

# NEWS in a NUTSHELL

THE NEWSLETTER FOR THE EMPLOYEES OF MARYVILLE



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## Helping Kiernan KO Sanfilippo

Sergeant Shaun O'Neal, (MPD) met his wife, Amanda, at William Blount High School when they were juniors. They have been married for 23 years. They have four children, one girl, Lierin, and three boys, Kellen, Rory, and Kiernan.



Kiernan, their youngest, was born on October 6, 2014. He was a beautiful, healthy, and happy baby. However, Amanda and Shaun noticed that his progression had slowed by the time he was three. It seemed to the O'Neals that Kiernan was often chewing on something. He wasn't particular about what it was either, just whatever was handy, he would pop

it in his mouth and chew on it. One day while riding in the back of the car, he picked up a bungee cord and started gnawing on it. Soon, the hook on the end of the bungee had become lodged in the soft part of his mouth under his tongue. Amanda pulled it out, but a few days later, the wound became infected, so she took him to the pediatrician. Their regular doctor wasn't available, so they saw a Nurse Practitioner they had never met before. He noticed Kiernan's thick eyebrows and extra-long eyelashes. His constant desire to chew on objects came up as well. Thinking that all these things were related, the Nurse Practitioner encouraged Shaun and Amanda to have genetic testing run.

On June 8, 2020, they received the test results. Kiernan was diagnosed with Sanfilippo Syndrome, a neurodegenerative disease that is best described as Alzheimer's for children. Just 41 days before they received the diagnosis, a friend from high school lost his young son to the same disease. Shaun and Amanda immediately knew what the future held for their precious boy, and they found themselves in the throes of anticipatory grief. It has been three years now. Shaun and his little family are starting to accept that they will eventually lose Kiernan. They have since adopted two core policies that help them to cope with the crushing pain. 1). We will not say "no" if we can say "yes" instead. The O'Neals are determined to pack a lifetime of happiness with Kiernan into the next five to ten years. Being a tired or worn-out parent is no excuse to pass on fishing if that is what Kiernan wants to do, even though being tired and worn out is an issue 24/7 for Shaun and Amanda. 2). We will enjoy the little things in life because one day we'll look back and realize they were the big things.

At this point in Kiernan's life, three things bring him the most joy. Horse Assisted Therapy at STAR (Shangri-La Therapeutic Academy of Riding) in Lenoir City, Aquatic Therapy (an exercise program

with a physical therapist, performed in a pool to decrease pain and stress on weight-bearing joints), and camping. Several times a year, Shaun and Amanda pack up the family in a pop-up camper and head to a campground close to home. It's a lot of extra work to pull it off, but Kiernan is happy there, and his infectious laughter is a precious payout for their efforts. At the age of nine, Kiernan can still speak, feed himself, and walk with the help of leg braces, all of which is unusual for a child with Sanfilippo Syndrome. He does have a wheelchair because walking a long distance is difficult for him.



This is an update Amanda posted on Kiernan's Facebook page, **Kiernan KO's Sanfilippo**: "We've recently started Kiernan on a trial of fluoxetine (yes, Prozac). It is, of course, normally used as an antidepressant. However, it has shown in studies to reduce inflammation and slow cognitive decline. When you have a child with a terminal illness which has no cure and no approved treatments, you'll try anything to, at the very least, improve their quality of life. As always, prayers are appreciated!"

On July 14, 2022, Amanda added this post: *Kiernan's seizures, so far, are not the tonic-clonic seizures everyone thinks of when they hear the word epilepsy. His are more a state of confusion, during which he doesn't recognize us or his surroundings. For example, after his tonsils and adenoids were removed, his pain killer interfered with his seizure meds. One day I was holding him, and he was crying and asking if his mommy was going to come get him and take him home. His meds are currently controlling the seizures very well however, we fully anticipate that he will one day begin having tonic-clonic seizures, as most of his brain is affected by epileptiform activity.*

Shaun and Amanda's older children regularly make their parents proud with their decisions and the why behind their choices. Lierin is a talented singer who was accepted into the School of Music at Brown University in New York City. She was also accepted at Maryville College. She



Kiernan and his dad, MPD Sgt. Shaun O'Neal

**Continued:** See Kiernan on page 2

# People are the Key

## Requirements of Title VI

It's the policy of the City of Maryville that all its services and activities be administered in conformance with the requirements of Title VI.

