A 5-Month-Old’s Plight Shows Need For Donors

By Stephanie A. Faughnan, 2024-11-18

The Mojica family pose together. (Photo by Stephanie Faughnan)

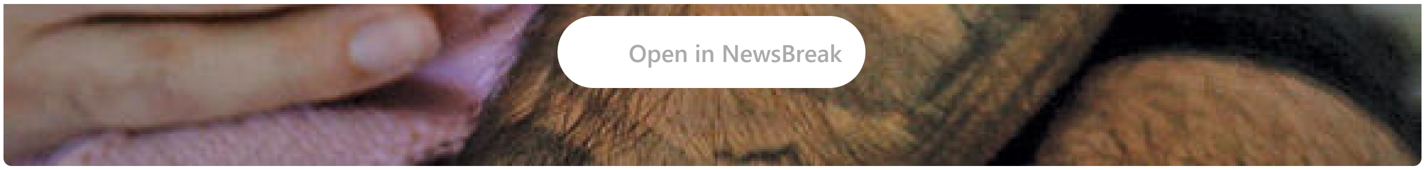
HOWELL – A local couple’s prayers have been answered. After a desperate search for a living liver donor for their five-month-old daughter, Florence, a family member has selflessly agreed to donate a portion of his liver. The glimmer of hope comes after facing setbacks with other potential donors who were ruled out as matches.

Lina Mojica said she and her husband are relieved that Florence will have the lifesa transplant. However, they still want to tell their daughter’s story and raise awareness about the rare liver disease that made her condition so precarious.

The Howell couple were overwhelm they brought their twins Florence and Noah home from Monmouth Medical Center in early June. The pregnancy had been uneventful, and both babies weighed in healthy. However, within months, the family's world was turned upside down as Florence began to show signs of something seriously wrong.

It began subtly. Florence was fussier than Noah, had trouble napping, and struggled to settle down. Doctors suggested that colic could be the problem and advised removing dairy from her diet. But her condition only worsened, and soon, Florence's skin took on a troubling yellow tint.

“At first, we thought the yellowing was due to Florence's olive skin tone,” Lina shared. “She's always been darker than her brother.”



Five-month-old Florence Mojica suffers from a rare liver disease and needs a liver transplant. (Photo by Stephanie Faughnan)

When the pediatrician saw Florence for her three-month check-up, the doctor referred them to the emergency room at Monmouth Medical Center. Florence was clearly jaundiced and in need of immediate evaluation.

That day, August 24, would forever change the Mojica family's lives. As they sat in the emergency room, they received the devastating news that their daughter's fussiness was not just colic but a symptom of a serious underlying health condition.

"They did bloodwork and found her bilirubin was really high," said Lina. "The hospital tried to do two separate ultrasounds and couldn't find Florence's gallbladder."

Doctors confirmed Florence was born without a gallbladder, a condition that often indicates underlying liver issues. As a result, the Mojicas were instructed to transfer Florence to NewYork-Presbyterian/Columbia University Irving Medical Center for specialized care.

After a series of tests over four days, including a liver biopsy, the Mojicas learned that their daughter Florence was born with biliary atresia, a rare liver disease. According to Biliary Atresia Research & Education (BARE), biliary atresia occurs when the bile ducts carrying bile from the liver to the gallbladder do not develop properly. This blockage prevents the normal flow of bile, resulting in liver damage and potentially life-threatening cirrhosis if left untreated.

Researchers say that while the disease is congenital, they have not yet determined the cause. The American Liver Foundation estimates that biliary atresia occurs in 1 in 8,000 to 1 in 18,000 live births worldwide.

The National Institute of Diabetes and Digestive and Kidney Diseases reports that the appearance of jaundice is one of telltale signs of biliary atresia. It is due to a buildup of bile in the body. Stools also become pal he case for the first time when Florence was seen in the emergency room.

The protocol after diagnosis is for doctors to perform a surgery known as the Kasai procedure. The specialists in the New York hospital connected Florence’s liver to her small intestine, bypassing the blocked bile ducts. It offered hope but was only a temporary solution. Florence remained hospitalized until September 9, at which time she went home with her parents.

A common complication of biliary atresia is ascites, a buildup of fluid in the abdomen that causes it to distend. This painful condition has forced Florence to undergo weekly drainage procedures. As her condition escalated recently, doctors decided to keep Florence hospitalized at until a suitable liver donor could be found.

Florence was placed on the transplant list, but finding a liver for an infant is incredibly difficult. Her best chance was finding a living donor. The Mojica family appealed to the public to consider the life-saving act. Prospective donors who went through the process were ruled out as matches.

And, then a miracle happened. A family member agreed to become a living liver donor and help save baby Florence. Importantly, only a small portion of the donor’s liver, around 15-20 percent, is needed for the transplant, and the remaining liver will fully regenerate.

To Be A Liver Donor

In a video presentation, Dr. Benjamin Samstein, Chief of Liver Transplantation at Weill Cornell Medicine and NewYork-Presbyterian, highlighted the urgent need for living liver donors. According to Dr. Samstein, over 16,000 people are currently on the liver transplant waiting list, and thousands more die annually due to a shortage of available organs.

Potential living donors undergo a rigorous evaluation process to ensure their suitability. This includes medical tests, psychological evaluations, and consultations with healthcare professionals. The goal is to minimize risks and provide comprehensive support throughout the donation process.

While living liver donation is a majo [illegible] ntial risks, the majority of donors recover fully and experience minimal long-term complications. The recovery time typically varies from a few weeks to a few months, and most donors are able to return to their normal activities within a reasonable timeframe.

Twins Florence and Noah Mojica are now five months old. (Photo by Stephanie Faughnan)

“All donors to children under the age of eight are performed with a full laparoscopic technique,” explained Samstein, who added that the left lobe of the liver is used with smaller recipients. Recipients also do better if the donor is living.

“If approved for surgery, the donor needs to stay for about a month in New York between the immediate preoperative testing, surgery, hospital stay, and ensuring that they’re safe,” Samstein added. There are follow-up visits and phone calls.

Samstein also addressed concerns about expenditures associated with being a living donor. He said the costs of donating, donor testing, surgery, routine visits are covered by the recipient insurance, travel, lodging and wages are not covered by insurance or the transplant center.

There are no requirements for donors to live in the immediate area. The National Living Donor Assistance can assist donors with finances. Donors may also be eligible for state tax credits.

The Road Forward

The Mojicas have received support from friends, family, and even strangers touched by Florence’s story. The family has partnered with the Children’s Organ Transplant Association (COTA), a non-profit that assists families with transplant-related expenses. Donations made through COTA go directly towards helping Florence receive the life-saving transplant she desperately needs.

Florence is currently at Columbia Presbyterian under close medical supervision and scheduled for surgery. Lina and her husband both expressed their gratitude to all who have tried to help them in some way.