

**Virtual
Event**

**Sept. 25
2020**

#Moonshot4Kids



Opens:
8:30pm
Program:
9 - 10pm EST

Rally!

for

our children



Virtual, live-streamed event with live and pre-recorded content

Social Media Kit!

THANK YOU!-for participating in the **#Moonshot4Kids** **Social Media Support for Childhood Cancer Awareness Month!**

This is DIPG Advocacy Group's contribution kick-off to [CureFest](#), the most important community event of Childhood Cancer Awareness Month Saturday, Sept. 26th, this year also a virtual event!

#Moonshot4Kids

[Register](#) 5K

The "[Race for the Angels](#)" honoring the 10s of thousands of children lost to brain cancer over recent decades begins **sunrise Sept. 25th** and closes sunset, Sept. 27th. The launch will be live at Red Rock Amphitheater at 8:30am EST. Livestream links tba on our [website](#).

The "[Rally for Our Children](#)" features current legislation and research developments and calls for RECOGNITION of those fighting for their lives. With 163 Members of the House of Representatives (and climbing) now aware of the urgent, needs of kids with deadly brain cancer like **DIPG**, we're appealing to House Leadership to simply allow due process for "the Little Bill That Could". Now. THIS Congress. #HouseVOTE! #Moonshot4Kids

STREAMS LIVE beginning 8:30pm EST,

With outlets on [DIPGadvocacy.org](#), facebook, and youtube tba at [dipgadvocacy.org](#).

Event BASICS:

Hashtags: **#Moonshot4Kids #RALLY**

#HouseVOTE! #KIDSFIRST #CREATINGHOPE #FAIRNESS

Dates: **September 25** (and all weekend, add **#CureFest2020**)

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About #Moonshot4Kids. [summary/history](#). [Letter to Congress](#)

The National DIPG Awareness Resolution in US Congress raises crucial awareness to the urgent, unmet needs of children with cancer using the statistics of childhood brain cancer, now **the most prevalent form of pediatric cancer and the deadliest**. **DIPG**, the second most common type of brain tumor in children, is responsible for the majority of pediatric brain tumor deaths annually. One child out of 100 so diagnosed generally survives to adulthood.

Yet due to lack of attention, and a research investment culture which does not prioritize children or the dying, the standard treatment protocol and terminal prognosis for DIPG have not changed since 1962 when Neil Armstrong's daughter Karen died of it. This horrific killer has been taking the lives of our children unchecked for decades, representing a world of unseen suffering.

With H. Res. 114 we're asking our Members of Congress to help us sound the alarm to help children with cancer fighting for their lives, right NOW!

Today, in 2020, we possess the technology, our scientists are working hard and moving the needle!—but funding, provided mostly by parent-led foundations, is scarce. The urgency of the need for cures for children is not widely known; the DIPG AWARENESS RESOLUTION alerts Congress and the national public to the reality that families of children with cancer are expected to endure—to **watch their children die in utter helplessness** with few, if any, out-dated, ineffective therapies available.

“And WHY?”

Because, *“the numbers aren't great enough for investors”,*
Parents here this routinely... *in the wealthiest country in the world.*

Only 6 treatments have been developed for children with cancer over the last 4 decades. This is unacceptable. “Go make memories” is not a plan.

WE MUST DO BETTER! #Moonshot4Kids! #RALLY!

The DIPG Awareness Resolution was first introduced 1/13/2016, the day after the Cancer Moonshot Initiative announcement. By the end of 2020 and three introductions, 2000 more children will have died of DIPG since then.

Childhood Cancer Awareness Month 2020

#Moonshot4Kids #RALLY

Sad fact: the current medical research investment culture does not prioritize children or the dying.*

→**BRAIN CANCER is the most prevalent form of childhood cancer**, and the leading cause of cancer-related death in children.

→**AWARENESS CAN SAVE LIVES.**

The proper diagnostic tools are often late in coming due to issues with insurance or doctor approval.

Due to the lack of general knowledge and recognition of symptoms, too many childhood brain tumors for which we do have life-extending treatments are discovered at autopsy.

→**Awareness creates knowledge of and access to clinical trials** which are often beset with disqualifying conditions or protocols when a matter of days can mean life or death. The effects of the Covid-19 pandemic, and at times of government shut-down, children have reduced access to live-saving treatments.