### What is Title VI?

"No person in the United States shall, on the grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

### What is the purpose of Title VI?

The purpose of Title VI of the Civil Rights Act of 1964 is to prohibit programs and activities which receive federal funds from discriminating against participants or clients on the basis of race, color, or national origin. The intent of the law is to insure that all persons, regardless of their race, color, or national origin are allowed to participate in federally funded programs. To insure that the City of Maryville meets its compliance responsibility, comprehensive monitoring procedures have been established to provide for continual compliance with Title VI.

### The Areas Covered by Title VI

Construction, transportation, parks and recreation, community block grants, location of facilities, law enforcement, environmental issues, contracting, distribution of benefits and services, hiring, equipment and building loans, and tax benefits enjoyed by private, fraternal and nonprofit organizations.

### Title VI Actions

- Prohibits entities from denying an individual any service, financial aid, or other benefit.
- Prohibits entities from providing services or benefits to some individuals that are different or inferior to those provided to others.
- Prohibits segregation or separate treatment in any manner related to receiving program services or benefits.
- Prohibits entities from requiring different standards or conditions as prerequisites for serving individuals.
- Encourages the participation of minorities as members of planning or advisory bodies for programs and activities receiving federal funds.
- Prohibits discriminatory activity in a facility built in whole or part with Federal funds.
- Requires entities to notify the eligible population about applicable programs.
- Prohibits locating facilities in any way that would limit or impede access to a federally funded service or benefit.
- Requires assurance of nondiscrimination in purchasing of services.

*Title VI complaints involving recipients and beneficiaries may be filed with the City of Maryville Title VI Coordinator: Manager of Human Resources Leslie Crawford, Maryville Municipal Center.*

## In Memory of Joe Tipton

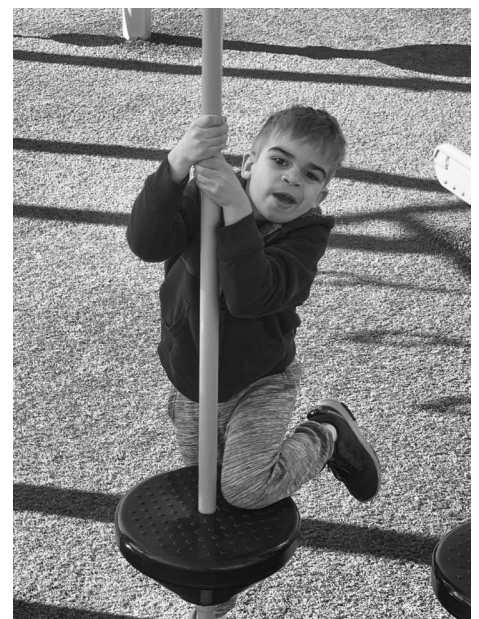


Joe Tipton passed away Sunday, July 2, 2023 at the age of 62. Joe worked for the City of Maryville at the Wastewater Treatment Plant as a Utility Plant Mechanic. Joe had completed 35 years of service to the City. Rest in peace, dear friend!

**Kiernan:** Continued from page 1

chose Maryville College because she wants to be close to home and because she doesn't want her little brother to forget who she is. Kellen is 16. When picturing his dream car, as most 16-year-olds do, he dreams of a Jeep, not because he loves a Jeep, but because Kiernan loves riding in a Jeep with the doors and top taken off.

The O'Neals life was changed forever when Kiernan was six years old. They have since come together as a family to love and support their precious son and brother for as many years as they are given. Amanda has become a medical parent. She has educated herself to the point that she understands and can participate fully in conversations with doctors. She is Kiernan's advocate as are all the O'Neals. They are determined to make Kiernan's life as sweet as possible, and they are soaking up the memories they will no doubt carry with them forever.



