



October 26, 2018

Wendy Long, MD  
Director  
Division of TennCare  
310 Great Circle Road  
Nashville, TN 37243

Re: 1115 Waiver Amendment 38 to the TennCare II Demonstration

Dear Dr. Long:

The Epilepsy Foundation, and our local affiliates Epilepsy Foundation of East Tennessee, Epilepsy Foundation of Southeast Tennessee, and Epilepsy Foundation Middle & West Tennessee appreciate the opportunity to submit comments on Tennessee's 1115 Waiver Amendment, "Amendment 38 to the TennCare II Demonstration."

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the at least 3.4 million Americans with epilepsy and seizures. The local affiliates, Epilepsy Foundation of East Tennessee, Epilepsy Foundation of Southeast Tennessee, and Epilepsy Foundation Middle & West Tennessee advocate and provide services for the almost 74,000 individuals living with epilepsy throughout the state. Collectively, we foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. According to the CDC figures there are 84,800 people living with epilepsy in Virginia. For people living with epilepsy, timely access to appropriate, physician-directed care, including epilepsy medications, is a critical concern.

The Epilepsy Foundation, Epilepsy Foundation of East Tennessee, Epilepsy Foundation of Southeast Tennessee, and Epilepsy Foundation Middle & West Tennessee believe everyone, including TennCare enrollees, should have access to quality and affordable health coverage. Unfortunately, this waiver creates new administrative barriers that will jeopardize patients' access to quality and affordable health coverage, and we therefore oppose the proposed waiver.

The Tennessee Amendment 38 seeks to add a work and community engagement requirement for most TennCare enrollees. This would increase the administrative burden on all TennCare patients. Individuals will need to either report that they meet certain exemptions or the number of hours they have worked. Increasing administrative requirements will likely decrease the number of individuals with TennCare coverage, regardless of whether they are exempt or not.

Arkansas is currently implementing a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. As of October 1, four months into implementation, the state has terminated coverage for 8,462 individuals and locked them out of coverage until January 2019.<sup>i</sup> An additional 12,589 individuals had one or two months of noncompliance and are at risk for losing coverage in the coming months.<sup>ii</sup> In another case, after Washington state changed its renewal process from every twelve months to every six months and instituted new documentation requirements in 2003, approximately



35,000 fewer children were enrolled in the program by the end of 2004.<sup>iii</sup> Battling administrative red tape in order to keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health.

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with serious, acute and chronic diseases. If the state finds that individuals have failed to comply with the new requirements for two months out of a six-month period, they will be locked out of coverage until they demonstrate their compliance. People who are in the middle of treatment for a life-threatening disease, rely on regular visits with healthcare providers or must take daily medications to manage their chronic conditions cannot afford a sudden gap in their care.

The Epilepsy Foundation, Epilepsy Foundation of East Tennessee, Epilepsy Foundation of Southeast Tennessee, and Epilepsy Foundation Middle & West Tennessee are also concerned that the current exemption criteria may not capture all individuals with, or at risk of, serious and chronic health conditions like epilepsy that may prevent them from working. Additionally, Tennessee's "good cause" exemption is still not sufficient to protect patients. In Arkansas, many individuals were unaware of the new requirements and therefore unaware that they needed to apply for such an exemption.<sup>iv</sup> No exemption criteria can circumvent this problem and the serious risk to the health of the people we represent.

Administering these requirements will be expensive for Tennessee. States such as Michigan, Pennsylvania, Kentucky and Virginia have estimated that setting up the administrative systems to track and verify exemptions and work activities will cost tens of millions of dollars.<sup>v</sup> Tennessee's fiscal impact statement estimated the program would cost approximately the state and federal government \$39.8 million over the course of the waiver.<sup>vi</sup> These costs would divert resources from Medicaid's core goal – providing health coverage to those without access to care.

Ultimately, the requirements outlined in this waiver do not further the goals of the Medicaid program or help low-income individuals improve their circumstances without needlessly compromising their access to care. Most people on Medicaid who can work already do so.<sup>vii</sup> A study published in *JAMA Internal Medicine*, looked at the employment status and characteristics of Michigan's Medicaid enrollees.<sup>viii</sup> The study found only about a quarter were unemployed (27.6 percent). Of this 27.6 percent of enrollees, two thirds reported having a chronic physical condition and a quarter reported having a mental or physical condition that interfered with their ability to work.

In a report looking at the impact of Medicaid expansion in Ohio, the majority of enrollees reported that that being enrolled in Medicaid made it easier to work or look for work (83.5 percent and 60 percent, respectively).<sup>ix</sup> Terminating individuals' TennCare coverage for non-compliance with these requirements will therefore hurt rather than help people search for and obtain employment. Tennessee has experience with this. In 2005, when the state changed the TennCare program's eligibility and 170,000 people lost Medicaid coverage, there was no increase in employment and self-reported health and access to medical care declined.<sup>x</sup> The Epilepsy Foundation, Epilepsy Foundation of East Tennessee, Epilepsy Foundation of Southeast Tennessee, and Epilepsy Foundation Middle & West Tennessee oppose the work and community engagement.

