



Lynn County News



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Tahoka, Lynn County

Texas

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75¢

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Christmas Calendar

Dec 19 - Open House
10-2 at First National Bank of Tahoka, lobby

CHRISTMAS EVE SERVICES:
First Baptist Church of Tahoka, 5 pm
First Methodist Church of Tahoka, 6 pm
St. John Lutheran Church of Wilson, 6 pm

CHRISTMAS DAY SERVICE:
St. John Lutheran, Wilson, 10 am

THE LYNN COUNTY NEWS Holiday Hours & Deadlines:

Deadline for Dec. 27 issue is Noon Monday, Dec. 24

Dec. 24: Closing at 12 noon

Tuesday, Dec. 25: Closed

Deadline for Jan. 3 issue is Noon Monday, Dec. 31

Tuesday, Jan. 1: Closed

What's Outside

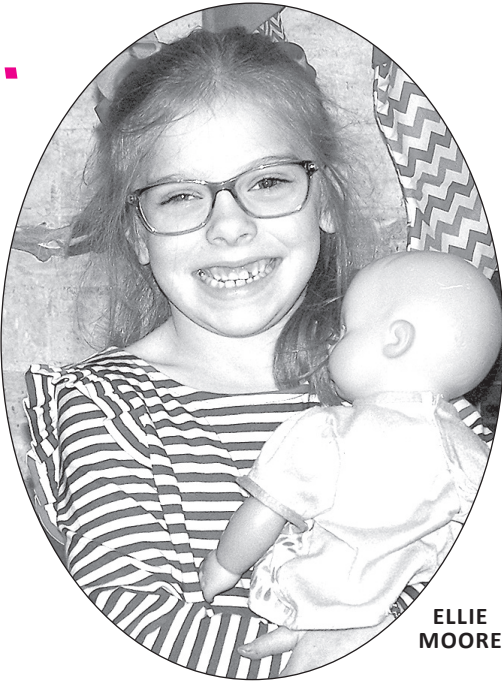
NWS official readings for Tahoka			
Date	High	Low	Precip.
Dec 11	57	28	
Dec 12	55	33	
Dec 13	62	34	0.17"
Dec 14	45	29	0.12"
Dec 15	67	28	
Dec 16	67	28	
Dec 17	57	37	
<small>(Precipitation/temps measured as of 8 a.m. on date reported, for the previous 24-hr period)</small>			
Total Precip for Nov:			0.51"
Total Precip for Dec:			1.29"
Total Precip. for 2018:			26.22"

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 MOORE

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 Laura Moore's daughter Ellie was born July 31, 2012, and they have spent the past six years visiting numer-

ous doctors and 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 genomes 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 Cooperative, 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 severity of them for each individual. In all cases though, the potential for rhabdomyolysis and life-threatening cardiac arrhythmia brought on by metabolic crisis is always there.

For Ellie, the disease affects her development in her muscular system, speech and coordination development, and she has suffered with rhabdomyolysis, which in simple terms is extreme dehydration that can be life threatening.

When Ellie, the third of Blake and Laura's children, was first born, everything seemed normal. Within in a few months, however, Ellie's

(See ELLIE'S STORY, page 8A)

Did you know? about CHRISTMAS



In Germany, *Heiligabend*, or Christmas Eve, is said to be a magical time when the pure in heart can hear animals talking. They can also see that rivers turn into wine, Christmas tree blossoms bear fruit, mountains open, revealing gems hidden inside and bell ringing can be heard from the bottom of the sea.

Jingle Bells

"Jingle Bells" was written for Thanksgiving, not Christmas. The song was written in 1857 by James Lord Pierpont and published under the title "One Horse Open Sleigh". It was supposed to be played in the composer's Sunday school class during Thanksgiving as a way to commemorate the famed Medford sleigh races. "Jingle Bells" was also the first song to be broadcast from space. Astronauts Tom Stafford and Wally Schirra sang it in space on December 16, 1965.

This way out

The US playing card company 'Bicycle' had manufactured a playing card in WW2 which would reveal an escape route for POWs when soaked. These cards were Christmas presents for all POWs in Germany. The Nazis were none the wiser!