→**DIPG, diffuse intrinsic pontine glioma, is the deadliest brain cancer, responsible on its own for a significant portion of the annual childhood cancer death toll.**

→*Since most of the children die, and families are too devastated to speak out, it's remained a voiceless population despite its cumulatively significant size, and the tragedy continues out of sight, out of mind.*

We are asking our Members of Congress to help us "sound the alarm" with H. Res. 114

To recognize this world of suffering, to alert the greater philanthropic and scientific world is a way that we can attract the help we need more immediately to save lives.

→**GREATER AWARENESS FOR THIS URGENCY OF NEED** will help bring down resistance to passing important, authorizing legislation for childhood cancer, like Creating Hope, Kids First, Fairness to Kids with Cancer, and STAR allocations.

→**Our scientists on the front lines need greater support NOW.** 95% of the research funding for pediatric brain cancer is provided by parents and parent-led foundations, with extremely limited availability of clinical trials.

→**DIPG represents the hidden untold story of childhood cancer.** By targeting it, by calling it out by name, we bring help more quickly and save more lives. As we targeted leukemia 40 years ago when it was a death sentence, there are now many survivable forms to date.

*THE DIPG AWARENESS RESOLUTION SUGGESTS THAT a) years of life lost, and b) the mortality rate of any given cancer type be given greater consideration in the research grant process.

1. Sign our [support letter!](#)
2. Call your [Representative's office](#) and ask them to support H. Res. 114

After 3 introductions and almost 5 years of advocacy just for "The Little Bill That Could", and another 2000 children gone to DIPG alone, we are asking House Leadership to allow the Resolution a vote now, this Session of Congress. There's never a convenient time to consider them.

More instructions will follow the Rally for our next Campaign for House Leadership's support, Oct. 1, at www.DIPGadvocacy.org

What You Can Do

Use the hashtag #Moonshot4Kids #RALLY with every post

Follow #Moonshot4Kids by clicking others posts or initializing a search for it

Follow suggested accounts and share contents and activities

Activate social media followers and ask them to share about childhood cancer

Commemorate/honor DIPG and childhood cancer angels

Celebrate warriors, and heroes in our community making a difference!

Share social media posts and pictures to show how you support #Moonshot4Kids and children with cancer

CREATE a video with your friends and family to share about what you're doing to raise awareness and support research, or warriors, etc...

PARTICIPATE! In the Rally 9/25!!
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VISIT:

www.childrenscancercause.org and familiarize yourself with the legislation needing support right now.

For information about Kids First #GMKF visit. <https://4sqclobberscancer.com/reference/building-on-success/>

For the Fairness Act, visit the Facebook group page: <https://www.facebook.com/groups/756865851427204>

Creating HOPE visit www.kidsvcancer.org. [St. Baldrick's Foundation](#). [Alliance for Childhood Cancer](#). [CAC2](#)

[DIPG Advocacy Group](#) supports #GMKF in Congressional Office meetings in conjunction with H. Res. 114

Social Media FAQs

Q When do I post?

A. Right away to generate some anticipation for Friday!

Q What platforms do I post to?

A. Any and all, we'll use mainly facebook and twitter. 😊

Q How often do I post?

A Twitter is more fast-paced so you could several times a day, whereas on facebook, probably 2-4 times on the actual date of the run and rally. I'd leave 1-2 teasers leading up to the event per day on facebook –you know your audience if you're oversaturating.

Accounts, Hashtags, Links

A few major orgs are listed but we encourage you to use all your childhood cancer and childhood brain cancer connections!

DIPG Advocacy Group

Facebook @Moonshot4Kids

Twitter @Moonshot4Kids

NBTS:

Facebook @braintumors

Twitter @NBTStweets

Instagram @Natlbraintumorsociety

PBTF:

Facebook @Curethekids

Twitter. @PBTF

Instagram @PBTF

St. Baldrick's Foundation

Facebook: @StBaldricksFoundation

Twitter: @StBaldricks

Coalition Against Childhood Cancer

Facebook:

@CoalitionAgainstChildhoodCancer

Twitter: @CAC2org

KidsVCancer:

Facebook: @kidsvcancer

Twitter: @kidsvcancer

Smashing Walnuts Foundation

Facebook: @smashingwalnuts

Twitter: @smashingwalnuts

Michael Mosier Defeat DIPG Foundation

Facebook: @defeatDIPG

Twitter: @defeatDIPG

Carson Leslie Foundation

Facebook: @carsonlesliefoundation

Twitter: @carsonleslie3

The Cure Starts Now Foundation

Facebook: @TheCureStartsNow

Twitter: @CureStartsNow

The Nicholas Connor Institute (TNCI)

