Did you know?

The Statue of Liberty was gifted to the US by the French on Christmas Day in 1886. It weighs 225 tons and thus you could consider it as the biggest Christmas gift in the world.

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**Ellie’s Story...**

Tahoka 6-year-old girl has rare disease, diagnosed as one of only 48 in the world

**by JUANELL JONES**

Christmas is about joy, and hope, and love. For one Tahoka family, this Christmas is all of that, plus a hope that their daughter will have a day relatively free of some of the serious symptoms of a mysterious disease that until 2016 didn’t even have a name. Eleanor Moore (Ellie for short) is 6 years old, and she has TANGO2.

Ellie is an adorable 6-year-old girl that in many ways lives like any other little girl – she loves her baby dolls, and both of her big brothers, and she knows that Mama and Daddy love her and care for her. But Ellie is one of only 48 people in the world to be diagnosed with a relatively unknown disease called TANGO2, a rare genetic disease that has changed her life, and the lives of her family, dramatically.

TANGO2 is a genetic mutation. Both of Ellie’s parents were unknowingly carriers of a recessive gene mutation that had a one in a million chance of affecting their daughter. But it did. Blake and Lan- ry Moore’s daughter Ellie was born July 31, 2012, and they have spent the past six years visiting numerous doctors and hospitals, trying to find out why their daughter has so many health issues. In 2017, Ellie was diagnosed with TANO2, a disease so rare that it hadn’t even been named until 2016, and only a handful of children in the world have been diagnosed with it. TANO2 doesn’t stand for anything. The way that her genome in her genetic sequence line up, the names of the ones that are missing just happen to spell out TANO2,” explains Ellie’s father, Blake, who is employed as a Member Services Advisor for Lyntegar Electric Coop- erative, Inc, in Tahoka. TANGO2 mutations affect children at the most basic cellular, metabolic, and biochemical level. Although there are some common symptoms and conditions across those affected by TANGO2 disease, there is also broad variability in terms of presentation and sever- ity of them for each individual. In all cases though, the potential for diphtheromyelopa and life-threatening cardiac arrhythmia brought on by metabolic crisis is always there.

For Ellie, the disease affects her development in her muscular sys- tem, speech and coordination devel- opment, and she has suffered with symptoms and conditions across hospitals, trying to find out why their daughter has so many health issues. In 2017, Ellie was diagnosed with TANGO2, a disease so rare that it hadn’t even been named until 2016, and only a handful of children in the world have been diagnosed with it. TANGO2 doesn’t stand for anything. The way that her genome in her genetic sequence line up, the names of the ones that are missing just happen to spell out TANGO2,” explains Ellie’s father, Blake, who is employed as a Member Services Advisor for Lyntegar Electric Coop- erative, Inc, in Tahoka. TANGO2 mutations affect children at the most basic cellular, metabolic, and biochemical level. Although there are some common symptoms and conditions across those affected by TANGO2 disease, there is also broad variability in terms of presentation and sever- ity of them for each individual. In all cases though, the potential for diphtheromyelopa and life-threatening cardiac arrhythmia brought on by metabolic crisis is always there.

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MOORE FAMILY... Ellie and Laura Moore, with their children, Denton and Reese, have tattoos in Tribute to Life, a national organization of Rare Diseases, of which TANGO2, a genetic disorder, is now a member. In April of 2017, the Moores discovered that their daughter, Ellie, was diagnosed with TANGO2.

Since April, the Moores have found other parents whose children have been identified as having TANGO2, after finding a website started by the family of the disease.

We joined this group and now there are more than 30 us. We will meet in the spring at a convention in June. At the same time, the parents and the children will give seminars in the hospital and schools.

Researchers at Baylor College of Medicine and Texas Children’s Hospital in Houston.
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New FNB Director ... Worth Whitworth, left, President of First National Bank of Tahoka, welcomes Trent Levee to the Board of Directors.

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