

Request to the DOH and HSD Regarding Rett Syndrome

We respectfully ask the Department of Health and the Human Services Department in New Mexico to add Rett syndrome (RS) to the list of conditions that qualify a person for the Developmental Disability Waiver and Medicaid supports and services.

Rett syndrome is considered a profound Developmental Disability. Until 2013, RS was included under the Autism umbrella and thereby qualified affected individuals for services. In 1999 the genetic cause for RS was discovered. As a result, RS was reclassified as a neurologic disorder with a known genetic cause and removed from the autism spectrum with the printing of the 2013 Diagnostic Statistical Manual of Mental Disorders.

Individuals with RS are some of New Mexico's most medically fragile individuals. Symptoms of RS include:

- a rare neurodevelopmental disorder
- intellectual/cognitive disability and autism-like symptoms, especially in the early stages of life
- often misdiagnosed as autism, cerebral palsy, or non-specific developmental delay and has no cure
- 100% dependency for activities of daily living
- inability to speak
- loss of purposeful use of the hands and distinctive hand movements
- complete loss of ability to walk or problems with walking, muscle and joint problems
- seizures
- heart issues including a long QT
- scoliosis
- sleep problems
- difficulty eating, many will require feeding tubes at some point
- constipation which can be a severe as well as other GI problems
- anxiety and difficult behavior
- risk of shortened life span, but many will live into adulthood
- severity of symptoms can change quickly
- no cure available, but medications, physical, occupational, speech, and other therapies, and nutritional support help manage symptoms, prevent complications, and improve quality of life

Alignment with the Social Security Administration's Compassionate Allowance Qualification List

The Social Security Administration has recognized RS as a qualifying condition for the *Compassionate Allowance* based on applicants whose "medical conditions are so serious that their conditions obviously meet disability standards." We are asking for alignment with this recognition.

Previous attempt to add RS to the DD Waiver and Medicaid supports and services

Senator Michael Padilla submitted Memorial SM81 during the 2016 Legislative Session and received a Do Pass from the first committee, but SM81 is currently inactive. Senator Padilla has re-opened the file for the 2017 Legislative Session.

Conclusion

Rett Syndrome is clearly a profound developmental disability. We respectfully ask the New Mexico Department of Health and the New Mexico Human Services Department add Rett Syndrome to the New Mexico's list of qualifying conditions for the DD Waiver and Medicaid supports and services.