

1 A JOINT MEMORIAL

2 REQUESTING THE SECRETARY OF HEALTH AND THE SECRETARY OF HUMAN
3 SERVICES TO SEEK FEDERAL AUTHORITY TO ADD RETT SYNDROME TO
4 THE LIST OF CONDITIONS THAT QUALIFY INDIVIDUALS AS MEDICALLY
5 ELIGIBLE FOR THE MEDICAID DEVELOPMENTAL DISABILITIES
6 HOME- AND COMMUNITY-BASED SERVICES WAIVER, ALSO KNOWN AS THE
7 DD WAIVER.

8
9 WHEREAS, Rett syndrome is a neurodevelopmental disorder
10 that affects one out of every ten thousand to twelve thousand
11 girls, only in rare instances affecting boys; and

12 WHEREAS, according to the department of health, there
13 were twenty-six thousand two hundred forty-two children born
14 in New Mexico in 2013, of whom it may be assumed that roughly
15 one-half, or approximately thirteen thousand one hundred
16 twenty, are girls; and

17 WHEREAS, it can therefore be concluded that there is at
18 least one girl born in New Mexico with Rett syndrome every
19 year; and

20 WHEREAS, Rett syndrome is an intellectual and physical
21 disability with no cure that renders those with the syndrome
22 one hundred percent dependent for activities of daily living;
23 and

24 WHEREAS, while each individual's symptoms are unique,
25 most individuals living with Rett syndrome are unable to

1 speak and have epilepsy, scoliosis of the spine, anxiety and
2 other behavioral conditions, gastrointestinal issues and
3 difficulty with motor skills, eating and sleeping; and

4 WHEREAS, individuals with Rett syndrome require
5 assistance twenty-four hours a day, seven days a week, with a
6 great many supports and services, including physical,
7 occupational and speech and language therapy; orthotic
8 braces; eye-tracking and speech-generating devices; diapers;
9 and special nutrition; and

10 WHEREAS, the federal social security administration has
11 recognized Rett syndrome as rendering applicants for social
12 security benefits who are otherwise eligible for social
13 security disability benefits as medically eligible on the
14 basis of their condition; and

15 WHEREAS, applicants for the DD waiver who have Rett
16 syndrome are ineligible for the DD waiver on the basis of
17 having Rett syndrome without another qualifying condition
18 such as an intellectual disability; and

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

22 WHEREAS, individuals with Rett syndrome must have these
23 supports and services to avoid permanently losing the
24 abilities that they do have; and

25 WHEREAS, most commercial insurers offer only limited or

1 no coverage at all for Rett syndrome supports and services;
2 and

3 WHEREAS, without DD waiver eligibility, individuals with
4 Rett syndrome and their families in New Mexico face an
5 inability to obtain essential care or face financial
6 destitution;

7 NOW, THEREFORE, BE IT RESOLVED BY THE LEGISLATURE OF THE
8 STATE OF NEW MEXICO that the secretary of health and the
9 secretary of human services be requested to seek federal
10 authority to add Rett syndrome to the list of conditions that
11 qualify individuals as medically eligible for DD waiver
12 supports and services; and

13 BE IT FURTHER RESOLVED that the department of health and
14 the human services department be requested to report on the
15 status of their efforts to add Rett syndrome to the list of
16 conditions that qualify individuals as medically eligible for
17 DD waiver supports and services to the legislative health and
18 human services committee by December 1, 2017; and

19 BE IT FURTHER RESOLVED that copies of this memorial be
20 transmitted to the secretary of health, the secretary of human
21 services and the chair of the legislative health and human
22 services committee. _____

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