



## Rylee Kinnett's Story

People come and go in our lives, even if they are at a time one of the most important people we ever knew. But some people, the most special ones, remain with us wherever we go, despite the length of time or the distance between us. Rylee is one of the special ones. To sum her up at only 12 years old ... spunky, sassy, beautiful, outdoorsy, happy, and was sassy already mentioned?



Growing up in Florida with 3 equally active brothers, Rylee's boisterous personality attracts others. Maybe even without a word spoken. That sly little

grin expressed through her big brown eyes conveys confidence, playfulness and, well, you better be aware at all times.

As pictured on her 4wheeler, Rylee loves the outdoors ... getting dirty, being tough, hanging with family and buddies, and hurdling every boundary she encounters. She's unstoppable despite immune deficiency issues earlier in life.



On August 10, 2014, Rylee announces on Facebook her proud accomplishment of completing a babysitting class, boldly welcoming opportunities to start earning her own money.



## “My first day of middle school.”

- Rylee, 9/18/14

Rylee easily makes friends. And they love her. Adore her. Despite her petite frame, she seems older than she is because she is wise beyond her years.

She wears her strong faith as a badge of courage, not afraid of sharing that she is a believer in Jesus Christ. In fact, she posts faith-based messages frequently to share with her friends. At such a young age, she’s remarkably influential.

She loves animals and they return her love ... cats and dogs equally, although her cat Oreo is almost attached to her.

## And Then Everything Changes

**9/27/14 - 10/9/14**

Rylee and her brother get fevers. The fever goes away overnight and life/school resumes. The next day, Rylee wakes with a rash all over, plus the miserable fever. Her brother is fine. She grows lethargic, never leaving bed during the next day, so they head to the ER, where she suffers from tachycardia with a heart rate of 220. She stays for observation. Fast forward 3 days and her head pounds and her neck stiffens, escalating to dizziness and the inability to walk without assistance, a dramatic change for a “leave-me-alone, I’ve-got-this” go-getter.

Her mom, Shara Love, paces at the ER, waiting for news. Rylee’s heart rate fluctuates from the 130 to 200, so they await the results of an ultrasound on her heart. She misses her envied first day of fall weather, where the crisper air typically teases her high energy level to do even more.

Rylee is weak and lethargic. Her mute voice creates deafening silence. She can’t sit or stand, so Shara anxiously waits while smoothing her hair and whispering encouraging words, waiting on an ambulance transfer since insurance denies airlift. This compels the doctor to testify against them in a lawsuit if anything goes awry during a 3-hour transport by ambulance.



## The Roller Coaster

10/10/14 - 10/14/14

Doctors discuss theories and plans, including putting her under anesthesia to conduct a spinal tap based on the neurological symptoms. In the brief moments she's awake, she's confused and mumbling gibberish. Fear rises in Shara.

The doctor's initial assessment is infection of the right cerebellum, so he orders an MRI, also wanting to rule out a blood clot in the brain stem. Shara's eyes fix on Rylee's foot, which unnaturally rotates out. Weakness plagues her right side, the doctor commenting this is potentially a temporary condition from the seizure, which hopefully corrects itself with physical therapy.

**“I hate this! I just want them to find out what's wrong and fix it. I feel helpless. I just want her to be okay. I'm on an emotional roller coaster. I can't believe this is happening. ”**

- Shara, 10/10/14

After 2 hours for the MRI, Rylee returns. Shara notices more ... her legs aren't working at all. Her feet cross with no control over where they go. Her whole body is stiff.

A day later, Rylee's confusion comes and goes. She's incontinent. Doctors believe it's either meningitis or encephalitis, uncertain of the type or her prognosis.

**As her condition declines**, they put Rylee on a ventilator. An anti-inflammatory med drips in hopes of stopping the bronchial spasms so she can breathe on her own. But a turn in events means they insert a feeding tube. They sedate her for another MRI ... this time on the spine, looking for an abscess that may be causing the immobility. Thankfully the results don't reveal any setbacks. She's in a medically induced coma since attempts to lower meds causes her lungs to spasm.

As doctors reduce the albuterol for her lungs to do the work, Rylee fights the ventilator, so the meds are increased again. Despite the induced coma, Shara squeezes Rylee's hand and gets a squeeze back, producing happy tears and hope. She's in there. *Fighting in typical Rylee style.* Although when she verbally asks Rylee to squeeze her hand, she doesn't respond. Not giving up hope, though.

**Moments of encouragement** arise the next day as Rylee responds to yes/no questions by shaking and nodding her head. She opens her eyes on command occasionally. However, she has no mobility in her left leg or right arm. Her legs are weak. Just seeing her eyes again lift Shara's crushed spirits.

The cause of Rylee's illness remains a mystery. One doctor admits she's losing sleep as she struggles to determine what torments this formerly active girl's body, running tests she's never even heard of before, afraid she is missing something. Her doctors talk to many specialists.

**It's the 12th day in the hospital**, fever coming and going. Attempts at turning off sedation produce gagging and tears from Rylee, yet her lungs show more strength. She realizes she is very sick. You can't ignore a 179/94 blood pressure nor a 154 heart rate. A head CT is next.



**“I'm missing my daughter, I miss her sassy attitude. I miss her smile and hearing her laugh. I'm grateful she is here, and I'm grateful I still have hope. I'm just missing her.**

**Look at all the lines running to my poor girl, please keep praying for her.”**

- Shara, 10/13/14

## **When Answers Don't Change the Outcome**

**10/15/14 - 10/17/14**

More rounds of tests ... another head MRI, abdominal MRI, ultrasound of lymph nodes that show infection and another spinal tap. The medical team takes precautions to do a stat MRI, taking measures to treat and maintain the brain swelling.

The results are in ... neuro-invasive West Nile virus (WNV) from a mosquito bite. The virus can result in irreversible brain damage, permanent muscle weakness and even death. However, they say it's also possible to make a full recovery. There's no treatment for the virus ... it's a “wait and see” process that tests patience.

Rylee becomes more responsive. Her discomfort wills her to push a hand away with her mobile foot. As Shara speaks to her, she makes direct eye contact, while crying. Her mom reassures her of how strong she is and that she must fight hard. Shara checks for understanding, asking her to blink. Rylee blinks hard and long. More happy tears falling.

## The Community Rallies

10/18/14 - 10/21/14

Rylee's alert! She moves her left hand, flickers the right and pushes with both feet. Her nurse wakes Shara to show the progress.

Shara's coworkers host a fund raiser to help with the growing medical expenses. Girl scouts bake cookies to help their friend and her family. This offers a temporary diversion from reality for Rylee's family, who is so grateful for the outpouring of support. Anne Harris even writes "Rylee's prayer," below on the left.

Is this a dream?  
It's all surreal,  
I pray to God ,  
Can we make a deal?

Please let her be,  
Please let her thrive,  
She has many things of yet to strive,

Her dreams and hopes, not yet attained,  
Her body's sick, our minds are drained,

Is there something else, we need to do,  
To have our blessings , answered by you?

So very young, not yet a chance,  
To see her strengths, to see her dance,

I'm asking you , please hear our prayers,  
You know our worries, and you know our cares.



**"I hate seeing her like this, it's heartbreaking. We have a long hard road ahead, please continue to pray for her recovery, pray she will regain her mobility, pray for her to heal."** - Shara, 10/20/14

The doctors decide a tracheotomy is in Rylee's best interest. The anxiety shoots her heart rate up. When asked if she's scared, despite how brave she is, she raises her eyebrows to indicate "yes, I'm scared."

