

Congress of the United States

Washington, DC 20515

Support Awareness and Research Funding for the Most Deadly Pediatric Cancers

Dear Colleague:

Please become an original cosponsor of a bipartisan House resolution calling for increased attention and funding for research on pediatric cancers with an emphasis on Diffuse Intrinsic Pontine Glioma (DIPG).

Chad Carr, the five-year old whose brain cancer battle became the cause of the University of Michigan football team, brought national attention to an extremely deadly form of pediatric cancer. Each year 200-400 children, typically aged 5-7, are diagnosed with a cancerous brain tumor in the Pons part of their brain stem, but details about the cases are often obscured in the news, referred to generically as “a rare pediatric cancer.”

In fact, DIPG is one of the more common pediatric brain tumors, and less than one percent of its victims live more than five years after diagnosis. Partly due to the disease’s fatality, which leaves few surviving patients to demand treatment, and with the media’s silence on the issue, there is no market incentive to research cures. Each and every parent whose child is diagnosed with DIPG is told the same thing by doctors: “There is no solution.” Parents of children in our districts, and in many of yours, feel helpless because there is almost nothing outside of palliative care that they can do for their children.

Chad Carr and the #ChadTough message his supporters used to elevate his case are helping to break the silence, drawing attention to the long list of children who shared his experience and shedding light on a disease whose victims are in desperate need of treatments, and of course, a cure.

DIPG is responsible for the most pediatric brain tumor deaths each year and has maintained one of the lowest survival rates – less than 1 percent of patients are still alive 5 years after they are first diagnosed. However, only 4% of the NCI budget for research targets pediatric research as a whole, and many forms of pediatric cancer, considered rare, receive almost no funding. Without strengthening awareness for DIPG and other lesser known pediatric cancers, the youngest and most vulnerable patients will continue to fight without treatment.

This resolution: (1) calls for the recognition of a “DIPG Awareness Week” around which pediatric cancer advocates can organize events; (2) focuses attention on the disease; (3) supports expanded research for treatments and care; (4) encourages the National Cancer Institute to factor in the number of life years lost when considering disease research grants.

Should you have any questions, or should you wish to cosponsor, please contact Adam Brooks with Rep. Knight at Adam.Brooks@mail.house.gov or 2-4671, or Molly Fishman with Rep. Jackie Speier at Molly.Fishman@mail.house.gov. Thank you for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read "Steve Knight".

Steve Knight
Member of Congress

A handwritten signature in black ink, appearing to read "Jackie Speier".

Jackie Speier
Member of Congress