

Across the world, June is Lymphangiomyomatosis (LAM) Awareness Month. LAM is a rare and progressive lung disease that primarily affects women. LAM has no cure, even with a transplant. It is estimated that there are 3-7 cases for every million women, with the average woman being 35 years old when diagnosed. Diagnosis is difficult, as the symptoms are often similar to other lung diseases, such as asthma and bronchitis. LAM progresses differently in every person. Many patients will require oxygen at some point. LAM can be treated in a variety of ways to help improve quality of life and delay the need for invasive interventions. Many patients benefit from medications, inhalers, and/or oxygen. Transplant is often a last resort and is a very personal choice. Patients are the judge of their quality of life. Being informed on the disease, prognosis, and treatment options will benefit patients in the long run and make them their strongest advocates.

## Melanie's Story

Almost 13 years to the day, I was a mom of two beautiful boys, ages 2 and 4, with an incredibly loving husband. I was sick and dying of an incurable lung disease called lymphangiomyomatosis and was completely dependent on oxygen. I relied fully on my husband to do everything for me. This was a hopeless life I never thought I could escape from. In 2011, I developed respiratory failure and was air-lifted to Iowa City where I waited and prayed for a lung transplant to save my life. Under the amazing care of the doctors and nurses there, I not only received my gifts of lungs, but I am here 13 years later, still living a blessed life with them.

I am overwhelmed with emotions this month. I remember vividly praying to just live long enough for my boys to get out of grade school. I just wanted them to be old enough to remember me and have memories of me at school functions and family events. And now, I can't believe I get to watch my oldest graduate from high school in a few weeks. And I have been the loudest and most proud sports mom in the world. The gratitude and joy I feel in my heart every day when I wake up breathing is more than I can express. Not a holiday or special day goes by where I don't feel immense gratitude to this transplant team who has done absolutely everything for me to be sure that I make it to the next monumental memory with my family. I live a life of thankfulness every day to my family, this hospital, transplant team, and to my donor family.

*~ Melanie Putnam*

## What is LAM?

LAM is characterized by the abnormal growth of muscle-like cells (especially the lungs, lymphatic system, and kidneys). Over time, this growth leads to a loss of lung function, destruction of healthy lung tissue, benign tumors in the kidneys, and accumulation of lymph fluid in the chest/abdomen. These cells block the small airways of the lungs, reducing airflow and oxygen absorption in the blood. Common symptoms of LAM include shortness of breath, fatigue, chest pain, coughing, and abdominal bloating. LAM can develop slowly or quickly—each case is different.

Patients may experience a variety of emotions when diagnosed—shock, denial, anger, confusion, fear, and maybe even relief. Our physical health is significantly affected by our mental health. Patients should communicate their needs to social supports so that they feel supported, understood, and strong in their ability to cope with the diagnosis. No one can do this alone.

# ADDITIONAL INFORMATION

*This section of our monthly newsletter will focus on support and resources offered both by the Organ Transplant Center and throughout the nation. Please utilize these as you need them and reach out with any questions!*

**Kidney line: 319-356-1136**

**Heart line: 319-356-1028**

**Liver line: 319-356-1137**

**Lung line: 319-356-2016**

## Medicare and Transplant

Medicare eligibility is based on age, disability, having end-stage kidney failure, or receiving a kidney transplant. No other organ transplant or need for organ transplant qualifies one for Medicare. There is a 1-year enrollment window for Medicare from date of kidney transplant. Delaying enrollment can increase chances of higher out-of-pocket expenses for anti-rejection medication. Medicare Advantage plans cover anti-rejection medications, and out-of-pocket expenses are subject to plan.

\* For further questions or coverage changes, please contact the Organ Transplant Center financial counselors.

## Video Resources

The Organ Transplant Center has put together videos to better explain the transplant evaluation process and provide additional patient education. Please click the links below to access these videos.

- [Kidney Transplant - Patient Education Videos](#)
- [Liver Transplant - Patient Education Videos](#)
- [Pancreas Transplant - Patient Education Videos](#)

## Organ Transplant Support Group

Starting in February 2024, the Organ Transplant Center will begin having our support group every other month. The support group will also be a hybrid version—both in-person and by Zoom. Each group will be focused on a specific topic, with speakers followed by time for discussion. If you have any questions, please contact 319-467-8385.

**Location:**

Iowa Donor Network  
550 Madison Avenue  
North Liberty, IA 52317

**Date:**

Thursday, June 13  
Speaker: Iowa Donor  
Network staff

**Zoom Information:**

Meeting ID: 959 4042 7920  
Passcode: 678643

We will be having an  
indoor picnic, so bring  
something to eat for  
yourself!

## Additional Resources

Social Security Disability

- [Adult Disability Starter Kit](#)
- [SSI Child Disability Starter Kit](#)

National Living Donor Assistance Center (NLDAC):  
[How to Apply](#)

Iowa Anatomical Gift Fund: [Application](#)

Iowa Donor Network / Writing Your Donor Family:  
<https://www.iowadonornetwork.org/transplant-recipients/writing-your-donor-family>