

3/10/2022

To Senator Longbine and Respected Members of the Insurance Committee:

Thank you for your service to the state of Kansas and for hearing our testimony today. The stories of my family's history and my professional history with this illness are long and profound, and I am tired. In this moment, our story: the over \$120,000 we incurred in out-of-pocket expenses; the hours we put into daily research to find answers and treatment; and the work we put into attempting to maintain a normalized family life for our children is not important. In this moment, the individual stories of the families for whom I tried to successfully guide to appropriate medical treatment are not important.

In this moment, we come to you as parents, and as professionals, because the children of Kansas whose families pay monthly premiums for health insurance, deserve accessible medical treatment for an illness that was first described in the medical literature over 30 years ago. These children, and their families, deserve access to medical care for an illness that is largely not properly diagnosed and treated because physicians and health systems do not know that the appropriate treatments may be financially accessible. These children, and their families, deserve relief from endless and costly (in time, money, effort, and lost family opportunities) rounds of failed therapies, psychiatric medications and developmental services. These children, and their families deserve medical coverage.

Please support our request for a senate bill to provide that state insurers cover the costs of this illness. The power to do what is just and right is in your hands.

Respectfully,

Andi Bonge, BSEd, MOTR/L  
13931 W 71st Terr  
Shawnee, KS 66216  
(913) 544-3681  
ahbonge@gmail.com