

An illustration of a diverse group of people of various ages, ethnicities, and genders standing on a colorful, multi-level staircase. The people are dressed in casual and professional attire. The word "KERATOCONUS" is written in white capital letters on a blue rectangular background that is part of the staircase structure.

KERATOCONUS

THE TRIED-AND-TRUE METHOD IS TO BUILD TRUST



Retain patients with keratoconus by showing them sincerity and empathy.

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BY EMILIO A. TORRES-NETTO, MD, PHD

Winning patients for life is not difficult. The ELZA Institute, where I practice, uses several strategies to attract and retain patients. What may surprise you is that social media doesn't play a big role in our efforts. The essential strategic elements are a solid knowledge base, sincerity, and empathy.

A large portion of our patients have keratoconus. Dozens of people present each month with all stages of the disease. Keratoconus disproportionately affects children and adolescents, but it can affect people of all ages (Figure 1).¹ If the disease is not treated in a timely fashion, corneal steepening and thinning typically result in significant visual impairment.

Our relationships with patients—particularly those with keratoconus—

often lasts many years. Establishing trust and an empathic connection is the key to maintaining these relationships for the long term.

PROVIDE EDUCATION WITH EMPATHY AND COMPASSION

Children and young adults with keratoconus are typically accompanied by their parents, guardians, or other family members. All of them are anxious about their diagnosis and worried about what comes next. They are generally confused and overwhelmed because the treatment strategy can be complex and vary by disease stage and the age of the patient.

Most important is to inform and reassure everyone involved that treatment options are available that

address the spectrum of the disease—from its earliest, subclinical forms to its advanced stages. It's also important to explain that there are two aspects of treatment: halting disease progression and rehabilitating vision.

Demonstrating empathy and compassion during discussions builds trust between the patient, their family, you, and your team and forms the foundation of a positive and long-lasting relationship.

MANAGING EXPECTATIONS

Managing patient expectations and being clear about their responsibilities are important to the doctor-patient relationship. For children with keratoconus, the high likelihood (77%–88%) of disease progression without treatment

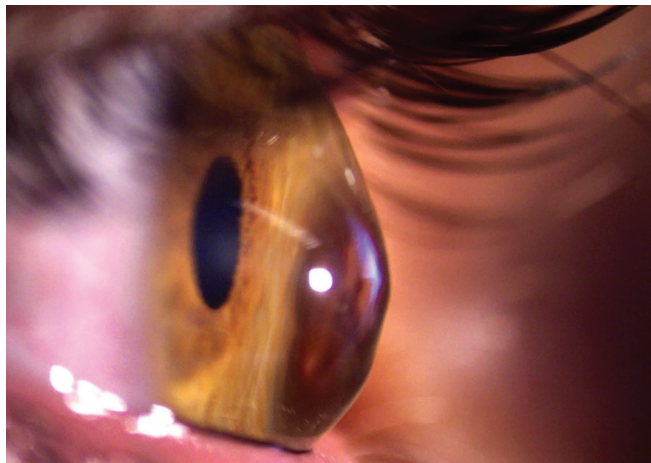


Figure 1. The eye of a middle-aged patient with advanced keratoconus and an intolerance of contact lenses.

means that they and their families must be informed that CXL should be performed shortly after diagnosis unless there is a strong reason against it.^{2,3} It's also essential to educate them that eye rubbing exacerbates the disease⁴ and that concomitant ocular diseases such as allergies can worsen symptoms and require treatment.⁵

Systemic diseases and conditions can also influence keratoconus progression, particularly in older patients. Conditions such as pregnancy that result in dysregulations in hormone homeostasis (eg, estrogen⁶ or thyroid⁷) can hasten disease progression. In contrast, diabetes, smoking,⁸ and aging⁹ tend to protect against disease progression.^{7,10}

Clearly communicate the risks and how best to manage them, including the importance of follow-up visits.

KEEP IT REAL

When speaking with patients and their families, be open and honest about the disease, its treatment, and the prospect of visual rehabilitation. A mantra in the refractive surgery field is to underpromise and overdeliver. It is also important to offer hope.

Many patients with keratoconus or similar forms of ectasia can benefit from visual rehabilitation, typically with scleral or rigid gas permeable contact lenses. In some instances—usually older patients with stable disease and sufficiently thick corneas—therapeutic excimer laser surgery can be beneficial. When possible, reassure patients that their situation can improve.

A patient of mine with keratoglobus and a cornea that was approximately 200 μm thick underwent CXL using a novel protocol called *sub400* (Figure 2).^{11,12} His ectasia has been stable and his visual acuity with scleral contact lenses satisfactory for the 3 years since he underwent intervention. Two or three years before he received treatment, CXL would not have been possible because of his thin corneas. I share this case to illustrate that there is always hope that what isn't possible today may be possible tomorrow.

It is important to balance hope with realism—particularly



Figure 2. Recent advances in CXL allow the treatment to be performed on eyes with ultrathin corneas.

when a patient's situation is at the edge of what is possible or multiple interventions are required. Be frank about the risks and benefits. Explain the decision-making process and, if possible, the scientific evidence underlying your recommendation.

CONCLUSION

The way to win patients for life is to earn their trust. Be open and honest about the pros and cons of every procedure and the likelihood of success. Take the time to explain the science and medicine to them so that they understand the decision-making process and know the advantages and limitations of the options available to them. In short, treat patients how you would like to be treated. ■

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