If you gave all the gifts listed in the Twelve Days of Christmas, it would equal 364 gifts.

Me and Santa, we're good buddies!

Leighton Knox and Santa are good buddies, with Santa catching a ride on Leighton's train, the Tahoka Polar Express, that was here last Saturday night. The Tahoka Area Chamber of Commerce sponsored the event, and expresses their appreciation to First Baptist Church for hosting the "Depot" for this year's ride.

(LCN PHOTO by Gary Jones)



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.

ELLIE'S STORY ...

(Continued from page 1)

parents began noticing that she was not progressing with her motor skills and knew that something was not right.

“Eleanor was a normal birth, after a normal pregnancy. She is our third child, so when she was about six months old we began noticing that she had delayed development – her motor skills were not progressing, she wasn’t crawling or trying to walk. Both of our boys, Denton and Reese, were early developers that both began walking at about 9 months old. And she was such a quiet baby, she wasn’t trying to babble or talk,” explains Laura.

“Around 9 months old she still wasn’t able to sit up, so we started therapy. The doctors said they didn’t know why she was not developing, but regardless they wanted to start physical therapy. So we just started doing therapy, but by the time she was a year old she would have random bouts of Torticollis, which is a tightening of the muscles in the neck that would cause her head to tilt to one side. All day long I would carry her and hold her, and her head would be stuck that one way. But then after she would go to sleep, she would wake up and her head would be back upright. Or sometimes her head would be tilted the other way. With Torticollis your muscles are stiff, and it doesn’t just randomly change sides, so that baffled the doctors.

“I started noticing episodes, and I thought I was going crazy. The older she got, these random episodes would happen, like the tilted head, or slumping to one side. One day she was sitting up but slumped over to one side, and she couldn’t straighten, and I called the doctor and said, something is not right, I can’t get her to sit straight. She’d literally be trying to sit up but she couldn’t, she would either slump to one side or the other.

“Episodes like that kept happening, and before she turned 2 years old, finally I pushed our pediatrician to get us in with a neurologist. She wasn’t developing right, she wasn’t walking, and no one could tell us why,” Laura said.

The Moores were referred to Cook’s Children’s Hospital in Ft Worth.

“Before we could go to the appointment, we had gone to Ruidoso with Blake’s parents. Ellie was sitting up and suddenly she



Ellie and Mama ... Eleanor (“Ellie”) and her mother, Laura Moore, spend much of their days together, as Laura is vigilant in keeping a close watch on her daughter’s health.

just flopped back and her eyes were rolling. She could respond with a sound, but she couldn’t control anything. It was like a seizure, except that she could respond with sounds. I called the pediatrician and she said to go to the emergency room because it sounded like a seizure.

In the ER, they did several tests, including an EEG, MRI, blood work, and found nothing wrong. “That basically was the starting point [of the more aggressive symptoms], at about 2 years old. After that we started seeing a neurologist in Cook’s Children’s Hospital. But all of this time, none of the tests showed anything, and we could get no diagnosis. We went through all these physicians, and went to a movement neurologist. She didn’t walk until she was 26 months old. But still no diagnosis, the doctors had no idea of what it was, and just said try this, and they couldn’t explain it. Even the neurologist told us that probably 75 percent of his patients had no diagnosis but that you still just treated the symptoms. That was very frustrating for us,” said her mother.

Eventually, the Moores were sent to a geneticist. Ellie went through a lot of blood work,

three spinal taps, three EEGs, a lumbar MRI, full scan with dye, and everything came back normal. Finally, one of the geneticists recommended that they get a Whole Exome genetic test, where they draw blood on both parents and the child and look for any genetic abnormalities.

“The Whole Exome test is the most extensive genetic testing that you can do. We did that in the spring of 2015, and the results came back inconclusive, no genetic abnormalities identified, which again was very frustrating. But they said that something might be found later, because there are so many genes in your DNA, and there are genes that have not even been translated and they cannot identify what they do. So as more research is done, more genes are translated, and it is possible that they could find something later,” Laura explained.

In the meantime, Ellie continued to have episodes with her muscular system, affecting her motor skills, and speech issues similar to strokes.

