Dravet Syndrome Awareness Day Proclamation Guide

Proclamation Objectives

To spread awareness of Dravet syndrome in order to improve healthcare access, research funding, and support services for individuals with Dravet Syndrome and their families.

Types of Proclamations

State-Level Proclamation: Some states may require the request to be submitted as a bill/resolution through the legislature, so you would need a member of the legislature to sponsor it and there may be a very tight timeline for these requests each year. Some states may have a way for you to submit through the Governor's office in addition to or instead of the legislature.

County or City-Level Proclamation: It may be a lot easier to get a proclamation done on a more local level since you are more likely to have a personal connection with those in your community. They are also less likely to have a strict schedule and process to make it happen. It could be as simple as sending an email to your city council representative or mayor (or your county commissioner) to ask.

Proclamation Request Information

Regardless of where or how you are submitting the request, you will need to provide context about Dravet syndrome, its impact, and the importance of raising awareness. You can use <u>the sample request letter template</u> provided by DSF, but be sure to personalize it with information about your child/family.

They may require that you submit draft text for the proclamation, typically including several "Whereas" clauses that outline the purpose and significance of the proclamation. DSF has a <u>sample proclamation template</u> that can be used as a guide, but it will be up to you to review any final proclamation to ensure it is what you were expecting and is accurate.

A few suggestions for your request:

- Be sure to share your personal story
- Make sure to include your full name, address, phone number, and email for correspondence

- Be on the lookout for any responses so that you can provide additional information, if requested
- If there is any Dravet syndrome research taking place in your state universities, let them know about it
- Recognize your state's efforts in prioritizing the needs of individuals with rare diseases, if applicable

Submitting a State-Level Proclamation Request Through the Legislature

Each state has its own procedures and requirements for such requests. Also, the terminology may vary from state to state. Below is a general guide to help you navigate this process.

1. Review Request/Submission Process

- Before you ask anyone or submit a formal request, be sure to check if there are specific guidelines that must be followed for your state. Each state has specific bill drafting guidelines, including deadlines, a detailed list of these deadlines is listed below.
- Ensure you understand and comply with these guidelines to avoid delays or rejections
- If the request must go through the legislature, you will be dependent on the legislative calendar for the year. Many states are only in session for the first few months of each year, then adjourn until the following January. Bill drafting deadlines vary across the 50 U.S. state legislatures, as each state sets its own schedule for legislative sessions and associated deadlines. These deadlines are subject to change and may not be uniformly published. But typically bill drafting deadlines are within a few weeks of the start of a legislative session. A comprehensive list of all states 2025 session information is provided below.

2. Utilize Personal Connections

• If you know someone in the state legislature, your best bet may be to approach them directly to ask for their help. If you don't personally have a connection but know someone who does, ask if they would be willing to introduce you to the legislator or staff member.

3. Contact Your State Representative and/or Senator

- If you don't have any connections, you can call to ask to schedule a meeting with your own representative and/or senator or send the request by email/mail
- If you do not know who your state representative and senator are, many state legislature websites will allow you to search for your representative and senator by providing your home address

4. Contact the Chairperson of the Health Committee in the House and/or Senate

• If your state legislative members are not open to filing the proclamation for you as their constituent, then you can try to get someone (preferably the chairperson) on the Health committees in either the House or Senate to submit on your behalf. DSF can help you identify these individuals, if needed.

State Legislature Information

21	125	Session	Dates	and	Deadlines	
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State	Prefiling May Begin	Prefiling and Introduction Deadline	Convene	Crossover Deadline	Adjourn Date
Alabama	5/21/2024		2/4/2025		5/15/2025
Alaska		1/10/2025: 1st Prefile Release 1/17/2025: 2nd Prefile Release	1/21/2025		5/21/2025
Arizona	After election certification	2/3/2025: Senate Introductions 2/10/2025: House Introductions	1/13/2025		4/26/2025
Arkansas	11/15/2024	1/27/2025: Certain HC bills 2/12/2025: Constitutional amendments 3/3/2025: Appropriation bills	1/13/2025		4/16/2025 (Anticipated)
California		2/21/2025: Introductions	12/2/2024	6/6/2025	9/12/2025
Colorado	12/2/2024	1/3/2025: Prefiles 1/31/2025: Senate Introductions	1/8/2025	3/14/2025	5/7/2025

