

Massachusetts Mom Storms the State House

If you spent any time in the Massachusetts State House during the past year, chances are you are familiar with Carrie Howland. Carrie and her husband Bob are the parents of two beautiful children, 7-year old Caitlin and Bobby, who turned 5 last February. Caitlin is a happy, bright, healthy girl. Bobby was born with Down Syndrome and several chronic medical diagnoses including hypothyroidism, epilepsy and long segment Hirschsprung's disease.

After Bobbie's birth Carrie, who had temporarily (she thought) suspended a successful career in secondary market research, found herself and her family suddenly plunged into a world of medical terminology, doctors, surgery, emergency rooms and home health care. She learned firsthand just how slow, inefficient and incomplete health care systems can be.

Carrie credits Meg Comeau, now at Boston University, with understanding and helping channel her frustration by introducing her to the Massachusetts Consortium for Children with Special Health Care Needs. It was at one of their meetings that Carrie learned about the Data Resource Center and the National Survey of Children with Special Health Care Needs. She logged on to the DRC, hoping to find information she could add to testimony she was preparing for a legislative budget hearing.

Faced with screen after screen of topics and questions about a whole range of issues, Carrie wasn't sure how to start. So she clicked on "Ask a Question." With help from Deb Read of the Data Resource Center, Carrie learned how to identify and locate the information she needed, copy and paste it into her document, and how to understand and communicate the meaning of the results.

Carrie presented her testimony with DRC screen shots and statistics for Massachusetts and the nation at a budget hearing in the fall of 2004 and again in March, 2005. After the March testimony flexible funding for support to families with special needs children was increased for the fiscal 2006 budget year. Her testimony was later used by a legislator to confront state government about lack of services for CSHCN.

Postscript:

In June of 2005 Carrie included data from the DRC in a presentation at the National Respite Coalition event in Washington DC, in support of the National Lifespan Respite Care Act. In November she spoke again at the Massachusetts State House. She continues to work tirelessly to increase medical and support services for families of children with special needs, who, regardless of their income or socioeconomic status, need and deserve support for their efforts to provide a safe and nurturing environment for the lifetime of their children with special needs, siblings, parents and other caregivers. Carrie's presentation can be found [here](#) and a link to her most recent presentation to Massachusetts legislature in February 2007 is [here](#).