“Rest was the only way we could figure out how to help her. She began getting more and more symptoms. One of her brothers came home from school with a stomach bug, and she caught it and it just seemed to affect her more strongly, and we became worried and called the doctor. He said to get to the emergency room because she may become dehydrated. Well, we had tried taking her to the ER in Lubbock previously, and they didn’t know what to do for her because we still had no diagnosis on her illness. So we loaded up and drove to Fort Worth and they ran all the tests, and could tell she was dehydrated and treated that, and they sent us home. We went to the hotel and stayed another day because we were afraid to come home, but she continued to improve so we

came back to Tahoka.

“But four days later, on Christmas morning of 2016, she woke up and she couldn’t move anything. She couldn’t hold her head up, or anything. So we drove back to Fort Worth on Christmas Day, and that was the first of a 58-day stay in the hospital.

“They were afraid it was sepsis, and her urine was brown, which they said was the muscles burning themselves out, which is an extreme dehydration called Rhabdomyolysis. Her labwork numbers were off the charts, but the neurologists couldn’t explain why. They were concerned about liver and kidney damage, and so they were afraid to give her pain meds. She was in a lot of pain, but all she could have was Tylenol, or sometimes they would give her a little Valium. Fortunately, they found that we had taken her to the ER early enough for treatment that there was no kidney or liver damage.

“So we were there for 58 days, and the whole time we were praying and thinking, there’s a reason for this and maybe staying in the hospital with all the tests they are running will give us an answer to what is wrong with her. But even after all of that, when we left the hospital in late February, we still did not have an answer. I was so scared to leave the hospital, because we still did not know what was wrong and what may happen,” Laura recalls.

However, while they were in the hospital, the geneticist decided to run the Whole Exome test again, and added the Rhabdomyolysis trait to see if something might get flagged. Several months later, the Moores got a call that, finally, identified the disease that their daughter had.

“In April of 2017, we got a call from the geneticist saying, ‘we found something on your Whole Exome test’. They told us that they literally just identified TANGO2 in 2016 and that there were only two papers on it in the world,” said Blake.

“The geneticist wanted us to come back to Fort Worth and talk to them, and so we made an appointment the next day. When we got there they had both papers printed out for us to read, but they actually knew very little about the disease, and they told us it was going to be a learning process. It turns out, I am a carrier of the recessive gene, and Laura is a carrier of the recessive gene, and there’s literally a one in a million chance that a child could end up with this particular gene sequence missing and have TANGO2. So we tell Ellie she’s our one in a million – and she is,” he said.

Although the diagnosis had finally been made, there is so little known about TANGO2 that the Moores are still facing trial and error in trying to manage Ellie’s symptoms.

“There’s not really a specific treatment for the gene itself, it can’t be fixed, there’s not enough research on it yet. There is no gene therapy available at this time. So we treat symptoms.

“She needs rest, and she needs a high level of hydration, and to eat every 1-2 hours every day. Something metabolic in the



Moore family ... Blake and Laura Moore, with their children, Denton, Ellie and Reese, live in Tahoka. Blake is employed as a Member Services Advisor for Lyntegar Electric Cooperative, Inc., and Laura is a stay at home parent who cares for their three children and shuttles their daughter to therapies and school. Their daughter, Ellie, was diagnosed with TANGO2 in 2017, and their two older sons are not affected.

genetics affects her energy level. We have not found a specific diet that works, but we sort of treat it like low blood sugar. Proteins seem to help her, we think. We do therapy, because we are behind in all levels – physical therapy, occupational therapy, and speech therapy.”

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

“We joined this group and now there are over 30 of us. We will meet some of them this summer at a convention of the TANGO2 Research Foundation, which was founded by the parents in Connecticut. They have a 17-year-old son that went undiagnosed for 15 years with the

illness,” Laura explained.

Blake has joined the TANGO 2 Research Foundation as a director, and they will meet other families this summer at a convention in June. At the same time, they plan to attend a conference of the National Organization of Rare Diseases, of which TANGO2 is now a member, to try to focus more attention on the disease.

