

GO2 Foundation for Lung Cancer  
ATS

**August 4, 2020**

GO2Foundation.org

April 2019, Bonnie J. Addario Lung Cancer Foundation and Lung Cancer Alliance joined forces to become the GO<sub>2</sub> Foundation for Lung Cancer.

**Go<sub>2</sub> Foundation for Lung Cancer is the place where everyone impacted by lung cancer finds personalized care, powerful connections, and purposeful collaboration-uniting around shared goals to empower people, increase survival, drive innovative research, and transform the future of lung cancer.**

**Screening Centers of Excellence Program (SCOE)** - Our network of Screening Centers of Excellence (SCOE) are committed to responsible, high quality screening practices. The designation of SCOE ensures low dose CT screening for lung cancer is carried out safely, efficiently and equitably assuring follow-up is provided in a multidisciplinary setting.

**Care Continuum Centers of Excellence Program (CCCOE)** - The Program is a nationwide network of community hospitals that deliver patient-centered standard of care to communities that is similar to the specialty care provided at leading academic institutions. CCCOE Impact study has been created to understand and track the impact of the participation on lung cancer treatment, diagnostics, and outcomes at participating hospitals.

**Both Screening and Care Programs, provide sources of quality improvement initiatives within their facility setting. Annual surveys are sent with dashboards to help identify areas of opportunity. Both annual screening and care conference and CCCOE summit are held with best practices shared.**

**Assistance is provided to hospitals, imaging facilities and healthcare providers in starting or streamlining their program anywhere along the lung cancer continuum of care.**

**Support Groups-** GO<sub>2</sub> realizes the need for ongoing local lung cancer support groups and maintain an active list online. For healthcare providers or others interested in starting a program, we have a brochure on how to start a lung cancer support group in addition to a troubleshooting guide.

**Lung Cancer Registry** - The International Lung Cancer Patient Registry is an organized system to directly involve patients in the collection of their disease data and engage the medical community in the analysis and use of this data to improve patient care and drive innovative research.

**Addario Lung Cancer Medical Institute (ALCMI)** –Supports multi-centered correlative studies, driving forward cutting-edge studies on the inheritance of lung cancer, blood-based approaches to understanding the mechanisms of reoccurrence and resistance, and creation of new cancer models with patient groups.

# Education & Awareness

**Patient Education Handbook and Brochures** – A comprehensive, centralized, up-to-date resource exclusively devoted to lung cancer. It provides detailed info (disease overview, diagnostics, treatment options, clinical trials, etc.) in laymen's terms in an easy-to-read format. Is also available in Spanish and Simple Chinese. We also provide those facing lung cancer and those at risk for lung cancer with the most up-to-date and reader-friendly information on a variety of topics specific and relevant to each patient and caregivers' unique needs. Topics include nodules, diagnosis, molecular testing, staging, treatment options including clinical trials, psychosocial support and more. all materials are free of charge.

**Educational Video Library** – GO2's Video Library/Archive is an enduring educational resource. Site provides content for the lung cancer community with access to diverse information: 20 Minute educational video's on tailored lung cancer topics, Unique and unique patient stories; Lung Cancer specific PSAs and news about GO2 and Addario Lung Cancer Medical Institute (ALCMI) research studies.

**Personalized Navigation** -Our toll-free helpline is available by calling 1-800-298-2436.

**LungMatch**- Personalized service that informs and guides patients through the many medical and clinical trial alternatives, helping identify the appropriate treatment options to discuss with their doctor.

**Phone Buddy and Guides**- Personalized peer support patients can access from anywhere. Our Phone Buddy Program matches those diagnosed with lung cancer with trained volunteers (Phone Buddies) who have gone through similar clinical situations (diagnosis and treatment) and can help by sharing their experiences. Guides is a matching program offering caregivers support at the end of life.

**Lung Cancer Living Room™ “Bringing Hope Home”** – A free monthly Support Group/Patient Education, Speaker Series & World-Wide Live Stream held at our West Coast Office. Expert speakers are invited to speak on specific topics around lung cancer. Where monthly we receive the patient perspective and feedback.

