

# Jack's Angels Foundation: Advocacy Campaign and General Update for Collaborative Individuals, Groups, and Organizations

"What your money's been doing."



*General Description:* This follows a journey in advocacy for children and their families with DIPG, that more can be done for them in the future, and more awareness can be raised to the inequities in research funding for our children with cancer in the United States. Brief summaries of organizational business for contributing or potentially collaborating organizations or individuals.

## 1 WHY DIPG?—THE SILENCE OF DEATH.

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I personally experienced losing a child to DIPG as a particularly dark and isolating experience. We began the 2015 “Just Say It!—DIPG, getting a National Day” campaign with the obvious goal of seeing DIPG<sup>1</sup> Awareness fulfill this seemingly impossible task—achieving a National Awareness Day—but also to research the conditions surrounding the fact that this disease has been largely fought in silence and darkness for the past 40+ years. What has strongly inspired the campaign has been the outrage experienced by so many parents, being told over and over again how rare the disease is—mostly to excuse the lack of solutions developed—only to find out, before or after the death of their child, that DIPG is in fact prevalent, with a steady stream of new cases each year, and is responsible for the majority of pediatric brain tumor deaths annually in the US. Learning that brain tumors are the leading cause of cancer-related death in children exacerbates the outrage, along with the knowledge that cancer kills more children in our country than any other disease. “Rare” certainly does not mean irrelevant, not for us.

So, why the silence? Why is it that almost every case of terminal pediatric cancer on the news this year has been DIPG, but no one really knows it? DIPG is rarely mentioned; for example, at the 2015 ESPY Awards this year, collegiate basketball hopeful Lauren Hill, who had succumbed to the disease in April, was honored for her bravery, but there was no mention of what she was fighting. My experience as a parent of a child diagnosed with and lost to DIPG, has been this: DIPG is the “Great Embarrassment”. Not only has nothing significant been done about it in decades, but it exemplifies so perfectly the experience of most childhood cancers. The disease is marginalized as rare, and receives little to no research funding.

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<sup>1</sup> Diffuse intrinsic pontine glioma(DIPG), an almost exclusively pediatric brain cancer characterized by its diffusely infiltrating location in the pons area of the brainstem, is responsible for the majority of pediatric brain tumor deaths annually in the United States, with virtually no survivors, and no progress to that effect in over 35 years.

*It points to the fact that research funding is first and foremost for profit for the investor. Medical research is a business first, and we've neglected our children for decades. Of course no one wants to talk about that.*

The expression on the doctors' faces says it all; not even meeting our eyes, we were seeing the helplessness, embarrassment, and years of the heartache of prior cases. But we parents, those who are directly affected, experience this as a concrete reality: to our system our children are just a number, and we hear, "the numbers aren't great enough for research investors." I did, from several parties.

With the advent of social media, parents are becoming less and less accepting of this reality. The more we discover that we are not alone, and that DIPG is not some freakish, rare thing—as if that were an excuse to not try to save our kids!—that other families with not just DIPG, but most cancer-diagnosed children are discovering that childhood cancer as a whole receives only 4% of our National Cancer Institute's budget for research<sup>2</sup>, we are reaching a critical mass of outrage. Change is inevitable, and it is on the horizon. We see it, and we'll fight for it to the death because we've got nothing to lose. We have everything to fight for to make our child's life count: be part of the solution—help those fighting now and those to come. It's horrible watching others go through it, knowing almost exactly what they're experiencing; I personally can't do it without attempting to be an effective force for positive change.

## 2 DIPG AWARENESS AS FULCRUM FOR LEVERAGING EQUITY IN FUNDING FOR CHILDHOOD CANCER RESEARCH

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I feel we have an extraordinary opportunity here. Of course this problem of "money before people" is not going to be solved overnight. It is a pervasive and underlying problem throughout the world of human beings today. Whether or not you agree with that, the issue of our children is something upon which all of us, or at least most of us, can come together. Our children are our future, and the future of our planet. We need to start looking further into the future for "payback" than the next quarterly report. Most scientists agree that attaining a greater understanding of and finding solutions to some of these most resistant childhood cancers will not only save lives, and bring our understanding of biology to a whole new level, but invariably create new industry, jobs, and economy. Resistance to change is the biggest factor for us to overcome. There is invariably fear of loss somewhere to those who value strongly the idea of being "in control" or "in power." This is where stressing the solution is vitally important. We do not wish, or have the authority for that matter, to blame or "point the finger" at any one institution, group, or person. We do feel that raising awareness to the problem, the neglect of our children with cancer, is urgent, and this will create inspirations for possible courses of action that we have not been able to imagine. It also creates a responsibility; to do nothing in the face of injustice to our most vulnerable citizens is unconscionable, and there are too many of us willing to raise the banner as a reminder for it to be ignored.

