EXECUTIVE SUMMARY

Pre-Conference Patient Survey – CONNECTED 2025
TED Community Organization

1. Purpose and Context

Ahead of the CONNECTED 2025 Global Virtual Conference, the TED Community Organization surveyed people living with **Thyroid Eye Disease (TED)** and often **Graves' disease**, along with a smaller group of care partners.

The survey explored:

- Who respondents are and where they live
- Their experience with TED and Graves'
- Use of TED Community resources
- Symptom burden and disease course
- Care pathways and provider types
- Hopes for CONNECTED 2025
- What "NED – No Evidence of Disease" means to them
- Priorities for a TED Quality of Life (QoL) Program
- Graves' support needs
- Willingness to share their story
- What they wish their doctors understood

The full dataset now includes **dozens of responses from multiple countries and U.S. states**, giving a robust view of the lived experience of TED.

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2. Who Responded

2.1 Geography and roles

Respondents come from:

- Across the **United States** (e.g., CA, CO, NY, MA, MI, MN, NC, SC, FL, TX, WA, WI, OH, AZ, HI, ME, PA, NJ, LA, IN, SD, MD, etc.)
- And **internationally** from **Mexico, Canada, the United Kingdom, France, Israel, Hong Kong, New Zealand, Uruguay, South Africa/Austria, India, Colombia, Puerto Rico** and more.

Most identify as:

- **Living with TED**, and
- A large proportion also **living with Graves' disease**.
- A smaller but important group are **care partners / family members**.

2.2 Time living with TED and time with TED Community

- TED duration ranges from **less than 1 year** to **more than 5 years**; many have lived with TED for **3–5+ years**.
- Some respondents are connecting with the TED Community **for the first time**, while others have been engaged **for several years**, using multiple resources.

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3. Engagement With TED Community Resources

Respondents report using or knowing about:

- **Online Support Groups** – widely used and often described as a lifeline.
- **TED ART & Creative Studio** – a valued space for expression and connection.
- **TED Connect (peer mentorship / discussion spaces)** – key for peer support and shared wisdom.
- **Information about treatments and clinical trials** – heavily used by patients making treatment decisions.
- **Educational videos and newsletters** – central for ongoing learning.
- **Other resources** – emails, Tepezza patient assistance (PAL), and various local supports.

Across comments, people repeatedly express **gratitude** for TEDCommunity.org, saying it has reduced isolation, informed major decisions (e.g., avoiding or postponing thyroidectomy), and provided hope.

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4. Symptom Burden and Disease Course

4.1 Most impactful symptoms

The symptoms most often reported as affecting daily life are:

- **Double vision (diplopia)**
- **Bulging / proptosis**

- **Dry eyes**
- **Pain or pressure** behind the eyes
- **Swelling** around the eyes and lids
- **Light sensitivity**
- **Watery/tearing eyes**
- **Eyelid retraction**
- **Bags under the eyes**

Double vision, in particular, is described as:

- Making **driving, reading, computer work, and walking safely** difficult
- Interfering with work, independence, and social life
- Emotionally exhausting and isolating

Several respondents note that, even after Tepezza or surgery, **bulging may improve but double vision remains**, which is a major source of frustration and fear.

4.2 How symptoms evolve

Patients describe a spectrum:

- **Improved but not fully resolved** – common after treatment or surgery.
- **Fluctuated with flares and improvements** – many live with unpredictable ups and downs.
- **Worsened without relief** – a smaller group experiencing ongoing active or refractory disease.
- **Fully resolved** – a minority; some report near-normal life with only minor dryness or light sensitivity.

Overall, TED emerges as a **long, often non-linear journey** rather than a single episode.

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5. Care Pathways and Provider Landscape

Most patients see combinations of:

- **Endocrinologists**
- **Ophthalmologists**
- **Oculoplastic surgeons**
- **Neuro-ophthalmologists**
- **Primary care providers**
- Occasionally **rheumatologists, internal medicine physicians, functional medicine practitioners**, or others.

Key problems reported:

- **Fragmented care** and poor coordination across specialties.
- **Long wait times** (e.g., months to see a TED specialist).
- Providers who **lack specific TED knowledge** or treat it as a minor cosmetic issue.
- Overreliance on a single treatment (especially Tepezza) without fully explaining **risks (e.g., hearing loss)** or alternatives.
- Out-of-date beliefs (e.g., assuming TED will resolve completely once thyroid hormones are controlled).

Patients want clinicians who:

- Are **up to date on research and treatments**
- Acknowledge the **quality-of-life and emotional impact**
- Refer early to **specialists** and to **TEDCommunity.org**
- Collaborate across disciplines rather than working in silos.

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6. Hopes for CONNECTED 2025

Across the dataset, patients hope to gain:

- **Deeper understanding of the science of TED and Graves'** – causes, antibodies, mechanisms.
- **Clear information on current and emerging treatments** – medications, biologics, infusions, surgeries, timing, repeat rounds, hearing and other side effects.
- **Practical daily-living strategies** – coping with vision, mobility, appearance, driving, work, and fatigue.
- **Emotional and mental-health support** – ways to manage fear, grief, anxiety, depression, and changes in identity.
- **Quality of Life research** – how TED affects functioning and what long-term outcomes look like.
- **Advocacy and patient voice** – how to push for better care, coverage, and awareness.
- **Caregiver support** – especially for family members navigating care alongside patients.

