

8/06/2012

Dear Sirs,

As you work to create and implement an Exchange for California, please consider the needs of the Huntington's disease community. A quality Essential Health Benefits package would have a dramatic impact on the quality of life for individuals with Huntington's disease, as well as other individuals affected by chronic conditions.

Huntington's disease is a hereditary and degenerative brain disorder for which there is no cure or treatment to delay onset or halt progression. HD manifests as a triad of disabling cognitive, psychiatric and motor symptoms which begin gradually and continue to worsen over 15 to 20 years. HD not only affects those who inherit the gene, but also has a negative impact on their families and close friends.

Under the Department of Human and Health Services' guidance, each state must choose an EHB package that meets ten categories of care. While all of these categories are vital, three are of particular importance to the HD community – mental health coverage, prescription drug benefits, and rehabilitative/habilitative services.

Mental health: Comprehensive mental health coverage in the EHB package is integral to managing the neurologically and psychologically degenerative diseases such as HD. When choosing an EHB package, please ensure that it will provide adequate mental health coverage without limitations regarding provider, duration, or number of annual treatments.

Prescription drug coverage: Gaps in coverage can lead to high out of pocket expenses and/or the inability to purchase necessary prescription drugs, especially for individuals with chronic diseases and complex needs, such as people with HD. It is imperative that you choose a package that closes as many of these coverage gaps as possible.

Rehabilitative/habilitative services: Access to rehabilitative and habilitative services can extend the time that individuals can live independently, as well as improve their overall quality of life. These services -- especially occupational, physical, and speech therapy – will help maintain or lessen the deterioration of physical and mental abilities caused by degenerative diseases like HD. When choosing an EHB package, please ensure that these types of services are provided.

These three categories of care are of utmost importance to those with chronic, degenerative diseases. When selecting an Essential Health Benefit plan, please choose a plan that offers the most protection for this vulnerable population. I urge you to create a state-based Exchange with a comprehensive Essential Health Benefits (EHB) package that provides sufficient and affordable coverage for all aspects of health including **mental health, prescription drugs, and rehabilitative/habilitative services.**

My great grandmother, grandmother, and father died from Huntington's Disease without any proper health coverage. Throughout my father's illness, my mother cared for him at home. Every night, we talked about how we were going to pay for health care and prescription drugs. My father never had any rehabilitative services, as we could not afford them.

I look forward to hearing back from you and to following our state's progress. Thank you for your consideration.

Sincerely,

Lisa Schneider