

Sarah Griffiths
Falmouth

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Good morning and thank you for this opportunity to speak in support of the LD 529 Bill. My name is Sarah Griffiths and I live in Falmouth with my husband and our daughter Mamie who is 10. Like many of her peers, Mamie loves her friends, she laughs easily, and has BIG ideas for the future. Unlike her peers, Mamie has Cystic Fibrosis.

Living with cystic fibrosis is complex and expensive. It requires medical equipment for daily treatments, multiple prescription drugs, routine testing and x-rays. Mamie sees her doctors at the CF Clinic at Maine Medical Center multiple times throughout the year. Above and beyond her appointments at the clinic we have regular appointments with gastroenterologist, ophthalmologist, endocrinologist, ENT specialists, and at times, with a therapist. This treatment and care regimen can be expensive even for families like mine who have private insurance. Despite having the benefit of a comprehensive insurance plan, our family spends between \$8,000-\$10,000 out of pocket annually for Mamie's care. We quickly met the Maine Children with Special Needs program cap for reimbursement of \$3,000 which we used to offset the cost of copays of medications, office visits, equipment, and hospitalizations. With the assistance of this program we did not have to shoulder the entirety of this financial pressure and we were so grateful for this support.

In Mamie's lifetime, therapeutic advances and new medications have transformed cystic fibrosis. The year she was born the median life span was 37, today it is 44, just imagine that... the gift of seven years of life! We are confident the outcomes for Mamie and others living with CF will continue to improve with more advancements and high quality care. That is why I am urging you to pass this bill and restore funding for families and adults with CF, regardless of their income or insurance. No family should have to make difficult decisions related to accessing healthcare because of the financial burden of this disease.

I would like to personally thank Representative Teresa Pierce and Senator Cathy Breen who took the time to correspond with my husband and I and stepped forward to co-sponsor this bill with Senator Anne Carney. Thank you all for your time and consideration of support of LD 529.