

Peggy Anderson LD 529 Testimony

06/16/21

My name is Peggy Anderson and I appreciate the opportunity to provide testimony in support of LD 529 - An Act To Restore the Maine Center for Disease Control and Prevention Cystic Fibrosis Assistance Program.

My husband and I live in Freeport Maine and we have an amazing, funny, creative 12-year-old daughter, Gabriella (she goes by Gabbie), who has Cystic Fibrosis. She was diagnosed at 10 days old after a standard newborn "heel-prick" blood screening. I am a passionate advocate for Cystic Fibrosis families and work for a bank in Maine. I am a graduate of Northeastern University and hold an MBA and a Graduate Certificate in Health Care Administration from Plymouth State University.

Gabbie has had several stays in Barbara Bush Children's Hospital in her 12 years. She has a stomach feeding tube to help her gain weight and recently began taking (what we call) a miracle drug last August called Trikafta that is helping her improve her lung function every day.

By all accounts my husband and I are doing well and can provide for our child's healthcare needs. We are both educated and have good-paying jobs and we have always had private health insurance. Many assume that because we have private health insurance that we are not impacted negatively financially by having a child with a chronic illness. The truth is that we have had thousands of out-of-pocket expenses every year as part of Gabbie's care that are not covered by insurance or any grants. Many (most) of these grants we do not qualify for, as our income is too high.

Our insurance (like many others) has a deductible for prescriptions of several thousands of dollars that must be met each year before copays kick-in for prescriptions drugs. Depending on the plan year, this amount varies. This means that the first order we make in January (of more than a dozen medications) are billed at full-cost and we must pay that upfront cost before they start billing just the copays. Trikafta alone costs more than \$28K/per month so the deductible is reached immediately. Even after this prescription deductible is reached, her drug copays are still between \$25-50 each and amount to several hundred dollars each month. Because of this, we save all year to prepare for the next year when the plan renews. We also pay for supplemental high-calorie juice boxes called "Breeze" that are not covered by insurance because Gabbie cannot maintain her weight on her own. These single-serve juice boxes cost \$44 for a case of 24 and we use about 2 ½ cases each month and equates to ~\$1,320/year. Our health plan also requires 20% coinsurance costs and office visit copays that are separate from the prescription deductible. The Cystic Fibrosis Assistance Program helped with these costs before the program was changed.

In January of 2018 Gabbie was not doing well. We had seen it coming for a year in advance and suspected that she may be headed for a hospital visit. I was working as a government auditor, traveling overnights for weeks at a time out of state on-site at client locations. I decided to leave

my job to be closer to Gabbie, though she was insured through my employer, and we had just hit our prescription deductible for the year. I quit my job on a Friday and Gabbie was admitted to the hospital the following Wednesday. She stayed at Maine Medical and was released after 2 weeks, having received a diagnostic bronchoscopy, CAT scan and antibiotics through a PICC line. During that time, I slept on the couch in her hospital room and, while she was in appointments, interviewed for other jobs locally. We paid for two months of COBRA insurance out of pocket (at more than \$600/month) and more than \$5000 for the 20% hospital coinsurance. This was after the thousands of dollars for prescriptions that were already paid in January. We knew we would still have hundred of dollars left for the 11 months in copay costs and juice box expenses throughout the year. The Cystic Fibrosis Assistance Program made a huge difference during this time. It was a lifeline. We never thought we would need it. Even after all these expenses in 2018, we still couldn't deduct a single penny on our taxes because it didn't exceed 7% of our taxable income.

On two occasions in the last year, employees at the bank I work for (based in Washington County) have put me in touch with two families who have had recent newborns diagnosed with Cystic Fibrosis that have had difficulty making ends meet. As you know, Washington County has the lowest per capita income in Maine. These families did not qualify for several drug copay programs because they were on Mainecare and therefore excluded. They could have benefited from this program if it had the same benefits as it once did.

Many people create GoFundMe pages for immediate needs – lung transplants or cancer - but Cystic Fibrosis means lifelong expenses. These financial needs go on forever. Cystic Fibrosis families are also very much like most Mainers. We are proud people who put our heads down, don't complain, and simply get the job done. It is hard to even provide testimony like this, as it requires reflection on just how hard this fight can be, but sometimes we do need help, and this is one of those times. Please support LD 529.

Sincerely,

Peggy Anderson

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Freeport

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