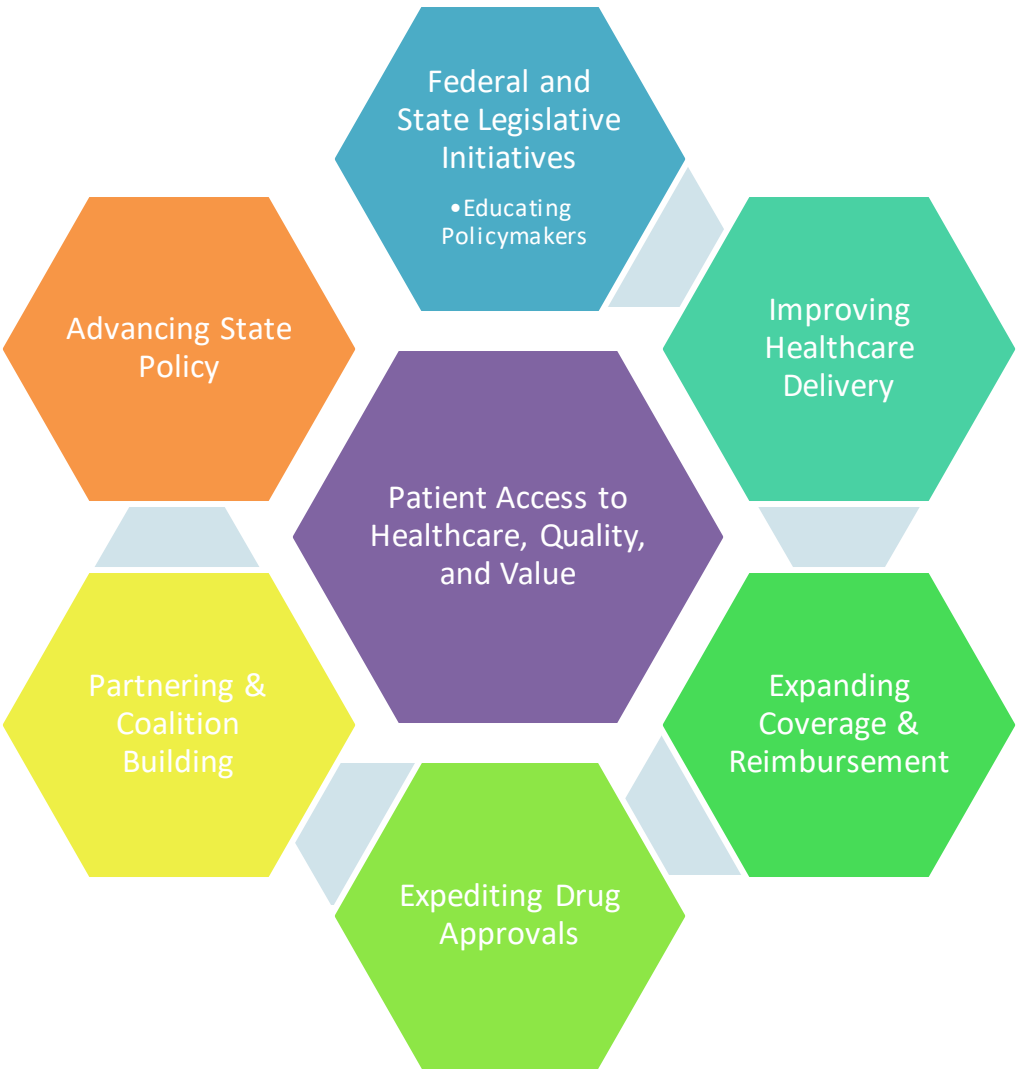
**Belong App & HealthUnlocked** – We are growing a lung cancer community which is accessible simply by mobile phone or internet that provides accurate, up-to-date content about lung cancer diagnosis, treatment and survivorship. These online communities are able to ask questions, share information and offer support.

**Shine a Light** – Free awareness and educational events—for both organizers and attendees—hosted by healthcare facilities as a way to connect with the lung cancer community during November, Lung Cancer Awareness Month or Shine a light your way, anytime of the year.

**National Events Series** –Awareness event opportunity including physician keynote presentations and patient education information shared within patient services booth.

Our central goals include:

- Make lung cancer a national public health priority
- Coordinate a comprehensive federal plan
- Link prevention to early detection and treatment research
- Increase survivorship



- **Federal and State Legislative Initiatives; Educating Policymakers**
  - Recalcitrant Cancer Research Act
- CDMRP – \$20 million lung cancer funding request and 20/20 Campaign
- Women & Lung Cancer Research & Preventive Services Act and Save Her Lungs Campaign
  - Congressional Briefings
  - National Advocacy Summit
  - Member & staff meetings
  - Community Action Alerts
  - Op Eds & Awareness campaigns
- **Improving Healthcare Delivery**
  - Patient centric/value health policy
  - Preserving essential health benefits
  - High quality and affordable screening and care
- **Expanding Coverage & Reimbursement**
  - Biomarker testing, screening & treatment, palliative care
  - Drug pricing
  - NGS NCD, CAR T-cell NCD, ICER, Medicare Part D, 6 protected classes, rebate rule, Rx pricing reform, step therapy, payment models, Medicare/Medicaid/commercial payer policies
- **Expediting Drug Approvals**
  - Patient perspectives, PEAC, FDA
  - Advocate for PRO data; registry
  - 21<sup>st</sup> Century Cures, ODAC, LungMAP
- **Partnering & Coalition Building**
  - CMS, ACR, ACS, NLCRT, STS, PIPC, NHC, Aimed Alliance, PMC, IASLC etc.
- **Advancing State Policy**
  - State cancer plans
  - Step therapy
  - Steerage, Medicaid, value based economic assessments
  - KYLEADS, ALCASE