Again, why DIPG? Brainstem gliomas originating in the pons area have been (diffuse intrinsic pontine glioma) identified since the 1950s, with a regular and steady stream of new cases each year. Karen Armstrong, Neil Armstrong's baby daughter, died of DIPG. The exact nomenclature came later, perhaps

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<sup>2</sup> February 14, 2014 NIH Conference "Focus on Pediatric Cancer" at the NCI, Bethesda, MD

not until the 80s, but the condition has certainly been known of for that long. DIPG has a 0% survival rate, and parents are told there's nothing they can do. In fact, doctors have been reported saying that they cannot give the families any hope on account of avoiding a lawsuit. Imagine finding out your child has this, they have no idea why, and there are no solutions because it's too rare for companies to invest in the research.

***For forty-plus years, these children, with their families, have been facing death with a bravery and desperation that cannot possibly be imagined. It is time for them to be honored as well, after fighting so long in the dark with literally no help in sight but God on the other side.***

We parents must wait until we die to see our children again when something *could* be done, but we're just not doing it. No, a decision must be made to prioritize these children and their families who have faced death so bravely, with a 0% survival rate, for so many years neglected. We know also that this research invariably helps all cancer research and our understanding of medicine and biology. The more one knows, the more impossible it is to turn away, and a decision must be made.

### 3 RELATIONSHIP WITH THE ADMINISTRATION AND CONGRESS

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With no real pre-planning or "deciding" ahead of time that I would be an advocate and activist for DIPG children, I was drawn to attend CureFest in Washington DC in 2014, not knowing how in the world I would ever get there, but it happened. More important than CureFest was the Summit for the Congressional Caucus for Childhood Cancer, led by co-chairs Congressman McCaul (R-TX-10) and Congressman VanHollen (D-MD-3). Francis Collins, Director of the NIH spoke, as well as the CEO of Anderson Medical Center in Texas, and finally Amrit Ray, the CMO of Janssen, global component of Johnson and Johnson. Earlier that year, in February, it was first reported that only 4% of the NCI research budget was targeting pediatric research at the NIH Conference "Focus on Childhood Cancer", Feb. 14 2014 in Bethesda MD. And so, at that point, the 4% was only referred to very defensively. In fact, Dr. Ray was so bold as to say that only 1% of all hospital patients are children so 4% is actually very generous. The room was quietly horrified. I decided this was the last time I would be quietly horrified, with my 4% is not enough sign, angel wings and halo, which I decided was an absolute necessity for the Summit, everyone else in silent attire. I thought I was lucky they let me in. The consensus of those who attended the White House Briefing for Childhood Cancer last year, with Dr. Varmus, then Director of the NCI, was that there was little to no willingness to converse about this issue. In fact, Dr. Varmus said that it simply "would not be discussed at this time." I was ecstatic when I heard earlier this year 2015 that Varmus was "stepping down." I had written many an angry letter to the President about it, so at least my thoughts were resonating appropriately, hesitant to suspect having had any personal effect.

I had made contact with the offices and aides of my own Congressional and Senate Representatives, as well as those of the Caucus Chairs when in Washington in 2014, and kept in touch with them over the last year, so that when I returned there had already been a relationship established for our cause. Though we lost money on our 2015 Music and Art Festival for Children "Art for Jack" event, donations from the *Agua Dulce Royal Court*, *ADK Sorority*, and *Vasquez High School* made it possible for us to cover expenses and keep functioning. I appealed to my Facebook friends in a Kickstarter campaign to cover travel expenses in part, and was given a personal donation paid for ½ of my airfare. The 2015 trip to

Washington DC has been most favorable and has indeed helped pave the way for possible new legislation, the details of which are not yet public; I cannot stress the importance of these donations from local groups and organizations, and friends.

