**Testimony from Tina Fellows, Executive Director, Scleroderma Foundation Ohio Chapter for HB 412:**

1. We need to take advantage of existing research momentum. In 1950, there were 62 scleroderma research papers published. In 2015, there were 990 research papers published.
2. Creating more opportunities for scientific breakthroughs is crucial.
   1. Classification of systemic sclerosis dramatically aided diagnosis and treatment.
   2. Better treatments have reduced mortality rates.
   3. Understanding the role of genetics vs. environment is a whole new opportunity.
3. We have a real challenge to retain researchers who will study scleroderma and other rare diseases. Figuring out how to attract good researchers to study rare diseases is of utmost importance.
   1. Experienced researchers naturally follow paths of study that offer more reliable and larger funding to sustain their laboratories (i.e. more well-known diseases).
4. We must accelerate the pace of discovery.
   1. Fibrosis is one of the hallmarks of scleroderma. It affects other rare diseases as well.
   2. Solving the fibrosis puzzle in scleroderma could be the key to unlocking other diseases.
   3. Fibrotic disorders are typically chronic and can often be fatal. Overall, 45 percent of deaths across the U.S. each year are attributed to fibrotic disorders. Many are unaware of this shocking statistic because the cause of death in these cases is end-stage organ failure.
5. This needs attention urgently. Systemic scleroderma and other rare diseases can be fatal. We are moving too slowly to save lives for people diagnosed today.