2025 Session Dates and Deadlines						
State	Prefiling May Begin	Prefiling and Introduction Deadline	Convene	Crossover Deadline	Adjourn Date	
		2/7/2025: House Introductions				
Connecticut			1/8/2025		6/4/2025	
Delaware		12/19/2024: 1st Prefile Release 1/9/2025: 2nd Prefile Release	1/14/2025		6/30/2025	
District of Columbia			1/2/2025		1/2/2027	
Florida	12/6/2024: House 11/20/2024: Senate	2/28/2025	3/4/2025		5/2/2025	
Georgia	11/15/2024		1/13/2025	3/6/2025 (Anticipated 28th Constitutional Day)	4/3/2025 (Anticipated 40th Constitutional Day)	

2025 Session [2025 Session Dates and Deadlines						
State	Prefiling May Begin	Prefiling and Introduction Deadline	Convene	Crossover Deadline	Adjourn Date		
Hawaii	1/8/2025	1/17/2025: Non- Executive Branch Packages 1/21/2025: Executive Branch Packages 1/23/2025: All other bills 3/7/2025: Substantive Resolutions	1/15/2025	3/6/2025: Non- Budget bills	5/2/2025		
Idaho		1/17/2025: Senate personal introductions 2/10/2025: Committee bill introductions, Constitutional amendments, and joint resolutions	1/6/2025	3/3/2025	TBD		
Illinois	11/30/2025	1/8/2025: Prefiling 2/7/2025 House & Senate Introductions	1/8/2025	4/11/2025	5/31/2025		

2025 Session D	2025 Session Dates and Deadlines						
State	Prefiling May Begin	Prefiling and Introduction Deadline	Convene	Crossover Deadline	Adjourn Date		
Indiana	11/19/2024	1/9/2025: Senate Filing1/14/2025: House Filing	1/13/2025	2/20/2025	4/24/2025 (Anticipated)		
Iowa	12/1/2024	2/14/2025	1/13/2025	3/21/2025	5/2/2025		
Kansas	After election certification	2/5/2025: Individual introductions 2/7/2025: Non-exempt Committee introductions	1/13/2025		3/28/2025 (Veto session scheduled for 4/10 - 4/12/2025)		
Kentucky		2/18/2025: Senate Introductions 2/19/2025: House Introductions	1/7/2025		3/28/2025		
Louisiana	1/24/2025	4/4/2025: Prefiling 4/23/2025: Introduction	4/14/2025	6/9/2025	6/12/2025		
Maine		1/10/2025: Once sworn in, legislators must agree to a closure date	12/4/2024: Legislators sworn in		6/18/2025		

2025 Session D	2025 Session Dates and Deadlines						
State	Prefiling May Begin	Prefiling and Introduction Deadline	Convene	Crossover Deadline	Adjourn Date		
		for prefiling, which is currently 1/10/2025.	1/8/2025: Session convenes				
Maryland	11/1/2024	11/20/2024: Prefiling 2/7/2025: House Introduction 2/3/2025: Senate Introductions	1/8/2025	3/17/2025	4/7/2025		
Massachusetts			1/1/2025		12/6/2026		
Michigan			1/8/2025		12/31/2025		
Minnesota			1/14/2025		5/19/2025		
Mississippi		1/20/2025	1/7/2025	2/27/2025	4/6/2025		
Missouri	12/1/2024	1/8/2025: Prefiling 2/27/2025: Senate Introduction	1/8/2025		5/30/2025		
Montana	9/1/2024	2/21/2025: General bill requests 3/4/2025:	1/6/2025	3/4/2025: General bills	5/9/2025		

