

NEWS & BLOG

BRAIN TUMOR ADVOCACY AND RALLYING FOR RESEARCH

By Lainey Titus Samant, Director of Public Policy | Published September 21, 2015



Last week, National Brain Tumor Society Advocates were in our nation's capitol participating in a number of activities both in support of Childhood Cancer Awareness Month and advocating for medical research funding. A special thanks to Lisa Peabody, Gina Memmott, Brian Spillman, Mary Dunn, and BethAnn Telford for their efforts on behalf of the brain tumor community this past week.

Rally for Medical Research

The busy week in D.C. began with the Rally for Medical Research on Wednesday evening (9/16) and Thursday (9/17).

Maryland Brain Tumor Advocates Lisa Peabody and Brian Spillman attended Wednesday evening's reception that kicked off the Rally for Medical Research. During the reception, held on Capitol Hill, our advocates heard inspiring remarks from National Institutes of Health (NIH) Director Francis S. Collins, MD, PhD, Senator Dick Durbin (D-Illinois) and Senator Amy Klobuchar (D-Minnesota). Senators Durbin and Klobuchar are two of Congress's biggest champions for medical research funding.



Director Collins spoke about the recent advances taking place thanks to government funded medical research, including unraveling the mysteries of glioblastoma multiforme (GBM) thanks to genomic research and expanded knowledge. Dr. Collins closed his remarks by saying that he likes to think of the NIH as the National Institute of Hope, and we must continue to fund hope.

The next morning, Lisa and Brian joined Virginia State Lead Advocate Gina Memmott, representing NBTS as part of a group of 300 different health and research organizations from around the country calling for increased funding for the NIH and the National Cancer Institute (NCI). During the Rally for Medical Research's advocacy day on Capitol Hill, our advocates visited their Members of Congress with their state groups made their asks for an increased investment in brain tumor research and to prioritize investment in the NIH for Fiscal Year 2016.

Golden Toast for Childhood Cancer



On Thursday (9/17) evening, the National Brain Tumor Society joined with the childhood cancer community to honor Congressman Michael McCaul (R-Texas) and Congressman Chris Van Hollen (D-Maryland) at "A Golden Toast for Childhood Cancer." Congressmen McCaul and Van Hollen are the Co-Chairs of the Congressional Childhood Cancer Caucus. This year, the community

showed their appreciation of the Congressmen's introduction of the Childhood Cancer STAR Act, along with Congresswoman Jackie Speier (D-California).

National Brain Tumor Society advocates and board members enjoyed an intimate opportunity to mingle and share personal stories with Members of Congress and fellow childhood cancer advocates.

Sixth Annual Childhood Cancer Summit

On Friday morning (9/18), the Congressional Childhood Cancer Caucus held their 6th Annual Childhood Cancer Summit, entitled "Progress and Opportunities in the Fight Against Pediatric Cancer." This year, the conversation focused on the Creating Hope Act, a pilot program passed in 2012 intended to incentivize pediatric rare disease drug development, as well as the President's Precision Medicine Initiative.

Dr. Lee Helman, the Acting Director of the NCI's Center for Cancer Research, noted that the Creating Hope Act was an example of what can happen when the NCI, patient advocates, and the pharmaceutical and biotechnology industries collaborate. Dr. Helman suggested that more collaboration will be needed in the future to bring about treatments and cures for childhood cancer – of course a focus of NBTS'.



White House National Childhood Cancer Awareness Month Briefing

For the second year in a row, the White House invited childhood cancer advocates to participate in a briefing on the administration's efforts to address childhood cancer. National Brain Tumor Society advocates Lisa Peabody and BethAnn Telford were both in attendance, as well as Jenny Mosier, Team Captain of Big Hero Michael and one of the top fundraisers at the Race for Hope DC this year. Both Lisa and Jenny lost children to brain tumors, and BethAnn is a survivor who participates in race events on behalf of children fighting childhood cancer.

The president's Precision Medicine Initiative was again a topic of discussion, as well as the Pediatric MATCH Trial. The MATCH trial was announced at last year's White House briefing and Dr. Peter Adamson, Chair of the Children's Oncology Group, informed attendees that the trial, which will be led by the NCI-funded Children's Oncology Group, is still under development and details on a timetable for launch or patient enrollment are not firm. However, the aim is to start the trial in 2016.



CureFest for Childhood Cancer

Sunday (9/20), CureFest for Childhood Cancer was held on the National Mall. Over 100 childhood cancer foundations and groups were in attendance. Our Regional Director, Lauren Bogart, was in attendance along with advocate Mary Dunn, and met with our community members as

they participated in the festival and the three-mile walk on the National Mall. The event united families that have been affected by childhood cancer and allowed for the opportunity to connect with others and raise their voices for more research and treatments for pediatric cancers.

The fight's not over yet. [Check out our recent action alerts](#) and urge Congress to increase funding for more research.

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