

# KIDS CANCER

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## **Kids v Cancer Applauds the President's Signing of the Creating Hope Act as Part of the FDA Reauthorization**

WASHINGTON, July 10, 2012 -- President Obama signed the Creating Hope Act as part of the Food and Drug Reauthorization Act of 2012. The Creating Hope Act is the first Congressional effort to address the profound scarcity of drugs for pediatric cancer and other pediatric life-threatening and rare diseases.

This is a story of a mother, Nancy Goodman, who lost her son Jacob to brain cancer when he was 10 and responded by building an advocacy movement to promote pediatric cancer drug development.

Said Goodman, "The Creating Hope Act will create incentives for the development of new treatments to treat sick kids, so that one day, some sick children will not share Jacob's fate. I am profoundly grateful to bipartisan efforts in Congress to pass the Creating Hope Act, to the FDA for its support, and to President Obama for signing it."

"The American people do not know how much worse pediatric cancer is than most adult cancers – that the treatments are far harsher, that survivors do not usually go on to lead healthy lives and that there is almost no drug development for kids with cancer in the United States," said Goodman.

There has been only one initial FDA approval of a pediatric cancer drug in 20 years. The National Cancer Institute spends less than 4% of its budget on children. And funding for other serious and rare pediatric diseases is equally bleak.

Dr. Henry Friedman, a leading Duke University Medical Center pediatric neuro-oncologist noted, "The reason that companies don't make pediatric drugs is all market force driven. Companies have an obligation to their shareholders to make money. The pediatric diseases by and large are such low numbers. The incentive to make pediatric drugs is very small."

The Creating Hope Act spurs drug development for pediatric cancer drugs and drugs for other kids with rare diseases by offering vouchers as "big fat carrots" as Goodman describes them. "The vouchers come with rights to a speedier FDA review of another drug, possibly a blockbuster drug, and it does not require taxpayer funding."

Goodman's effort to pass the Creating Hope Act was homegrown. "Jacob died on a Friday, and Saturday morning I put my laptop on the dining room table and started working," said Goodman. Jacob's friends and other young cancer survivors lobbied members of Congress for passage of the Creating Hope Act. Other families of children with cancer joined in.

Goodman noted, "My goal now is to work on implementation so that we can finally have new drugs for kids with rare and serious illnesses."

Photos on request.

*KIDS V CANCER is changing the landscape of pediatric cancer research by identifying structural impediments at key junctures in the research process – access to drugs, tissue and funding – and developing strategies to resolve them.*

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