

# GLOBAL LAM PATIENT SUMMIT 2008

---

**Location:** Eynsham Hall - Oxford, England

**Dates:** Friday, January 11 through Sunday, January 13, 2008

**Overview:** This meeting is focused on concrete steps to ensure that patient coordination is useful to making LAM research progress in the fastest time possible. Sessions will address ways that patients can support treatment research through tissue procurement efforts and other areas where patient involvement is crucial. Other topics include updates on clinical trials underway or in the pipeline, and ways for LAM patients to coordinate with researchers and drug companies seeking candidates for drug trials.

## PATIENTS

- \*Havi Carel, *PhD, UK*
- S. Ben Hur, *Israel*
- Stephanie Dreyer, *USA*
- Corine Durand, *France*
- Patricia Elliott, *Ireland*
- Reina Endo, *Japan*
- Lucy Falconer, *UK*
- \*Amy Farber, *PhD, USA*
- Michelle Gonsalves, *France*
- Tuija Helander, *Finland*
- Sara Melloni, *UK/Italy*
- Eleonora Miano, *Italy*
- \*Anke Müller, *Germany*
- Janna Mure, *UK/Finland*
- \*N. Navarro, *Spain*
- Viera Reptova, *Austria*
- Flavia Sobroza, *Brazil*
- Susanne, *Germany*
- Maria Luz Vila Otero, *Spain*

## Clinicians - Researchers:

- Álvaro Casanova Espinosa, *MD, Hospital Universitario la Princesa, Spain*
- Ulrich Costabel, *MD, FCCP, RuhrlandKlinik, Germany*
- Vincent Cottin, *MD, PhD, Hopital Louis Pradel, Reference Center for Orphan Lung Diseases, France*
- Sheila Curristin, *PhD, National Disease Research Interchange, USA*
- Anna Maria Di Giulio, *PhD, University of Milano Medical School, Italy*
- Jim Egan, *MD, Mater Hospital, Ireland*

## GLOBAL LAM PATIENT SUMMIT 2008

### Clinicians - Researchers: (continued)

- Ian Eslick, *Massachusetts Institute of Technology Media Lab, USA*
- Maryam Fathi, *MD, PhD, Karolinska Institute, Sweden*
- Alfredo Gorio, *MD, University of Milano Medical School, Italy*
- Sergio Harari, *MD, Ospedale San Giuseppe, Italy*
- Caroline Heckman, *PhD, Alitalo Lab University of Helsinki, Finland*
- Simon Johnson, *MD, University of Nottingham, UK*
- Jacques Lacronique, *MD, Centre Hospitalier Cochin, France*
- Romain Lazor, *MD, Klinik und Poliklinik für Pneumologie, Switzerland*
- Sherry Marts, *PhD, Society for Women's Health Research, USA (\* Facilitator)*
- Joel Moss, *MD, PhD, NIH-National Heart, Lung, and Blood Institute (NHLBI), USA*
- Tommaso Nicolosi, *MD, Cannizzaro Emergency Hospital, Italy*
- \*Michael Nurok, *MD, PhD, Harvard Medical School, Brigham and Women's Hospital, USA*
- David Rodman, *MD, Novartis Institutes for Biomedical Research, UK/USA*
- Anne Tattersfield, *MD, University of Nottingham, UK*
- Jeffrey Thomas, *National Disease Research Interchange, USA*
- Henrik Watz, *MD, Pulmonary Research Institute GmbH, Germany*
- Vicky Whittemore, *PhD, Tuberos Sclerosis Alliance, USA*
- Kai-Feng Xu, *MD, Peking Union Medical College Hospital, China*

### Family Members and Patient Representatives:

- Sebastiano D'Avanzano, *UK/Italy*
- Cezar Caluschi, *Romania*
- Richard Elliott, *Ireland*
- Guy Fesherman, *Israel*
- Bronwyn Gray, *New Zealand*
- Teijo Hietanen, *Finland*
- Jan Johnson, *UK*
- Krista Kenner, *USA*
- \*Gonzalo Lainez Gutierrez, *Spain*
- Michael Nurok, *MD, PhD, USA*
- Berit Öberg, *Sweden*
- \*Samir Okasha, *D.Phil, UK*
- Solange Sobroza, *Brazil*

### Special Thanks To:

Myles Brown, *MD*  
 Alissa Caron  
 Jennifer Cook, *PhD*  
 Lee Ducat, *NDRI*  
 Ian Eslick  
 Eynsham Hall Staff  
 Melvyn Farber & Betty Heron  
 Global LAM Patient Summit Org. Cttee  
 Caitlin Harvey  
 Gonzalo Lainez Gutierrez & N. Navarro & Bodegas Roda

