

### **Question regarding number of girls and fiscal affect.**

Rett Syndrome affects 1 in 10,000-12,000 girls. According to the DOH, 26,242 births in NM in 2013. If ½ are female = 13,121. \*\*\*Likely 1 girl per year born with Rett in NM.

Most existing girls with Rett in New Mexico are older and grandfathered into the waivers and Medicaid supports under the Autism umbrella prior to 2013. **This legislation will affect only 1 to 2 girls diagnosed per year after 2013.**

**The families at the greatest risk are working, middle class families with commercial insurance, those that do not qualify for Medicaid or Waivers as secondary payors.** I am concerned these families will end up in poverty, due to medical costs over and above commercial insurance payments, thereby qualifying for Medicaid.

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### **Rough example of unpaid costs after Commercial Insurance has paid in 2016:**

Kallai, 4 years of age. Kallai cannot walk, speak, or use her hands...is **100% dependent on someone for every activity of daily living**, yet currently does not qualify for the DD Waiver or the Medically Fragile Waiver.

- covered under father's commercial insurance, a CDHP. Her father pays 100% of the first \$3000 in medical cost. Then the insurance pays 80/20 for the next \$1000. The max out of pocket is 4,000 in network/\$5000 out of network.
- -In spite of max OOP of \$4000 or \$5000, **many Rett related costs are not covered at all or have limited numbers of visits under commercial insurance. Without these coverages, Kallai risks losing abilities that she will "never regain"** no matter what future treatments she receives.
  - **Orthotic Leg and Foot Braces:** Insurance pays up only \$200 year. Actual cost in 2016 = \$4,100. Unpaid by insurance 2016 = \$3,900.
  - **Tobi eye-tracking, speech-generating device:** Not covered: \$18,000-20,000. Father current asking for a re-review.
  - **Physical, Occupational, and Speech Therapies:** a large amount not covered by commercial insurance. Many providers will not even consider Kallai because they do not want to deal with commercial insurance.
    - **Home Physical Therapy: 100% not covered**, providers do not accept commercial insurance.
    - **Speech and Occupational Therapies at facility:** covered at 80/20 after \$3000 deductible. Limited visits per year. **Expected unpaid for cost 2016 approx. \$6000**

Medicaid and the Waivers will provide diapers and pediatric drinks not paid by commercial insurance.

Treatments at Rett Clinic/Denver Children's Hospital twice/year: In-network provider fees covered. Travel costs not covered.

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**Question about DOH's response:** DOH correctly claims there are many supports in place for girls with Rett. However, that may be because most have been grandfathered in prior to 2013. Also, once girls have progressed to extreme states (on feeding tubes, need home nursing care, etc.), they qualify. However, therapies prior to these states can help girls keep their existing skills and health. Once lost, they cannot be brought back with even the best of therapies.

**Closing:** Kallai will be re-evaluated for Medicaid in January. Her father picked up overtime and worked hard to do the right thing and provide for his family in 2016. We are concerned that his hard work and attempt to do the right thing providing for his family will be "rewarded" by Medicaid denying further Medicaid coverage at that time leaving the family with medical costs that no middle income family possibly could afford. This puts the family at risk of ending up in poverty and thereby qualifying for Medicaid. It also puts the affected girls at risk of not receiving the treatments they need for their best possible future.