

Jessika Douglas, a concerned citizen and childhood cancer survivor

February 5th, 2016

The Honorable Henry C. Hank Johnson Jr.
United States House of Representatives
2240 Rayburn HOB
Washington, DC 20515

Dear Mr. Johnson,

I would like to bring your attention to H.R. 3381: Childhood Cancer STAR Act. This act if it were to eventually become law has the potential to change my life and the lives of future generations. Currently, only two representatives from our fine state support this act into becoming law, but I am certain that with this being your fifth term in office you have the power to increase the number of representatives that will support this act. As I write to you the Childhood Cancer STAR Act has sat within the House of Representative's Subcommittee of Health since July 29th 2015. I fear the Childhood Cancer STAR Act will die if more action is not taken to push it through. This act means so much to me as a childhood cancer survivor. Although my initial diagnosis was over eighteen years ago, I still live with debilitating late effects from both the chemotherapy and cranial radiation treatments used to treat my cancer.

The Childhood Cancer STAR Act stands for survivorship, treatment, access, and research. If passed this act will expand childhood cancer research opportunities, improve childhood cancer surveillance, improve quality of life for childhood cancer survivors like myself, ensure patients access to publically available compassionate use policies, and ensure pediatric expertise at the National Institutes of Health. All of this is stated in just a short summary of the act. Current Congressional findings within the Childhood Cancer STAR Act report that by 2020 the population of childhood cancers survivors is expected to be 500,000 individuals. Without adequate research and care many survivors will live with untreated side effects and permanent disabilities due to the primitive childhood cancer treatments currently in place. From Congressional findings within the bill, as many as two-thirds of childhood cancer survivors are reported to suffer late effects from their disease or treatment including secondary cancers and even organ failure. Think of the lives we could change if we could stop what causes these late effects or even cancer itself. Pulling straight from the act, the Childhood Cancer STAR Act would enhance research on the late effects of childhood cancers including a study on insurance coverage and payment of care for childhood cancer survivors; improve collaboration among providers so that doctors are better able to care for this population as they age; and establish a new pilot program to begin to explore innovative models of care for childhood cancer survivors. I can personally say that I am concerned about finding good health insurance coverage once I age off of my parent's plan. I understand that children's healthcare is one of your top priorities as a United States Representative and that you proudly voted to expand the Children's Health Insurance Program coverage in 2009. Unfortunately, there are still gaps in the quality and provision of care that children with cancer will receive. As a result of disparities in the delivery of cancer care, minority, low-income, and other medically underserved children are more likely to be diagnosed with late stage disease, experience poorer treatment outcomes, have shorter

survival time with less quality of life, and experience a substantially greater likelihood of cancer death. This report is straight from the Congressional findings.

I implore you to at least consider voting for this life changing act. I believe the Childhood Cancer STAR Act has the potential to change children's lives for the better. We could have a world where children dying from lack of new treatments for rare cancer types are unheard of. I have hope for a future where children surviving cancer are free of debilitating cancer treatment late effects, and have equal opportunities to contribute and further society with new inventions and ideas. I hope you will be able to envision this future as well, and will vote for the Childhood Cancer STAR Act. Thank you for your time.

Respectfully,

Jessika Douglas