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# Lymphangiomyomatosis (LAM)

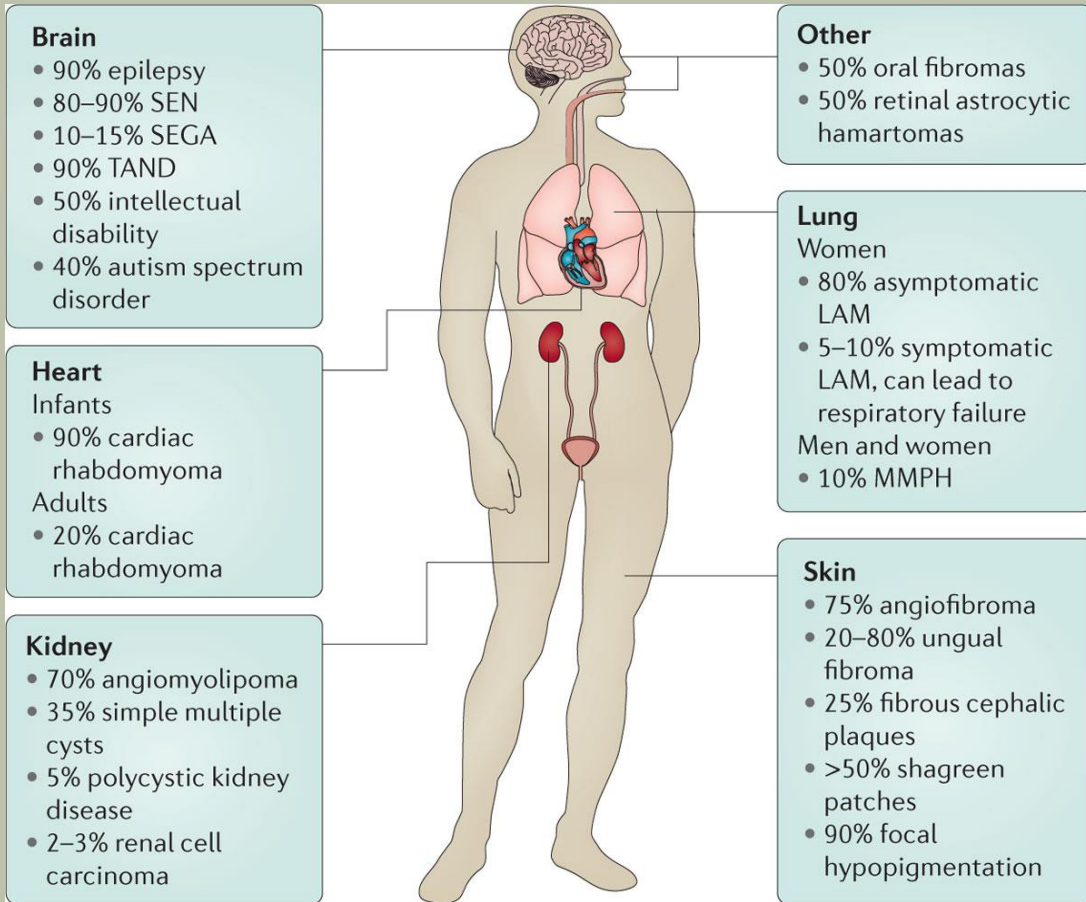
- Rare, progressive, cystic lung disease, primarily in women, no cure
- The LAM Foundation (TLF) – founded in 1995
- Patient registry, 60+ clinics, NHLBI and NIH involvement
- Annual International Conference-scientists, clinicians, patients
- Tissue bank, cell models, animal models
- Molecular pathways, LAM gene, biomarker
- MILES Trial, FDA approved treatment-sirolimus targets mTOR pathway
- RESULT Trial-resveratrol, phase 2

# Future Directions in LAM

- Additional drugs for treatment
- Additional biomarkers for diagnosis and prediction of disease progression