“I am extremely honored to be asked to serve on this board,” said Blake. “Our prayer is that through the TANGO2 Research Foundation, we can work to find answers for TANGO2 treatment and to provide support to families dealing with TANGO2.”

Researchers at Baylor College of Medicine and Texas Children’s Hospital in Houston

(See **ELLIE’S STORY**, page 10A)

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NOTICE OF APPLICATION
FILED WITH THE PUBLIC UTILITY COMMISSION OF TEXAS

On November 30, 2018, Oncor Electric Delivery Company LLC (“Oncor”), Sharyland Distribution & Transmission Services, L.L.C. (“SDTS”), Sharyland Utilities, L.P. (“Sharyland”), and Sempra Energy (“Sempra”) (collectively, “Joint Applicants”) filed a Joint Report and Application for Regulatory Approvals (“Joint Application”) with the Public Utility Commission of Texas (“PUC” or “Commission”), copies of which are kept at Oncor’s office at 1616 Woodall Rodgers Freeway, Suite 6000, Dallas, TX 75202. The Joint Application requests Commission approval of three transactions (the “Proposed Transactions”), as described below, that will result in SDTS becoming an indirect wholly owned subsidiary of Oncor that will own transmission and distribution assets held today by Sharyland and SDTS in central, north, and west Texas, and Sharyland will remain a utility in south Texas, with Sempra owning a 50 percent indirect interest in Sharyland. First, Sharyland will transfer its assets in north Texas, along with associated assets, liabilities, and working capital, to SDTS. In return, Sharyland will receive all of SDTS’s assets located in south Texas. In connection with this asset exchange, Sharyland’s equity interest in SDTS will be cancelled, and the certificates of convenience and necessity of Sharyland and SDTS will be amended to authorize the “North Texas Utility” (referring to the post-closing assets to be owned by SDTS) and the “South Texas Utility” (referring to the post-closing assets to be owned by Sharyland) to own, operate, and maintain their respective post-exchange assets. Second, Oncor will acquire InfraREIT, Inc. (“InfraREIT”) and InfraREIT Partners, LP and, as a result, will own and operate all of SDTS’s post-transaction assets. Finally, Sempra will purchase a 50-percent indirect limited partnership interest in a newly formed Delaware limited partnership expected to be named Sharyland Holdings, LP, which will own a 100-percent interest in Sharyland. The Joint Applicants also request Commission approval of certain regulatory terms listed in Exhibit A to the Joint Application, some of which are regulatory conditions to closing.

The Joint Application does not seek Commission approval of a modification to Oncor’s rates. Oncor is requesting a Commission finding, however, that Oncor may consolidate the North Texas Utility’s wholesale transmission rates with Oncor’s rates as part of Oncor’s next base-rate case. Oncor also requests Commission approval to establish a regulatory asset to track any make-whole payments or other expenses that may be required to extinguish, transfer, or restructure the debt of InfraREIT and its subsidiaries under the Proposed Transactions, so that Oncor may seek recovery of that regulatory asset in its next base-rate case. The Joint Applicants also seek Commission approval to split the current Sharyland wholesale transmission service tariff into two separate tariffs—one for the North Texas Utility and one for the South Texas Utility—which rates, when taken together, would be equal to Sharyland’s rate in effect at the time the Proposed Transactions close.

Any person wishing to intervene in this proceeding must file a written request with the Public Utility Commission of Texas, 1701 North Congress Avenue, P.O. Box 13326, Austin, TX 78711-3326, no later than January 4, 2019. This case has been assigned PUCT Docket No. 48929. Further information may also be obtained by calling the Public Utility Commission at (512) 936-7136 or (888) 782-8477. Hearing- and speech- impaired with text telephones (TTY) may contact the Commission at (512) 936-7136.

ONCOR ELECTRIC DELIVERY COMPANY LLC, SHARYLAND DISTRIBUTION & TRANSMISSION SERVICES, L.L.C., SHARYLAND UTILITIES, L.P., AND SEMPRA ENERGY

ELLIE'S STORY ...

(Continued from page 8A)

are conducting research on TANGO2-related disease. Participation in this study by as many patients as possible is critical in learning more about how to prevent crisis, treat those children currently in crisis, and begin the work of finding new treatments and therapies for TANGO2 disease.

