SCLERODERMA FOUNDATION

SUPPORT · EDUCATION · RESEARCH

TRI-STATE CHAPTER

SCLERODERMATRISTATE.ORG

Scleroderma

Mary Beth Bobik-Kadylak

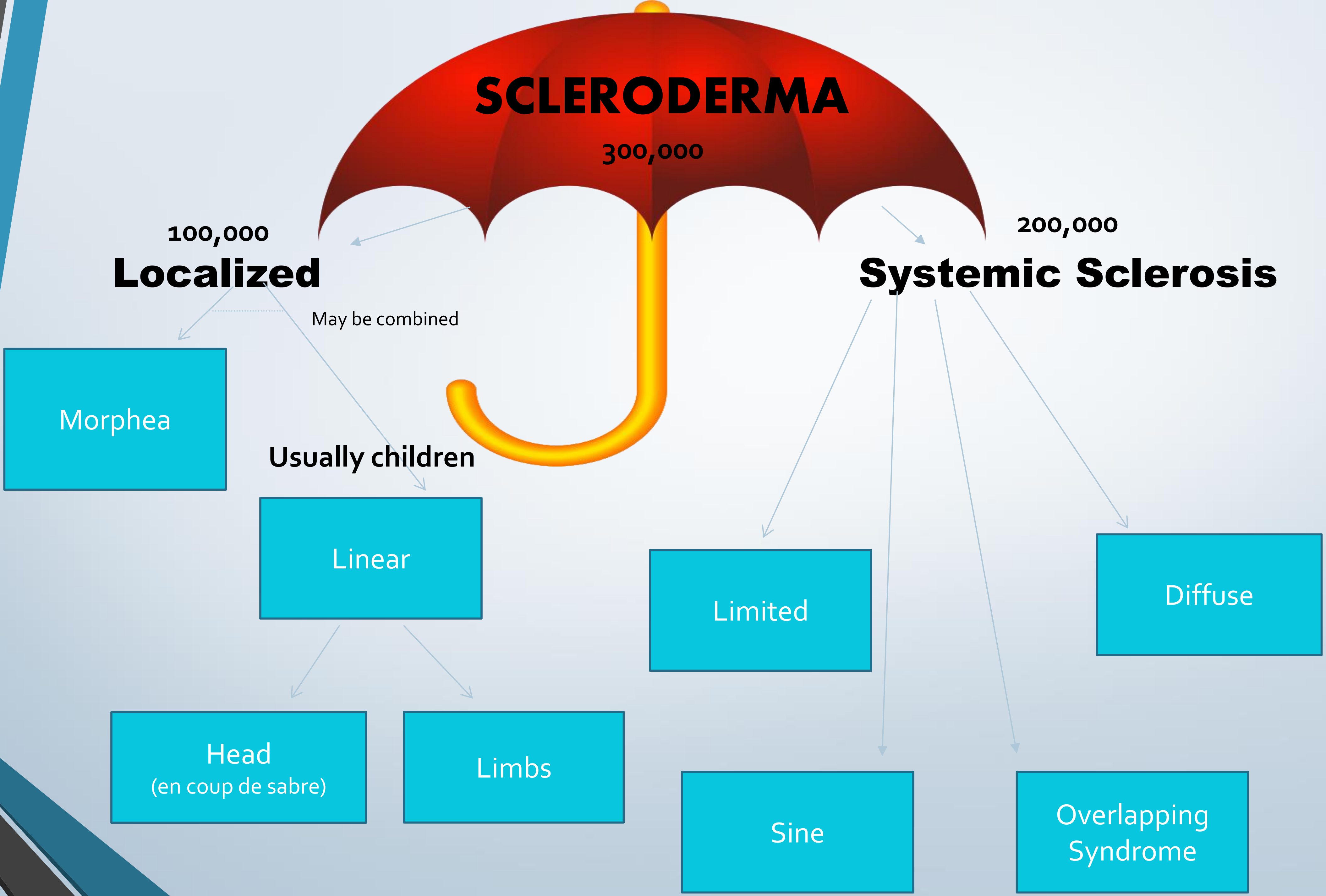
Director of Patient Education & Support

Scleroderma Foundation, Tri-State Chapter

mbbkadylak@sclerodermatristate.org

Scleroderma Overview

- Genetic, not hereditary
- Needs a triggering event to set the wheels in motion
- This disease is complex - categorized now as autoimmune disease or connective tissue disease or rheumatological disease
- Can affect anyone at any age
- Women vs men: 4:1 – childbearing years
- Often progressive, debilitating, life threatening
- No known cause or cure



SCLERODERMA

300,000

100,000

Localized

May be combined

Morphea

Usually children

Linear

Head
(en coup de sabre)

Limbs

200,000

Systemic Sclerosis

Limited

Diffuse

Sine

Overlapping Syndrome

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Areas of Unmet Need

- Disease Awareness – how to provide awareness of the thousands of Rare and / or Autoimmune Diseases?
- Disease Education – to empower patients and families AND educate physicians and all variety of health care professionals
- Support for Patients and Families
- Participation in Research

Disease Awareness

- Our goal each year is to promote awareness of Scleroderma so those affected by this disease will know where to turn for help.
- We provide awareness through our Stepping Out to Cure Scleroderma Walks (Hartford on 6/10/2018)
- We have volunteers who promote our organization and the resources we provide at any appropriate health fairs that we can find to participate in.

