

## Registering for oral public comment

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Hello-

Thank you for the opportunity to share my family's story today. Here are my written comments for the record:

Thank you for the opportunity to speak on the drug selection process today and thank you for the hard work and careful consideration this Board and its staff are dedicating to these efforts. As you consider which drugs to review, I would like to raise a concern about patient assistance programs, something I have seen promised as an affordability solution in several written comments that were submitted. I come to you today to share both the practical concerns with patient assistance programs being touted as a way to guarantee patient access, and also my family's personal experience with falling through the gaps in drug assistance programs.

When my second child was about four months old. he had an immediate and severe allergic reaction to the formula that our nanny gave him. By the time I got to the ER at Hopkins, there were at least four adults all working on my little child to try to help him breath and control the allergic reaction. I will never forget that terrifying moment as long as I live. Fast forward to the pharmacy counter, I didn't bat an eye when it was \$300 for his medication. As prescriptions added up, it went to \$600, then \$900. Costs I am willing to pay and grateful I can afford, but still extremely expensive. When I asked about drug assistance, they said I didn't qualify because we had insurance. We spent all of our deductible right up front on Chris' allergy and asthma meds.

I know we are not the only ones in this situation. Copay assistance is generally not available for anyone enrolled in federal programs. Even those that qualify are often limited to one year of assistance from the manufacturer. The process can be complex and murky, requiring authorizations and lots of paperwork, and may not cover enough costs to make the drug accessible to those in need.

So, I'm glad companies offer drug assistance. You should know that they don't always work. And no one should have to rely on charity for essential, life saving medications. Thank you.