



## Description of Purpose—Jack's Angels Foundation

Jack's Angels Articles of Incorporation describe our basic purpose as to raise awareness for DIPG, support the afflicted, and support research for DIPG. Diffuse intrinsic pontine glioma is a pediatric brainstem tumor that is invariably terminal, the median survival time with treatment being 9-12 months. The tragic nature of this condition cannot be understated; there are no survivors to DIPG, and typically the afflicted child retains full cognitive awareness of his or her condition while losing control of bodily functions until finally respiration is affected, and death ensues.

Equally, the families of DIPG patients suffer. Further darkening their perspective is a pervasive yet dubious ideology of nomenclature espoused by the pharmaceutical industry and medical establishment that categorizes the incidence of DIPG as "rare" or "orphan" disease, although this is not the case. This phenomenon is not limited to DIPG. Most all children's cancers are marginalized as rare in this fashion; hence, very little funding is allotted to research for pediatric cancers.<sup>1</sup> DIPG has been relatively unknown until the most recent years; finally, enough parents and families are speaking out about this deadly disease that has been kept in the dark, so to speak, for decades. Our children are dying with regular frequency of DIPG, which is responsible for 80% of pediatric brain tumor deaths annually, brain tumors being the leading cause of cancer-related death in children.<sup>2</sup> Concerning research funding, our priority should be saving our children's lives, as cancer is the leading disease-cause of death in children today in the US. This is our Awareness Mission, that families have more hope and more options for aiding research than donation of autopsy tissue.

Being a small concern as a business entity, we have had to consider our primary means of effectively executing our mission. In our first year, we established through our awareness activities the DIPG Research Fund at Children's Hospital Los Angeles. We hope to encourage the beginnings of such funds at every major children's research hospital with active neuro-oncology research in the United States. Where clinical trials are able to get support more easily, the scientists themselves on the front lines doing clinical work need to have the creativity and the freedom to design data-search protocols and other research projects, facilitating collaboration between scientists country-wide and in the world. While we are too small to accomplish this ourselves, we continue to put the idea out there, writing to representatives in local, state, and federal government, and corresponding with other foundations of similar purpose.

More importantly, we hope to be effective in our local community, raising awareness by creating programs that support the arts and education for children. "Art for Jack—Celebrating Children's Art"

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<sup>1</sup> Only 4% of the National Cancer Institute's annual budget for cancer research benefits the entirety of children's cancer research. This is public knowledge, the most recent dissemination at the NIH, Conference on Children's Cancer, Bethesda MD, February 14, 2014.

<sup>2</sup> The Lyla NSouli Foundation for Pediatric Brain Cancer, [www.lylansoulifoundation.org](http://www.lylansoulifoundation.org), The Oxford Journal of Neuro-Oncology 2012.

was in 2013 our first event, with children's art workshops, exhibits of fine art, musical and family entertainment. The second annual "Art for Jack" was equally successful, with a stronger musical and entertainment program, so that our plans for the 3<sup>rd</sup> annual event are for it to be a veritable music and art festival for children, as we had initially dreamed of it to be; "Art for Jack" is scheduled for Sunday, May 3, 2015. Meanwhile, we have been collaborating with Center Stage Opera to start a children's choir, with the goal of adequate proficiency to participate in professional productions, beginning with Bizet's "Carmen" in June of 2015. The choir is to begin workshops on October 29, 2014 in Agua Dulce, and it is inclusive of children K-8 in the Santa Clarita, Agua Dulce, and Acton Communities. We are grateful for this and all community collaborations, believing very much in the healing power of the arts in our society today, and its importance in the education of our children.

Our mission is three-fold: 1. We raise awareness for the urgent need for research for DIPG 2. Support the afflicted 3. In raising awareness, we support the arts and education for children in our local community.

Thank you for your kind attention. For further inquiry, contact Janet Demeter at [jacksangels1@gmail.com](mailto:jacksangels1@gmail.com), or 661-977-3125. Currently, the website at <http://jacksangels.org> is under reconstruction. Please have patience as all of our operations are dependent upon volunteer generosity.

Respectfully,

A handwritten signature in black ink, appearing to read 'Janet Demeter', with a stylized flourish extending to the right.

Janet Demeter, President  
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