Meanwhile, Immunology discovers that the medication Gumunex has WNV antibodies in it and that 2 out of 3 patients recover to their normal state after being treated with it. Done deal. She's also got a diagnosis of flaccid paralysis (or poliomyelitis) in addition to WNV.

## A Mom's Perspective

Shara's strength deserves a book of its own. A single mom with 4 kids, forced to learn a whole new medical vocabulary, who fights day and night to save her only daughter. She's a source of inspiration for the many impacted by encephalitis, such a devastating yet unknown illness.

In each post, Shara faithfully requests prayers, her primary hope of unwinding from this nightmare. She realizes the long road ahead, but doesn't become its victim. After 3+ weeks in the hospital, she gets relief from Rylee's grandmother, offering her a respite to retreat to her 3 sons she misses sorely and her abandoned home.

Guilt nearly paralyzes her as Shara leaves the hospital, admittedly heartbroken to leave Rylee for the first time. When she reaches home, she immediately feels a kick in her gut when she looks at Rylee's bedroom, decorated with all her fun stuff, including the BPJ award for most likely to help a friend in need, a Miami ball cap, all sorts of fragrances and nail polishes, and a painting of Rylee's cat, Oreo.



Friends get a brief visit after Rylee's tracheotomy is complete, in hopes she'll be able to speak again soon.

**10/24/14**

The local Daytona Beach News-Journal runs an article highlighting Rylee's story:

## **4th West Nile case confirmed in Volusia County; 12-year-old girl being treated for virus, mom says**

By **JIM HAUG** and **DINAH VOYLES PULVER**

A fourth case of West Nile virus has been confirmed by state health officials in Volusia County, in what has already been a record-breaking year for the mosquito-borne illness.

Shara Love of Edgewater said her daughter, 12-year-old Rylee Kinnett, was diagnosed with the virus by a doctor at UF Health Shands Hospital last week. Citing privacy reasons, neither officials with the Florida Department of Health nor Shands would confirm whether Rylee is the county's fourth virus victim.

A New Smyrna Beach middle schooler, Rylee has been hospitalized for more than three weeks. She can't move any part of her body below the neck and is breathing with the help of a ventilator, her worried mother said this week.

Love was surprised when a doctor told her on Oct. 17 that her daughter had the virus, she said.

"It's unbelievable to me that a mosquito can do this to somebody," Love said. "I knew West Nile was out there. I never understood the severity of what can happen."

West Nile is transmitted when mosquitoes bite infected birds and then transmit the virus to a human.

The four confirmed cases so far are the most ever reported in the county and the first since 2003, said Bonita Sorensen, director of the health department's Volusia operations. The department posted a mosquito-borne illness alert for the county in early October.

Flagler County posted an alert on Thursday. No human cases have been reported in Flagler. However, like Volusia, caged chickens used to monitor the virus have tested positive in Flagler.

Health officials continue urging people to take precautions against the potentially deadly illness, to drain standing water where mosquitoes can breed and wear insect repellent.

Rylee's mother doesn't remember her daughter getting a mosquito bite. But Rylee, who suffers from an immune deficiency, was admitted to Halifax Health Medical Center on Oct. 2, after having a fever for three days. She was moved to Shands on Oct. 7, where she is being treated by doctors who specialize in immunology.

“She’s starting to get anxious. She can’t talk,” said Love. “She has a tube in her throat. They have been sedating her.”

Rylee can respond to her mother. “When she’s awake, she will raise her eyebrows to answer me or blink her eyes,” said Love. “She can lightly squeeze her left hand.”

Rylee is so weak, her mother said, that she can’t cough up the secretions in her lungs, already affected by her pre-existing illness.

Love said the doctors tell her the immune deficiency may have increased Rylee’s chances of contracting the virus.

“She gets weekly infusions of other people’s antibodies,” said Love, who works as a vet tech at Newman Veterinary Clinic in Edgewater. “She lives a really normal life. She does get her lungs cleared out (periodically).”

For Rylee to get her strength back, her mother said, is going to be “a really long process.” “They don’t know how long it will be before she will be able to breathe on her own,” said Love, of her only daughter and second-oldest of her four children.

“There’s no documentation of kids getting better with these severe symptoms,” she said. “They don’t know. Some people regain their mobility and others remain paralyzed. They don’t know what’s going to happen.”

On Friday, Love said she has been told it could take one to two years for her daughter to recover. According to the Centers for Disease Control and Prevention, less than 1 percent of the people infected with West Nile virus develop the more serious neurologic symptoms that Rylee is experiencing. Her mother said she is suffering with encephalitis and meningitis, an inflammation of the brain and surrounding tissues.

The effects could be permanent, the CDC reports. About 10 percent of those more serious cases result in fatalities.

Most people who become infected with West Nile develop no symptoms, the CDC states. About one in five will develop a fever with symptoms such as headache, body aches, joint pain and vomiting, but most usually recover completely.

Jim McNelly, director of East Volusia Mosquito Control, said it’s hard to say why the county has seen more cases of West Nile than ever before this summer. Part of the trouble, he said, could have been the above average rainfall that occurred between July and September. The disease is “relatively complex,” McNelly said.

“Something occurred this summer, with all the environmental influences, that went on that led to a situation where the disease built up in the bird population and then spilled out into our human population,” he said.



Statewide, the virus has been confirmed in a total of 11 people this year, more than twice as many as last year, but far less than the 68 cases confirmed in 2012, according to the state's website.

Nationwide, West Nile virus has been reported in 830 people this year, according to the CDC, including 317 in California, where they're experiencing record drought.

The virus "tends to cycle like this all over the country and world," said Sorensen. Both she and McNelly said sick birds are the link that is not yet well understood.

To make matters worse for the Love family, someone burglarized their home on Sunday night. "I'm sure somebody caught wind of it, that we're not home and broke out a window, went in and stole everything, ransacked my entire house," Love said.

Friends of the family in Edgewater have started trying to raise money to help and set up a page on Gofundme.com.

When Love does return home with all of her children, she said they will never go outside again unless they're wearing "bug spray with DEET in it."

— Staff Writer Skyler Swisher contributed to this report.

**“Just want to thank everyone for all the prayers, support, and well wishes for Rylee, this is the hardest thing I've ever been through or experienced, knowing we're not alone means so much!” - Shara, 10/27/14**

## One Step Forward, Three Steps Back

### 10/27/14 - 11/2/14

When asked if she'd like to sit up, Rylee's eyebrows stretch high. For the first time since getting intubated, Rylee shifts to a new position in a mobility chair (a bed that reclines). She's alert and responsive, finding her glowing smile despite the exhaustion. And while Shara and the medical team enjoy seeing her in a new position, they can't help but notice her sunken eyes, the 20 pounds she shed or the constant beep alerting her high heart rate.

### 11/3/14 - 11/4/15

Rylee's middle school calls to inform Shara that one of the teachers will be in the area and will drop by cards for well wishes from



everyone at the school. This, along with the doctors' willingness to dress up for Halloween a few days back lifts spirits, a good distraction from reality.

They celebrate the small milestones, such as:

- Increased alertness
- Harder squeezes from her tiny hand
- Ability to lift one thumb almost all the way
- Consistent use of her eyebrows to communicate

**“Missing my daughter....I just want her back, I want her healthy, and laughing, and being her sassy self. I'll never understand why this had to happen to her.**

**Missing my other kids, my pets, my house, and my life.... crazy how everything changes in a split second.”** - Shara, 11/3/14

The physical therapist retests Rylee's diaphragm in hopes of reaching the milestone to breathe on her own. She improves to a 40.3, better than her last score of 36 (100 is normal). Rylee moves her arm a bit during the test, a positive indication of improvement given the diaphragm and arm nerves stem from the same area of the brain. They privately celebrate this small breakthrough. Heart rate and blood pressure improving.

