

LAM and Exercise

GOAL of Workshop: Identify benefits of exercise, and explore novel avenues that help LAM patients in their ability to exercise.

Clinical Problem: LAM patients suffer exercise intolerance and fatigue

The Saturday morning workshop members broke into three groups focused on the following aims:

- Aim 1: Define functional and structural abnormalities contributing to impaired exercise tolerance and fatigue in LAM.
- Aim2: Collect data about physical activity and exercise habits, symptoms, fatigue and other endpoints important to patients.
- Aim 3: Using data collected in Aims 1 and 2 develop safe and optimized LAM specific exercise recommendations for all abilities

Project ideas and focus areas likely to move forward from this workshop (note 1,2 and 3 were focused on for the workshop presentation):

1. A clinical trial(s) to look at the structure of skeletal muscle in LAM patients
 - Evaluate women with LAM for exercise pH
 - High level of dyspnea with sats 88-92%, why?
 - Study if women with LAM have a mitochondrial deficiency
 - Biomarkers for skeletal muscle dysfunction
 - Evaluate sirolimus effects on skeletal muscle function
 - Monitor/measure pH in LAM patients that exercise. How? When?
 - Evaluate skeletal muscle (dys)function in LAM –in patients – in animal models
2. Development of a comprehensive eHealth system to be built in stages. LAM patients would be provided with fitbit like devices that would begin to capture as much data as possible to build a repository of LAM patient exercise data.
3. “Exercise Guidelines for LAM Patients”. Patient input clearly stressed the need for the guidelines to be tiered based on baseline exercise level of the patient at time of diagnosis. Patients want to know how to start if they had not been exercising. For those exercising – how and when to continue. And for those pushing themselves – when to stop.
4. Better rubric for pulmonary rehab so improvement is measurable. Most rubrics are designed for hospital patients. Need something Medicare accepts.
5. Specialized recovery methods that are individualized
6. Music therapy (harmonicas, recorders). Its helping COPD patients.
7. Vitamin/supplement/nutrition regimine that is LAM specific
8. Inpatient rehab facility dedicated to LAM specific rehab
9. Write in campaign to Shonda Rhymes to include LAM on Grey’s anatomy