

HOUSE BILL 502

By Littleton

AN ACT to amend Tennessee Code Annotated, Title 56
and Title 71, relative to TennCare.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF TENNESSEE:

SECTION 1. Tennessee Code Annotated, Title 71, Chapter 5, Part 1, is amended by adding the following as a new section:

(a) As used in this section:

(1) "Bureau" means the bureau of TennCare;

(2) "Enrollee" means an individual enrolled in TennCare;

(3) "Kleefstra syndrome" means a rare genetic disorder resulting from a mutation in the euchromatic histone methyltransferase 1 (EHMT1) gene or a deletion of a region of chromosome 9 that includes the EHMT1 gene that affects multiple organs and functions of the body, including the face, brain, heart, and kidneys, and that is characterized by features including, but not limited to:

(A) Developmental delay;

(B) Intellectual disability;

(C) Distinctive facial features;

(D) Speech and hearing disorders;

(E) Seizures;

(F) Gastrointestinal disorders;

(G) Respiratory infections;

(H) Autism;

(I) Obesity; and

(J) Organ defects.

(b) The bureau shall provide coverage and benefits on behalf of an enrollee for the diagnosis, including genetic testing, and treatment of Kleefstra syndrome in the same manner and to the same extent that the bureau provides coverage for autism spectrum disorder, Trisomy 21 or Down syndrome, and other similar or related genetic disorders.

(c) Coverage and benefits under subsection (b) must include, without limitation, early intervention and promoting improvements to the enrollee's quality of life and development throughout the life of the enrollee through:

- (1) Appropriate modalities of therapy;
- (2) Appropriate medications; and
- (3) Other interventive programs, education, treatments, clothing, devices, and equipment.

(d) The director of TennCare may apply for a federal waiver as the director deems necessary to effectuate this section.

SECTION 2. This act takes effect July 1, 2025, the public welfare requiring it.

Kumar
Signature of Sponsor

AMEND Senate Bill No. 522

House Bill No. 502*

by deleting all language after the enacting clause and substituting:

SECTION 1. Tennessee Code Annotated, Title 71, Chapter 5, Part 1, is amended by adding the following as a new section:

(a) As used in this section:

(1) "Bureau" means the bureau of TennCare;

(2) "Enrollee" means an individual enrolled in TennCare;

(3) "Kleefstra syndrome" means a rare genetic disorder resulting from a mutation in the euchromatic histone methyltransferase 1 (EHMT1) gene or a deletion of a region of chromosome 9 that includes the EHMT1 gene that affects multiple organs and functions of the body, including the face, brain, heart, and kidneys, and that is characterized by features, including, but not limited to:

- (A) Developmental delay;
- (B) Intellectual disability;
- (C) Distinctive facial features;
- (D) Speech and hearing disorders;
- (E) Seizures;
- (F) Gastrointestinal disorders;
- (G) Respiratory infections;
- (H) Autism;
- (I) Obesity; and
- (J) Organ defects.

(b) The bureau may provide coverage and benefits on behalf of an enrollee for the diagnosis, including genetic testing, and treatment of Kleefstra syndrome in the same manner and to the same extent that the bureau provides coverage for autism spectrum disorder, Trisomy 21 or Down syndrome, and other similar or related genetic disorders, when determined to be medically necessary pursuant to § 71-5-144.

(c) Coverage and benefits under subsection (b) may include early intervention and promoting improvements to the enrollee's quality of life and development throughout the life of the enrollee through:

- (1) Appropriate modalities of therapy;
- (2) Appropriate medications; and
- (3) Other intervention programs, education, treatments, clothing, devices, and equipment.

(d) The director of TennCare may apply for a federal waiver as the director deems necessary to effectuate this section.

SECTION 2. This act takes effect July 1, 2025, the public welfare requiring it.