Facebook: @thenicholasconorinstitute

Twitter: @TNCI

PNOC Foundation

Facebook: @PNOCfoundation

Twitter: @PNOCfoundation

CBTTC—CBTN (Children's Brain Tumor Network)

Facebook: @CBTNetwork

Twitter: @CBTNetwork

Rally Line-up

Members of Congress

Congressman Mike Garcia (CA-25)
*Congressman Brian Fitzpatrick (PA-1)
Congresswoman Jennifer Wexton (VA-10)
*Congressman Mike Kelly (PA-16)
Congressman G. K. Butterfield (NC-1)

Foundation/Organization Leaders

Sarah Milberg (St. Baldrick's Foundation)
Jonathan Daniels, Cystic Fibrosis Foundation
Elena Gerasimov (Kids v Cancer)
Annette Leslie (Carson Leslie Foundation)
*Jonathan Daniels (Cystic Fibrosis Foundation)
Mina Carroll (Storm the Heavens Foundation) Live
*Jenny Mosier (Michael Mosier Defeat DIPG Foundation)
Ellyn Miller (Smashing Walnuts Foundation)LIVE
Keith Desserich (The Cure Starts Now) Live
Rachna Prasad (Mithil Prasad Foundation)
Janet Demeter (Jack's Angels) Live

Researchers

Dr. Charles Keller (Children's Cancer Therapy Development Institute)
Dr. Adam Resnick (CHOP) Live
Dr. Adam Green (CHCO) Live
Dr. Michelle Monje (Stanford)

Survivors

Daniel Cloakey (neuroblastoma),
*Nicole Puglisi (DIPG survivor)
Anne Beatty (brain tumor survivor)
Grace Wethor (living with brainstem glioma)

#Moonshot4Kids Rally for Our Children Community Participation



Live Rally Participation! –Peanut Gallery

We are looking for families and advocates who would like to participate as part of a live audience through video platform, so that you would all be in squares on the screen Brady Bunch style, with random and coordinated close-ups. Let us know if you'd like to join us LIVE!

Email us at: moonshot4kids@gmail.com.

Tribute Videos

The #Moonshot4Kids Virtual Rally Sept. 25, 2020, kick-off to CureFest will be supporting the National DIPG Awareness Resolution and the line-up of important legislation for childhood cancer currently needing support! We **would like to include as many of you as possible** in our DIPG/pediatric brain cancer community to participate.

Please note: If your child is a survivor, and they wish to submit or your family wishes to submit a video, the time constraint does not apply.

About the easy, self-made videos:

- 20-30 seconds (this is a target and not strict—say what you need to say)
- Include a picture of your child
- State the child's name and age, city and state you're from
- Why awareness is important; say whatever you would like about DIPG and pediatric brain cancer to the world.

How to submit:

- **Name your file** first initial, last name, and submit to our [dropbox folder](#).
- **Include a liability waiver** to your video fully stating and spelling your name and giving permission to Guiding Angels Productions to use it and your images, or, [download form](#) to sign and submit with your video.

A good example:

—of lighting, of placement, of this kind of short video was created by the DIPG Dads Facebook Group, as an example of how to frame and how it should look, and for the length of the tribute (angel) videos: <https://youtu.be/r941msVO4aU>

The hyperlink when you click the image takes you to the webpage which the flyer imitates, so all of those links are there on the webpage.

Here is a hard [copy of flyer](#) you can download.

Here is the [dropbox file](#) where you can put your video and picture files; please follow the labeling directions.

And here is the example of what the video should look like, and how long a tribute video should be, from [DIPG dads](#).

[Video release form](#)

We need you

in the zoom peanut gallery!

Live Rally participation! Write to: moonshot4kids@gmail.com to let us know you want to participate!

Suggested links and hashtags...

#Moonshot4Kids #HouseVOTE
#KidsFirst2.0
#HRes114
#CreatingHOPE
#FAIRNESS
#ChildrensLivesMATTER
#NeglectedNotRare

www.DIPGadvocacy.org www.bit.ly/ms4k-rally
Sign support Letter: www.bit.ly/dipg_supportletter