



GOAL: To establish Diffuse Intrinsic Pontine Glioma Awareness Day on May 17, 2017, in as many states as possible.

Michael Mosier Defeat DIPG™ Foundation is proud to be partnered with an amazing team of individuals, families, and foundations who are working together to seek establishment of DIPG Awareness Day across the United States for May 17, 2017. We hope this information will be useful in your efforts to work with your state government and community.

CENTRAL PILLARS

- **By banding together to advocate for the same day in multiple states we will be able to gain more momentum and draw even more attention to DIPG on a unified awareness day.**
- **While every family and advocate should use their own personal story to urge their state government to adopt DIPG Awareness Day, the proclamations we seek should not be child-specific to ensure they include and represent ALL children who have faced or are facing this disease.**

METHODS

There are two potential avenues for establishing DIPG Awareness Day in your state.

- First, you may submit a request to your Governor's office for the issuance of a Proclamation to establish May 17, 2017 as DIPG Awareness Day. We have enclosed a sample letter and proposed language for a proclamation. We recommend this approach.
- Second, you may work with a member of your state legislature to seek recognition from the legislative branch of DIPG Awareness Day. This method could potentially be more difficult depending on the necessary steps within the legislature that require a vote for passage of such action. If, however, there is a true champion on the legislature for this cause, you may be able to work with them to achieve the desired result.

SUGGESTED TIMELINE

We suggest that you compose a letter to submit to the Governor's Office in your state (or other state officials you seek to work with) by January 2017. Submitting the materials at this time will allow for at least 5 months to engage with the office, send additional letters of support from constituents (if necessary), and allow for the administrative processing of the request. *Note that if you are in a state where there is a new Governor assuming office in January, we would recommend waiting to submit your letter until February. We are happy to work with you on timing strategy.

STATE TEAMS

In a number of states we have multiple volunteers to work on this effort, which is wonderful! The more voices we have, the better. We will connect you with other volunteers in your state and help coordinate your efforts.

SAMPLE MATERIALS

To assist you in making this request, we are providing models for your use. This includes a template for a personal letter making the request, in addition to draft language you may propose.

- Attachment 1 – Sample Letter
- Attachment 2 – Proposed Proclamation Language

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Michael Mosier Defeat DIPG™ Foundation is here to support your efforts and help to coordinate across and within each state. Please use us as a resource, and keep us updated on your progress. You may contact us at info@defeatdipg.org.

We welcome all participants – other families, foundations, and supporters. Please pass along and ask additional volunteers to sign up at defeatdipg.org/dipgacrossthemap.

ATTACHMENT 1 – Sample Letter

[LETTERHEAD/RETURN ADDRESS]

[DATE]

The Honorable [Name]
Governor of [State]
Street Address
City/State/ZIP

Dear Governor [Last Name]:

I am writing to respectfully request that you issue a proclamation recognizing May 17, 2017, as “Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Day,” to help raise awareness of this devastating childhood cancer. My family, which lives in [City], was personally impacted by DIPG, when my [child/niece/sibling/friend/etc.] was diagnosed in [Month & Date].

In 2016, both Maryland and Pennsylvania established DIPG Awareness Day on May 17, and we hope that [State] will join in this important effort in 2017, which will be very meaningful to the many families impacted in [State] and beyond. May is Brain Tumor Awareness Month across our country, and having this particular day of recognition for the deadliest pediatric brain tumor would be a meaningful step for your office to take as a way to stand in solidarity with the families who have had to confront this disease.

In September 2016, the Centers for Disease Control announced that brain tumors have become the leading cause of childhood cancer death, surpassing leukemia. DIPG is the second most common malignant brain tumor found in children and is the leading cause of childhood death due to brain tumors. DIPG essentially has a zero percent survival rate. This brainstem tumor impacts 200-400 children in the U.S. alone each year, and the median survival from diagnosis is 9 months.

[ADD PARAGRAPH OR TWO WITH DETAILS ON YOUR OWN PERSONAL STORY. INCLUDE CURRENT STATUS FOR CHILD (WHETHER BATTLING OR IF THEY HAVE PASSED AWAY.)

[ADD NOTE ABOUT ANY MEDICAL INSTITUTIONS IN YOUR STATE THAT TREAT PATIENTS, DO RESEARCH, OR ARE OTHERWISE CONTRIBUTING TO DIPG EFFORTS. IF YOUR CHILD WAS TREATED IN THE STATE, MENTION THAT.]

We are just one of the [State] families who have confronted this disease. [OPTIONAL: You can learn about the disease and many children who have faced it at www.DefeatDIPG.org.] By declaring an awareness day in [State] for DIPG – the deadliest pediatric cancer – we will take the concrete steps of both raising the profile of this disease and supporting the [State] families who have had to battle this grave illness, demonstrating that they are not alone in their fight.

As mentioned above, both Maryland and Pennsylvania established DIPG Awareness Days on May 17, 2016. Efforts are already underway in those states to renew those

proclamations for 2017, and families are working in at least 30 other states to have May 17, 2017 recognized as DIPG Awareness Day across this great country.

Attached to this letter you will find draft language for the Proclamation, which tracks language used in Maryland and Pennsylvania in 2016. I welcome the opportunity to speak with you or a member of your staff to answer any questions and provide additional information. We appreciate your leadership in the fight against cancer and your consideration of this request.

Sincerely,

[NAME]

Attachment

ATTACHMENT 2 – Draft Proclamation Language

NOTE: This language is modeled after the 2016 proclamations in MD and PA.

[PROPOSED] PROCLAMATION

May 17, 2017: Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Day

Whereas, Diffuse Intrinsic Pontine Glioma (DIPG) affects between 200 and 400 children in the United States each year; and,

Whereas, brain tumors are the leading cause of cancer-related deaths in children; and,

Whereas, DIPG is the second most common malignant brain tumor found in children and the leading cause of childhood death due to brain tumors; and,

Whereas, prognosis has not improved for children with DIPG in more than 35 years, but new medical technology and research finally offer hope for treatments for children afflicted with this disease; and

[Include if applicable] Whereas, leading **[INSERT STATE]**-based medical institutions are on the forefront of fighting cancer and researching cures, and

Whereas, **[INSERT STATE]** is pleased to help increase public awareness of this deadly childhood cancer.

NOW THEREFORE, I, **[INSERT NAME]**, Governor of **[INSERT STATE]** do hereby proclaim May 17, 2017 as Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Day in Maryland, and do commend this observance to all citizens.