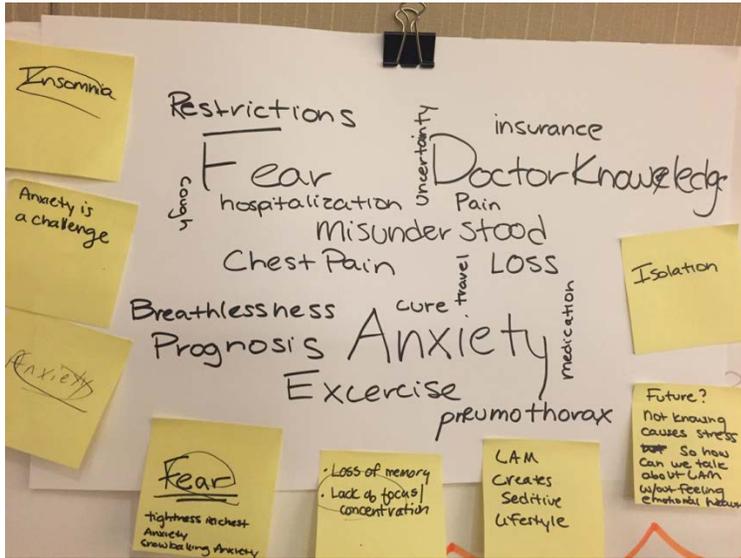
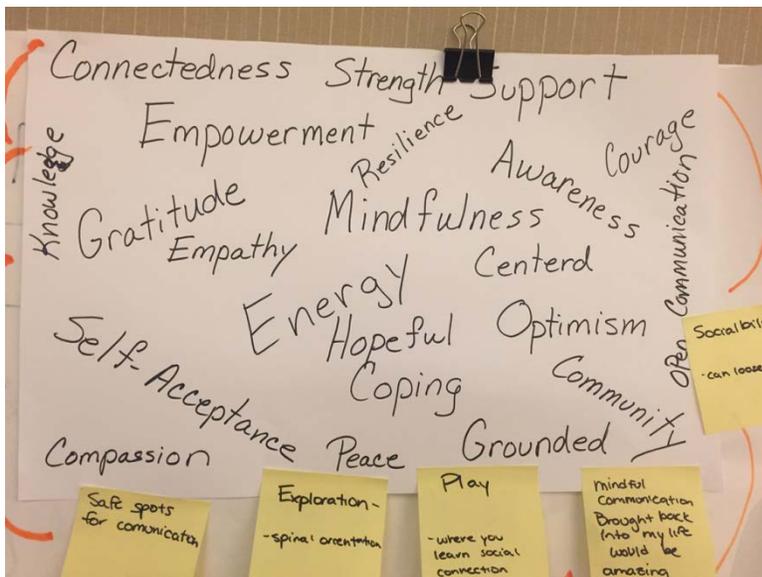


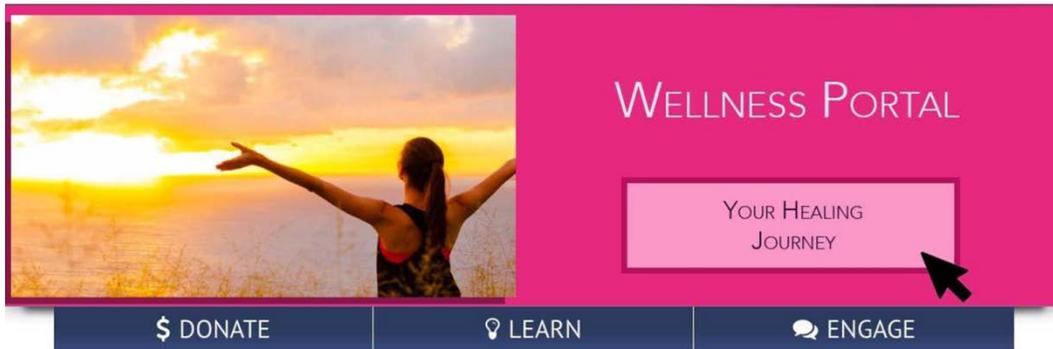
Coping, Mental Wellness, and Fatigue

Support and tools to help LAM patients cope with the daily issues they face. New approaches to managing fatigue in LAM.