## Forklift Training

On Monday, July 17th Shawn Garnett (Warehouse Inventory Coordinator - Finance), taught a Forklift Operator Training Class required by OSHA, at the Op. Center. 12 employees from Public Utilities, Public Services, Finance, and Safety completed the course. Shown at right, Katie Kerr, (Finance) completes the practical driving section of the class.



# Congrats to These Folks

**Meet Sanfillippo Syndrome** (a Facebook post frequently shared by parents of children with Sanfillippo to increase awareness)

Hello, my name is Sanfillippo Syndrome. I am an awful childhood genetic disease. I affect about 1 in 70,000 children. I cause their bodies to be unable to produce an enzyme that is needed to break down dead tissue inside of their bodies. Since the waste cannot be broken down, I store it in the brain, central nervous system, bones, joints, and in vital organs. 10-15 years is the life expectancy for Sanfillippo children. There is no treatment or cure to get rid of me.

Within in the first two or three years the child will have several developmental delays. This includes their ability to walk, talk, and feed themselves. They will remain unsteady on their feet after learning to walk. This is because I have already began affecting their joints. He/she will have several ear infections resulting in ear tubes, then will lose some or all hearing. I will sit back and laugh while the parents scurry around to all the different specialists trying to find out what's wrong. The parents' schedule will soon fill up with appointments from specialists to therapy visits. I will let them enjoy their time of semi-normalcy for another two or three years before I really start getting nasty.

By this time the parents usually know what is going on. They see their child constantly chewing on things and starting to have behavior problems. This is because I'm storing the waste in his/her brain and slowly deteriorating it. He/she will start to become more aggressive, hyper, and harder to control. He/she will have many sleepless nights, their behavior will be much like that of an Autistic child. It will become harder to walk without constantly falling. He/she will become more resilient to pain and have thicker skin. Parents will have no idea how bad their child hurts because they won't cry like a normal child. I will start to change the child's outward appearance. Their hair will become coarse and eyebrows thicker. Their jaw will widen, and teeth will begin to gap. All the complements of how cute and handsome they are will soon change to stares, gawks, or people simply looking away.

Soon I will take away the ability to walk because of all the waste I've stored in the joints. I will see that this child stays confined to a wheelchair. At this point he/she will no longer be able to use the toilet or feed themselves. Most of the children that I affect must get a feeding tube put in. I will no longer let him/her communicate with anyone. You will look into his once beautiful eyes only to see a loving child trapped inside of his/her very own body. To make things really hard, I am also going to cause this child to have frequent and violent seizures. This will come along with the complications that I have stored up in his/her heart and immune system.

The insurance companies will be reluctant to cover some medical needs and equipment because I am such a rare disease. The parents will need to care for this child full time. I will mentally, physically, and financially drain the family. Then finally, after all the torment and anguish that I have caused, I will take the life of this child in his/her teen years.



Promotion  
**Russel Burns**  
EPW  
Street Construction  
Worker



Promotion  
**Matt Stewart**  
EPW  
Grounds Maintenance  
Crew Leader



Promotion  
**Kevin Stoltenberg**  
EPW  
Assistant Public  
Services Director



Promotion  
**Logan Turbyfill**  
Electric  
Apprentice Electric  
Line Technician



New Employee  
**Tyran Harrison**  
MPD  
Police Officer



New Employee  
**Brent Loveday**  
MPD  
Police Officer



Retiring 8/24  
**Danny Frye**  
Electric  
31 Years of Service

## Sink Hole Opens in Employee Parking Lot

On Monday, July 24 employees found a water main break over the weekend had caused a large hole to open up in the parking lot. The Water and Sewer Department spent most of the morning repairing the damage.



Above: Cody Whitehead, Jason Cable, and Jerry Hall wait for Jason Potter (pictured at left) to break open the sink hole so they can get started with the repair. Not pictured: Tyler Kirkland and W&S Construction Supervisor, Scotty Martin.