# Tuberous Sclerosis Complex (TSC) Affects Multiple Organs Throughout the Lifetime



Henske, E. P. *et al.* (2016) Tuberous sclerosis complex  
*Nat. Rev. Dis. Primers* doi:10.1038/nrdp.2016.35

Nature Reviews | Disease Primers

- TSC impacts: 1 in 6,000 live births, 50,000 in the US, 1 million worldwide
- Lymphangiomyomatosis (LAM)
- Multifocal micronodular pneumocyte hyperplasia (MMPH)
- For more information: [www.tsalliance.org](http://www.tsalliance.org)

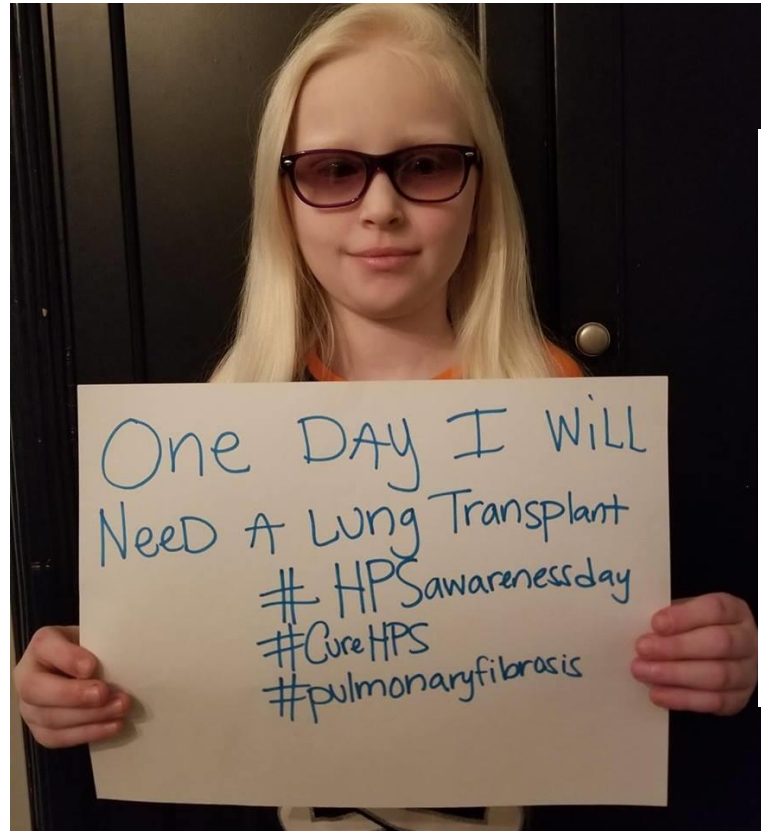




**ATS / MITT Student Scholars  
Virtual PAR PATH Tour  
August 4, 2020**

# Single gene disorder – HPS 1 – 11

Characterized by: Albinism / Legal blindness / Platelet defect – bleeding disorder / Crohn's-like Inflammatory Bowel Disease / Pulmonary Fibrosis (HPS 1,2 &4)







First Responder QR  
Safety Cards

"We're Drawn Together"

Individual  
Research Plans

Why are we important to your career?

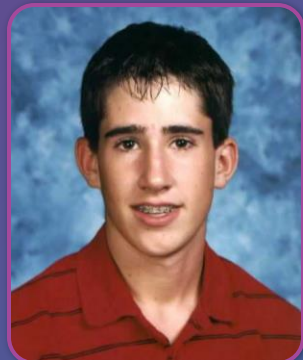
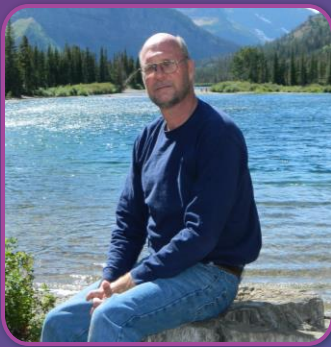
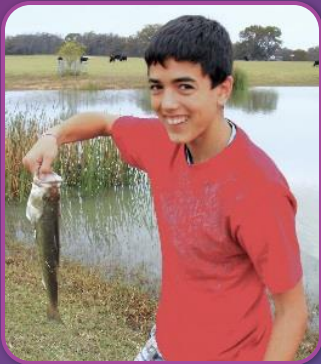
We fund  
Researchers

We add depth to careers  
for advancement

We inspire and  
motivate







# ASAP

Alliance of Sleep Apnea Partners

[www.ApneaPartners.Org](http://www.ApneaPartners.Org)

Designed with Patients in Mind



**COPD Foundation Overview  
ATS Virtual 2020 Conference  
Patient Advisory Roundtable PATH  
August 2020**