

If No One Knows, No One Cares: #Moonshot4Kids Delivers Urgent Message to President Biden at the White House

At the White House Cancer Moonshot Announcement, a childhood cancer advocate gets a golden opportunity to share an urgent message with the President.

LOS ANGELES, CA, USA, February 9, 2022 /EINPresswire.com/ -- Janet Demeter, childhood brain cancer advocate and leader of Jack's Angels Foundation (Agua Dulce, CA) and a founder of [DIPG Advocacy Group](#), a coalition of childhood brain cancer advocates and organizations supporting the [DIPG Awareness Resolution](#) in US Congress, took the #Moonshot4Kids campaign to the White House on Feb. 2, 2022 to attend and witness President Biden's 2022 Cancer Moonshot Announcement. "I'd

been involved in a White House OSTP roundtable of stakeholders in the childhood cancer community at the end of last year to relay our messages to the President about the need for children and childhood cancer to be more prominently featured in a new Cancer Moonshot, as cancer is the #1 cause of disease-related death in children in our country. When I was asked not to share about the participants and content of the roundtable until after 'the announcement', I had no idea I would have the honor of being invited to this event," says Demeter.

As with approximately 400 other families across the United States in any given year, Janet's 3 year-old son Jack was diagnosed in October of 2011 with DIPG, diffuse intrinsic pontine glioma, arguably one of the deadliest childhood diseases. Virtually all of its victims die; it is one of the world's most rapacious killers of children, yet it is virtually unknown to the public. "I didn't realize until after Jack had died in July of 2012 that brain tumors lead in childhood cancer deaths, or that DIPG was actually not a 'very rare pediatric brain tumor', which is the usual narrative. DIPG is the



Childhood cancer advocate Janet Demeter meets President Biden at the Cancer Moonshot Announcement

2nd most commonly diagnosed brain tumor in children, and is responsible for the majority of childhood brain cancer deaths, a significant portion of the annual childhood cancer death toll,” notes Demeter. “At diagnosis, I was told it was so rare that we might have been struck by lightning twice,” a notion at which she now scoffs with antagonism.

Demeter’s work in activism began in 2014 when she began running for awareness with signs and angel wings to visibly symbolize DIPG’s fate, and also attending the newly begun CureFest events in Washington DC in September. The first resolution in a state legislature (California) was introduced and passed in both chambers, for DIPG/pediatric brain cancer. 2014 was also the first year of the White House Briefings for Childhood Cancer under the Obama Administration, which Demeter attended in 2015 and 2016, advocating for childhood brain cancer research and DIPG visibility.

“It dawned on me, congregating with hundreds of advocates for CureFest, that with DIPG we have a

powerful opportunity to raise awareness for all children who are suffering without hope of survival, or relief. Neil Armstrong’s daughter Karen died of DIPG in 1962, and today in 2022 we are presented with the same standard treatment protocol and terminal prognosis. Yet, with the



Jack Demeter, 8/30/2008 -
7/30/2012, Agua Dulce, CA

technology of the day, we sent men to the moon and brought them home safely because we had a strong national resolve. Together, we can do anything! But, if no one knows, no one cares, and no cures come quickly enough. This is the inspiration for DIPG Awareness Day, #Moonshot4Kids. Amid St. Jude’s commercials and the billions we invest in NIH, people don’t realize the neglect of pediatric disease research funding. Pediatric brain cancer, one of the leading causes of childhood mortality in the United States, is one of the least-funded areas of cancer research by the federal government and private sector. All

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Janet Demeter

the progress we’ve made in childhood brain cancer research in the last 10 years, which has been enormous, has been paid for by bereaved parents and parent-led foundations, thanks to social media and our collective outrage.”

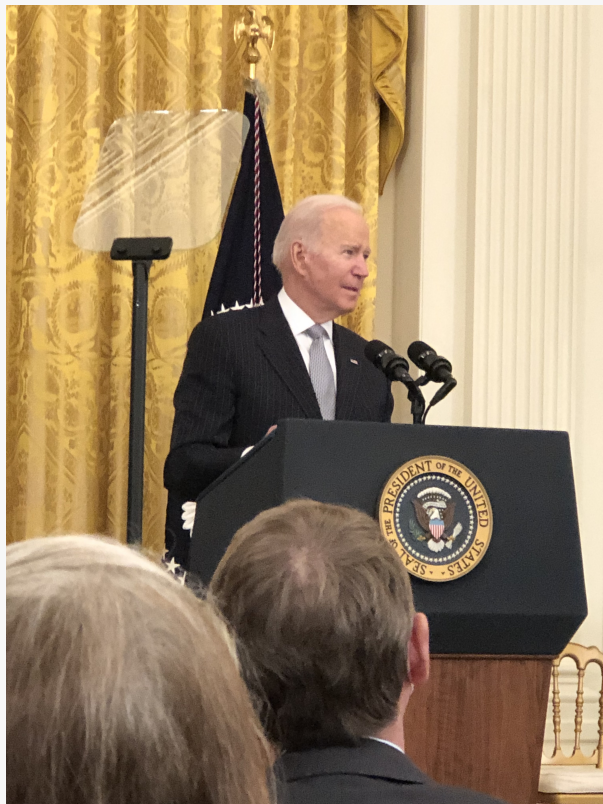
The first DIPG Awareness Resolution was introduced to U.S. Congress on January 13, 2016 by Congressman Steve Knight (R-CA-25) and Congresswoman Debbie Dingell (D-MI-12), the current

lead sponsor, one day after Vice President Biden's Cancer Moonshot Initiative was first announced. Dubbed #Moonshot4kids ever since, Mrs. Demeter continues to chase success for the resolution, insisting that if ever anyone needed a cancer moonshot, it's America's children. "There's an enormous subculture of suffering which is literally unseen and unheard, and as long as it is, solutions will continue to be slow in coming, and the deaths prolific, and torturous for the witnessing family members, completely helpless to save them," Demeter maintains. "The DIPG Awareness Resolution is an opportunity for our Members of Congress to help us make this issue more visible, to attract a cure more quickly, where we cannot."

