

Robin Payson  
Lincolntonville Maine

My family benefitted immensely from the Cystic Fibrosis Assistance pilot program. We would love to see the program be restored for us as well as other Maine families facing cystic fibrosis. My daughter was diagnosed with cystic fibrosis at eight days old in 2018. The fear that gripped my husband and I when we received her diagnosis was unlike anything else we've ever experienced. Our new, perfect looking brand new baby has a genetic disease? We couldn't believe what we were hearing. The fear for our daughter's life soon turned to fear of how we would possibly pay for what seemed to be a lifetime of medical expenses before us. We both work full time but we had so many questions about insurance coverage for our daughter and what types of expenses we would need to cover personally. When the social worker at our cystic fibrosis clinic mentioned the assistance pilot program, it brought us a sense of relief. Relief that we could focus on our daughter's health during her first year of life, perhaps the most crucial year of all to get her meds and treatments rolling, and not on how much we would pay for gas to make the three hour round trip from home to her provider's office, for example. The reimbursement funds from the pilot program were very much appreciated. My husband and I urge you to restore this wonderful program.