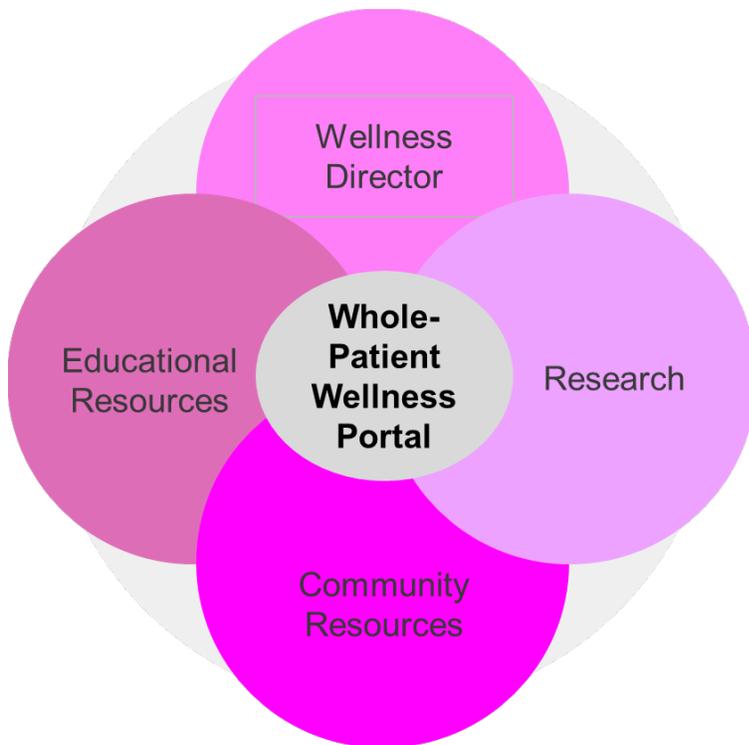
WHAT IF WITHIN 5 YEARS, LAM PATIENT WORD CLOUDS LOOK LIKE THIS.





About The LAM Foundation

The LAM Foundation urgently seeks safe and effective treatments, and ultimately a cure, for



Wellness Director

- Education & Outreach for Mental & Emotional Wellbeing
- Advocacy
- Research & Grant Writing
- Thought Leadership

Educational Resources

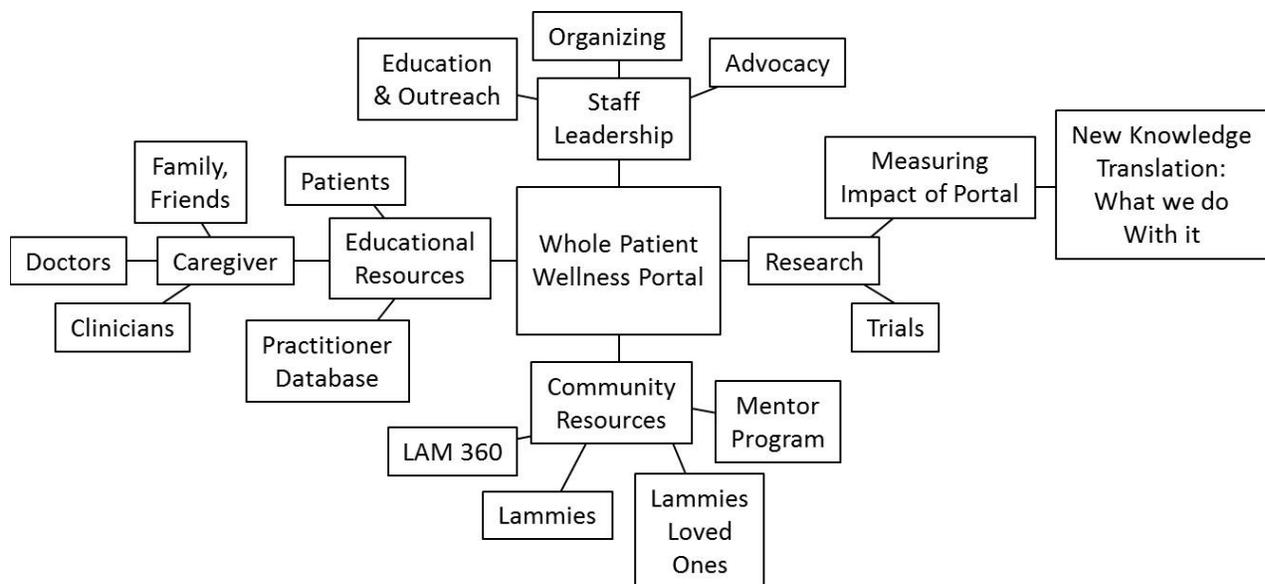
- Web-based educational resources for patients, caregivers, friends and family.
- Integrative Practitioner Database
- Meditation, Mindfulness, Movement resources
- Tips for Patients
- News on research on social/emotional wellbeing
- Spanish language (and other?) content

Community Resources

- Connections to LAM360, LAMMIES, LAMMIES Loved Ones, Mentor Program
- Husband/brother/son men-specific support
- Talk to another LAM patient
- Facebook Live or Videochats

Research

- Measure Impact of Portal and MEWB Support
- New Knowledge - Integrate and Share
- Peer-Reviewed Funding/Grant Writing
- MBSR for LAM Patients
- Qualitative Mixed Methods Studies on Wellness
- Fatigue Study



From the workshop the following were grouped under

Educational resources:

- Workshop or session on dealing with guilt, self-forgiveness and the role of gratitude in healing
- A workshop or session on the role of vulnerability in building trust, intimacy and more effective healing/renewal
- You tube channel offering guided mindfulness and meditation practices designed for LAM women
- A session of workshop on understanding how suffering or pain can awaken or renew our lives
- Practicing mindfulness breathing helped me experience a lift in emotional heaviness
- I've learned about mindfulness and benefits now how do I practice it?
- Is there a lack of conversation between patient and doctor – need lifestyle coach?
- Raise awareness to importance of treating fatigue
- Workshop or session on educating caregiving partners, spouses and friends on how they can help patients heal
- Training mechanisms for physicians, nurses, RTs etc. – referral list
- A workshop or session on techniques/tools for communication, exercises that increase intimacy, trust and connection between patient and caregivers
- Integrative health on-line toolbox with weekly updates
- Counselors/coaches trained in LAM available by phone at no charge to LAM patients
- A session or workshop on religion, faith and science in healing and mental wellness

Clinicians

- CME accredited training for physicians
- Making health care provider part of the therapeutic alliance

Doctors

- Care givers listen to patients

Family and Friends

- Caregivers can go through empathy and anxiety when loved ones have LAM
- Whole family support

Educational resources

- Access to resources
- Facilitate access to wellness resources

Lammies

- VR videos chatting with LAM sister to make connection more personal

- LAM sister communication events on Facebook
- Can we set up an online community to talk to a fellow LAM sister
- LAM Facebook for family members and loved ones (caregivers)
- Support for family members for mindful communication
- Facebook live events to share common issue without feeling stupid or judged
- Husband/brother/son – men specific support
- Talking with another LAM patient made me feel comfortable and could empathize more

Wellness Portal

- How do we reach all LAM patients
- Tool to capture attention about coping and wellness issues on main page of website
- For Spanish speaking patients too!!

Trials

- Trial on impact of MBSR (mindfulness-based stress reduction) on women with LAM
- Publish a scientific paper on fatigue – clarify definition!
- People took pictures when lecture slides contained info about diet and low impact fitness
- A lot of people took pictures of vitamin and natural medicine/herbs so trials on organic needs?
- Qualitative mixed methods studies on wellness
- Can there be trials of every aspect of integrated medicine?
- VR stress relief and yoga or meditation
- Can you create a diet that improves health but reduces stress?
- Clinical trial for LAM patients and benefits of yoga

Products/Trial Ideas

Anxiety/depression tool to remove the need to ask for help – Develop, as well as study for validation and subsequent use in trials.

Publish a scientific paper on fatigue – maybe together with other lung diseases

Identify the pathophysiological basis for fatigue in patients with LAM and explore potential treatment approaches (Western, as well as Alternative) to tackle fatigue

Identify other common Non-LAM causes of fatigue that might co-exist and can be treated.

Needs that will be addressed by this innovation

Addressing completely predictable mental health issues that arise with a new diagnosis, as well as dealing with a chronic, disabling disease.

Raise awareness in medical community that this is a major manifestation of LAM

The clinicians are not paying attention to the complaint of fatigue.

Explore all possible causes of fatigue

Benefits of having it

Make getting help with new diagnosis automatic and not an admission of weakness

Tool for raising the issue with caregivers- getting caregivers to listen, patient is not just whining

More informed treatment options for management of fatigue.

Proper treatment of these co-existing conditions may provide symptom relief

Other ideas

I wish to be able to talk to a person with LAM because they understand me like no one else can

LAM group on line for women 40 and under

Parenting with LAM can be stressful esp with difficult kids. Help with this to reduce stress

Literature search and consolidation on what is known about fatigue (the science)

Burn out epidemic in physicians. How does this impact a patients attitude/ emotional status?

Integrated medicine is a personal approach