

KIDS CANCER

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- PRESS RELEASE -

Kids v Cancer Supports the “Creating Hope Act of 2011” A Mother’s Effort to Promote Drug Development for Children After the Death of her Son from Brain Cancer

Washington, DC (September 23, 2011) Kids v Cancer applauds Congressmen Michael McCaul (R-TX), G.K. Butterfield (D-NC, Susan Myric (R-NC) and Christopher Van Hollen (D-MD) for their commitment to promote the development of drugs expressly for children by introducing the “Creating Hope Act of 2011.”



Nancy Goodman, Founder and Executive Director of Kids v Cancer explained:

“My son, Jacob, died two and a half years ago of a pediatric brain cancer. Jacob was a beautiful 8 year old boy when he was diagnosed. Overnight, he went from being a loud and precocious kid who loved to play any sport with a ball, to a boy in a wheelchair who at times couldn’t talk, who had serious cognitive impairments and who couldn’t eat or control his basic bodily functions. He spent 9 of his remaining 23 months of his life inpatient in hospitals.

“If there had been effective drugs to treat Jacob, I would have had the chance to watch him grow into a healthy young man. But no new drugs have been introduced to treat Jacob’s cancer in decades.

In fact, in the last 20 years the FDA has initially approved only ONE drug for any childhood cancer. The only drugs kids have are “hand-me-down” drugs developed for adults. These treatments are so toxic that the lucky kids, the survivors, are left with a raft of impairments. Markets for childhood cancer drugs are small and pharmaceutical companies are unwilling to develop childhood cancer drugs.

Nancy responded to Jacob’s death by establishing Kids v Cancer and championing the Creating Hope Act.

The Creating Hope Act of 2011 provides market incentives to pharmaceutical companies to develop drugs for pediatric rare diseases.

The Creating Hope Act was introduced with bipartisan support in the House of Representatives by Congressmen Michael McCaul (R-TX) and G.K. Butterfield (D-NC). It was introduced in the Senate in March, 2011 by Senators Robert Casey and Scott Brown.

In an era of fiscal austerity, the Creating Hope Act does not require an appropriation.

The Creating Hope Act of 2011 will encourage the creation of new drugs for children who suffer from serious and rare medical conditions, including life-threatening cancers, by providing a voucher to pharmaceutical companies who develop such drugs. This voucher would be used to gain a priority FDA review for any *other new* drug, including a blockbuster drug, which would allow that drug to get to market sooner. The voucher would constitute a strong market incentive for pharmaceutical companies to develop drugs for children with serious and rare diseases, such as cancer. The Creating Hope Act builds on the “FDA Amendments Act of 2007,” which established a voucher for drug development for neglected tropical diseases.

“This is a tragedy for thousands of childhood cancer victims and their families,” said Congressman McCaul, the founder and co-chairman of the House Childhood Cancer Caucus. “The Creating Hope Act offers the best chance of encouraging pharmaceutical companies to develop new treatments for children with cancers and other rare pediatric diseases, at no cost to taxpayers.”

Notes Congressman Butterfield, “Encouraging the development of innovative and effective treatments for patients diagnosed with rare diseases, especially children, is vitally important. The Creating Hope Act of 2011 provides a much needed incentive to promote research and development that will ultimately save lives.”

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

For more information on the “Creating Hope Act of 2011,” please visit www.kidsvcancer.org or contact Nancy Goodman at nancygoodman@kidsvcancer.org.

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