

Advocate Spotlight: Tomisa Starr



For many, simple errands like going to the grocery store or the post office don't require much planning.

That's not the case for **Tomisa Starr**, who has used supplemental oxygen since 2015 to manage her fibrotic interstitial lung disease, in addition to scleroderma and pulmonary arterial hypertension.

Tomisa receives a steady stream of oxygen through a nasal cannula, which requires her to carry a rolling cart with a heavy oxygen tank that must be changed every 45 minutes. These limitations make it difficult for her to leave her home – even for doctor and specialist appointments. Other seemingly simple activities, like a trip to the grocery store, seeing a movie at a theater, or taking an overnight trip, are mostly out of the question for Tomisa. Her lifelong dream is to return to school and complete her undergraduate degree in mathematics, but long lectures are nearly impossible when her oxygen supply cannot sustain her for an extended period.

While Tomisa is an ideal candidate for liquid oxygen, it remains out of reach with no supplier offering liquid oxygen in her hometown.

Liquid oxygen is lighter, more portable, and delivers higher-flow oxygen for those with advanced lung disease. Yet, Medicare payment policies for supplemental oxygen – including a system known as the Competitive Bidding Program (CBP) – have driven payment rates for liquid oxygen below the actual supply and delivery costs. As a result, liquid oxygen options are now scarce for Medicare beneficiaries and even for those on other forms of insurance, like Tomisa.

Tomisa Starr is an American patient advocate and activist for the chronic autoimmune disease scleroderma. Her work includes raising awareness and supporting research for the disease, with an emphasis on addressing the disparate treatment outcomes for African Americans.

What would **THE SOAR ACT** mean for Tomisa?

- Access to liquid oxygen.
- Better disease management and higher quality of life.
- Increased independence and activity outside home.
- Opportunity to complete her education and engage in her community!

On behalf of Tomisa and other advocates across the country, **the oxygen community calls on Congress to pass the Supplemental Oxygen Access Reform (SOAR) Act (S. 1406/H.R. 2902)**, which would stabilize payments for liquid oxygen, better align Medicare payments with the costs of care, and establish patient support resources.