

Recipient Story

A Story of Patience, Persistence and Hope

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A few years ago, my mother, Ms. Usha Agarwal, had been diagnosed with a rare genetic disorder known as Polycystic Kidney and Liver disease. This condition involves the formation of cysts in both her kidneys and liver, leading to bloating and a significant increase in liver size. The cysts began to develop around the time of my sister's birth, who is currently 19 years old and over the time, the situation worsened. Typically, a healthy liver weighs between 800gm to 1.5kg whereas in my mother's case, her liver weighed around 12 kg.

It all began when my mother started experiencing acute stomach pain. Doctors suspected an enlarged liver just by appearance. With time, her health deteriorated and doctors suggested that she might soon require a liver transplant.

In 2021, she developed an umbilical hernia due to the immense pressure from the liver cysts, which had taken up much of her abdominal space. Her physical condition worsened, confining her to bed for several months. Walking became impossible, and the hernia began to worsen. The medical advice strongly leaned towards a transplant, with the added complication of Polycystic kidneys, necessitating a dual transplant. The major challenge was finding a suitable donor for this dual transplant, a task complicated by the minimal likelihood of such donors.

With our backs to the wall, and having no other option whatsoever apart from helplessly standing by and watching her health deteriorate, we registered her with the "Jeevandan" for a combined liver and kidney transplant. We had tried out all options including registering her for a transplant in many places such as Bengaluru and Chennai. We even tried to explore possible avenues in other countries like Singapore.

We reached out to our close relatives and friends who could be potential donors. My aunt's son agreed to be a donor, and we completed the required documentation. The cumbersome process took about a month and we were filled with hope that she would receive her transplant soon. At the eleventh hour, he opted out and decided against donation - perhaps fearful of the surgery. In addition to her declining physical health, my mother experienced extreme emotional fragility, pushing us to the brink of an emotional breaking point. In 2022, we decided to move her to KIMS Hyderabad under the guidance of Dr. Ravichand Siddachari, Consultant and Chief of Liver Transplant and HPB Surgery.

The most emotionally draining part of the whole experience was waiting anxiously for updates from the hospital regarding the availability of a compatible donor. Every dawn brought hope for news we eagerly awaited. Each day's end, without the expected call from the hospital, we remained patient, offering prayers and maintaining optimism. During this time, we received donor calls from both Telangana and Tamil Nadu. However, due to various reasons, the transplants couldn't be carried out.

The wait was unbearable as my mother's condition deteriorated steadily. Just as we felt we were reaching our breaking point, in November 2022, a miraculous event unfolded. A donor call, presenting a suitable match emerged, and we held onto hope once again, wishing fervently for a successful transplant.

The surgery was performed in the first week of November, 2022 and this was the first time in India that transplant was offered to patient whose liver weighed 12 kg. The marathon operation, lasting 14 hours, was successfully done by liver transplant surgeons Dr. Ravichand Siddachari, Consultant and Chief of Liver Transplant and HPB Surgery, Dr. Sachin Daga, Senior Consultant HPB & Liver Transplant, Dr. K.N. Paramesha, Consultant HPB & Liver Transplant, and Dr. Uma Maheshwara Rao, Consultant Urologist and Renal Transplant Surgeon. Postoperatively, my mother was in the hands of Hepatologist Dr. Sharat Putta, and Nephrologist Dr. V. S. Reddy. This was one of the most difficult surgeries for the surgeons as the liver had completely occupied the entire abdominal cavity.

The day after the transplant, tears of joy flowed as we envisioned the prospect of freedom from the persistent pain my mother had endured. The happiness both she and our family experienced wouldn't have been possible without the profound act of selflessness exhibited by the donor's family.

My mother's journey stands as a testament to perseverance in the face of seemingly insurmountable challenges, showcasing the remarkable outcomes born from the fusion of medical expertise and human compassion.



Ms. Usha Agarwal (liver and kidney transplant recipient) with her daughter Ms. Samridhi Agarwal before and after transplant

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