Shara wakes early in the morning to check on Rylee, who has tears pouring down her face. Eyebrows up to the pain question. Shara asks if that's why she's crying. No response, so Shara asks if she's scared and her eyebrows shoot up, breaking Shara's heart. Again, helpless, missing her daughter's laugh, her voice, her crazy "isms."

**11/5/14**

The Daytona Beach News-Journal runs a second article on Rylee:

**As her 12-year-old daughter fights for her life, Shara Love has been amazed by the support her family has received from the community**

**By Skyler Swisher**

EDGEWATER — As her 12-year-old daughter fights for her life, Shara Love has been amazed by the support her family has received from the community.

Countless gift baskets, gift cards and get-well packages have arrived since Rylee Kinnett, a student at New Smyrna Beach Middle School, was sickened with West Nile virus, her mother said, adding: "It's really amazing the support we've gotten in the community from strangers."

The girl remains in the intensive care unit at UF Health Shands Hospital in Gainesville, where she has been for a month, and is unable to speak or walk, Love said. “She is responding,” said Love, a single mother with four children who has been unable to work while caring for her daughter. “She can raise her eyebrows up and lightly nod her head. She can squeeze my hand with her left hand.”

Citing medical privacy laws, neither officials with Shands nor the Florida Department of Health in Volusia County would discuss Rylee’s condition.

A fundraiser is planned for Rylee on Sunday at the No Name Saloon at 2001 S. Ridgewood Avenue in Edgewater. A motorcycle poker run will begin at 9 a.m. at the saloon. Melonnie Kelly, one of the owners of the bar, said she heard of Rylee’s story and wanted to help. “Her story just grabbed my heart as a mom,” Kelly said. “She’s our neighbor, and it could happen to any one of us. It’s heartbreaking.”

Four people in Volusia County have been sickened this year with West Nile virus, a potentially deadly mosquito-borne disease, according to Volusia County’s health department. The last confirmed case of West Nile virus in Volusia County before this year was in 2003, health officials said.

Rylee’s mother doesn’t remember her daughter getting a mosquito bite.

But Rylee, who suffers from an immune deficiency, was admitted to Halifax Health Medical Center in Daytona Beach on Oct. 2, after having a fever for three days, the mother said. She was moved to Shands on Oct. 7, where she is being treated by doctors who specialize in immunology.

Only about 1-in-5 people who are infected with West Nile will develop a fever and other symptoms. Less than 1% of those infected can develop a serious, sometimes fatal, inflammation of the brain called encephalitis, according to the U.S. Centers for Disease Control and Prevention.

About 10% of those who develop the more serious form of the disease die, according to the CDC. For those who survive, the effects of the disease can be long lasting and include memory loss, chronic pain and tremors. A person’s recovery can vary depending on the part of the brain affected, said Wendy Station, founder and president of Encephalitis Global, a nonprofit group that seeks to raise awareness about the condition.

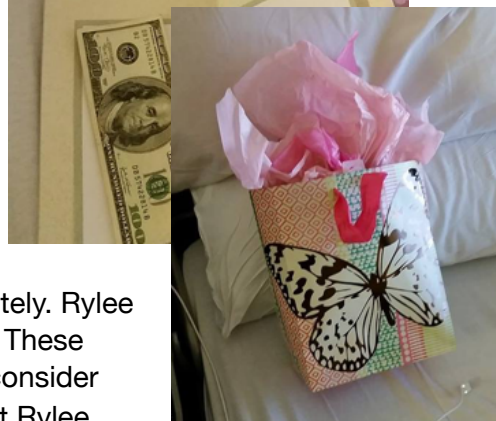
“They have to relearn these skills and abilities,” said Station, an encephalitis survivor. “For some people the impact is dreadful. For some people the impact is almost nonexistent.”

Once Rylee is stabilized, her family hopes to have her transferred to Shepherd Center, a rehabilitation hospital in Atlanta. “It’s terrible,” Love said. “I don’t want her to be trapped in her own body — not able to talk or move. I am trying to be optimistic and stay positive.”

**11/6/14 - 11/12/14**

Some new improvements provide encouragement in Rylee's condition:

- She moves an entire arm and is able to repeat it on demand
- The family receives an anonymous gift basket
- Talk about a new trach tube that allows her to talk
- The generous fund raiser
- Being overwhelmed by people's kindness
- Hitting a new diaphragm high number of 46.6
- Eyes tracking better
- Use of her other hand
- Her body maintaining sodium levels
- Protein added to diet as she's down 27 lbs
- Lifts her left thumb for the first time
- Moves her left arm
- Nodding and shaking head consistently to answer questions
- Smiles that only-Rylee smile that steals hearts



## The Power of Unity

Shara repeatedly asks for prayers in the West Nile FB forum and in her own profile. And people respond immediately. Rylee has captured the attention of people across the entire U.S. These people, bonded mostly through their own fight with WNV, consider her family by now. Everyone tunes in each day for the latest Rylee update. And if there isn't one by noon, concerned followers prompt for the latest.

It's rare illnesses where only those who have lived the crisis truly understand. And as much as our friends and family love us, they can never grasp the uncertainty, the fear, the unknowns and the sheer fatigue of learning the new language of medical jargon. So Shara embraces her new encephalitis "family" gracefully, acquiring knowledge, tips and questions to prepare for doctors based on their first-hand knowledge.

## Another Turn of Events

### 11/13/14 - 11/19/14

Bad news meets bad news. Another insurance denial means Rylee doesn't receive the rehab program hoped for. They must wait until she's off the vent to revisit the rehab topic. Her fever spikes again, resulting in a zillion new tests on blood, urine and sputum (respiratory matter). Responsiveness declines. Unable to take even one breath during her diaphragm strengthening exercises. Even raising eyebrows is too exhausting.

Shara, exhausted and overwhelmed (and with warranted concern), has a meltdown, as any good parent would. The doctor explains that any patient with all the external equipment hooked up (port, trach, IVs, vent, etc.) typically encounters a secondary infection. She feels certain this is a temporary bump in the road. Yet, now there's a UTI.

Despite having the trach in, Rylee vomits violently. Doctors surround her, suctioning to prevent aspirating. Her head bobs, an indication of respiratory distress, as her heart rate and BP escalate. Unresponsive again.

Pancreatitis sets in, doctors uncertain if this or the UTI caused the setback. Diaphragm strength declines.

### Moms Are Superheroes

What's amazing about Shara, beyond her obvious resilience and strength, is her unwavering focus under stress to grasp all the new information coming at her. Many families have a medical lifeline or multiple family members to digest this information to help make decisions. And while Shara isn't completely alone, she's the one absorbing this, studying it, bouncing ideas off her newfound WNV family and ultimately exploring options for her precious daughter.

Charm radiates from Shara, even in trying moments ... one more admirable trait people notice about her (and now we know where Rylee gets it). Despite the immense pressure of maintaining a home, raising kids, making ends meet and tending to an extremely sick child, Shara finds the humor in ridiculous matters. Perfect example: she gets home to discover a notice to appear in court for Rylee missing the last 7 weeks of school. The state evidently does no research (not difficult with 2 publicly available articles in the newspaper) and files charges against her for failure for her daughter to attend school. Luckily she laughs it off. One more reason to respect her.



## Go, Rylee, Go!!

**11/20/14 - 11/25/14**

Rylee the fighter. Her unyielding will to overcome this takes over, despite how much her body has taken. Her bones protrude, revealing the toll. Yet she bounces back, scoring her highest on the diaphragm exercise at a whopping 48.8. Her determination ... is it to prove everyone wrong? Or to prove her strength? Either way, go, Rylee, go!