Barry Demeter, Janet's husband, is a retired contractor and estate manager in the Santa Monica Mountains which makes his time at home extremely limited, yet as such he supports the family, Janet's work and occasional foundation expenses. As host of Childhood Cancer Talk Radio, mom to Sophie-Marie (15), manager of the family's rented property and their animals, Janet continues to hold Congressional Office meetings on zoom each week to inform our representatives of the plight of childhood cancer, encouraging them to seize the opportunity with the DIPG Awareness Resolution ([H. Res. 404](#)) to draw attention to the neglect of pediatric disease research funding. A similar effort continues in the Senate, as the 2022 Resolution is currently being planned. DIPG Advocacy Group co-founders Paul Miller, of Littleton, CO, Elizabeth Psar, President of Julia Barbara Foundation (Knoxville, TN), Scientific and Medical Advisor Marcelo Ortigao (Ft. Collins, CO), International Liaison Gerry Tye (Sydney, AUS), and Community Liaison Katherine Bader (Rhineland, MO) all contribute to the effort.



Demeter explains why awareness is so important for childhood cancer before heading to the White House, donning pictures of DIPG children who died last year.



President Biden shares his commitment to ending cancer as we know it, lending the full power of his office.

The “Cancer Moonshot Announcement” event on February 2nd, 2022 at the White House in Washington, DC was attended by members of Congress, leaders of philanthropic organizations, pharmaceutical industry leaders, and medical industry leaders, and leaders in advocacy, assembled with the excitement of hope and optimism. The opening speech was intensely direct and heartfelt from First Lady Jill Biden underlining the President’s commitment to the Cancer Moonshot and the Biden family’s personal experience with cancer, and with grief. Vice President Harris gave a moving account of her own personal, tragic losses to cancer, inspiring solidarity in our collective commitment moving forward. Finally, President Biden gave a powerful speech in which he emphasized his commitment to employ the full power of his office in realizing the ultimate goal of the Cancer Moonshot: to end cancer as we know it.

Awareness...

...for DIPG,
Childhood Brain
Cancer,
and the
URGENT
UNMET
NEEDS
of ALL
CHILDREN
WITH CANCER.

#MOONSHOT4KIDS


May 17

The National
DIPG Awareness
Resolution

H. Res. 404
HOUSE VOTE!
In the
117th
Congress

TO SUPPORT:
SCAN ME

Let’s make children with cancer a national priority.
Support #Moonshot4Kids, H. Res. 404! Ask Your Rep. in Congress to sign it today!



Demeter’s initial reaction was mixed: “It was a beautiful event, and I was very moved, but not once was the word child, or children spoken. Our work on the roundtable effort, the proposals, the painstakingly drafted letters, the hour and a half of testimonials and deliberations, and this is what happens. Let me be clear: I was not surprised! This is the reality for childhood cancer; we all assume—even the President!--that if we invest in something it will of course trickle down to our children. This is the wake up call of #Moonshot4Kids: medical research investment into cures for children is one area where our priorities as Americans are completely upside-down. You don't know it until it directly affects you. We spend more dollars on potato chips annually than our government invests into childhood cancer,” insists Demeter, who had no idea she would get to actually speak with President Biden.

After the event, in a hallway adjacent to a glorious sitting room filled with chamber music performed by United States servicemen and women, President Biden couldn't help but see the hundreds of pictures in which Demeter was cloaked, along with a halo and a #Moonshot4Kids sign on her shoulder. “I told him that virtually all of our DIPG children die a horrific death, and that if anyone truly needed a moonshot, it’s children with cancer... I told him I'd been working for 6 years on the DIPG Awareness resolution (H. Res. 404), now in its 4th iteration in Congress. He asked me ‘how many cosponsors have you got,’ and I told him of our attempt to gain back and surpass 218 after the near House majority we had last Congress...but now they want a supermajority of 290. He instructed his kind assistant to take my information and follow up, as I'd mentioned a May 17 event. I hope he does. Either way, there will be a #Moonshot4Kids

Briefing for childhood brain cancer on that day in Washington, DC. And, agreeing to work with my friend and hero Nancy Goodman, author of the Creating Hope Act, there will be a childhood cancer community event for the Cancer Moonshot in September. And so, it was a great day for kids after all!"

More information about the #Moonshot4Kids effort can be found at dipgadvocacy.org, jacksangels.org, or on the "DIPG Advocacy Group" facebook page. To contact Mrs. Demeter or DIPG Advocacy Group directly about this project for a response, email moonshot4kids@gmail.com.

Janet Demeter
Jack's Angels Inc

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