2025 Session D	2025 Session Dates and Deadlines						
State	Prefiling May Begin	Prefiling and Introduction Deadline	Convene	Crossover Deadline	Adjourn Date		
		Appropriations bills request 4/15/2025: Study Resolutions requests		4/3/2025: Appropriation bills			
Nebraska		1/22/2025: Last day to file bills, bills must be filed by the 11th session date.	1/8/2025		6/9/2025		
Nevada	7/1/2024	3/17/2025: Legislator Introductions 3/24/2025: Committee Introductions	2/3/2025	4/22/2025	6/2/2025		
New Hampshire	9/3/2024: Incumbents 9/6/2024: Electeds		1/8/2025	4/10/2025	6/30/2025		
New Jersey			1/14/2025		1/13/2026		

2025 Session Da	2025 Session Dates and Deadlines						
State	Prefiling May Begin	Prefiling and Introduction Deadline	Convene	Crossover Deadline	Adjourn Date		
New Mexico	1/2/2025	1/17/2025: Prefiling 2/20/2025: Introduction	1/21/2025		3/22/2025		
New York	11/15/2024	11/15/2024: Introductions	1/8/2025		6/13/2025		
North Carolina		3/6/2025: House Introductions 3/25/2025: Senate Introductions	1/1/2025	5/8/2025 (appropriations bills exempted)	7/31/2025		
North Dakota	12/2/2024	1/20/2025: House Introductions 1/27/2025: Senate Introductions	1/7/2025	2/28/2025	5/2/2025		
Ohio			1/6/2025		12/31/2025		
Oklahoma	11/15/2024	1/16/2025: Introductions	1/7/2025: Pro Forma 2/3/2025: Session		5/30/2025		

2025 Session Da	2025 Session Dates and Deadlines						
State	Prefiling May Begin	Prefiling and Introduction Deadline	Convene	Crossover Deadline	Adjourn Date		
Oregon	9/27/2024	2/25/2025: Introductions	1/21/2025		6/30/2025		
Pennsylvania	12/15/2024		1/7/2025		12/31/2025		
Puerto Rico			1/13/2025		12/31/2029		
Rhode Island	11/15/2024	2/27/2025: House Introductions	1/7/2025		TBD		
South Carolina	Mid- November	12/5/2024	1/14/2025		5/8/2025		
South Dakota	12/15/2024	2/5/2025: Individual Member Introductions 2/6/2025: Committee Introductions	1/14/2025	2/25/2025	3/31/2025		
Tennessee			1/14/2025		4/25/2025		
Texas	11/11/2024	3/14/2025: Introductions	1/14/2025	5/16/2025	6/2/2025		

2025 Session D	2025 Session Dates and Deadlines						
State	Prefiling May Begin	Prefiling and Introduction Deadline	Convene	Crossover Deadline	Adjourn Date		
Utah	5/1/2024	1/31/2025: Introductions	1/21/2025	3/4/2025	3/7/2025		
Vermont		1/31/2025: House Introductions	1/8/2025		5/9/2025		
Virginia	7/15/2024	1/8/2025: Prefiling 1/17/2025: Introductions	1/8/2025	2/4/2025	2/22/2025 (Veto session scheduled for 4/2/2025)		
Washington	12/2/2024		1/13/2025	3/12/2025	4/27/2025		
West Virginia	12/9/2024	3/18/2025: House Introductions 3/24/2025: Senate Introductions	1/8/2025: Opening Day 2/12/2025: 1st Day of Session	4/2/2025	4/12/2025		
Wisconsin			1/6/2025		12/31/2025		
Wyoming	7/1/2024	1/29/2025: Senate Introductions	1/14/2025	2/12/2025	TBD (Scheduled for 3/6/2025, but 3 additional legislative days exist for use)		

2025 Session Dates and Deadlines							
State	Prefiling May Begin		Convene	Crossover Deadline	Adjourn Date		

2/3/2025: House Introductions

Submitting a State-Level Proclamation Request Through the Governor

If the bill drafting deadline for your state has passed for 2025, another option is to approach the Governor's office to have a Proclamation filed. Each state has its own procedures and requirements for such requests. Below is a general guide to help you navigate this process.