Another surgery down and the tubes in her nose are out. What a relief! She's defeated the virus, which is now negative. The medical professionals think the worst is behind them, even though progress may be slow.

With Rylee's face being tube-free for the first time in nearly two months, it's a cause for a celebration to see her beautiful face again.

**“If you would have asked me 2 months ago what I was grateful for, I would have said, ‘I'm grateful for my kids, grateful I have a job, grateful we have a roof over our heads and food in our bellies...’**

**Well my views have changed drastically; today I'm grateful Rylee is still with us, I'm grateful for the outpouring of love and support we've received from family, friends, our community, and complete strangers. I'm grateful my kids are being cared for so I can stay by Rylee's side, I'm grateful that I work for such an understanding and compassionate company.**

**I no longer care about my home, or material belongings, I'd give it all up in a second if things were different. I'd leave everything behind without batting an eyelash.**

**Thank you guys for everything, you will never really know how much it means, or how much easier you've made this horrible situation!!**

*- Shara, 11/25/15*

## Brotherly, Motherly and Grandfatherly Love

**12/5/14**

Children surprise us sometimes. When we think we must “protect” because they can’t handle something yet, they tend to rise to the occasion. Until this point, Rylee’s brothers haven’t seen her. And for good reason. Shara battles her decision, and thankfully reasons that this visit serves a healing purpose.

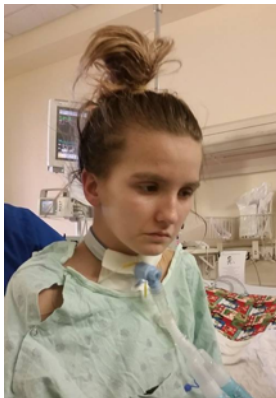
She asks one of the younger boys, Colt, on the way to the hospital if he was scared to see her. In his innocence, he admits, “yes.” Being a brave boy, he didn’t unmask it. Shara explains that Rylee looks different and can’t talk, but will be thrilled to hear his voice. She clarifies that Rylee is still Rylee and she still loves him.



The visit goes smoothly without apprehension. If the family left Rylee’s room, on return both Colt and Caden would announce “Hey, Ry, we’re back!”

**12/17/14**

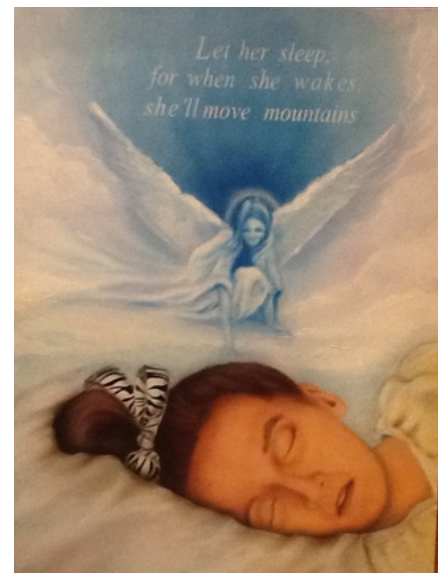
Moms know what girls like ... to always look their best, even on a bad day. So what does Shara do when Rylee hits a new turning point of holding her head up by herself? She worries about doing something about her hair! LOL ... quite a shift from infections, vomiting, high heart rates and searching for rehab homes. A refreshing change in thinking ...



**12/20/14**

Everyone deals with stress differently. Some people take a long drive. Some take it out on others. Some grow silent, distancing themselves from everyone who might offer hope. Some express humor to displace the fear and

uncertainty. We all have our comfort zones. In the case of Shara’s dad, he depicts his concern in an artistic portrayal of Rylee getting the sleep her body desperately needs to thrive, while emphasizing one of her deepest passions ... her faith. This painting he creates provides hope and comfort in ways that words cannot imagine. The image almost opens an entirely new chapter of healing that Rylee, Shara, and the entire family deserves.

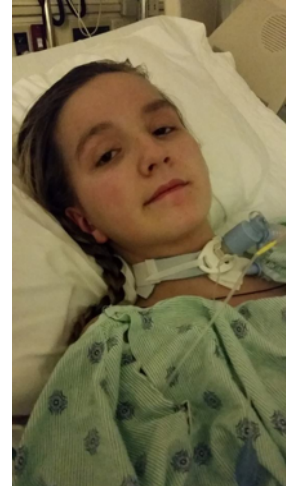


## Herculean Steps Toward Recovery

**12/26/14 - 2/4/15**

Alert. Responsive. Eyes open more than before. Insurance saying that progress indicates skipping over nursing facility straight to rehab. Best news in a long time. Rylee is reaching for objects for the first time vs. simple nodding/shaking or eyebrow raising. We've turned a major corner.

Vent weaning going well. She's even making "mean faces," which makes Shara laugh because it's "soooo Rylee!" And this prompts Rylee to laugh, too. Happy tears we haven't seen in a while, which creates a sense she's on her way back.



**"I just want to thank everyone for all the prayers ..."**

- Rylee herself, 2/9/15



**2/15/15**

Rylee gets to make a road trip to the gift shop with her grandma to spend money on what SHE wants.

**3/4/15**

Realizing Rylee holds her head to the left. When asked to straighten her head up, her neck leans to the left. Interesting new observation.



**4/1/15**

Rylee is driving ... the rehab is no longer safe! ;-)



**4/3/15**

Rylee with assisted standing.

**4/27/15**

A PT has never heard of poliomyelitis, researches it, and decides Rylee needs this treatment.

She reminds that nerves grow 1 cm a day, so it will be a long process. She wants to splint Rylee's legs because they're really getting tight.



## Great Distraction from Reality

4/30/15

Big occasion today: it's Rylee's birthday. She's joined by 2 best friends, brothers, grandparents, cousin and aunts to celebrate with her. Her smile beams, filling the room with abundant happiness. Yet among the festivities, Rylee hyperventilates, which turns the room's laughs into tears. Shara asks why she's upset and she signs back, "I don't want to be sick." She's reminded by video of the dark place where she was only a couple of months ago. And in typical Rylee fashion, she quickly glances around, looks at the video again, and she can't hide that little smirk that transitions to an outright big grin.



5/5/15 - 7/22/15

A whirlwind of new developments inspire Rylee and Shara:

- Getting the trach out
- Ordering a power chair of her own (hot pink at that!)
- In the process of booking a "Dreams Come True" Disney vacation
- A breeder following Rylee's journey will train a dog to assist Rylee
- Custom leg braces being made
- Shara's able to finally return to work
- Going home is now in sight after 7+ long months ... HOME!!!



