

April 30, 2025

Chair Susan Donovan and members of the Committee  
State House  
Smith Street  
Providence, RI 02903

Dear Chair Susan Donovan and the members of the Committee,

I am a long time Providence resident and a parent of a child with cystic fibrosis (CF). On behalf of the over 110 people with CF in Rhode Island, I write to express my support for H 6209. Patients with chronic diseases like CF often struggle to afford their care and rely on copay assistance to access vital medications. H 6209 would help ensure patients' health and financial wellbeing are not sacrificed in the ongoing, systemic debate between payers and pharmaceutical companies about prescription drug pricing.

Cystic fibrosis is a life-threatening, progressive genetic disease that affects nearly 40,000 children and adults in the United States. Our son has worked diligently all his life to keep up with his daily medications and treatments so that he can live his life as fully as possible. A new medication was developed recently that has been a game changer for our son's life. Due to the high cost of developing this drug and the targeted use for those with CF, this medication is expensive. Along with the other medications and treatments our son requires, his medical costs are huge, especially as a young adult at the beginning of his career.

Accumulator programs prevent third-party payments from counting towards deductibles and out-of-pocket limits and therefore increase out-of-pocket costs for patients. This is an incredible burden to those people with significant health issues including those with CF. Maintaining his medication and treatment regimen is critical to our son's quality of life and life expectancy. From a strictly financial perspective, if he was not able to afford his medications, the cost of his care would actually be higher as he would spend more and more time in the hospital.

I understand the challenge insurers face in managing the rising cost of drugs, and that copay assistance programs mask bigger cost and affordability issues in the health care system. However, cost containment strategies that further burden patients are damaging. Accumulators are especially challenging for a disease like CF, which has no generic options for many of the condition's vital therapies.

I urge you to support H 6209 to help ensure continued access to quality, specialty care for people with CF. Please contact me if you have any questions. Thank you for your consideration.

Sincerely,

Amy Lupica