

Patty Morris  
Cape Elizabeth

My daughter, Ali, has cystic fibrosis. At 32, she works full time, is a wonderful wife and cares for her 19 month old daughter. To keep her health, especially her lung function, high enough to be so active and productive, Ali exercises, eats a whole foods based healthy diet, and sticks with the intense treatment protocol prescribed to her by her CF clinicians at Maine Health. To keep her family financially viable, Ali works hard at her job and does the research required to find and tap into any resources that may help her family stay afloat despite the high health care costs CF brings. Senator Carney's bill, LD529, seeks to restore Maine's assistance program to this state's CF families, whether the person with CF is an adult or a child. Ali found the previous program Senator Carney seeks to restore to be one of the vital pieces to the puzzle her family routinely patches together to cover the extraordinary costs related to keeping Ali healthy against the ravages of cystic fibrosis. The program filled (and we hope will again fill) gaps that were not covered anywhere else, whether by health insurance, a needs based disease specific grant program, or any drug manufacturer copay assistance programs. Coming up with an additional \$3,000 per year to fill the gap left when the previous program was largely ended for folks with CF has added to Ali and her family's financial, health, and emotional burdens. I fully support Senator Carney's bill and hope you will, too. Thank you.