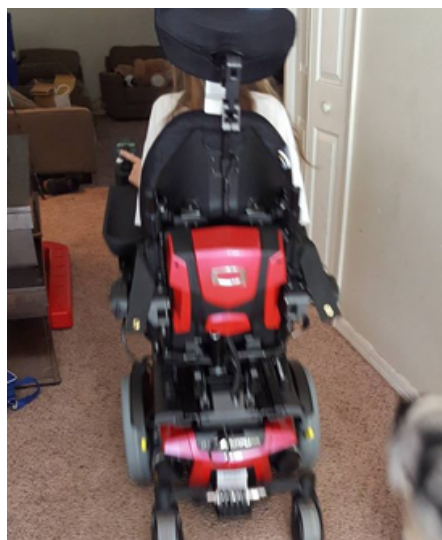
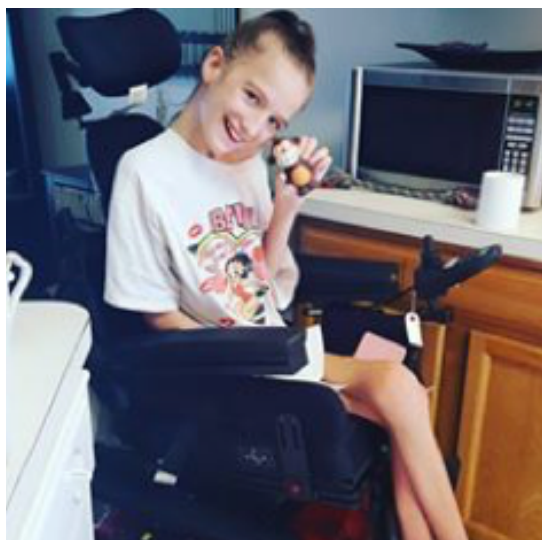
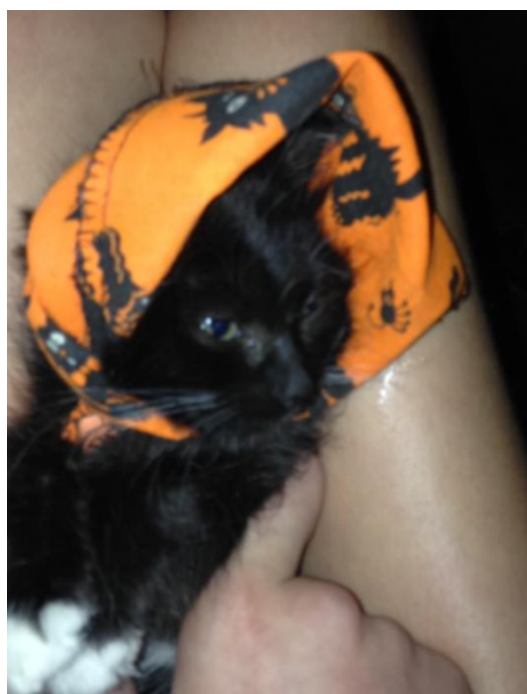
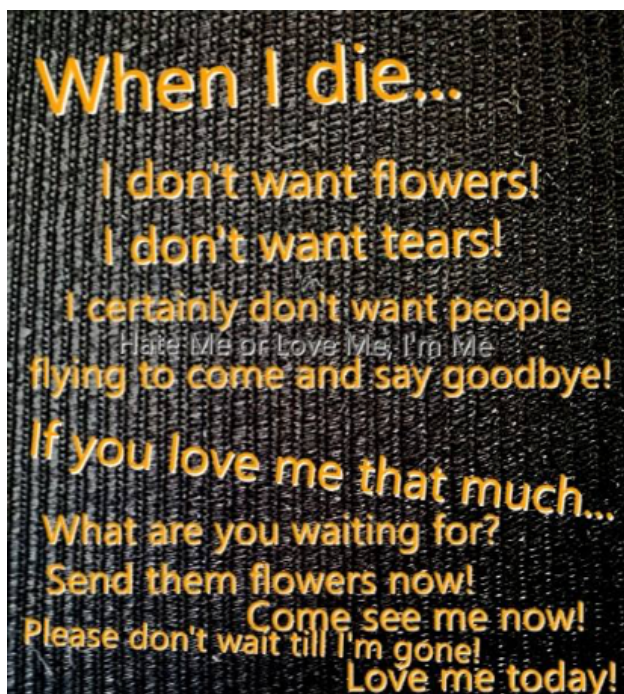
On 6/11/15, Rylee, in her amazing young wisdom, posts this photo to recognize her mom's sacrifices, unconditional love and ability to manage a home while taking care of 4 kiddos. What a selfless teen to take notice to such adult things. Impressive. Astute.



**August - December 2015**

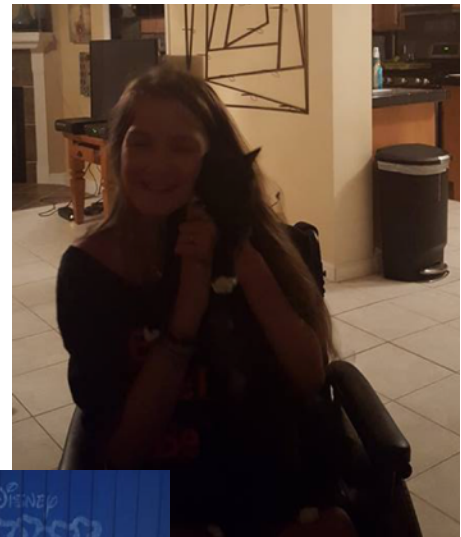
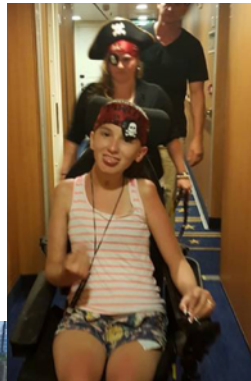
After going home mid-May, Rylee suffers a setback with 11 days in the hospital due to another central line infection, so they remove her port. Therapy has slowed since insurance took 2 months to approve. They await approval for home therapy since the nursing facility won't allow a nurse to ride with her to the therapy center. Rylee's weight increases slightly, from 58 to 63 pounds. Her right hand regains more movement. She returns to school for special needs kids, where nurses can do therapy, but she's one of the few with higher mental functioning, so it's not ideal, but the level of care is beneficial. Talking still a strain, but she smiles despite it all.

As Rylee's strength improves, she becomes active on social media, sharing what's on her heart and mind ... hoping for more visitors, celebrating her new hot pink power chair and doting on her sweet kitty, Oreo. She states that she misses her old life and really looks forward to returning to church again.



**January 2016 - May 2016**

Rylee posts more about her faith, “loving her cat from the moon and back. She expresses her appreciation for a roof over her head, food on the table, and a great family and friends. Her hair grows longer, the color returns to her face. She celebrates her 14th birthday. And coolest of all, she has the wonderful experience of a Disney Bahamas cruise for the whole family. A well-deserved trip!



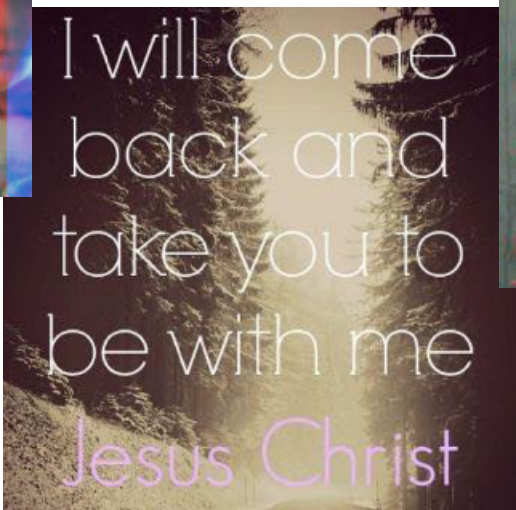
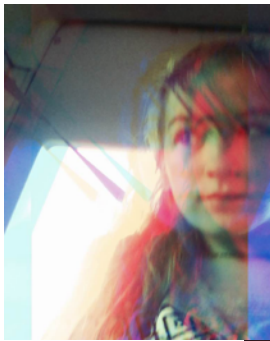
June 2016 - August 2016

Rylee starts to express fear, frustration and anger, but intersperses it with her faith. The reality of how a mosquito changed her life settles in and it's clear that as she improves, this fate disturbs her, and rightly so.

