



*... speaking on behalf of children and youth with special health care needs*

June 18, 2009

Edward M. Kennedy, Chairman  
Senate Committee on Health, Education, Labor & Pensions  
United States Senate  
Washington, DC 20510

Dear Chairman Kennedy:

Family Voices would like to thank you and your staff for your tremendous efforts in crafting the “Affordable Health Choices Act.”

As an organization of families whose children have special health care needs (CYSHCN), we are all too familiar with the problems in our current health care system. Thus, we applaud the provisions in your bill that would address some of these problems by eliminating pre-existing condition exclusions, benefit caps, and premium disparities based on disability, as well as make other insurance reforms that would benefit CYSHCN and their families. In addition, we applaud the other provisions in your bill that will help CYSHCN, including the expansion of Medicaid eligibility, allowing dependents up to age 26 to be covered by their families’ insurance plans, provisions to address the high cost of premiums and other out-of-pocket expenses, the establishment of pediatric benefit and quality-of-care standards, and incentives to increase the supply of pediatric subspecialists.

We are also encouraged by the bill’s support of the “medical home,” concept and of the consumer’s role in making health care decisions. In addition we commend you for recognizing that consumers will need significant assistance in selecting the best possible insurance products for their families. Thus, we support the creation of “navigator” entities that are community-based and consumer-driven. In fact, as you further develop this legislation, we would encourage you to specifically support the role of existing, federally funded entities (Family-to-Family Health Information Centers) that currently serve a “navigator” function by helping families of CYSHCN secure the health care needed for their children.

As you advance in your efforts to improve the health care system, we urge that you keep in mind the nation’s 10 million children and youth with special health care needs and their families. We look forward to working with you as you continue in your steadfast efforts to improve the nation’s health care system for all Americans.

Sincerely,

A handwritten signature in cursive script that reads "Sophie Arao-Nguyen".

Sophie Arao-Nguyen, Ph.D.  
Executive Director  
Family Voices

cc: Ranking Member Michael B. Enzi