

Community rallies together to keep 'Faith for Fallon'

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Details

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Family and friends are organizing a benefit for Fallon Schlautman on May 16 in Bartelso. Event will include a "Be the Match" bone marrow donor drive.

Friends and relatives of a Beckemeyer family are rallying together and keeping faith for Fallon.

Ten-month-old Fallon Schlautman has been diagnosed with a rare genetic disorder. In fact, she is one of only seven others in the world who is diagnosed with SIFD syndrome.

Fallon's parents, Kevin and Katie Schlautman of Beckemeyer, are keeping faith for their infant daughter.

Their story begins on Christmas 2013, when the Schlautmans held a "gender reveal" for the new addition to their family.

They opened the box and friends and family were happily surprised as pink balloons floated out of the box.

A baby girl was on her way. In January 2014, Katie went to the doctor for a routine ultrasound.

At that point, she had no complications with her pregnancy, however, at that doctor's appointment, it was learned that the baby had hydrops fetalis (fluid on the abdomen).

A more extensive ultrasound was scheduled for later that week to determine the cause and path forward.

At the follow-up ultrasound, it was determined the baby had severe anemia. Initially, doctors thought a virus was to blame, and a single blood transfusion would fix the issue. Katie went to St. Mary's Hospital in St. Louis for the transfusion and was sent home to rest.

During a follow-up visit, the doctor found that the baby's condition did not improve — the baby was again severely anemic.

Kevin and Katie were devastated and left without answers. During the remainder of Katie's pregnancy, the baby was monitored every few days and would go on to receive four in utero transfusions.

All the while, the Schlautmans were still left without answers as to what was going on with their baby girl.

Katie was induced four weeks early in hopes that doctors could find the root of the problem that was causing the chronic anemia.

On May 21, 2014, Fallon Grace Schlautman made her grand entrance into the world. She spent 11 days in the Neonatal Intensive Care Unit (NICU) at St. Mary's Hospital in St. Louis due to a collapsed lung from early induction (which was unrelated to the anemia) and feeding issues.

The lung healed and Fallon started eating, so the family went home with hopes of putting the anemia behind them.

Fallon was monitored closely through weekly blood tests, and unfortunately, her anemia returned. In addition to the anemia, Fallon began to have GI (gastro-intestinal) problems. She refused bottles and had to undergo surgery for a Gastrostomy Button, or G-Button, because she was not gaining weight.

A G-Button is a button on her belly that she is fed through. However, up until recently, Fallon hasn't been able to tolerate any feeds in her stomach, due to digestion problem from the disease, so she is fed by IV nutrition through a Picc line (which is a central IV line in her left arm).

Over the course of the last nine months, Fallon has received 18 blood transfusions and has spent more than four months in Cardinal Glennon Children's Hospital in St. Louis. She continued to have the anemia, poor feeding, GI issues, and high



Family and friends are organizing a benefit for Fallon Schlautman on Saturday, May 16, beginning at 2 p.m. at Bartelso Park, just days prior to Fallon's first birthday. She is pictured with her parents, Katie and Kevin Schlautman.

fevers without explanation.

Two months ago, on Jan. 30, Kevin and Katie received the official diagnosis — SIFD syndrome. SIFD syndrome is a genetic disorder that has been diagnosed less than 15 times worldwide. It is characterized by sideroblastic anemia, immunodeficiency, febrile episodes, and development delay, hence SIFD.

"The diagnosis for SIFD was made from a bone marrow sampling on Fallon which she underwent in January 2015," said Katie. "That's when they saw the sideroblastic anemia, which is very rare, so they sent the blood from the marrow off for more testing, which came back within three weeks for a confirmed diagnosis in SIFD."

So, what does this mean?

It means that Fallon has a weak immune system and has spontaneous fevers, vomiting and seizures. Once that happens, they immediately have to go to the hospital in St. Louis to be treated.

Since Fallon has a weak immune system, the family is at the hospital anywhere from one to 13 days.

There are only seven living children (including Fallon) with SIFD disease and Fallon is the only one in the United States.

