness #CMawareness #CM #CMwarrior

- **Share your story with us at 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!

For more ideas on amplifying your voice, or to get involved, contact the advocacy team at advocacy@dysautonomiasupport.org.



Sample Press Release: use this as an example for wording if you have the opportunity for a formal press release with your proclamation signing.

[Insert your name and Title]

[Your phone number]

[Your email]

Mayor *[insert name of your mayor]* Declares September, “Chiari Malformation Awareness Month”

[Insert City, State, Date] -- *[Insert City and Mayor’s name]* has proclaimed September, “Chiari Malformation Awareness Month”. Chiari Malformation is a medical term used to describe a defect in the cerebellum, the part of the brain that controls balance and coordination, that creates pressure on the cerebellum and brain stem, restricting the normal flow of cerebral spinal fluid to and from the brain. These disorders affect many people and treatments are limited. According to Dysautonomia Support Network (DSN), raising awareness will offer hope and further support to those suffering with this chronic and sometimes debilitating condition.

“We appreciate Mayor *[name]*’s help in raising awareness of Chiari Malformation,” 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]*.”

[Insert your name], who lives in *[town, state]*, was diagnosed in *[year]* when *[he/she]* was *[age]*. “Our support group is a place where people with dysautonomia and their families can gain support and education from those who have been living with Chiari Malformation and related conditions.” *[Insert a quote about your support group meetings]*.



[Insert information for your DSN support group meeting: Date, time, location, contact information, event link on Facebook]

The Dysautonomia Support Network (DSN) recognizes Chiari Malformation as a related condition to dysautonomia. DSN 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.

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.



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: _____



General Photography Release Form for Minors

I hereby authorize the Dysautonomia Support Network, hereafter referred to as "DSN," to publish photographs taken and likenesses of the children listed below ("the Undersigned Children") on *(insert month, date and year)*, 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 the names of the Undersigned Children will not be used in association with said photographs without my consent.

I attest that I am the parent or legal guardian of the Undersigned Children and I have the authority to authorize DSN to photograph and to use the photographs of the Undersigned Children. 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 participation by the Undersigned Children is voluntary and that neither I nor the Undersigned Children will 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, the Undersigned Children or any third party in connection with my participation.

Printed Name of Parent/Legal Guardian: _____

Signature: _____ Date: _____

Street Address: _____ City: _____

State: _____ Zip: _____

Name of Child: _____ Age _____