😡😡😡😡😡 So y'all think y'all hard because y'all jumped me!??  
Right on 🙌 ...I pulled up to MY house got out the car and immediately was attacked. Smh....they hit me in my face..my arms..my neck...I fought as hard as I could...but it was too many of them...thinking if I can just get in my house Im going to OFF them all....swinging all the way to my door I was running, hoping I didn't drop my keys...the streets are one thing but attacking me at MY house ..OH HELL NAW ALL Y'ALL gotta die tonight. I get in my house and grab my shit ...I prayed for strength. Braced myself. And went back outside.. they came at me again ...but this time I was ready.... I sprayed them all..... DIE DIE DIE!!!!!!!!!!...I was so mad.....I hate mosquitoes .....bugs are not my friends , copy & post to get your friends hyped for nothin.....goteem again!!!!!!😂😂



- Rylee, 6/30/16



**September - November 2016**

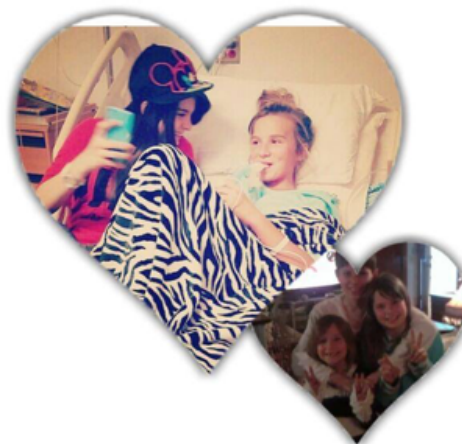
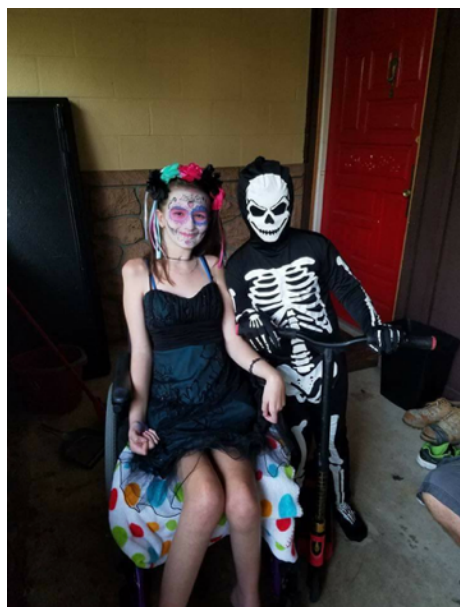
Rylee got casts on as an attempt to straighten her ankles out. Her weakness still comes and goes, but she is making slow progress. She celebrates Halloween, one of her fun times of the year. Her 2-year onset mark greets her with a minor setback. As her mom watches her friends grow up, changing into young ladies, Shara mourns who Rylee would be if this wouldn't have happened to her.



**“I love you mom [Shara Love](#) 💖  
 💖💖💖..... You are the best mom  
 a Daughter could have. I just  
 want to thank you so much for  
 everything you have done for  
 me.” - Rylee 10/21/16**

11/8/16 - 11/10/16

Admitted again on the 8th, but thankfully it's a short 3-day stay, shorter than any other time. Rylee suffers from 3 different bugs causing lung/ear/GI issues. The medical team chooses to treat her at home given her immune deficiency issue to prevent any further complications.



## Living Life

### Mid 2017

Rylee gets a break from hospitals, nurses and healthcare in general for a while to spend time with family and friends. She enjoys going out on the 4wheeler again. Going to the river. Cuddling on her pets. And exercising her faith.

**“Who needs a wheelchair when we have a river, salt water and friends?!”** - Rylee 5/28/17

**“Thank u mom for cleaning out my fish tank.”** - Rylee 7/16/17



## And Then This ...

**8/27/17**

New issues develop ... her urine turns the color of Pepsi for about a month. She has a large stone in each kidney after WNV. After lots of bloodwork, urinalysis, urine cultures, and an ultrasound of her kidneys, liver, and bladder, the doctors don't find anything wrong. Except the stones are gone, possibly breaking up on their own, causing bloody urine and evidently passing them without pain.

She suddenly loses 10 pounds, menstruation stops, and now she has edema in her ankles, feet, and face. More bloodwork ordered. The doctor thinks it could be kidneys or heart.

Rylee's kidneys are barely working. They are placing a dialysis Cath in her neck and she'll be started on dialysis ASAP. Next step is a kidney biopsy. Unknown if this is reversible. Need to find the cause.

**8/28/17**

The nephrologist says they're doing a bilateral kidney biopsy tomorrow with 3 different tests. Results will be available in 24 hours, another 48-72 hours, and the 3rd will take a week. Depending on the results we will know if this is treatable or not. If it's not she will go on the kidney transplant list.

He asked me to keep all the pictures of her urine when it was bloody and of the stages of swelling because he's writing a case study on her and putting it in the books because it's so unusual. They still aren't listening to the possibility of West Nile Virus causing this and believe it was from her having strep A when she had the bloody urine, but we will never know because her test was negative. It only stays positive for a couple of weeks.

Rylee got very upset when she heard "kidney transplant."

**8/29/17**

Doctor just came in to say Rylee's kidney function is worse. He said that's to be expected because they don't know what's causing this, therefore they don't know what to treat. He said they don't want her to get dialysis every day because that will create more issues. Yet she keeps a positive attitude.



**8/30/17**

Now Rylee is twitching really bad. Her kidney values are worse again. She'll be getting dialysis today. The swelling is bad also. Her hemoglobin was at 10 after the blood transfusion, but it's back down to 8.2, so if it continues to trend down she will get another transfusion today. No results from biopsy yet.

**8/31/17**

Nephrologist says half of the filtration cells they extracted are permanently damaged from scar tissue. The other cells show acute damage. They discussed starting her on a chemo drug that's very toxic, but decided to go with an antibody drug (if her immunologist says it's okay to use with her immune deficiency).

They will start it today with the okay and she will get it once a week for 4 weeks. The urine output and how she responds will determine if this is acute or end stage renal failure.

If it's end stage, she will go home needing dialysis 3 times a week while we start jumping through all the hoops to get on the transplant list. He said she will have to meet all kinds of criteria, then they will determine if she needs a live donor or cadaver.

If they determine a live donor is best, they also have all kinds of criteria to meet before they will even test to see if they're a match. They still don't know the cause. They tested for lupus and a bunch of other things that all came back negative. They sent out another test looking for other causes. He wants to exhaust every option to try and repair her kidneys before going the transplant route. He did say her kidneys are enlarged, not small like with normal kidney failure, and it doesn't match the biopsy, which is a good thing.

**9/1/17**

Ry needed an xray during the night because her O2 stats were dropping. She has pulmonary edema



**9/2/17**

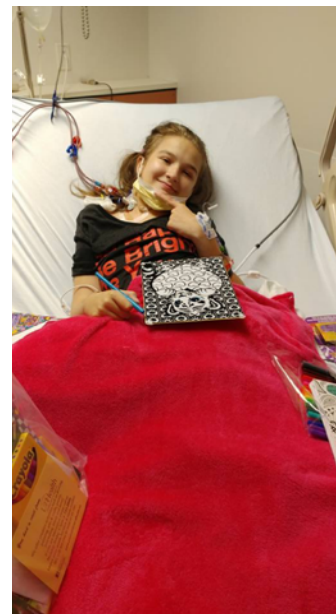
Rylee's doctor ordered dialysis again today, and tomorrow (she had it yesterday) to get the chemo out (Cytoxan). Her phosphorus is low, which is very unusual. It's usually high with kidney failure, and dialysis will bring it down even lower so they're going to start giving her phosphorus. She also needs another blood transfusion.