While the statistics are indeed grim — the median survival rate is 48 months, or 4 years old — the family is holding out hope for their little Fal-Fal.

In late May, Fallon is expected to undergo a bone marrow transplant in hopes of curing the anemia and immunodeficiency.

However, prior to the transplant, Fallon will undergo chemotherapy to wipe out her immune system so a new one can take over.

Following that, since Fallon will essentially not have any immune system, the Schlautmans are planning to live at least six months near the hospital.

Katie previously quit her full-time job as a dental assistant at Troy Family Dental and is now a full-time mom/nurse to Fallon. Kevin is self-employed and is a partner with TDK Consulting of Beckemeyer.

Right now, they are still waiting for a bone marrow match for Fallon.

Without a bone marrow transplant, Fallon's whole body would shut down.

As for Fallon?

"She's more tired than the usual baby and is developmentally behind," said Katie. "She is now sitting up on her own, however, it's difficult for her to be on her belly because of her G-Button."

Despite her diagnoses, Katie said Fallon is a "happy baby girl."

Fallon is on an IV 20 hours per day and gets a four-hour break. During that break, that is usually when a physical therapist and a developmental therapist comes to the home for therapy.

There is currently a medical team of nine specialists at Cardinal Glennon who are involved with Fallon's case, including hematology, immunology, rheumatology, neurology, cardiology, surgery, GI, audiology and ophthalmology.

"Faith For Fallon"

Family and friends are organizing a benefit for Fallon on Saturday, May 16, beginning at 2 p.m. at Bartelso Park, just days prior to Fallon's first birthday.

There will even be a birthday cake for Fallon, however, Fallon, due to her condition, will probably not attend.

There will be bags and bocce ball tournaments, music, food, drinks and more. For more information about the bags and/or bocce ball tournaments, check out the information at www.faithforfallon.org.

There will be a "Kids Korner," which for \$20, it gives you a wristband of all-day fun, including bounce houses, pony rides, kiddie train, face painting, firetrucks display and more.

Anna and Elsa (from "Frozen") will also be in attendance to meet and take pictures with children.

A "Be the Match" drive will also be at the event.

Fallon's uncle/godfather Chris Schlautman of Aviston explained that the "Be the Match Donor Drive" is a drive similar to the American Red Cross blood drive.

"There will be a donor drive to recruit donors and they are entered into a database that could help coordinate bone marrow matches," Chris said.

He added that donors need to understand that if you join the registry, it may be a match for someone else (not necessarily for Fallon).

"We wanted to bring awareness to the community about bone marrow," he said.

A silent auction will be from 2 to 6 p.m. and an oral auction will begin at 7:30 p.m.

Big ticket items up for grabs for the auction include a one-week stay at a Branson condominium, St. Louis Cardinals tickets, homemade quilts, a Henry Golden Boy .22 S/L/LR Firefighter Tribute Edition and more.

There will be several raffles at the event, including 50/50s, a raffle for a bouncehouse voucher and a 6-gun raffle.

The 6-gun raffle is a chance (for \$20) to win: a Rock River Elite, Operator AR-15; a Smith & Wesson SD9 9mm pistol; a Winchester SX3 20-gauge camp; a CZ Mallard Over & Under 20-gauge; a Ruger SR 1911 45 pistol; and a Remington 783-243

with scope.

Organizers are also accepting gift baskets/donations for the silent/oral auction.

Also, trending are "Faith for Fallon" T-shirts. To order yours, send an e-mail to faithforfallon@gmail.com and include your size. T-shirts are \$15.

How can I help?

Monetary donations are accepted through Germantown Trust & Savings Bank in Germantown, however, friends have also started a GoFundMe page (which is linked on the Web site, www.faithforfallon.org).

Ideally, those who donate are encouraged to donate directly to GTSB Banks, make checks payable to the "Faith for Fallon Benefit Fund." Donations can be mailed to the bank at: Germantown Trust & Savings Bank, PO Box 246, 601 Main Street, Germantown, IL 62245.

For more information, check out the Web site, www.faithforfallon.org; the Facebook page, www.facebook.com/Faithforfallon or go online to www.gofundme.com/faithforfallon.