The Epilepsy Foundation, Epilepsy Foundation of East Tennessee, Epilepsy Foundation of Southeast



Tennessee, and Epilepsy Foundation Middle & West Tennessee also wish to highlight that the federal rules at 431.408 pertaining to state public comment process require at (a)(1)(i)(C) that a state include an estimate of the expected increase or decrease in annual enrollment and expenditures if applicable. The intent of this section of the regulations is to allow the public to comment on a Section 1115 proposal with adequate information to assess its impact. However, on pages 5 of this proposal, the Department states that *“Some number of individuals may transition off of TennCare and into other coverage options as their earnings increase; however, it is not possible to reliably project the magnitude of this decrease in enrollment at this time.”* We urge the TennCare to update the waiver amendment with the estimated expenditure and estimate enrollment change and reopen the state comment period for an additional 30-days.

The Epilepsy Foundation, Epilepsy Foundation of East Tennessee, Epilepsy Foundation of Southeast Tennessee, and Epilepsy Foundation Middle & West Tennessee believe healthcare should be affordable, accessible, and adequate. Tennessee’s Amendment 38 does not meet that standard. Thank you for the opportunity to provide comments.

Sincerely,

A handwritten signature in black ink that reads "Pam Hughes".

Pam Hughes  
Executive Director  
Epilepsy Foundation of East Tennessee

A handwritten signature in blue ink that reads "Mickey L. McCamish".

Mickey McCamish  
Executive Director  
Epilepsy Foundation of Southeast Tennessee

A handwritten signature in black ink that reads "Elisa Hertzán".

Elisa Hertzán  
Executive Director  
Epilepsy Foundation Middle & West Tennessee

A handwritten signature in black ink that reads "Philip M. Gattone".

Philip M. Gattone, M.Ed.  
President & CEO  
Epilepsy Foundation

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<sup>i</sup> Arkansas Department of Health and Human Services, Arkansas Works Program, August 2018. Accessed at: [https://ccf.georgetown.edu/wp-content/uploads/2018/09/091218\\_AWReport\\_Final.pdf](https://ccf.georgetown.edu/wp-content/uploads/2018/09/091218_AWReport_Final.pdf); Arkansas Department of Health and Human Services, Arkansas Works Program, September 2018. Accessed at: <https://m.arktimes.com/media/pdf/9.18 - aw work requirements report.pdf>.

- <sup>ii</sup> Arkansas Department of Health and Human Services, Arkansas Works Program, August 2018. Accessed at: [https://ccf.georgetown.edu/wp-content/uploads/2018/09/091218\\_AWReport\\_Final.pdf](https://ccf.georgetown.edu/wp-content/uploads/2018/09/091218_AWReport_Final.pdf).; Arkansas Department of Health and Human Services, Arkansas Works Program, September 2018. Accessed at: [https://m.arktimes.com/media/pdf/9.18\\_-\\_aw\\_work\\_requirements\\_report.pdf](https://m.arktimes.com/media/pdf/9.18_-_aw_work_requirements_report.pdf).
- <sup>iii</sup> Tricia Brooks, “Data Reporting to Assess Enrollment and Retention in Medicaid and SCHIP,” Georgetown University Health Policy Institute Center for Children and Families, January 2009.
- <sup>iv</sup> Jessica Greene, “Medicaid Recipients’ Early Experience With the Arkansas Medicaid Work Requirement,” Health Affairs, Sept. 5, 2018. Accessed at: <https://www.healthaffairs.org/doi/10.1377/hblog20180904.979085/full/>.
- <sup>v</sup> Michigan House Fiscal Agency, Legislative Analysis of Healthy Michigan Plan Work Requirements and Premium Payment Requirements, June 6, 2018, <http://www.legislature.mi.gov/documents/2017-2018/billanalysis/House/pdf/2017-HLA-0897-5CEEF80A.pdf>; House Committee on Appropriations, Fiscal Note for HB 2138, April 16, 2018, <http://www.legis.state.pa.us/WU01/LI/BI/FN/2017/0/HB2138P3328.pdf>; Misty Williams, “Medicaid Changes Require Tens of Millions in Upfront Costs,” Roll Call, February 26, 2018, <https://www.rollcall.com/news/politics/medicaid-kentucky>.
- <sup>vi</sup> Tennessee General Assembly Fiscal Review Committee. Fiscal Note HB 1551- SB 1728. February 12, 2018. Accessed at: <http://www.capitol.tn.gov/Bills/110/Fiscal/HB1551.pdf>
- <sup>vii</sup> Rachel Garfield, Robin Rudowitz, and Anthony Damico, “Understanding the Intersection of Medicaid and Work,” Kaiser Family Foundation, February 2017, <http://kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/>
- <sup>viii</sup> Renuka Tipirneni, Susan D. Goold, John Z. Ayanian. Employment Status and Health Characteristics of Adults With Expanded Medicaid Coverage in Michigan. *JAMA Intern Med*. Published online December 11, 2017. doi:10.1001/jamainternmed.2017.7055
- <sup>ix</sup> Ohio Department of Medicaid, 2018 Ohio Medicaid Group VII Assessment: Follow-Up to the 2016 Ohio Medicaid Group VIII Assessment, August 2018. Accessed at: <http://medicaid.ohio.gov/Portals/0/Resources/Reports/Annual/Group-VIII-Final-Report.pdf>
- <sup>x</sup> DeLeire, Thomas. The National Bureau of Economic Research. NBER Working Paper No. 24899: The Effect of Disenrollment from Medicaid on Employment, Insurance Coverage, Health and Health Care Utilization. August 2018. Accessed at: <https://www.nber.org/papers/w24899>