

1 SENATE JOINT MEMORIAL 2

2 **53RD LEGISLATURE - STATE OF NEW MEXICO - FIRST SESSION, 2017**

3 INTRODUCED BY

4 Michael Padilla

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10 A JOINT MEMORIAL

11 REQUESTING THE SECRETARY OF HEALTH AND THE SECRETARY OF HUMAN
12 SERVICES TO SEEK FEDERAL AUTHORITY TO ADD RETT SYNDROME TO THE
13 LIST OF CONDITIONS THAT QUALIFY INDIVIDUALS AS MEDICALLY
14 ELIGIBLE FOR THE MEDICAID DEVELOPMENTAL DISABILITIES HOME- AND
15 COMMUNITY-BASED SERVICES WAIVER, ALSO KNOWN AS THE DD WAIVER.

16
17 WHEREAS, Rett syndrome is a neurodevelopmental disorder
18 that affects one out of every ten thousand to twelve thousand
19 girls, only in rare instances affecting boys; and

20 WHEREAS, according to the department of health, there were
21 twenty-six thousand two hundred forty-two children born in New
22 Mexico in 2013, of whom it may be assumed that roughly one-
23 half, or approximately thirteen thousand one hundred twenty,
24 are girls; and

25 WHEREAS, it can therefore be concluded that there is at

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1 least one girl born in New Mexico with Rett syndrome every
2 year; and

3 WHEREAS, Rett syndrome is an intellectual and physical
4 disability with no cure that renders those with the syndrome
5 one hundred percent dependent for activities of daily living;
6 and

7 WHEREAS, while each individual's symptoms are unique, most
8 individuals living with Rett syndrome are unable to speak and
9 have epilepsy, scoliosis of the spine, anxiety and other
10 behavioral conditions, gastrointestinal issues and difficulty
11 with motor skills, eating and sleeping; and

12 WHEREAS, individuals with Rett syndrome require assistance
13 twenty-four hours a day, seven days a week, with a great many
14 supports and services, including physical, occupational and
15 speech and language therapy; orthotic braces; eye-tracking and
16 speech-generating devices; diapers; and special nutrition; and

17 WHEREAS, the federal social security administration has
18 recognized Rett syndrome as rendering applicants for social
19 security benefits who are otherwise eligible for social
20 security disability benefits as medically eligible on the basis
21 of their condition; and

22 WHEREAS, applicants for the DD waiver who have Rett
23 syndrome are ineligible for the DD waiver on the basis of
24 having Rett syndrome without another qualifying condition such
25 as an intellectual disability; and

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1 WHEREAS, the expense of the twenty-four-hour, seven-day-a-
2 week care and the many supports and services renders Rett
3 syndrome care prohibitively expensive for most families; and

4 WHEREAS, individuals with Rett syndrome must have these
5 supports and services to avoid permanently losing the abilities
6 that they do have; and

7 WHEREAS, most commercial insurers offer only limited or no
8 coverage at all for Rett syndrome supports and services; and

9 WHEREAS, without DD waiver eligibility, individuals with
10 Rett syndrome and their families in New Mexico face an
11 inability to obtain essential care or face financial
12 destitution;

13 NOW, THEREFORE, BE IT RESOLVED BY THE LEGISLATURE OF THE
14 STATE OF NEW MEXICO that the secretary of health and the
15 secretary of human services be requested to seek federal
16 authority to add Rett syndrome to the list of conditions that
17 qualify individuals as medically eligible for DD waiver
18 supports and services; and

19 BE IT FURTHER RESOLVED that the department of health and
20 the human services department be requested to report on the
21 status of their efforts to add Rett syndrome to the list of
22 conditions that qualify individuals as medically eligible for
23 DD waiver supports and services to the legislative health and
24 human services committee by December 1, 2017; and

25 BE IT FURTHER RESOLVED that copies of this memorial be

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1 transmitted to the secretary of health, the secretary of human
2 services and the chair of the legislative health and human
3 services committee.

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