

# What You Need to Know About your NIH Visit

Are you interested in contributing to LAM research by visiting the NIH?

## How to start the NIH process:

1. Visit the [The LAM Foundation website](#) and read about the current studies being conducted at the NIH.
2. Contact Tat'Yana Worthy [the Research Nurse Specialist] [worthyt@nhlbi.nih.gov](mailto:worthyt@nhlbi.nih.gov) to learn more about specific research that you can contribute to.

### Location:

LAM Team  
NHLBI, Critical Care Medicine and Pulmonary Branch  
National Institutes of Health, Bldg. 10, Room 7N222  
10 Center Drive, MSC 1590  
Bethesda, MD 20892-1590

## Who you need to know:

1. **Research Nurse Specialist** (Tat'Yana Worthy): This person will handle all things related to the research protocol, as it relates to eligibility, enrollment, and submission of medical orders, etc.

### Tat'Yana Worthy

- Email Address: [worthyt@nhlbi.nih.gov](mailto:worthyt@nhlbi.nih.gov)
  - Phone Number: (301) 496-3632
2. **Patient Care Coordinator:** This person will handle all of the logistics of the visit (scheduling tests, disseminating the schedule, coordination of travel, lodging, mileage, and meal vouchers).
  3. **Nurse Practitioner** (will be assigned at your visit): This person will provide clinical care during your visit, medical orders, and study management.
  4. **Dr. Moss's Tuesday Evening Meeting:**
    - Typically, Dr. Moss hosts a meeting on Tuesday nights at 5:00 PM. Ask your Nurse Practitioner to confirm the meeting while you are there.
    - This meeting covers general questions around the LAM research being done at NIH.

\*Individualized patient specific questions can be asked during your discharge conference before you leave.

## Important Emails to Save:

You will receive **three** important emails, please be sure to check your spam folder regularly to ensure you receive them.

- The "**Greetings**" email
  - This email will be sent from the NIH Research Nurse Specialist **after** your initial intake phone call confirming your eligibility and starting the NIH process. This email contains a scheduled date for your appointment, along with important information including protocol consent documents.
  - If you need to check your schedule or coordinate with your family before confirming, then the "Greetings" email will be sent **after** the NIH Research Nurse Specialist confirms the date you selected.
  - This email will also include a checklist of actions and documents needed prior to your scheduled visit.
- The "**Admissions**" email
  - This email is sent from the NIH Patient Care Coordinator, **2 weeks prior** to your scheduled appointment. This email contains information regarding your travel arrangements, lodging, meals, and schedule of events for your visit. A suggested packing list will also be provided.
- The "**Protocol Consent**" email

This will be sent by the NIH Research Nurse Specialist, **1 week prior** to your visit to complete the consent process. The NIH Research Nurse Specialist will call you to explain the three protocol links in your "Greetings" email and go over any questions or concerns you may have. You will sign the consent forms while you are on this phone call. If for some reason you do not hear from her please call her at: (301)-496-3632.

## What to know before you go:

### Check-List for NIH:

- Appointment confirmation
- Travel arrangements and lodging confirmation
- Schedule of events secure email
- Make sure the following items are packed:
  - A note pad, pen, and prepared questions for the Clinical Trials Team.
  - Walking shoes and comfortable exercise clothes.
  - A print out of your "Admissions Email" sent by your Patient Care Coordinator.
  - Create a "Medical Resume" with Family History
  - Toiletries, comfortable clothing. Similar packing for a 4–5-day vacation. You will notice patients in exercise clothes rather than the stereotypical hospital gowns.
  - Medications: Pack all your medications.