



Why should I request a proclamation? A proclamation is an official designation of an event. Proclamations are a great way to educate the public about a specific issue and bring attention to a cause.

STEP 1: Contact the State or Local Government Office - Governors, county executives, mayors, state legislatures, municipalities, counties, cities or towns can issue proclamations

STEP 2: Draft your Proclamation (sample draft included p.2)

STEP 3: Follow the Local Guidelines for Submitting a Proclamation Request – the easiest way to research your city, county or state’s guidelines is to look on its website and search for the term “proclamation.”

STEP 4: Allow Enough Time - The wheels of government turn slowly, so be sure to begin the proclamation request process at least two to three months in advance of your event date or as soon as possible.

STEP 5: Make an Event Out of It! A proclamation is an effective tool for gaining public recognition of your event because it carries the full support of a key government official in your state or community. Notify your local paper or media outlets about the proclamation.



Sample Proclamation Draft

[City/State] of [City/State Name]

Executive Department

Office of the [Government Office Name]

[Government Office City Name]

Resolution

WHEREAS, CDKL5 Deficiency Disorder is a rare neurodevelopment disease caused by mutations in the CDKL5 gene that usually begins in infancy, and

WHEREAS, the individuals affected by CDKL5 Deficiency suffer from broad range of clinical symptoms and severity, though the hallmarks are early-onset, intractable epilepsy and neurodevelopmental delay impacting cognitive, motor, speech and visual function, and

WHEREAS, the need for widespread awareness and understanding of CDKL5 Deficiency is critical for meaningful research to continue so that the quality of their lives is improved, and that hope for a brighter future is real, and

WHEREAS, CDKL5 Worldwide Awareness Day and CDKL5 Awareness month will be celebrated annually, and is sponsored by the International Foundation for CDKL5 Research, who supports research, family programs, and ongoing awareness efforts, and

NOW, THEREFORE I, (Name/title), [GOVERNMENT OFFICE TITLE] OF THE [CITY/STATE] OF [CITY/STATE NAME], hereby proclaim the month of June as CDKL5 Awareness month, and June 17 as CDKL5 Awareness Day, bringing hope to those families affected by CDKL5 Deficiency Disorder. And I call on all scientists and doctors to support continued research of CDKL5 Deficiency, recognizing that advancements in research and care will mean a brighter future for all those affected by CDKL5.

On this _____ day of June, 20 ;

[Name of government official]

[Government office title]

[City/State] of [City/State Name]