Her kidney values were lower last night (most likely from dialysis), but have gone up a little during the night. She's on oxycodone, which seems to be helping her pain.

**9/3/17**

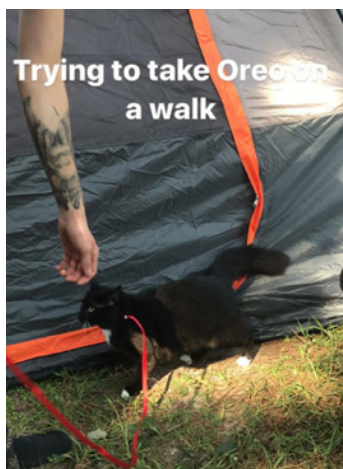
The doctor says we won't know how Rylee is responding to chemo for 2 weeks. In the meantime she will be getting high doses of steroids (M/W/F), which will make her BP even higher (it's been really high all week). And 3 hours of dialysis again today.

Rylee getting her dialysis yesterday. After everything she's been through she "just keeps swimming"! She took her face mask off to give her mom a smile. She loved it! ♥

**9/6/17**

Doctors suspect Rylee is producing an antibody that is depositing in her kidneys, causing the damage. They're worried it's doing the same to her lungs. So now she's going to have a chest CT scan, among other tests. They treat this antibody with plasmapheresis.

Diagnosis in ... Ry has Goodpastures syndrome, which is an autoimmune disorder caused by a virus. It usually attacks the kidneys and lungs. They will start plasmapheresis tomorrow and do 6 treatments to remove the antibodies. She will probably have to get a tunneled dialysis Cath and go home needing dialysis 3 times a week and hope we start seeing improvement in kidney function. They said to plan to be at the hospital another 3 weeks.

**9/8/17**

**“My cat is safe in Alabama”** - Rylee 9/8/17

(during Hurricane Irma)

**9/11/17**

Rylee before dialysis. Doctors don't know where all the fluid is coming from with her getting dialysis daily and being on Lasix twice a day. She's on a kidney diet and a fluid restriction. After 4 hours of dialysis she looks a little more like herself, but still puffy.



**9/13/17**

No improvement in her kidneys, so they're getting super aggressive with treatment. At least 50% of her kidneys are permanently damaged and 25-30% are in the process of becoming permanently damaged, which is what they're trying to stop. They're adding 2 more immuno-suppressive drugs. One is experimental but they've used it in patients with Lupus and had good outcomes, although these drugs come with big risks. If these don't work, she will end up losing both kidneys and needing a transplant.

They said this is such a rapidly progressing disease, they said there's no time to sit and wait for something to work. They said plan to be here at least 5-6 more weeks.

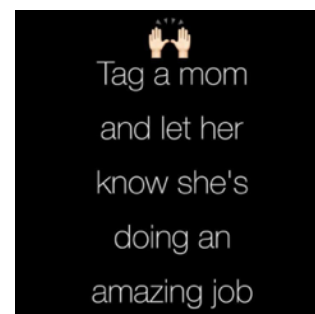


**9/18/17**

Rylee is getting another dose of chemo tonight, and the doctor informs it will be 2-3 more weeks to see if there is any return in kidney function. If not, then a transplant is the next step.

**9/18/17** post by Rylee:

Despite her pain, fatigue and everything else, Rylee always finds a moment to thank her sweet mom.



**9/19/17**

Nephrologist says he's 95% sure Rylee will need a kidney transplant. He's already connected with transplant contacts to get her on the list. He's also waiting to talk to Immunology to see how far they want to go with treatment before deeming it unsuccessful. He doesn't want to cause more damage to her body with toxic drugs. Immunology must agree or they won't put her on the transplant list.

**9/27/17**

Rylee's lymphocytes are low, and since they're doing surgery to place a different dialysis Cath again, they're going to get a bone marrow sample to check for cancer/leukemia. She's coughing and they can hear crackles in her lungs, so another MRI is scheduled to make sure Goodpastures isn't affecting her lungs. The bad antibodies are back so Rylee will have 6 more rounds of plasmapheresis and another immune suppressive treatment.

**10/7/17**

Nearly 6 weeks since returning to the hospital. Rylee is having surgery today to have another dialysis Cath placed, a port placed, and a bone marrow biopsy to rule out leukemia/cancer. Treatment requires a 3-hour drive 3 times a week until the end of the month. This prevents Shara from returning to work as quickly as expected.

She is on morphine IV and Tylenol. The medical team had to remove the membrane and fat that separates the intestines from the abdominal wall, so she's "pretty beat up" internally.

**10/10/17 - 10/11/17**

Doctors discharge Rylee on the 10th. She gets dialysis at home for the second time. When Shara puts her to bed, she's moaning, in a full-blown seizure. Shara calls 911. They airlift her to the hospital. Her brother Collin plans to donate his kidney, but must be 18 years old, which isn't until May 30th. As he anticipates that date, Collin plans to tattoo "my sister's keeper" just above his scar from the kidney donation.

**10/13/17**

Rylee is much more alert. She's able to sign and her eyes are open but she's still confused and her memory is off. She doesn't recall her seizures and 5 minutes later, asks why she's in hospital. She's very agitated and crying constantly.

**10/14/17**

Today's a bad day. Rylee thrashes around, screams, cries, pulls her hair, and rips at her clothes and her lines. She pulls her gtube line off and throws it on the ground. The doctors think she's delirious and administers meds for that. She's finally sleeping. She also coughs up bloody mucous. She has officially been diagnosed with PRES syndrome and this behavior is likely due to the brain injury.

**10/23/17**

Was just told Rylee has to take meds for this CMV virus for the rest of her life, and they're bone marrow suppressive, so she also has to take another medication IV for the rest of her life. Her West Nile IGM levels are positive, but they aren't sure if that's from previous infection, if it's a flare up, or if she was reinfected again, or if it's from the IVIG she's been getting since she was 2, as it contains WNV antibodies.

Her immune system is so poor the only antibodies she's producing are the AGBM antibodies that are attacking her kidneys.

**10/24/17**

One IV dose of Gamcylovir dropped Rylee's CMV numbers from almost 10,000 to 2,900 (under 200 is the goal), which means she may not need as much IV treatment as anticipated.

The medical team also decides it's better for Rylee's mental status to be able to get out of bed and go outside. The weather is beautiful. Fall has arrived.

**11/2/17**

Lack of updates due to a lost phone from Shara. She can't seem to pry Rylee's phone out of her hands. 😊

**11/4/17**

Friends, colleagues and the community organize another fundraiser to help with the continued stack of medical bills.

Shara's touched by the support, even beyond the initial stages of the onset of the illness. The community loves Rylee and her family.

During these events, supporters learn about the devastating impact of West Nile virus, especially of the neuro-invasive type. No mom, daughter or anyone else should have to suffer from this horrible illness that leaves so many residuals.

And while Rylee's case is extreme, the ongoing impairments that patients suffer isn't unusual.

**BEACHSIDE TAVERN**  
**FOR RYLEE KINNETT**  
 West Nile Virus Awareness  
**SATURDAY 11-4-2017**  
**\$15k GOAL 12PM - 4PM \$15k GOAL**  
 TO HELP CALL: Brittany 386-314-9620

Meet Rylee Kinnett, she is a 15 year old girl from Edgewater, who in 2014, was infected by The West Nile Virus with encephalitis and later developed meningitis. She initially spent 10 months in the hospital, 7 months in the ICU, and 6 months on a vent. This left her wheelchair bound with flacid paralysis(severe muscle weakness). She has been fighting hard. Eight weeks ago Rylee was diagnosed with end stage renal failure, due to the later effects of WNV, and is currently awaiting placement on the transplant list to recieve a new Kidney. She was diagnosed yesterday with a new virus called CMV with encephalitis and encephalopathy.