# But Wait, There's More

## August Birthdays

- 1 Ben Keck, W&S
- 2 Bryson Dykes, MFD
- 4 John Cogburn, MFD
- 6 Michael Doherty, MFD
- 7 Brian Boone, EPW  
Tony Hatcher, W&S  
Mariah Lopez-Allard, MPD
- 8 Josh Lawson, EPW  
Chet Hanns, Finance
- 11 Brentley Riddle, Electric  
Ronnie Pryor, MPD  
Niki Freshour, Finance
- 15 Golman Myers, Electric
- 16 Sandy Rinicker, MFD
- 17 James Bond, Electric  
Shawn Ridings, EPW
- 18 Jeff Bitner, EPW
- 21 Ben Belitz, MPD
- 24 Danny Frye, Electric
- 25 Jesse Stott, W&S
- 26 Jim Hurst, Electric
- 28 Darrel Pharris, EPW
- 29 Heather Giger, EPW
- 30 Russel Burns, EPW
- 31 Laura Seery, Finance  
Tyler Norton, EPW



## August Anniversaries

- Paul Gilley, W&S 43 years
- Kent Roberts, Electric 43 years
- Tom Bible, W&S 40 years
- Mark Taylor, MPD 37 years
- William Murphy, Electric 31 years
- Rom Everett, MFD 31 years
- Terry McCoy, IT 29 years
- Keith Church, IT 26 years
- Michael Doherty, MFD 25 years
- Chad Wilson, EPW 25 years
- Thomas Vananda, EPW 25 years
- Edmond Greene, EPW 24 years
- Jason Cable, W&S 24 years
- Mickey Gorman, W&S 24 years
- Glenda Brinley, Finance 22 years
- Doug Chapman, EPW 20 years
- Sandy Rinicker, MFD 18 years
- Eric Middleton, EPW 17 years
- Cindy Karnoupakis, Finance 16 years
- Travis Brown, MPD 15 years
- James Long, MPD 15 years
- Casey Ryding, Electric 11 years
- Golman Myers, Electric 11 years
- Steven Talbott, MFD 10 years
- Mike Bell, W&S 9 years
- Jacob Kagley, EPW 9 years
- Brian Smith, W&S 8 years
- Justin Brown, MPD 8 years
- Dwayne Shoffner, Electric 7 years
- Matthew McKeel, MPD 7 years
- Don Kitts, W&S 6 years
- Tyler Breazeale, EPW 4 years
- Brentley Riddle, Electric 4 years
- Patty Cox, Admin 4 years
- Ernie Herin, EPW 4 years
- Cody Whitehead, W&S 4 years
- Brandon Nichols, EPW 3 years
- Austin Headrick, MFD 3 years
- Cory Tipton, W&S 3 years
- Chase Tilley, MFD 2 years
- Austin Ray, EPW 2 years
- Seth Murphy, EPW 2 years
- Brandon Carter, MPD 1 year
- Kaleb Pharris, MPD 1 year
- Sarah Freels, MPD 1 year
- Matt Hulihan, MPD 1 year
- Tate Murphy, EPW 1 year
- Jarod Walker, W&S 1 year

## We Love Jane Too!

Ralph Goodson, (Finance), received this email from a soon to be customer on Friday, July 21, 2023.

Good Morning,

We are so often quick to criticize or complain yet rarely take the time to compliment or praise great work. I would like to express my sincere appreciation to Jane Ellis for her guidance, assistance and overall helpfulness as we get ready to relocate to Maryville. I called with questions needing help and of course, everything is happening quickly. Jane listened, guided me, and assured me that we would be able to accomplish our mission and get our services scheduled to be turned on 7/31. I received confirmation yesterday and it's a great feeling to check another box on my 'to do' list!



I can only hope that half of my other tasks are handled so well! Please pass along my gratitude and congratulations on having such a dedicated and professional person on your team!

Best regards,

Ann McGovern

(Future) Doral Drive