People with both high and low baseline knowledge describe wanting **trusted, patient-centered education** they can't easily get from their own providers.

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7. What NED Means to Patients

Across all responses, **NED (No Evidence of Disease)** is described less as a lab result and more as a **felt state of freedom**:

- **No or minimal double vision** – being able to drive, work, read, navigate stairs, and move independently.
- **Reduced or resolved bulging, swelling, and redness** – looking more like themselves, or at least feeling comfortable with their appearance.
- **Relief from pain, pressure, tearing, headaches, and eye strain.**
- **Stable, non-flaring disease** – not living under constant fear of relapse.
- **Regained confidence, independence, and social connection.**

Some also include **clinical metrics** (e.g., CAS of 0, normal antibody levels, normal intraocular pressure), but the central idea is:

A life where TED no longer dominates every decision, thought, or interaction.

8. Priorities for the TED Quality of Life Program

When asked which topics they want in an 8-module TED Quality of Life Program, respondents consistently prioritize:

- **Nutrition** – especially for inflammation, immune regulation, Graves' management, and energy.
- **Movement / exercise** – safe ways to stay active and build strength without triggering flares.
- **Sleep hygiene** – protecting the eyes at night, coping with disrupted sleep, fatigue.
- **Stress management** – mind–body tools, relaxation, trauma-informed practices, nervous-system regulation.
- **Social connection** – reducing isolation and building supportive community.
- **Mental & emotional wellness** – anxiety, depression, body image, fear, resilience.
- **Career & financial security** – work accommodations, disability, financial stress.
- **Healthy environment** – light sensitivity, digital strain, home/work adaptations.
- **Other dimensions** – notably: **healthcare navigation**, and for some, **spiritual well-being**.

This confirms that patients are asking for a **whole-person, lifestyle-oriented program** that complements medical care.

9. Graves' Disease: Support Needs

For respondents living with Graves', major needs include:

- **Understanding the relationship between Graves' and TED** – including whether one implies the other and how antibodies behave.
- **Decision support around treatment options** – medication vs. RAI vs. thyroidectomy; timing; what happens afterward.
- **Post-thyroidectomy / post-RAI life** – what to expect physically, hormonally, and emotionally; how to manage long-term.
- **Help interpreting labs** (T3, T4, TSH, TSI/TRAb), especially when endocrinologists resist ordering certain tests.
- **Lifestyle tools to help reduce antibodies and flares** – nutrition, supplements, stress reduction, movement.
- **Protection from misinformation** – patients want **evidence-based resources**, while still being curious about integrative/functional approaches.
- **Education for endocrinologists and other doctors** – some explicitly ask for **guides they can give to their providers**.

For many, Graves' support is inseparable from TED support.

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10. Storytelling and Patient Voice

Many respondents are:

- Willing or "maybe later" open to sharing their story via **written blogs, recorded videos, social media features, and panel discussions.**

This presents a strong pool of potential **patient storytellers and ambassadors** for:

- Future campaigns
- Educational materials
- Conference panels
- Advocacy initiatives

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11. What Patients Wish Doctors Understood

Across open-ended responses, patients wish their doctors and care teams better understood:

- The **constant, exhausting nature** of symptoms (pain, pressure, double vision, headaches, tearing, balance issues).
- The **emotional and identity impact** – how appearance changes personality, confidence, and social behavior.
- The **degree of isolation** – many feel they have lost the person they once were.
- The **mental load of self-advocacy** – switching providers, fighting for referrals, insurance appeals, and patient-assistance programs.
- The **limits of current treatments** – especially that Tepezza is not a universal solution and can have serious side effects.
- The need for **compassionate communication and honest referrals** when clinicians are uncomfortable treating TED.
- The importance of **community support**, not just prescriptions.

Some explicitly ask for doctors to **stay current on research**, acknowledge TED as **multi-disciplinary**, and **work together** across specialties.

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12. Key Implications for the TED Community Organization

The combined dataset points to clear priorities:

1. **Education & Clarity**
    - Deepen education on the science of TED/Graves', treatment options, and long-term management.
    - Create tools for lab interpretation and treatment decision-making.
2. **Quality of Life & Self-Management**
    - Build the TED Quality of Life Program around the core modules patients requested: nutrition, movement, sleep, stress, mental health, social connection, career/financial security, and environment (with optional spiritual/values content).
3. **Navigation & Advocacy Support**
    - Provide resources for evaluating and finding knowledgeable providers, navigating insurance and assistance programs, and coordinating multi-specialty care.

4. **Community, Emotional Healing, and Creative Expression**
    - Continue and expand support groups, TED ART & Creative Studio, TED Connect, and other spaces that address the emotional toll and foster belonging.
5. **Global Perspective & Equity**
    - Recognize the needs of international patients who may have limited local expertise or access to treatments, and explore ways to support regional chapters or local connections.
6. **Elevating Patient Voice**
    - Engage willing respondents as speakers, writers, and advisors for CONNECTED 2025 and future initiatives, ensuring that **patients co-create** the agenda and solutions.