

March 5, 2020

Chairwoman Shane Pendergrass
Health and Government Operations Committee
Room 241, House Office Building
Annapolis, MD 21401

RE: Jana Mattheu Testimony in Support of HB 1360

Chair Pendergrass and Members of the HGO Committee,

Good Afternoon and thank you for allowing me to speak on behalf of House Bill 1360. My name is Jana Mattheu. My husband and I have had the opportunity to raise our 2 wonderful sons' in Harford County, for the last 20 years.

Shortly after the birth of our second child, we noticed as a toddler he seemed to battle common illnesses frequently and the illness always escalated to a more severe infection lasting longer in duration than his older brother. After recognizing the frequency and severity of the multiple infections his PCP began testing for an explanation. During that time, I have never been more thankful to have a medical institution such as Hopkins in our backyard. After years of monitoring his blood and vaccination levels a diagnosis was confirmed at 12 years old. Caden has CVID, Common Variable Immune Deficiency. The treatment for this diagnosis is to receive weekly subcutaneous IgG immunoglobulin therapy. Caden began treatment and responded very well. At 14 years old his immunology team decided that we should take him off the immunoglobulin therapy to see what his immune system could do. There was still a small hope that his body was just delayed in developing a mature immune system and by using the IgG we may have helped jump start his own immunities. During trial off IgG the infections came rapidly, complications multiplied and many antibiotics later he was hospitalized for 6 days with C-Diff.

We learned two very important things following this experience. First that our son was going to require IgG therapy for the rest of his life to remain in a relatively normal healthy state. Secondly, we learned that we would have to work diligently to pay the quickly surmounting pile of medical bills. CVID is a chronic illness that has a lifelong risk of infection. With the high deductible health insurance coverage, it makes it practically

impossible to meet our out-of-pocket co-pay without struggling to meet our other financial obligations as a family of four. At that time our co-payments for Caden's monthly immunoglobulin therapy was averaging \$900 every 4 weeks.

After struggling for the first 2 years after our son's diagnosis trying to make ends meet, we had the realization that we needed more assistance to help cover our deductible. The co-pay assistance program has helped us regain a level of balance in achieving and maintaining our fiscal responsibility. I come here before you to share our hardship as well as explain the magnitude of benefit to co pay assistance programs. My husband and I are both hard working college graduates who have worked at the Johns Hopkins Institute for over 25 years. Our family has annually hit our high deductible co-pay by the end of February every year, since our son's diagnosis. If co-pay assistance were ever to be denied or not applied to the insurance deductible, many patients and families such as mine or those less fortunate than ours may suffer greatly. Understand that the risk of discontinuing treatment due to financial hardship is a very dangerous game, one that could result in the loss of life. By showing your support for HB1360, you are helping to aid Maryland residents and their families with chronic illness reach financial stability in a world of many medical uncertainties.

Thank you for your time.

Jana Mattheu