



What is the LAM Patient Benefit Conference?

This all-new concept for a LAM patient gathering is the result of hours of preparation by LAM experts, dedicated planners, and patients like you – all designed to help address the most important and relevant issues for those living with and treating lymphangioleiomyomatosis (lim-FAN-je-o-LI-o-MI-o-ma-TO-sis), or LAM for short.

The format for the LAM Patient Benefit Conference germinated from the idea that we could **accelerate problem-solving for short- and long-term challenges that individuals with LAM and their doctors face.** And we wanted to do it together in a concentrated period of time with patients, researchers, clinicians and thought leaders all at the table.

The 6 Big Topics to Address at the Conference

Prior to the conference, The LAM Foundation conducted two surveys – one for individuals with LAM and one for LAM clinic directors. Needless to say, the LAM community responded loud and clear. The collective feedback of 250 patients and half of the practicing clinic directors led us to identify the six big topics we will address head on at the LAM Patient Benefit Conference. Through moderated solutions workshops, patients, researchers, clinicians and thought leaders will discuss how to cultivate solutions in these areas:

- The Clinic Experience and Patient Reported Outcomes
- Biomarkers and Imaging for LAM
- Supplemental Oxygen and LAM
- Coping and Mental Wellness
- Fatigue
- Exercising and LAM

1. The Clinic Experience and Patient Reported Outcomes

“It is challenging to deal with the unknown.”

In the patient and clinician surveys, respondents concurred that the clinic experience, including communication and patient-reported outcomes, ranked high on their areas of priority. Some ideas for improving the care experience include:

- Enhancing clinician knowledge about LAM
- Increasing clinician compassion for patients with mild cases of LAM
- Elevating the importance of mental health and wellness, including how LAM patients feel physically and emotionally
- Improving communication between clinicians and patients to ensure that patients’ symptoms are taken seriously

While discussing **the Clinic Experience and Patient Reported Outcomes**, participants will discuss creating potential tools for patients to use to track disease progression and communicate effectively with their care team. This could include using technology such as online apps. Other ideas include home spirometry and new ways to support patient-reported outcomes.

2. Biomarkers and Imaging for LAM

“Let’s focus on developing tools to track progression, optimize medication, improve remission and identify biomarkers.”

Continued research, innovation, and new technology can help move LAM treatment forward. In surveys of clinicians, they sought three solutions that would help them in diagnosing LAM. These include:

- Identifying new predictive and prognostic biomarkers for LAM
- Developing a severity scale specific to LAM symptoms
- Defining various disease-specific phenotypes which can impact treatment responses

And for patients, they want to understand things such as:

- Knowing when to start treatment and the side effects of drugs and dosing
- Learning about disease progression
- Understanding diagnosis and prognosis

While discussing **Biomarkers and Imaging for LAM**, clinician and patients will spend time discussing how to find more accurate ways to improve LAM diagnostics, including identifying new predictive and prognostic biomarkers and trends in imaging.

3. Supplemental Oxygen and LAM

“Can we develop smaller, lighter and more powerful and portable oxygen therapy?”

Supplemental Oxygen and LAM is designed to enhance the quality of life for patients. In surveys, patients sought insights into how they can fully benefit from it and how this therapy can be improved. They struggle with:

- Getting supplemental oxygen that enables increased activity
- Determining oxygen needs throughout the day
- Improving the comfort and portability of oxygen equipment
- Coordinating the use of oxygen supplies

Experts are equally interested in improving the quality and technology of supplemental oxygen therapy. During the **Supplemental Oxygen and LAM** discussions, participants will talk about ideas for making oxygen easier to use and less burdensome among other ideas.

4. Coping and Mental Wellness

“There is loneliness in having something so rare.”

It’s not uncommon to feel isolated, lonely or afraid when living with a rare condition. From diagnosis and acceptance to living with and treating LAM, anxiety, fear and depression can be pervasive. Patients seek support and tools to help them cope with the daily issues they face.

While discussing **Coping and Mental Wellness** during the conference, patients and clinicians can delve into the sensitive and important topic of coping as they discussion topics such as:

- Developing tools to help with anxiety, fear and depression.
- Overcoming the stress, worry and financial burden on family
- Dealing with the unknown
- Understanding the role of food and lifestyle choices in helping manage the condition
- Dealing with the embarrassment associated with wearing oxygen
- Coping with limitations
- Deciding whether to have a lung transplant
- Finding resources for coping strategies

5. Fatigue

“It’s frustrating to be ambitious one day and needing two days to recover.”

Low energy level, tiredness, sleep problems, not feeling rested. Fatigue is a major issue. Patients ask, “Why am I tired all the time?” and “Why can’t I do the things I used to do?”

Over the course of the weekend, patients and clinicians will discuss how **Fatigue** may have potential links to LAM and other conditions as well as new means to address fatigue in LAM. Clinicians will also discuss if fatigue and muscle aches are symptoms of LAM or of sirolimus treatment.

6. Exercising and LAM

“Exercise! I can’t do what I used to do and I get frustrated.”

Due to the nature of LAM, exercise can be a challenge for patients. In surveys, respondents indicated that while shortness of breath and chest pain impact the quality their lives, they want know the benefits of and be able to exercise. Patients indicated that they seek to understand the following:

- Getting enough exercise
- Exercising too much
- Exercising to improve immunity to reduce illness
- Feeling limited by not being able to do desired physical activities
- Ensuring that they have enough oxygen to support physical activities

While discussing **Exercising and LAM**, clinicians will address the fact that few studies have been conducted around exercise and LAM. They will also discuss the possibilities and limitations for things such as better tests to evaluate oxygen needs to support exercise, self-initiated pulmonary rehab, and ideas for how to make exercise and daily activities more manageable.

Beyond the Conference...Patient Benefit Grant Program

The Patient Benefit Conference is an opportunity to accelerate problem-solving for short-and-long term challenges that individuals with LAM and their doctors face. Each solutions workshop is designed to encourage problem-solving and ideation with the goal of generating proposals that will help address these challenges. Each group will present the best ideas at the Closing Plenary session. These proposals may also be in the running to receive a grant from the Patient Benefit Grant Program.