

KIDS **V** CANCER

Changing the landscape of pediatric research.

www.kidsvcancer.org

20 December 2012



Dear Friend,

Happy holidays!

I want to update you on recent developments and our future plans .

I started Kids v Cancer **four years ago, the day** after I lost Jacob. This time of year brings back so many memories of Jacob – skating in Central Park, watching the Collegiate basketball games, throwing snow balls from snow on car windshields on the way to school, and becoming ill.

What I have learned is that my story is not unique. Every week a classroom of kids die of cancer. And unlike adult cancer survivors who usually go on to live full and healthy lives, the survivors of childhood cancers have profound and chronic illnesses including secondary cancers, cognitive compromise and neurological impairments. Had Jacob lived, he might never have been able to live independently.

There is a crisis in pediatric cancer funding. In the past 20 years, there has been only one initial FDA approval for a drug to fight a pediatric cancer. Funding from pharmaceutical companies is almost nonexistent because the markets are small. And, there is chronic underfunding from the National Cancer Institute.

I founded Kids v Cancer in Jacob's memory to address some of these challenges. It has been a remarkable ride since then:

- We were successful in authoring and championing the **Creating Hope Act**, which created a market-based incentive to spur pediatric cancer drug development. The Creating Hope Act was signed into federal law by President Obama in a moving ceremony with our daughter Sarah (now two years old) present in the Oval Office.
- We started an **autopsy tissue donation program** for pediatric brain cancers, which has already led to significant scientific discoveries.
- We raised the profile of pediatric cancer issues by having September declared to be **National Childhood Cancer Awareness Month** for each of the past three years.
- **We worked with the FDA** to accelerate the development of drugs potentially useful in treating pediatric cancer.

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More recently:

- I was selected to be a FDA Patient Representative, which will allow me to participate in the FDA's review of drug trials and approval applications.
- I brought together Stand Up To Cancer (SU2C) and St. Baldrick's to create the first ever competition for a pediatric dream team grant of \$14.5M. I was then invited to serve as the patient advocate on the Scientific Advisory Committee charged with selecting the recipients of the grant.
- I was honored with the Rare Disease Legislative Advocates Rare Voice award.

Along the way, Kids v Cancer has attracted some terrific media coverage for its efforts including a report on "ABC Nightline", a Washington Post op-ed by Ruth Marcus, an ABC blog by Richard Besser, and a "BioCentury This Week" TV show.

I have had the opportunity to speak at numerous conferences and hearings, including four U.S. House of Representatives caucus meetings.

Kids v Cancer has taken a quantum leap in its development and is now a leading voice in cancer advocacy and drug development for children. We now have the credibility and good will to continue to develop much needed policies to address the near absence of pediatric cancer drug development and pediatric drug development.

We've got a lot of work to do. I am excited about building on the successes we've achieved so far.

There are so many exciting projects to work on. We are fortunate to have been asked by leading pediatric cancer researchers, research institutions, Members of Congress and government agencies to engage on many issues. We have chosen to focus on:

- Implementing the Creating Hope Act to ensure it transforms pediatric cancer drug development.
- Building out the tissue program to provide researchers with much needed tissue to transform pediatric brain cancer research.
- Continuing to work with FDA to adopt policies that maximize the potential for pediatric cancer drug development.
- Working to identify areas of potential convergence between FDA and foreign regulatory practices that can help strengthen pediatric drug development.

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I started Kids v Cancer on a laptop on our dining room table in New York City the day after Jacob died. It has since grown to comprise the entire third floor of our house in Washington, DC, with a small staff of one full time and two half time staff, plus a stream of unpaid interns. We have benefitted greatly from excellent pro bono assistance from many DC law firms, as well as from the generous and free counsel of a long list of friends and numerous political strategists and public relations experts. We have an excellent accounting firm, which gives us reduced rates. Michael and I have made Kids v Cancer the focus of our philanthropic efforts and, of course, I do not pay myself.

In other words, Kids v Cancer has become one of the leading, most effective health care advocacy nonprofits on a shoe-string budget. We are now being asked to expand our program to address a number of important challenges. However, we can't do it alone.

Unlike just about every other health advocacy group in Washington, we have refused contributions from pharmaceutical and biotech companies because it is important to our credibility that we be seen as neutral and independent when we speak out on drug development issues. As a result, we need to raise the money the old fashioned way – asking for it.

I want to thank you for your past support of Kids v Cancer. It has been pivotal to our success. I would not have been anywhere without your financial and emotional support.

Thank you again. May this be a year of health for us all.

Sincerely,

Nancy Goodman

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