Please come join our cause and help raise money for Rylee's Mother to continue to concentrate on her daughter's health. Our goal is \$15,000, what has been estimated to be 6 months of all household bills. All monies donated will go directly toward the payment of household bills. (Rent, Electric, Water, Cable, Insurance, Phones, and car)

**BRING YOUR OLD GIFT CARDS OR GAS CARDS**  
**LIVE PERFORMANCES**  
**Silent Auction**  
**RAFFLES**  
**KID ZONE FOOD**

**12/15/17**

Rylee seems to finally be getting over a cold, although her cough remains taxing. Her immune system is improving incrementally. She's on a Z pack, and an antibiotic because she has purulent discharge from her ears. Next step is another infusion to help prevent pneumonia, then her monthly dialysis lab

Shara returns to work full time, trying to get ready for the overwhelming holidays. They no longer qualify for home nursing, even though she has more needs. Such a frustrating ordeal for a mom who is doing everything she can to improve her daughter's quality of life while being able to pay the bills.

**1/17/18**

Rylee gets admitted for a fever and possible UTI. She sleeps all day and then becomes unresponsive. Severe tremors rattle her entire body, creating agitation. She's airlifted to ICU where she has continuous seizures. She's sedated with a Versed drip.

She occasionally wakes to attempt communication, but is so weak she can't talk or sign. Their plan is to switch to Kepra long term. She now has a new diagnosis of epilepsy.

The urine sample has so much sediment it clogged the Cath. It's dark and cloudy, so may be attributed to a UTI.

They refer the family to palliative care, causing extreme stress. However, they assure it's not for end of life, but precautionary to help manage any extra needs she may have.

**1/21/18**

The immunologist reports that Rylee's IGM and IGG are both positive for West Nile, same as back in October. He says there's no way to know if this is a new infection or from her original WNV infection. He even looks to find case studies to explain this and couldn't. She is immune deficient so that plays into this also. He said she is getting better, and there is no treatment for WNV anyway. They haven't been able to prove if someone can actually become reinfected, so he said he's not going to stress it, but thought it was interesting.

**2/4/18**

It's Super Bowl Sunday and the family gathers to enjoy the game. Rylee proudly holds the son of a family friend, one more of her loves ... animals and babies.



**2/5/18**

Shara reports: "We lost Rylee this morning. She fought so hard and was so tired. Our hearts are broken. Please pray for us."

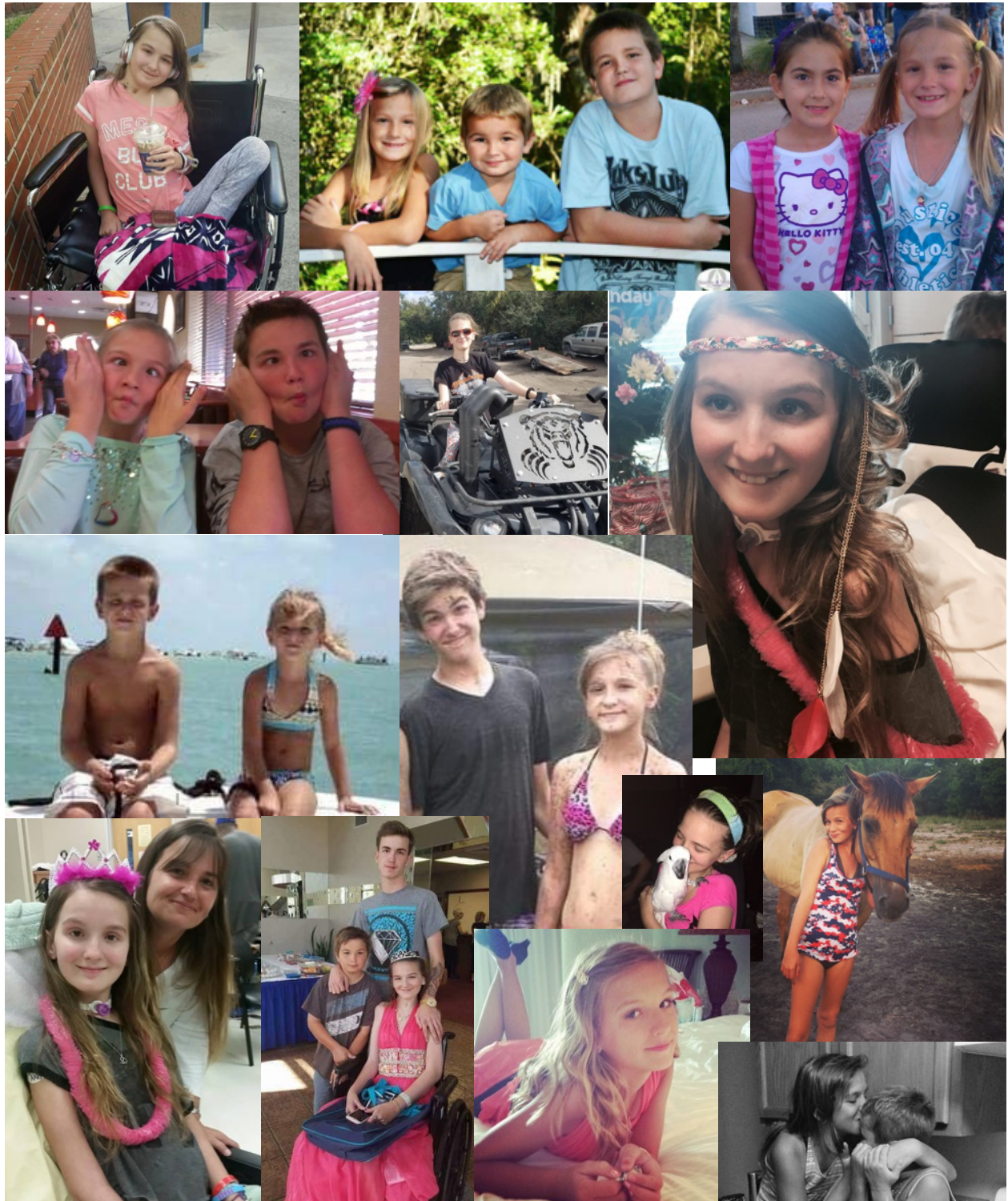
The shock catches everyone by surprise. What a battle. While she no longer suffers, her strong following grieves, paralyzed in disbelief. Her life will be celebrated and her story will help others. We know it will.

## The Rylee We Choose to Remember

For many people who followed Rylee's story so closely, Rylee will be a lifelong friend, comrade and heavenly spirit watching over those whose lives were impacted by her. Her fight will not be in vain. Please keep her family in your prayers as they find their way without her physically there to laugh, tease, sass and charm with that amazing, heart-warming smile.

Please take advantage of the opportunity to use this story as a means of educating those who aren't familiar with West Nile. Help people understand the importance of protecting against mosquitoes. They are, in fact, the most deadly creature among all living today.





**In Loving Memory of  
Rylee Madison Kinnett  
April 29, 2002 ~ February 5, 2018**



**A Letter From Heaven**

*When tomorrow starts without me  
And I'm not there to see;  
If the sun should rise and find your eyes  
All filled with tears for me.  
I wish so much you wouldn't cry  
the way you did today;  
While thinking of the many things  
We didn't get to say.  
I know how much you love me  
As much as I love you;  
And each time that you think of me,  
I know you'll miss me too.  
When tomorrow starts without me,  
don't think we're far apart  
For every time you think of me,  
I'm right here in your heart.*