“The idea for the TANGO2 Research Foundation was that by helping to fund, coordinate, and guide the efforts of researchers, scientists and doctors, we can rapidly accelerate the understanding around TANGO2 and pave the way to future therapies and positive outcomes for our loved ones,” said Blake.

For more information about the TANGO2 Research Foundation, or if interested in donating for research in TANGO2, visit their website at www.tango2research.org.

“We don’t know what is ahead. In the last six months we’ve lost two children in the TANGO2 group, a 4-year-old girl in Germany and a 17-year-old boy in Tomball who had seemed healthy. It’s been an emotional roller coaster for us all, but Ellie couldn’t have a better caregiver than her Mom. She keeps an eye on her and worries about every little thing. Ellie has every single one of her needs met,” said Blake.

Laura added, “Even from day one, people would tell me that Ellie looks normal, and it would just depend on the day on how her symptoms manifested. But her language has grown, her physical ability in the last six months has just blossomed, so I really think if we control what she eats, and her rest, as much as we possibly can, it helps. We are learning as we go. Daily life that affects her brothers one way, because all kids get tired and cranky, just seems to be magnified for her. We monitor her heart and other organs every six

months,” she said. “We just don’t know enough about it yet. So while it was somewhat of a relief to finally get a diagnosis, the children who have TANGO2 are basically the guinea pigs for research, to figure out what may help,” added Blake.

“We get through this by being there for each other, but we have to remind ourselves each morning that Ellie is not ours, she is God’s, and it is our job to take care of her. Honestly, this was the second round for us with our kids. Our son Denton was diagnosed with Type 1 Diabetes when he was 6, the same thing I have,” said Blake, “so we had been through a life-altering change once before. While TANGO2 is quite different, our family has become experts in it, and we do what we can. There have been times it was a whirlwind of uncertainty, but prayer has certainly got us through those.

“There are days that it wears you completely out, and can be very draining, but she’s our daughter and we’ve never looked at it like we had any other choice than to do everything we can for her.

“This community has been so kind to us, especially while Ellie was in the hospital for so long. From meals to anonymous donations sent in the mail, we have been blessed to live here. And we just take life one day at a time.”

So for now, like all other families, the Moores are looking forward to Christmas. They plan to go to Welch to spend Christmas with Blake’s parents.

The best gift, for Ellie and her family, is that it will be a good day where she has few symptoms of her illness, and a hope that research will soon provide more answers to the children and families whose lives are affected by TANGO2.



New FNB Director ... Worth Whitworth, left, President of First National Bank of Tahoka, welcomes Trent Leverett to the Board of Directors.

Trent Leverett named new FNB Director

The First National Bank of Tahoka’s Board of Directors is pleased to announce the appointment of Trent Leverett as a new director, elected in October.

Leverett was raised in Tahoka, graduating from Tahoka High School in 1975. He graduated from Texas Tech University with a degree in business. He has been in various aspects of agriculture since graduation and enjoys his involvement in

the cotton ginning industry. He owns farmland in Lynn County that has been family-owned for over 90 years.

Leverett is currently employed by Triangle Cooperative Service Company as safety and compliance manager. He resides in Lubbock with his wife, Cindy. They have two children, Celinda and husband Andy Moore of Lubbock, and Travis of Austin.

We wish  Joy

Merry Christmas & Happy New Year to ALL!

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Did you know? about CHRISTMAS

I’m dreaming of a white Christmas ...

It is estimated that the song “White Christmas” by Irving Berlin is the best selling single in history with over 100 million copies sold.

Let’s watch cartoons!

A large part of Sweden’s population watches Donald Duck cartoons every Christmas Eve since 1960.



In 1962 – the US issued the first Christmas postage stamp.

Kids did you know that in Hawaii, Santa is called **Kanakaloka?**



Hallmark introduced their first Christmas cards in 1915.

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The Directors, Officers and Employees of First National Bank of Tahoka

wish you *Joy & Peace* for the Holidays!



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FNB Holiday Hours:
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Dec. 25 - Closed
Dec. 31 - Regular Hours
Jan. 1 - Closed

