



August 16, 2022

Aaron Butler  
Director of Policy  
Division of TennCare  
310 Great Circle Road  
Nashville, Tennessee 37243

**RE: TennCare III Demonstration, Amendment 4**

Dear Mr. Butler,

Thank you for the opportunity to comment on the progress of Tennessee’s TennCare demonstration. On behalf of people with cystic fibrosis (CF) living in Tennessee, we write to applaud the state for the positive changes made to its 1115 waiver and express our concerns with some remaining proposals. Specifically, we want to recognize the positive developments of removing the closed formulary, the “shared savings” mechanism, and the aggregate cap payment structure. Eliminating these policies will preserve access for people with CF who rely on Medicaid. Despite these positive changes, we continue to oppose the retroactive coverage waiver provision. We fear waiving this benefit jeopardizes patient access to quality and affordable healthcare and therefore urge that Tennessee revise its waiver application and remove this harmful provision.

Cystic fibrosis is a life-threatening genetic disease that affects close to 40,000 children and adults in the United States, including over 750 in Tennessee. Roughly a third of adults living with CF in the state rely on Medicaid for some or all of their health care coverage. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. If left untreated, infections and exacerbations caused by CF can result in irreversible lung damage, and the associated symptoms of CF lead to early death, usually by respiratory failure.

**Funding Model and Formulary Changes**

We applaud Tennessee for removing its aggregate cap framework and its proposal to operate a commercial-style closed formulary. CFF recognizes that drug cost growth contributes to the increasing strain on state budgets, and we appreciate the state’s investment in its patients by removing the proposed closed formulary. Furthermore, the previous provisions to establish an aggregate cap and “shared savings” mechanism created incentives for the state to cut costs, which could adversely impact access to care. For people with CF, lack of proper care can severely compromise their health by leading to increased hospitalizations, reduced lung function, or decreased nutritional status. Removing these proposals will eliminate incentives for Tennessee to reduce costs that could curtail access to care for patients with serious chronic conditions like cystic fibrosis.

**Removal of Retroactive Eligibility**

The CF Foundation opposes Tennessee’s decision to continue to waive retroactive coverage in TennCare. Retroactive eligibility helps ensure continuous coverage for people with CF who experience changes in insurance status and become Medicaid eligible. There are many reasons why Tennesseans, including people with CF, may not be able to submit a timely Medicaid application when they become eligible. Someone with CF may be consumed by a complicated medical situation—such as an extended hospitalization—making it difficult to

complete an application. Applications can be burdensome and confusing, and people may not realize their coverage has lapsed until they seek care.

Retroactive eligibility helps adults living with CF in Tennessee who rely on Medicaid avoid gaps in coverage and costly medical bills and is an especially important safeguard for those who have lost their job or are experiencing changes in their insurance status as a result of the COVID-19 pandemic. Without it, people with CF may face significant out-of-pocket costs. Cystic fibrosis care and treatments are costly, even with coverage. According to a survey conducted by George Washington University of 1,800 people living with CF and their families, over 70 percent indicated that paying for health care has caused financial problems such as being contacted by a collection agency, having to file for bankruptcy, experiencing difficulty paying for basics like rent and utilities, or having to take a second job to make ends meet. And while 84 percent received some form of financial assistance in 2019 to pay for their care, almost half reported still having problems paying for at least one medication or service in that same year.<sup>1</sup>

### **Conclusion**

Thank you for the opportunity to provide comments on the TennCare III demonstration. As the health care landscape continues to evolve, we look forward to working with the state of Tennessee to improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward. If you have any questions about cystic fibrosis or would like to discuss the importance of access to care for the CF community, please contact Sage Rosenthal at [srosenthal@cff.org](mailto:srosenthal@cff.org) or (301) 841-2632.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', written in a cursive style.

Mary B. Dwight  
Chief Policy & Advocacy Officer  
Senior Vice President, Policy & Advocacy  
Cystic Fibrosis Foundation

---

<sup>1</sup> [https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs\\_policy\\_briefs](https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs)