Testimony of Stacey Morrison, Mother of CF Child in Support to LD 529

Senator Claxton, Representative Meyer, and members of the Joint Standing Committee on Health and Human Services; My name is Stacey Morrison, and I am the mother of Zachary Bowman, a 15-year-old with Cystic Fibrosis, a chronic illness. Thank you for the opportunity to talk to you today.

I am here to speak in support of LD 529, "An Act To Restore the Maine Center for Disease Control and Prevention Cystic Fibrosis Assistance Program. Zachary has been on a medical regiment since birth that includes ongoing medical visits to the Specialty CF Clinic in Portland and other CF disease related specialty doctors, various testing, oral and inhaled medications, and physical therapies utilizing a specialized air way clearance vest and nebulizer machines. In addition to this, he requires regular exercise and a diet that is high in fat, including nutritional supplements.

I am fortunate that I have a PPO insurance plan sponsored through my small business. Unfortunately, to keep the health insurance affordable to the business and my employees, we have always had to carry a higher deductible. Our parent child deductible is \$10,000 with a \$13,000 out of pocket maximum for in network medical costs. But remember, that deductible is only for medical related costs that the insurance company would pay, not the copays, the travel to Portland, high fat foods, supplements and exercise costs. As you can imagine, Zachary's healthcare and related costs are not typical for a boy his age. For instance, Zachary has a new Monarch vest that is much improved to the one he has been using the last 10 years. Our copay on the vest is \$875 a month. And those nutritional supplements are \$12.99 a 6-pack and he drinks about 4 a day, costing around \$260 a month! The copay on his oral and inhaled medications averages about \$250 month but has been higher depending on his treatment. I could go on with more examples, but I am sure you understand what we experience.

Before the Maine Children's with Special Needs program changed its eligibility requirements, we were able to participate and were reimbursed up to \$3,000 for copays, travel to doctors' appointments and for nutritional supplements. We typically used up the \$3,000 reimbursement within 3-6 months! It was the only program that we qualified for through the State of Maine. I can personally tell you it made a significant impact to our family!

I urge you all to vote to pass this bill. Thank you for your time and consideration.

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