

GM1 Day Congressional Resolution Request Letter

Subject line for email: Request for a resolution recognizing May 23 as International GM1 Gangliosidosis Awareness Day

Event: International GM1 Gangliosidosis Awareness Day

Organization: Cure GM1 Foundation

Requestor: XXX

Address: XXX

Phone: XXX

Email: XXX

Date Recognized: May 23

Dear [Representative / Senator] [FILL IN]:

I am your constituent from XXX and my child XXX who also lives in XXX, is affected by GM1 Gangliosidosis (GM1). GM1 is a rare inherited disease that primarily affects children. It has many debilitating ramifications, some of which are developmental regression, seizures, visual impairment, and neurodegeneration. The thousands of diagnosed children and adults who suffer from GM1 face the progressive loss of skills and abilities until death. This is a fatal disease that currently has no cure or effective treatment.

GM1 is a progressive disease, meaning irreversible damage occurs the longer someone is affected. The faster a diagnosis can be made, the sooner a patient can work to limit the damage by trying therapies, taking medications, and joining clinical trials which may slow disease progression or help with symptoms.

Unfortunately, most doctors are unaware this disease exists. Because of this, the diagnostic odyssey takes an average of four years for most families—too long. An officially recognized day of observance could more effectively spread awareness and improve outcomes. Awareness days and all initiatives leading to earlier diagnosis and improved outcomes could improve and even ultimately save lives.

I respectfully ask that you introduce a resolution in the [House of Representatives / Senate] expressing support for the designation of May 23 as International GM1 Gangliosidosis Awareness Day. I have attached sample resolution text that your staff are welcome to adapt. Many states have already proclaimed this day, and recognition from Congress would help bring GM1 to the attention of doctors and families across the country.

International GM1 Gangliosidosis Awareness Day is organized by the Cure GM1 Foundation (<https://www.curegm1.org>). Founded by parents of children who suffer from GM1, this nonprofit seeks to save the lives of all those with this wretched condition by funding research for treatments and a cure. If you would like additional information, I would be happy to provide it. Thank you so much for your time,

Sincerely,

XXX

Attachment: Sample resolution text