



Emilia's Anglers
Fundraising Event



EMILIA IN NICU



EMILIA'S
FAMILY



DADDY AND EMILIA

INTRODUCING



Emilia's Story

The pregnancy with Emilia was exceptionally uneventful until 34 weeks, where they estimated she had stopped growing around 29 weeks. She was born via c-section due to decreased fetal movement and severe growth restriction. She was 3 lbs. 3 oz of pure, adorable love. She was admitted to the NICU at Jupiter Medical Center, but transferred to Nicklaus Children's Hospital in Miami on day 12 due to abnormally concerning liver labs. She

Cirrhosis

A chronic disease of the liver marked by degeneration of cells

had a lot of difficulties growing during her 75 day NICU stay, but she was eventually discharged and able to spend Christmas with her three siblings.

The family spent three weeks at home before she developed ascites (fluid on the belly indicative of liver failure) and she was re-admitted back to the PICU at Nicklaus Children's Hospital on January 2, 2021, and then transferred to Jackson Memorial to be evaluated by the Miami Transplant Institute. The family was there for approximately 5 weeks for liver biopsy, and nutrition optimization for which included a central line, and an NG feeding tube. We made it home early February 2021 on IV nutrition that lasted 14 weeks. During that admission, she had a full genetic workup that unfortunately didn't point to answers or diagnosis for the cause of the liver fibrosis.

In May 2021, we surgically converted her NG tube (in her nose) to a G-tube (in her belly), and the surgeon was able to capture some photos of her very nodular liver as an incidental finding.

Since her February 2021 discharge home, things for Emilia have only stabilized and improved, and her lab work has stabilized. Everyone was hopeful that there was enough healthy liver tissue to regenerate and make the scar tissue insignificant, including her secondary hepatology team in Pittsburgh PA.

At a routine follow up in December 2021, new liver nodules appeared on her abdominal US, including an enlarged spleen due to back-flow. We were told the next course of action should be a repeat biopsy and MRI, which was completed in February 2022. Emilia was diagnosed with end-stage liver disease, cirrhosis, and the only cure for cirrhosis is a liver transplant. Although she is currently medically stable, we are watching closely for her to decompensate, and have been told to expect transplant in the future, potentially within the year. Our goal now is to keep growing her, watch and wait, and enjoy every moment we have with her.

Emilia's Anglers

Join us in raising funds this fishing season to help the family with cost of Hospital bills, insurance payments, and whatever the family needs to aide Emilia's search for a liver. We will be hosting this tournament starting April 1st - May 31st, 2022. The Cost is \$50 per angler. You can join anytime, catch 5 same species fish to qualify for prizes to be awarded after the season. This event is for all anglers Bank fishing, Kayak, Boat. Event will be held on Fishing Chaos soon.

What's Emilia's Current Stage?



Stage 4 is liver failure, which means your liver can no longer function or heal itself. In liver failure, the liver can no longer process toxins or drugs, and they build up in your body. Symptoms grow worse and can include mental and physical impairment, appetite and weight loss, diarrhea, and other problems.