1. Review Request/Submission Process

- Visit your state's official government website to find information on requesting proclamations. Look for sections like "Governor's Office," "Constituent Services," or "Proclamations."
- Each state has specific guidelines, including deadlines (often requiring requests several weeks in advance), formatting requirements, and eligibility criteria.
- Ensure you understand and comply with these guidelines to avoid delays or rejections.
- Follow your state's specified method for submission, which may include:
 - o Online Forms: Many states offer electronic submission through their official websites.
 - o **Email:** Some states accept requests via email; ensure you send it to the correct department or individual.
 - o Mail: If mailing your request, use the official mailing address provided, and consider sending it via certified mail for tracking.

2. Utilize Personal Connections

• If you or someone you know has a connection to someone in the governor's office, don't be afraid to reach out to let them know you are interested in getting a proclamation and see if they can help you through the process.

Governor's Office Information

ALABAMA http://216.226.177.218/forms/contact_procs.aspx

• In order to complete the document accurately and efficiently, please provide as much information as possible. If you are requesting a proclamation, please cut and paste a copy of a previous proclamation or include enough information to draft a new version. Please submit the form no later than 30 days prior to date needed

ALASKA http://gov.alaska.gov/parnell/contact/constituent-relations/proclamations.html

Please allow a minimum of 4-6 weeks advance notice when requesting a proclamation from the Office of the Governor. A
proclamation will be reviewed one month prior to its proposed issue date

ARIZONA http://azgovernor.gov/cs/Proclamations.asp

• Proclamation requests are accepted six weeks in advance of the event date or proclaimed date. Requests will be accepted no more than 6 months in advance and will not be issued more than 3 months in advance of the event.

ARKANSAS http://governor.arkansas.gov/proclamation-request-form

• All proclamations must be submitted to the Office of Communications with at least a 30-day notice to allow for the approval process and the production of the document itself. Organizations are limited to two proclamation requests within the same calendar year. Please prioritize your requests.

CALIFORNIA http://gov.ca.gov/m_contact.php

• When requesting a commemorative message a draft of the requested language (200 words or less) and background information on the organization or individual must be included. All requests must be submitted no later than 30 days prior to your requested deadline or event date, whichever comes first. Please include a contact name, email, address and phone number, date of the event, date message is needed, and background information.

COLORADO http://www.colorado.gov/govhdir/requests/proclamation.html

• Four weeks' notice is required to provide proclamations.

CONNECTICUT http://portal.ct.gov/Request_Proclamation.aspx

• Due to the volume of requests received, your request must be submitted at least four weeks prior, but no more than 3 months prior, to the due date.

DELAWARE https://governor.delaware.gov/request-proclamation-tribute/

• Organizations can request a Proclamation for its special recognition Day, Week, or Month provided they are located in Delaware or have a Delaware connection if they are a national group. Please allow two weeks for your request to be processed.

DISTRICT OF COLUMBIA http://os.dc.gov/service/ceremonial-services

• Please allow a minimum of three weeks to process your request. Please do not submit your request any more than three months before the date of your event.

FLORIDA http://www.flgov.com/request_a_letter

Please allow 4-6 weeks for review.

GEORGIA http://gov.georgia.gov/proclamation-request

• All requests must be submitted at least 45 days before the proclamation is needed for consideration.

HAWAII https://governor.hawaii.gov/contact-us/request-a-proclamation/

• All requests must be submitted a minimum of four (4) weeks prior to the date it is needed. Requests will be accepted no more than six (6) months in advance.

IDAHO http://www.gov.idaho.gov/mediacenter/proc/index.html

Your request must be submitted three (3) weeks prior to the date you wish to receive the document. "The Governor's Office only
fulfills requests from in-state organizations. If a national organization wishes to request a proclamation, please find a local affiliate or
sponsor."

ILLINOIS https://www.illinois.gov/gov/contactus/Pages/Proclamation.aspx

• Form to be completed online

INDIANA http://www.in.gov/gov/2916.htm

Requests must be submitted 6-8 weeks in advance of the requested delivery date or it will be denied.

IOWA https://governor.iowa.gov/constituent-services/proclamation-request/

• Requests must be made to the Governor's office 6 weeks in advance of the date needed.

