

Good morning, House Ways and Means Committee Oversight Subcommittee members, Chairman Schweikert and Ranking Member Sewell. My name is Heather Hollis Knuckles of Imperial, Missouri. I come before the subcommittee on Tuesday, December 2, 2025, regarding my mother's October 30, 2022, fatal liver and kidney transplant.

I want the world to know my mother, Mary Ann Hollis, was and is my hero and my world. Nearly seven years ago my mother was diagnosed with fatty liver disease, which evolved into cirrhosis. In November 2021 as the cirrhosis advanced, my mother became bedridden while my husband and I provided daily intensive care. We fed her, bathed her and provided physical therapy. By mid-2022, her kidneys were failing, and she was placed in a nursing facility awaiting a healthy donor liver and kidney. She never gave up hope that a new liver and kidney would be found. She ordered gardening tools, new clothes and cookware as she looked forward to a new lease on life. Our prayers were answered October 29, 2022, when a match was found. Coincidentally, this was my wedding day. I remember my mother smiling and saying, "I'm so glad I'll get to be a part of your life going forward. I can't wait to be a mother-in-law!" She held my hand, looked me in the eyes and said, "I really hope this goes ok because I wouldn't want to die or anything." We reassured her it would go well, and her new life would begin. It was the happiest day of our lives. Little did we know the nightmare was just beginning.

On October 30, 2022, my mother underwent the liver and kidney transplant at Barnes Hospital in St. Louis. Mid-America Transplant was the OPO in charge of procuring the organs. The day following surgery, she was happy, alert and was already looking forward to eating. She couldn't wait to be home to see her pets, family and friends. She had already purchased a 'welcome home' banner a couple of weeks prior to receiving the call that a matching donor liver and kidney had been found.

On November 3rd, five days post-transplant, surgeons informed us that the donor liver contained high-grade, metastatic, undifferentiated adenocarcinoma not reported on the donor records from UNOS but was discovered via pathology conducted at Barnes Hospital. We were informed this was a very deadly form of cancer and should it spread, she wouldn't be eligible for cancer treatment. Our dreams were shattered and our hearts sank. Fear and sadness washed over my mother's face. She was listed for re-transplant with an increased MELD score. Surgeons decided to not replace the donor kidney, which was questionable as it had a large cyst at time of transplant.

My mother underwent a second liver transplant on November 8, 2022. Prior to the second transplant, my mother looked at me with a very solemn expression and stated, "I bet I will never leave this hospital alive." We assured her that things would be ok, even though we all had our doubts. As my mother was wheeled back to surgery for the second transplant, she looked at me with a very haunting look in her eyes and a half smile. This was a four-hour procedure. She was extremely fragile afterward, hallucinated for days and suffered delirium. Occasionally, her wrists were restrained for

safety. This was heartbreaking to witness as well as extremely concerning as we all didn't know if the metastatic cancer had been eradicated or would later spread.

By late November she was transferred to The St. Louis Rehab Institute, affiliated with Barnes Hospital. She was mentally stable again, could sit up in her bed and was gradually eating and drinking on her own. We were impressed with this progress, but unfortunately, this would be temporary. Her appetite diminished, she remained unable to walk and became jaundiced. Tests revealed the donor kidney had a blockage and it was dysfunctional. Two attempts to insert stents in the donor kidney failed and it only survived with a nephrostomy bag. Throughout this time, my mother began weeping fluid from her body and required special wraps for her arms and legs along with absorbent pads on her bed. Our entire family, including my mother, realized this was not heading in a positive direction.

On December 16th, my mother was readmitted to Barnes Hospital and was placed on a feeding tube along with a nasogastric tube that removed bloody, gastric acids. She was not permitted to eat or drink. Day after day we watched my mother cry, beg and plead for a drink of water, tea or soda. On Christmas of 2022 we sat at her bedside, opening her gifts for her as she was too weak to do so. It would be our last Christmas together. Although my mother was rapidly losing weight, she was a fighter and still had an appetite and begged for a meal. Finally, the NG tube was removed, and I was permitted to feed her. This would be her last meal of mashed carrots, potatoes and turkey. After the meal she became violently ill, vomiting for hours and the NG tube was put back in place. She also began developing a large solid mass on her lower

abdomen, was becoming emaciated, was failing to absorb her tube feeding, requiring an IV feeding. She was communicative but could only whisper and had trouble holding her eyes open. On January 7th and 8th, we arrived to visit my mother. Her head was shaking, her eyes were turned far right, and her entire body was having tremors. The only sounds she could make were small grunts and groans as she lay in agony. Our family was beyond devastated.

We never received an explanation for her rapid decline. My father reached out to both the liver and kidney transplant teams seeking answers. One recommendation from the liver team administration to my father was to have 'hope and prayer' while my mother, unbeknownst to us, lay dying. Please bear in mind my mother's body never rejected these organs.

On January 9, 2023, my mother was transferred to the ICU and placed on life support. We will never forget that dreaded day. On January 10th, the transplant surgeon informed my father that based on the appearance of an abdominal CT scan as well as peritoneal fluid extracted during thoracentesis, pleural fluid cytology was positive for undifferentiated adenocarcinoma. The transplant doctor claims this confirmed their earlier suspicion and it was likely related to cancer from the first transplanted liver. He stated it was not curative, and she was not a candidate for chemotherapy. Family and friends stayed at her bedside daily. I quietly played her favorite songs and continually told her that I loved her. Per her living will, my father made the gut-wrenching decision to remove my mother from life support on Friday, January 13, 2023. We said our final goodbyes. She passed at 5:40 pm. To say my mother was a wonderful person would be

an understatement. She was a precious, beautiful soul and was loved by everyone who knew her.

Per UNOS records, the donor was hospitalized for four days and was placed on life support for a total of six days—plenty of time for Mid-America Transplant to conduct thorough testing. A CT with contrast was performed; however, no cancer cells nor abnormalities were reported. The radiologist's report states "conventional hepatic arterial anatomy. No liver surface nodularity or steatosis." Five days post-transplant, Barnes pathology revealed the deadly gastric undifferentiated adenocarcinoma that killed my mother 2.5 months later. Barnes pathology notes state, "Metastatic poorly differentiated adenocarcinoma involving donor gallbladder, present as scattered sub serosal tumor and prominent intravascular deposits, favor metastatic gastric adenocarcinoma." (BJC Notes p. 5085-5087). On one hand UNOS considers the donor eligible, yet five days later Barnes pathology reveals high grade metastatic cancer.

Following the passing of my mother, we suffered nearly three years as this horrific ordeal was ignored by law firms and local media. If no responsibility is applied, no implementation of safer standards or procedures may occur for other recipients. No one should ever have to experience what my mother and our family endured. It is time for the entities responsible to be addressed. That's why I'm here today.

My request to this committee is twofold—Firstly, please investigate how a donor in this condition is eligible for harvesting considering most of his internal organs were donated for research or discarded, listed as 'diseased'. Secondly, I request the

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subcommittee investigate or address the importance of donor screening prior to transplant. As a recipient, my mother had to undergo rigorous testing, even checking for cavities prior to becoming eligible for transplant, yet the donor, who we now know had cancer, somehow was eligible for harvesting. This doesn't make sense. Please investigate.

Mr. Chair, Ranking Member, and Committee Members, I thank you for your time and vested interest in my mother's horrific transplant case. Thank you for the honor of presenting my mother's story. I'm willing to answer all questions you may have.

Sincerely,

Heather Hollis Knuckles

Imperial, Missouri

