

ADVOCACY NEWS

National Brain Tumor Action Week (May 4 – 10)

Besides bringing national attention to the issues of research funding for pediatric and adult brain tumors, there were important developments in Washington, DC during the recent Brain Tumor Action Week.

On May 7th, it was announced that Rep. Deborah Pryce of Ohio had authored a \$30 million pediatric cancer bill, which was approved by the House Energy and Commerce Committee. Previously known as the Conquer Childhood Cancer Act of 2007, this bill was renamed the “**Caroline Pryce Walker Conquer Childhood Cancer Act of 2008**,” in honor of Rep. Pryce’s 9-year-old daughter who succumbed to neuroblastoma in 1999. On June 12th, the House of Representatives passed the Act, sending it now (with 66 co-sponsors) to the Senate. The full Senate vote is expected sometime this summer. Once enacted, this critical legislation will authorize Congress to spend up to \$30 million over five years on clinical trials and pediatric research programs at the National Cancer Institute, as well as set up a childhood cancer database and expanding education of parents and families about treatment options. This is a victory for Rep. Pryce and her supporters, who have long advocated increased funding for childhood cancer. As she eloquently phrased it, “*This legislation brings us one step closer to a goal universally shared by all of humanity – the eradication of pediatric cancer and an end to the incalculable misery cancer inflicts on so many young lives. I am increasingly optimistic that Congress will soon give pediatric cancer the attention and resources it so desperately needs.*”

Month of May Officially Named National Brain Tumor Awareness Month

In an effort to bring national awareness about the ongoing issues of the brain tumor community, U.S. Rep. Jan Schakowsky of Illinois introduced a resolution in the House of Representatives on April 22nd. Called House Resolution (HR) 1124, it sought to establish the month of May as **National Brain Tumor Awareness Month**. Over 100 Representatives signed on as co-sponsors. On May 21, 2008 the House passed this important resolution by voice vote, and the month of May is now officially designated as National Brain Tumor Awareness Month. Our hats are off to Rep. Schakowsky and the other Representatives who recognize the need for further awareness, patient and family support and research funding toward finding better treatment options. Senator Ted Kennedy’s recent diagnosis of a malignant brain tumor has brought intense media interest to the subject of brain tumors, and he has sought treatment at some of the nation’s top cancer centers. We certainly wish him well in his battle with this insidious disease.

CureSearch “Reach the Day” Advocacy Event (June 22 – 24)

CureSearch held its annual “Reach the Day” advocacy rally in Washington, DC on June 22-24. This event is presented each year to raise awareness among federal legislators about childhood cancer and to impress upon them the urgent need for research funding. The main focus of this rally was the passage of the **Caroline Pryce Walker Conquer Childhood Cancer Act of 2008**, as well as securing additional funding for the Children’s Oncology Group’s important pediatric cancer research work. Our own Janet

Waters, mother of young brain tumor survivor Michael, attended the rally and was one of more than 350 advocates from 36 states who walked the halls on Capital Hill urging their US House Representatives to pressure their Senate colleagues to pass the Conquer Childhood Cancer Act (S911) and their Senators to bring S911 to the floor for a vote. Support for the three appropriate requests was also urged at this time.

Janet had this to say about the event: "It was truly empowering to know that only a few days before our visit, the Conquer Childhood Cancer Act passed unanimously in the US House of Representatives by a vote of 416-0! We have never been closer to passage of this bill and bringing us one step closer to eradicating pediatric cancer."

LATEST UPDATE: We are pleased to report that the Conquer Childhood Cancer Act passed in the Senate unanimously on July 18th and was signed into law by President Bush at a White House Ceremony on July 29th. Visit www.curesearch.org to learn more.



Mike and Janet Waters with Congressman Chris Van Hollen of Maryland's 8th District



Janet Waters with Congressman Phil Gingrey, M.D., of Georgia's 11th District