The primary goal for the September 2015 trip to Washington was to elucidate, if possible, the decision-making process regarding the prioritization of research within the NCI. My Kickstarter campaign (to help fund the trip) was in its conception a promise to create a journalistic piece documenting my quest to get a National Day for DIPG, and to also bring to light the reasons for its silence—hence the name “Just Say It!”—because it seemed no one would. I began by reaching out to NCI officials in the hope of scheduling an interview. Where no one would grant one, I was eventually pointed to the OAR—Office of Advocacy Relations, and I spoke with Robin Rinker, then Advocacy Relations Manager, and we scheduled a phone meeting together with her partner-in-training. They weren’t able to adequately answer my questions about this decision-making, except to point me to their “Peer Review” process, where experiments are valued for potential effectiveness by several different scientists although what other affiliations they may have is not clear, nor was there any word or reference to an overseeing committee responsible to Congress or any guidelines for these decisions whatsoever. They also educated me about NCI history; it was President Nixon that created this government agency, which is in theory directly responsible to the President of the United States. I met both ladies at the 2015 White House Childhood Cancer Awareness Briefing. A Congressional aide I met with at length was wary of the idea that the NCI is directly responsible to the President, in reality.

Although the messages from different parties of our Government—OAR, Congress, White House—were mixed, and no one seemed to have a definitive answer for us, there was a willingness for conversation on my trip that I found relieving and most hopeful. Relations with Congressional Offices were particularly encouraging, giving me new faith in our system. I had actually been invited to the Briefing as a result of the contacts I made from my trip last year. While I had the opportunity to voice certain concerns I knew many of us had, such as the fact that in our experience as parents we are made to feel insignificant—that our children’s lives do not matter for all practical purposes—to which there was a sincere expression that it doesn’t reflect the intentions of the White House, the reality remains that there are no provisions in place to account for the allocation of funds, or the prioritization of this process—at least none that are responsible to the public, or to Congress. There was mention of DIPG—to which I gave my utmost thanks; I insisted on posing the question about a provision for those cancers with a 0% survival rate. Many parents thanked me afterward for speaking up for them, and some mocked my wearing the angel wings with ribbons for DIPG children. I was there for all those kids who have no voice; that’s why I wore the wings. I went to Washington for them, and those currently fighting, not me.

The Office of Congressional Relations at the NCI, to Congress, gives the same information basically that the Office of Advocacy Relations gives to advocates (parents), that they use “peer review” of experiments and “steering committees”. Again, the public and Congress don’t really know who these people are and what other commercial affiliations they might have. The argument is made that 50% of the research budget goes to general science, which of course then benefits other fields, trickling down to pediatrics—so it’s really more than 4%, they insist. At that rate, we’ll have answers for these families in another 50 years. This is why progress has been so slow in pediatric brain cancer research; we’re simply not targeting it. Raising awareness is the first step in the process of affecting accountability, transparency, and change.

## 4 WHAT CAN WE DO?

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In reviewing the events that Jack's Angels Foundation has created and funded over the past 3 years, we have learned a few things. Awareness is still quite low in the general population regarding the 4%, and of course DIPG, but it is definitely growing. Having no personal ties to the circles of individuals and businesses in our community that could help us, or sponsor events, I have not gained the sponsorships that our organization needs to survive in the long term. I have, of course, made it top priority to do my best in an attempt to make such connections as the Holidays of 2015 approach, and we have an event coming up with the Santa Clarita Valley Chamber of Commerce that shows some promise of supporting our cause at least through the Spring 2016, namely [the Santa Clarita 5k Fun Run and "Skip for Jack!"](#) Our music and art festivals for children have not received the support necessary for us to continue on that route into the next two years so we are changing gears, so to speak.

To raise more awareness with events, we're looking at relay races for the next 2 years. I have been using running as a tool in activism and have met many others along the way; "Relay for Life" grosses \$1-\$3M alone in its annual event in Santa Clarita. The American Cancer Society, like most other large cancer charities in the US, give less of a percentage of their research funding than our US government to pediatrics. So, the idea here is "RELAY FOR KIDS!"—exclusively benefiting pediatric brain tumor research. I feel it's very important for us to remain strongly allied with the Childhood Cancer Awareness Movement, brain tumors being the leading cause of cancer-related death in children. I'm also hoping to meet with ACS representatives here to see if they like the idea and want to be involved in any way. We also hope to meet with the Pediatric Brain Tumor Foundation, so see if they would like to partner with us.

