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Leaders in Washington Must Stand Up for Those Who Can't Stand Up for Themselves

At a moment when times are tough, when the debate in Washington is around how to cut spending, we've got to make sure we protect those least able to stand up for themselves. Take pediatric cancer research. Sick kids can't advocate for themselves. They don't vote. They don't contribute to campaigns. They have no lobbyists.

I for one think the Federal government should invest more in pediatric cancer research. Nonetheless, I recognize the reality of the time we're in. So let's use market forces and innovative financing techniques to fill to gap. Let's pass the Creating Hope Act.

Why do I care? Because I lost my 10-year-old son, Jacob, after a two year battle with brain cancer. One day he was a vibrant, carefree eight-year-old boy. The next, he was diagnosed with cancer. Jacob faced months of hospitalization and suffered cognitive impairments. He lost his ability to walk and speak, his digestive system shut down and he lost control of his bodily functions. Most of this was the result of the treatments. In fact, in many respects, the treatments were as bad as the cancer itself.

It would have been one thing if they worked. But they didn't. Jacob received treatments that hadn't changed in 30 years. His doctors knew the drugs they were giving him weren't working, but they carried on nonetheless because there were no other options. Only one new drug has been developed expressly for kids with any form of cancer in 20 years.

And, with our current quiver of drugs, even the "lucky" ones often face a shortened lifespan and a severely compromised quality of life. Three quarters of all kids who survive cancer have serious illnesses, like cognitive impairment and infertility. Forty percent of kids who survive cancer have life threatening conditions, including secondary cancers. Cancer is the number one disease killer of children.

There aren't enough good drugs for kids because there isn't enough funding for drug development for kids. Even before any possible budget cuts, only 4% of federal spending on cancer research goes to kids. And, unlike adult cancer, pediatric cancer gets almost no funding for research from drug companies.

That's why I am working with Republicans and Democrats in Congress to pass the Creating Hope Act. There's a little known provision in current law which gives an incentive to drug companies to develop drugs for neglected tropical diseases. For a number of reasons it hasn't

worked particularly well. With the Creating Hope Act, we can fix it and expand it to cover kids with cancer and other rare and serious diseases. Drug companies might not have an incentive to meet the needs of sick kids on their own. But, if you award them a voucher for a priority FDA approval for a blockbuster drug, provided they do develop a drug for a kid with cancer of another serious rare disease, it might well change their calculation. That's the gist of the Creating Hope Act. It costs the government nothing. It lets market forces work. And it could very well save lots of kids' lives.

There are a million ways to kill good legislation. You can ask for more studies. You can say the Creating Hope Act is more work for the FDA. You can say it's too pro-business. I don't get it. Are we really going to play politics over dying kids?

The Creating Hope Act may be one of the few things Democrats and Republicans can agree on and get done in this Congress. That's a good thing. But even more importantly, it might actually save some kids' lives. No kid should have to go through what Jacob did. Please join me in pushing for the passage of Creating Hope Act.

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For more, click on <http://www.kidsvcancer.org/new-drugs/>