

Dear Essential Health Benefits Work Group members:

I am writing this email message to encourage the Work Group to consider incorporating my comments/suggestions to the Essential Health Benefit plan for Colorado.

I am a social worker for the Huntington's Disease Society of America's Rocky Mountain Chapter based in Wheat Ridge, Colorado. Huntington's disease is an inherited brain disorder that results in the progressive loss of both mental faculties and physical control. Symptoms usually appear between the ages of 30-50 years old and worsen over a 10-25 year period. Ultimately, the weakened individual succumbs to pneumonia, heart failure, or other complication.

The Life-Altering Impact of the Essential Health Benefits Package The Huntington's disease (HD) community greatly appreciates your efforts to create a healthcare package that will help people in our state lead healthier lives. The creation of a state-based health insurance Exchange and comprehensive Essential Health Benefits (EHB) package will benefit every person, not only those with HD. Furthermore, ensuring that the EHB package fully addresses basic healthcare needs will better the lives of thousands of families across the country. Thank you for joining us in this effort.

Huntington's Disease Overview

HD is a hereditary and degenerative brain disorder for which there is no cure and no treatment to delay onset or halt progression.

HD manifests as a triad of disabling motor, cognitive, and psychiatric symptoms which begin gradually and continue to worsen over 15 to 20 years, until the death of the individual.

HD affects both those who inherit the defective gene and their families due to the devastating effects of the illness on all aspects of social and professional life.

Essential Health Benefits Recommendations Although the EHB Bulletin addresses a few needs of individuals with HD, there are other important factors that must still be considered. The HD community encourages you to further aid and protect individuals with chronic diseases by keeping them in mind as you oversee the creation of the EHB packages and the state-based Exchanges.

Mental Health Parity

Mental health services need to be delivered in a manner that allows patient choice without arbitrary limitations in regards to provider, duration, or number of annual treatments.

Under the EHB Bulletin's guidance, as long it meets the minimum standard in the ten required benefit categories, a plan with limited coverage for physical and surgical care can have equally narrow limitations on mental health care.

It is essential to ensure that insurance provided under the EHB baseline plan will not be so narrow and restrictive, in terms of coverage, that it becomes a meaningless option for those living with chronic disease, such as HD.

Coverage Gaps

The coverage offered by small group plans is often inadequate and leaves large gaps in coverage for prescription drugs, necessary therapies, and mental health treatment.

According to the Bulletin, coverage of prescription drugs can be limited to a single medication in each therapeutic class. The adequate treatment of certain symptoms of Huntington's disease will often require medications from several drug classes, and may, in some instances, require 2 drugs from the same drug class. Coverage of medications should reflect this need. There should also be mechanisms in place to obtain medications outside of the preferred agents, as well as brand name medications, with a prior authorization and/or clinical review.

We urge you to choose a plan that offers meaningful and cost-effective coverage and mitigates as many coverage gaps as possible.

Conclusion

As you develop the EHB package and state-based Exchange, please keep those with chronic degenerative diseases in mind. Because of the devastating effects of such illnesses, it is imperative that meaningful and affordable coverage for all aspects of health, both mental and physical, be the focus of your efforts.

***Attached please see a nice and tidy advocacy piece laying out our advocacy points to be integrated into the EHB plan for Colorado. Also, I've attached a "Fast Facts" brochure about Huntington's disease for your information. Please don't hesitate to contact me with more questions about Huntington's disease. My Helpline number is (303) 321-5503. I tend to work on Tuesdays, Wednesdays, and Thursdays.

Best wishes,

Sharon

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