



**VISION HEALTH**  
ADVOCACY COALITION

# The Patient Perspective

WITH JULIE OWENS

**Thyroid eye disease, or TED, is a rare autoimmune condition that causes inflammation and tissue buildup behind the eyes.** Symptoms can include eye bulging, vision changes, pain and even permanent vision loss. Because TED often develops alongside thyroid disorders, diagnosis can be delayed or missed. Early recognition and treatment are key to protecting quality of life.



## How did you first learn you had thyroid eye disease, or TED?

My health issues first began with Graves' disease, which eventually led to a thyroidectomy. After that, I started experiencing symptoms like watery eyes, sensitivity to light, eye bulging, chronic fatigue and rapid weight loss. At first, many of these symptoms were connected back to my thyroid condition, which can make it difficult to recognize that something else is happening. TED is often misunderstood or overlooked because it shares symptoms with other thyroid-related conditions. As my symptoms became more disruptive and persistent, my doctor referred me to an ophthalmologist. That referral was an important turning point, because it was the first time TED was clearly identified as part of what I was experiencing.



## Did you face any challenges in accessing your treatment, including issues with insurance coverage?

Getting access to the treatment my doctor recommended took time because we had to demonstrate to the insurance company that other options had already been tried. That process lasted about eight or nine months, and during that time my symptoms continued to worsen. By the time my treatment was approved, the disease had progressed and I was dealing with more severe symptoms, making it difficult to focus on everyday tasks. When a condition affects your vision and eye health, delays like that can make the situation much more serious.



## Why has advocacy been important in your experience?

Self-advocacy became a critical part of my journey, especially when I had to switch endocrinologists because of insurance changes and explain my entire medical history to a new doctor. That process can be mentally exhausting when you are already managing a complex disease. I work in education, so asking questions and clearly communicating my experience came naturally, but not everyone has that advantage. Over time, my experience pushed me to become more involved in advocacy by educating others about thyroid eye disease and helping connect patients with organizations and communities that can offer support.



## What advice would you give to someone who has just been diagnosed with thyroid eye disease?

If you are newly diagnosed, a few things can help guide you through the experience:

- 1. Acknowledge what is happening.** Pay attention to your symptoms and recognize when something is not right.
- 2. Give yourself time to accept it.** Acceptance helps you focus on learning about the disease and making informed decisions.
- 3. Stay informed and connected.** Keep close communication with your doctors, find the specialist who is right for you and take time to learn about the condition yourself.
- 4. Do not give up.** Thyroid eye disease may be rare, but there are others who understand what you are going through, communities that can support you and treatment options available.

## Policy solutions can help ensure patients are not left waiting.

Timely access to specialists and treatment, prompt coverage decisions and provider education are essential for managing this disease.



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