### 4.1 FUNDING CREATIVITY

In raising awareness for the urgent need for this research, I would like to introduce a concept to the philanthropic community—most likely not new, but I feel it needs some new heralding. More detailed information on this subject can be found at <http://fundingcreativity.com>, but basically the premise is this: let us create research funds for our Pediatric Brain Tumor Consortium members, and their graduate students working with them, to target this disease. Many favorable hypotheses are abandoned, and some researchers change direction with their work because there simply isn't any funding for the research. The idea here is simply to help speed up the process of finding solutions collaboratively to this disease. Already, according to Dr. Michelle Monje of the Monje Laboratory at Stanford University, devoted to DIPG research, the implications of what their research is already demonstrating has widespread possibilities for application in cancer research. In the long term, funding this kind of research makes sense. For Jack's Angels, we would begin with Dr. Dhall at Children's Hospital Los Angeles, for which there is already a DIPG research fund opened, Dr. Monje at Stanford University, and for the PBTC members at UCSF. All top DIPG researchers, right here in California. We would like to promote the relay races using this as a goal: \$1M for each research group. Let's change the 0% survival rate for DIPG.

## 4.2 GENERAL SUMMARY OF THE STATE OF JACK'S ANGELS INC

The report with all of its details will be out shortly, but I can summarize to say that donations began, in our first year, with approximately \$6000 from private individuals and diminished to roughly \$2500 in the second year, and down to \$1000 in the third. The reason for this is that our biggest donor has ceased giving due to financial duress. We received donations of material items our first year that turned out to have no significant value, thus having us amending our bylaws and adding new provisions regarding what we can accept as a donation. The "Art for Jack" events generally cost \$2500, all things considered, and we simply cannot afford to put on another event of this kind without having costs covered by other parties. Our first 2 ½ years we have given approximately \$5000 to the DIPG Research Fund at Children's Hospital Los Angeles, have attracted other donations directly for that fund, and have spent approximately \$1000 for Project Angel Box, and another \$1200 at least in gifts and promotional items, and another \$2000 for printing, and PR needs. IT, communications, travel, insurance, and other professional fees are also significant. Basically, we're trying to run a business on very little income, and initial plans for this failing; our idea was to have a coffee house/art gallery but we didn't have the capital or a partner with the capital to do this. This year, 2015, we've been operating on less than \$3500, and the end of that has been in sight for quite some time. We clearly need a new direction in fundraising, hence the relay race events and a more aggressive campaign to attract sponsors. My previous efforts had not been focused in that arena and I am seeing now that if I do not, our organization may cease, with two officers leaving and no one confirmed yet to replace them.

### 4.2.1 For 2016-17—this may be revised in the December Report:

In our Financial Report and 'Amendments to Bylaws' coming out in December 2015, we will be noting maximum amounts of all grants specified for research, and proceeds from events benefiting research, of different levels to benefit Jack's Angels. 5% maximum of \$0-\$9,999, 4% maximum \$10,000-\$99,999, 3% maximum \$100,000 to \$999,999, and 1% over \$1M, and all three officers must agree that Jack's Angels retains no more than immediate needs. None will be retained if there is no need for our survival as an organization, and none will be retained by request of donor for any specified fund.

## 5 FINAL THOUGHTS

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We cannot thank enough those individuals and groups who have supported us and who continue to support us. We feel we owe a detailed account of our advocacy activities to the public as part of raising awareness for what we do, and so that one can see concrete, actual results from our efforts. The focus of this essay is our advocacy work, and not our events, although they are important to mention as they serve of as a vehicle thereof. Where a small, unsponsored organization may fail at a music and art festival, a larger more established one may flourish and enjoy community involvement. We have fond hopes for this in the future, as these events—though not lucrative, were an incredibly inspiring and enjoyable experience for attendees and performers alike, and embodied the light and joy that Jack inspired in us.

"RELAY FOR JACK!" is slated for May 28, 2016, and DIPG Awareness Week in California is May 25-31<sup>st</sup>, if you're not already aware; the Santa Barbara shootings overshadowed the press in 2014. This was our accomplishment of 2014, and the DIPG Research Fund's opening was the accomplishment of 2013. 2015 promises the attempt at National Legislation, and a breakthrough in advocacy and raising

awareness to DIPG. We are currently seeking sponsors and/or partners in our first Relay Race to support pediatric research exclusively.



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