KANSAS https://governor.ks.gov/serving-kansans/constituent-services/proclamation-guidelines

• You are strongly encouraged to submit your request 6-8 weeks in advance of your requested date. Requests will be accepted no more than six months in advance. If less than two weeks' notice is given, the Governor's Office reserves the right to decline.

KENTUCKY https://secure.kentucky.gov/formservices/Governor/ProclamationRequestForm

• Proclamation requests are reviewed on a case-by-case basis.

LOUISIANA http://gov.louisiana.gov/index.cfm/form/home/13

• A minimum of two weeks' notice is required to provide the proclamation. The Governor's office may choose to decline any requests received with less than two weeks' notice. Proclamations are not sent to out-of-state individuals or organizations. All proclamations are limited to 200 words. No proclamation will be proclaimed more than 45 days in advance, and only 1 original copy of each proclamation will be made.

MAINE http://www.maine.gov/governor/lepage/citizen services/request proclamation.shtml

All requests must be made 45 days in advance.

MARYLAND http://governor.maryland.gov/mail/citations.asp

• Requests for citations and proclamations must be received by the Governor's Office at least 8 weeks in advance of your deadline.

MASSACHUSETTS http://www.mass.gov/governor/constituent-services/recognition/

• If you would like to request a proclamation, please email your request, along with suggested language and background materials, at least 20 business days before the print or event deadline. Please note the Governor does not issue proclamations more than thirty days in advance.

MICHIGAN https://www.michigan.gov/snyder/0,4668,7-277-57577 59874—,00.html

• To submit a proclamation or program book welcome letter request, please send a detailed e-mail to tributes@michigan.gov at least four weeks in advance of when the recognition is needed.

MINNESOTA https://mn.gov/governor/resources/proclamations/

• Complete the Proclamation Request Form (all requests must be in writing) at least 20 calendar days in advance of the date it is needed.

MISSISSIPPI https://www.governorbryant.ms.gov/Pages/Contact.aspx

• To request a Proclamation, which much must be submitted at least 30 days in advance of the proclamation date, contact Bonita Waters at bonita.waters@governor.ms.gov or (601) 576-2968.

MISSOURI https://governor.mo.gov/get-involved/request-proclamation-governor-eric-r-greitens

• Due to the volume of requests received by the Governor's Office and the time involved in processing the requests, please note that it can take up to three weeks for a proclamation to be issued.

MONTANA No process identified:

• You can contact the Governor's office by mail or by phone: Office of the Governor PO Box 200801 Helena MT 59620-0801 Phone: 406-444-3111 Toll-Free: 855-318-1330 FAX: 406-444-5529

NEBRASKA http://www.governor.nebraska.gov/proclamations/proclamation.html

• Please submit requests with appropriate notice of three weeks.

NEVADA http://gov.nv.gov/uploadedFiles/govnvgov/Content/Contact/ProclamationGuidelines.pdf

• Proclamation requests must be submitted at least 30 days in advance of the required issue date.

NEW HAMPSHIRE http://www.governor.nh.gov/citizen/index.htm

• Send a request in writing to the Governor's Office at: Governor Maggie Hassan State House 107 North Main Street Concord, NH 03301 Or by email. Please send requests at least two weeks in advance and include as much information as possible.

NEW JERSEY http://www.state.nj.us/governor/contact/

Select "requesting proclamation/special letter."

NEW MEXICO http://governor.state.nm.us/Proclamations 1.aspx

• Requests will be accepted no more than 6 months in advance and will not be issued more than 3 months in advance of the event. Four-week notice is required to provide proclamations.

NEW YORK https://www.governor.ny.gov/content/governor-contact-form

• Further information on obtaining a Proclamation is available by contacting Executive Chamber Operations/Proclamations at (518) 474-6499 or by writing to the Governor at: The Honorable Andrew M. Cuomo Governor of New York State NYS State Capitol Building Albany, New York 12224 (Attention: Proclamations)

NORTH CAROLINA https://governor.nc.gov/request-proclamation-letter-or-award

• Please note that all requests require 6-8 weeks prior notification

NORTH DAKOTA http://governor.nd.gov/contact-us

No formal process; contact the governor.

