

Office of the Governor
1205 Pendleton Street
Columbia, SC 29201

The Honorable Nikki Haley,

First, I want to sincerely thank you for declaring September as Childhood Cancer Awareness month in the state of South Carolina. I am sure you have seen the coverage after the Secret Service staff halted our candlelight vigil the evening of September 19, 2015. I do question why Cure Fest organization was granted a permit to rally in Lafayette Park and that was not honored. I appreciate the sincere apology and the acknowledgement that the situation should have been handled differently. However, I was disappointed in the turn of events. My family and I traveled to Washington, DC from South Carolina specifically for this event and had been looking forward to the candlelight vigil. The feedback from last year's event was amazing.

Unfortunately, we were unable to attend last year because our son was undergoing chemotherapy for a bilateral Wilm's tumor. His pediatrician felt a mass in his abdomen at his 4-year check-up, which incidentally was on his birthday. Instead of celebrating at his train-themed party, our son was admitted into the hospital where he began chemo treatments after having his port placed. This was followed by six months of chemo during which his body was injected with drugs designed for adult patients. Due to lack of research funding for childhood cancer over the past twenty years, the drugs administered to children have not changed. After undergoing surgery in which the malignant tumors were removed, our son is left with only one half of a kidney. This was followed with six consecutive days of radiation treatment.

On the evening of September 19, 2015, sick children and their families waited outside Lafayette Park, hoping their voices would be heard. Many parents had lost their children to cancer. There were children in attendance whose immune systems are so weak that even the onset of a fever is cause for hospitalization.

We were fortunate to attend with our son who is thankfully ten months into remission. We were all united in hopes of lighting the White House in gold since prior requests have been denied. We were hoping our children's lives will someday soon become a priority in the quest to combat childhood cancer.

In closing I ask, if your child were struggling with cancer, would you consider 4% of national funding for research to be adequate? My guess is you would respond No! Give our children hope for the future. Restore faith within their families. Alleviate their fear of long term side effects brought on by outdated treatment options. Please consider the need for much needed additional research funding.

Thank you for your attention to this matter.

Sincerely,



Erika Spracher, a concerned cancer mom
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