Dasa Jacisinova & Village Travel  
 LTA Board of Directors  
 LTA Scientific Advisory Board  
 Aaron Montague  
 Joel Moss & the NIH-NHLBI  
 Frank Moss & the MIT Media Lab  
 Caroline Nilsson  
 David Rodman, *Novartis*  
 Susan Robins

## GLOBAL LAM PATIENT SUMMIT 2008

---

### Patient Coordination in the Research Process

#### Friday, January 11, 2008

- ▶ **2:30 - 7:00 pm:** Arrivals/Check-In (LOC: Main Hall)
  - ▶ **7:00 - 9:00 pm:** Introductions and Light Dinner (LOC: Lacey Suite)
    - LTA Global LAM Patient Summit Organizing Committee
    - Amy Farber, PhD, Executive Director, LAM Treatment Alliance
- 

#### Saturday, January 12, 2008

- 7:00 - 9:00 am:** Breakfast (LOC: Main Hall - Oak/Red Restaurant)
  - ▶ **9:00 - 9:15 am:** Introductions (LOC: Main Hall - Green Room)
    - Amy Farber, PhD / Sherry Marts, PhD
  - ▶ **9:15 - 10:30 am:** Why Tissue Matters
    - "Why Tissue is Important," Simon Johnson, MD
    - "The Bridge from Tissue to Research, the Importance of Tissue and Relevant Clinical Patient Data," Caroline Heckman, PhD
    - An International Tissue Program & Network? Part I Will this work for us? (Clinicians, Researchers, Patients, Patient Representatives & Family Members)
  - 10:30 - 10:45 am:** Coffee Break (LOC: Main Hall Area)
  - ▶ **10:45 - 12:45 pm:** LAMsight: Towards a Global LAM Informatics
    - Project Goals - Amy Farber, PhD
      - Introduction to the MIT Media LAB/ LAMsight - Ian Eslick
      - IRB/Ethics Issues - Michael Nurok, MD, PhD
      - Risk/Benefit - Havi Carel, PhD / Samir Okasha, D. Phil.
      - Moderated Q & A - Sherry Marts, PhD et. al.
  - 12:45 - 1:45 pm:** Lunch (LOC: Main Hall - Oak/Red Restaurant)
-

# GLOBAL LAM PATIENT SUMMIT 2008

---

## AGENDA (continued)

- ▶ **1:45 - 3:00 pm:** LAMsight - A Deeper Dive
  - ▶ **1:45 - 4:00 pm:** Novartis Meeting, Room (LOC: Lacey 2, Ground Floor)  
\*Parallel Session (Invite Only)
  - ▶ **3:00 - 4:00 pm:** An International Tissue Program & Network? Part II  
(Patients, Patient Representatives & Family Members)
    - Regional / Country Facilitated Breakout Sessions
  - 4:00 - 4:20 pm:** Break (LOC: Main Hall - Oak/Red Restaurant)
  - ▶ **4:20 - 5:45 pm:** An International Tissue Program & Network? Part III  
(Clinicians, Researchers, Patients, Patient Representatives & Family Members)
  - ▶ **5:45 - 7:00 pm:** Additional Support for Coordinated LAM Structures?
    - Facilitated Q & A
  - 7:00 - 9:00 pm:** Dinner (LOC: Main Hall - Oak/Red Restaurant)
- 

## Sunday, January 13, 2008

- 7:00 - 9:00 am:** Breakfast (LOC: Main Hall - Oak/Red Restaurant)
  - ▶ **9:00 - 10:30 am:** Updates on Clinical Trials (LOC: Main Hall - Green Room)
    - "Update on LAM Clinical Trials," Simon Johnson, MD
    - "RAD001: Similarities and Differences to Rapamycin," David Rodman, MD
    - "Similarities and Differences Between Anti-EGFR and Rapamycin Treatments in a "in vivo" Model of LAM Based on Human TSC2-/-Cells," Alfredo Gorio, PhD
    - "The Use of Tryptoreline in LAM and Beyond," Sergio Harari, MD
    - "Co-Targeting of LAM and Lymphatic Metastasis with Small Molecule Inhibitors," Caroline Heckman, PhD
-

## GLOBAL LAM PATIENT SUMMIT 2008

---

### AGENDA (continued)

- ▶ **10:30 - 11:00 am:** Clinical Trials Coordination and the Challenge of Multiple Trials and Off-Label Drug Use
  - Ulrich Costabel, MD, FCCP
- 11:00 - 11:15 am:** Break (LOC: Main Hall Area)
- ▶ **11:15 - 12:30 pm:** Round-up / Next Steps
  - Tissue
  - Database
  - Organizational Structures
  - Family Member Resource Round-up
- 12:30 - 1:30 pm:** Lunch (LOC: Main Hall - Oak/Red Restaurant)
- ▶ **1:30 - 3:30 pm:** Networking and Departures