

Cynthia Fletcher  
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I am writing today to first thank Anne Carney for proposing this bill on behalf of our families in Maine who are affected by Cystic Fibrosis. I am the program Coordinator for the pediatric CF center in Portland. I have worked in this role for 13 years and have been a pediatric nurse at MMC for nearly 40 years. One of my very first patients at MMC was an adult woman with Cystic Fibrosis. I can say first hand that there are very few resources available to assist our families financially with the staggering costs associated with CF. Because this is a disease that is lifelong, there are many expenses that are not covered by insurance, especially private payors. It may be nutritional supplements to help patients maintain a healthy BMI which research shows leads to better outcomes. It could be a portable nebulizer machine that allows a patient just a bit of flexibility with the tremendous impact of multiple daily medications. It could be assistance to get some air exchange for the hot humid summer when breathing can be so difficult. The CF 'Pilot' program was such an incredible help to our families and it provided a small bit of relief to the financial burden each and every CF family faces. Thank you so very much for considering passage of this bill. It will truly be money very well spent on an often overlooked group requiring a lifetime of complicated healthcare regimes.