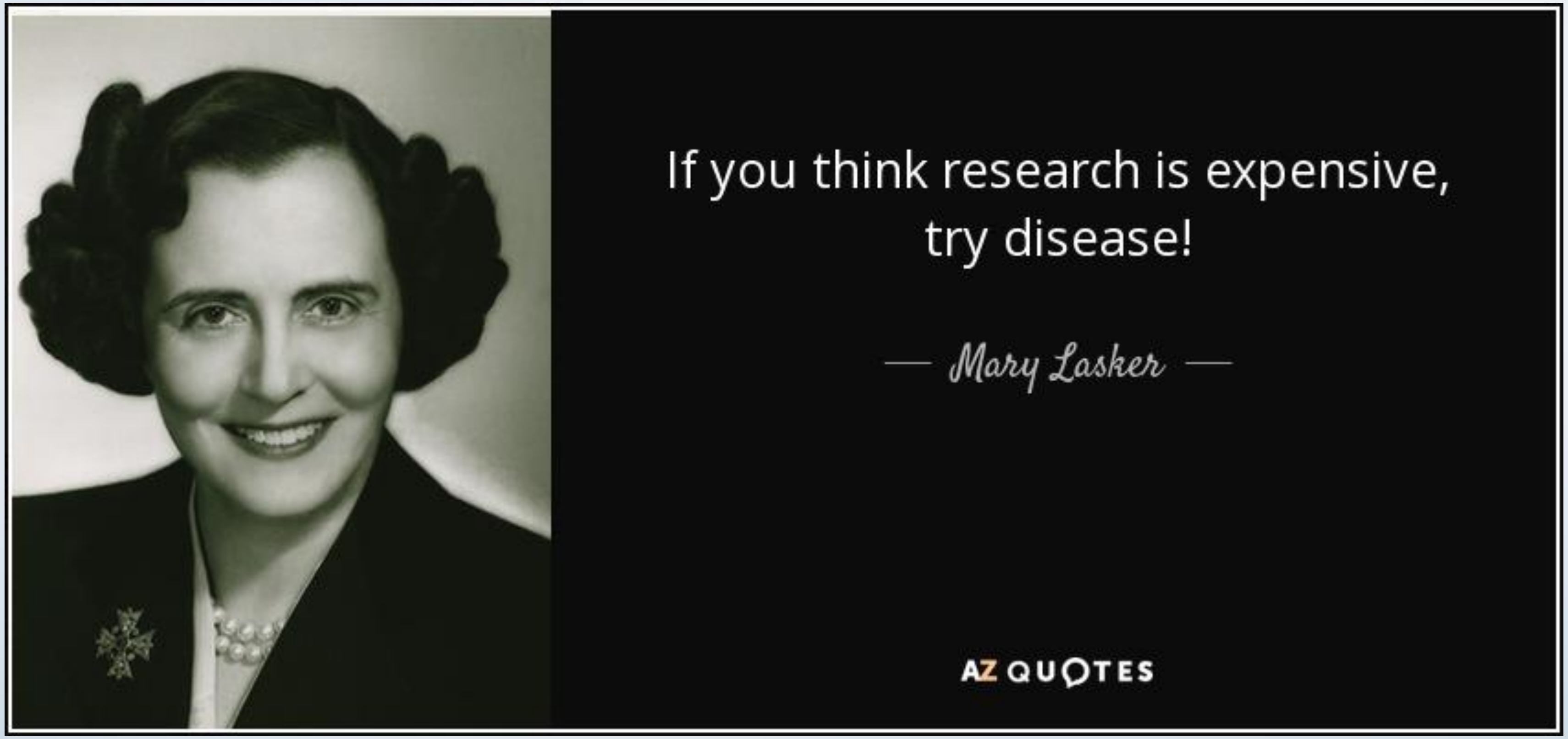
Disease Education

- Through our support groups (3 in CT)
- Through education programs – Yale and UConn
- Online videos at: SclerodermaVideo.com or through our lending library which also includes many print articles and books – listed online at sclerodermatristate.org
- Creating opportunities for physicians and med students, nursing students etc. to learn about the disease.

Support for Patients/Families

- In CT with a pop of about 3.6 million – potentially have at least 3600 individuals with scleroderma.
- CT has only 2 centers designated as treatment centers –Health & Yale – many patients will go to MA or NY for treatment. UConn
- We serve NYS, CT and Northern NJ – estimated patient population – 30,000
- Partner this with the total US population with rare diseases, the job of finding ways to support individuals is a task that seems nearly impossible – however once you have the programs in place and a process that we can refer patients to with the resources they need – it can by done.