OHIO http://www.governor.ohio.gov/Contact/ContacttheGovernor.aspx

• In Select Issue drop-down menu, select "requesting proclamation/special letter."

OKLAHOMA https://www.governor.ok.gov/contact/commendation-proclamation-request

All requests should be made at least 30 days in advance.

OREGON https://www.oregon.gov/gov/Pages/Proclamation-Request-Guidelines.aspx

 All proclamations must be submitted with at least a 30-day notice to allow for the approval process and the production of the document itself.

PENNSYLVANIA https://www.governor.pa.gov/contact/

• Requests must be submitted in writing and should include detailed information about the type of greeting you are requesting, the date you will need to receive it, contact information and a mailing address to send the final document. Requests can be submitted via email to governor@pa.gov, via fax to 717-772-8284, or via mail to the Governor's Correspondence Office, 508-E Main Capitol Building, Harrisburg, PA 17120. Contact the Governor's Correspondence Office at 717-787-5825 if you have additional questions about your request.

RHODE ISLAND http://www.governor.ri.gov/faq

• Click on "How to request a proclamation". Should be received at least 45 days before the delivery/pick-up date.

SOUTH CAROLINA http://governor.sc.gov/EXECUTIVEOFFICE/Pages/Proclamations.aspx

• Please submit your request 30 days in advance.

SOUTH DAKOTA <u>http://sd.gov/governor/contact.aspx</u>

• No formal process; contact the governor.

TENNESSEE http://www.tn.gov/governor/article/request-for-a-proclamation

• Requests must be made through the governor's website no less than 21 business days in advance. Proclamations may be requested, but will not be issued, more than three months in advance.

TEXAS http://governor.state.tx.us/contact/

• Click "I need assistance". Complete required fields. Under issue click "Ceremonial item request." Include request and draft proclamation in the comment box.

UTAH http://www.utah.gov/governor/declarations/

• All declaration requests must be submitted online on the Governor's website using the application form link. The application must be submitted at least six weeks in advance of the date needed.

VERMONT http://governor.vermont.gov/proclamation-request

• The public may request a proclamation 4-6 weeks before the desired date, and the governor may make a determination based on his review.

VIRGINIA https://governor.virginia.gov/constituent-services/make-a-request/proclamations/

 Requests must be made no fewer than 45 days in advance and no more than 120 days in advance of the date you need the proclamation.

WASHINGTON https://fortress.wa.gov/es/governor/contact/proclamation

All requests must be received at least 30 days before the date you need the item by or the print date.

WEST VIRGINIA http://www.governor.wv.gov/Pages/ProclamationRequestGuidelines.aspx

• All proclamations must be submitted at least 30 days in advance to allow for the approval process and the production of the document itself.

WISCONSIN https://appengine.egov.com/apps/wi/governor/document-request

• Requests must be made no fewer than 45 days in advance of the date you need the proclamation.

WYOMING http://governor.wy.gov/SiteCollectionDocuments/Proclamation%20Policy.pdf

• Requests for a proclamation signing should be made four to six weeks prior to the requested date. The Governor's Office tries to let requesters know the outcome of a proclamation two to four weeks before the requested date.

Additional Resources

- Organizations like the National Organization for Rare Disorders (NORD) provide toolkits and guidance for requesting proclamations.
- The State Contact List for Proclamations offers specific information for each state's process.
- EveryLife Foundation has a list of some state-level organizations: https://everylifefoundation.org/rdla-state-advocacy-hub/state-organizations/
 - o Alabama Alabama Rare
 - California Cal Rare
 - Colorado Colorado Rare
 - New England Rare New England
 - North Carolina <u>Taylor's Tale</u>
 - o Ohio <u>Little Hercules Foundation</u> (Kelly Maynard and Randi Clites)
 - o Oklahoma Oklahoma Rare (sky@oklahomarare.org)
 - o Kansas (Kansas City) Rare KC
 - o Washington NW Rare Disease Coalition