Research

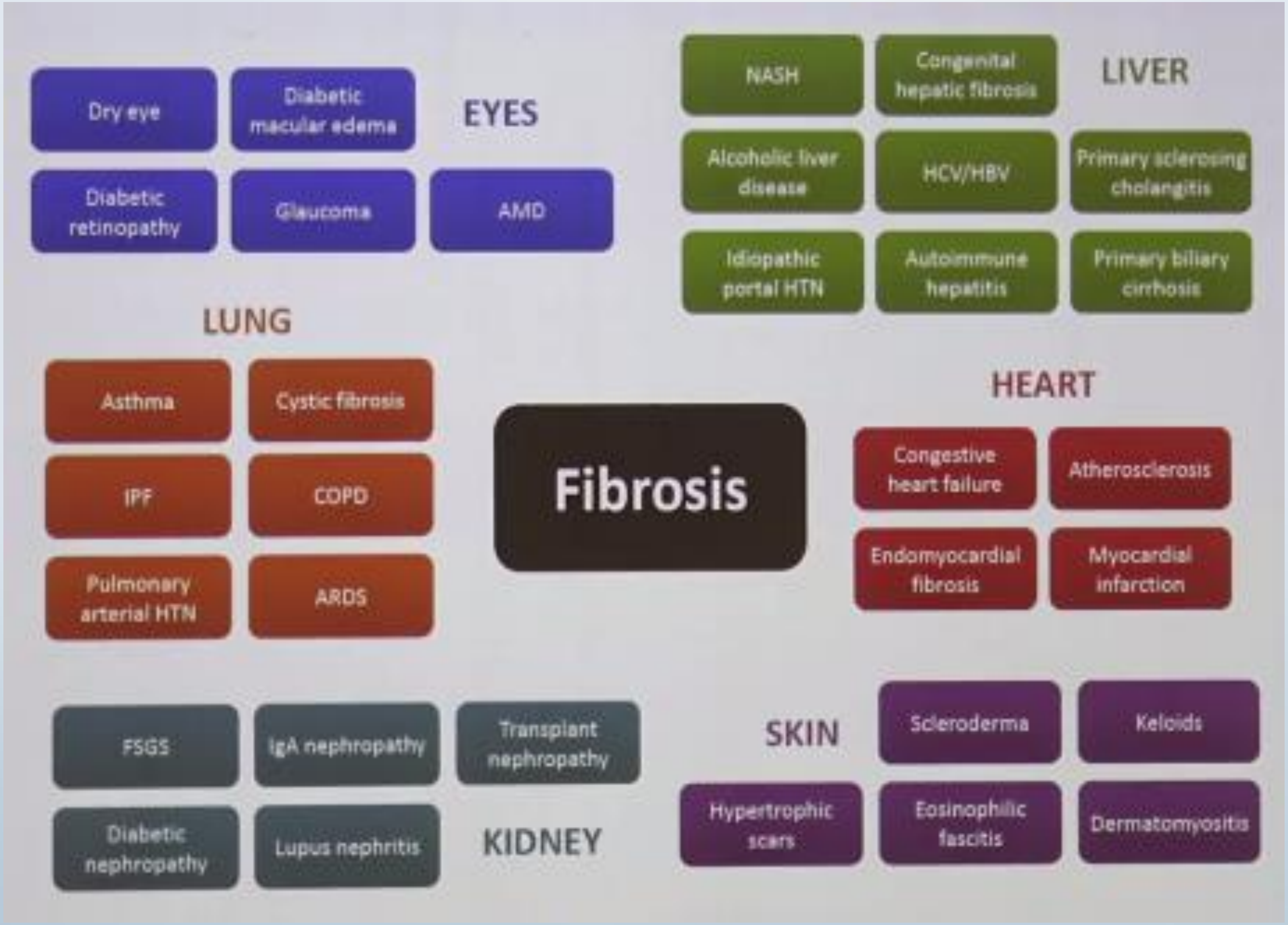


If you think research is expensive, try disease!

— Mary Lasker —

86% of the nation’s $2.7 trillion annual health care expenditures are for people with chronic health conditions

$2,300,000,000, 000



Fibrosis

EYES

- Dry eye
- Diabetic macular edema
- Diabetic retinopathy
- Glaucoma
- AMD

LIVER

- NASH
- Congenital hepatic fibrosis
- Alcoholic liver disease
- HCV/HBV
- Primary sclerosing cholangitis
- Idiopathic portal HTN
- Autoimmune hepatitis
- Primary biliary cirrhosis

LUNG

- Asthma
- Cystic fibrosis
- IPF
- COPD
- Pulmonary arterial HTN
- ARDS

HEART

- Congestive heart failure
- Atherosclerosis
- Endomyocardial fibrosis
- Myocardial infarction

KIDNEY

- FSGS
- IgA nephropathy
- Transplant nephropathy
- Diabetic nephropathy
- Lupus nephritis

SKIN

- Scleroderma
- Keloids
- Hypertrophic scars
- Eosinophilic fascitis
- Dermatomyositis

Support for HR4638

- **H.R.4638 - National Commission on Scleroderma and Fibrotic Diseases Act of 2017**

Contact Information

Mary Beth Bobik-Kadylak
800-867-0885
mbbkadylak@sclerodermatristate.org
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