Public Awareness and Education: From Comforting the Patient Toward Prevention and Treatment of Corneal Ectasia

Patient education is a major part of the medical profession and this is not different in ophthalmology. Interestingly, the effect of patient education and counseling to contribute for enhancing healthier behaviors, such as avoid smoking, alcohol abuse, and optimizing nutrition for weight control has been demonstrated in a meta-analysis study.¹ Nevertheless, some messages may have a higher epidemiological impact and a bigger difference for reducing suffering from disease, this being the case of "rubbing the eye is bad."² While this message should even become part of our cultural legacy, we invite every eye care professional to help spread the word "do not rub your eyes." It is a primary goal of the campaign "June Violet: The Keratoconus Awareness Campaign" (Fig. 1).

Considering the advances in diagnosis and treatment of keratoconus and related ectatic corneal diseases (ECD), we are facing a novel subspecialty (https://www.youtube.com/watch?v=mVQE7n0u3ZI). Thereby, this is our duty to provide patient education on such advances. This is because this is highly in agreement with the classic statement "Cure Sometimes, Treat Often, Comfort Always." Such sentence that was coined by Sir William Osler (1849–1919) refers to the foundations of Medicine since Hippocrates (460–377 BC). While comfort and hope should be offered to every patient, this may be particularly important for patients with keratoconus and their families.

Educating patients and their families has also become indispensable to enable patients to maintain realistic expectations on therapeutic treatments, such as cross-linking and intracorneal ring segment implantation. Refractive surgery is related to the developments on the diagnosis and treatment of keratoconus and ECD, which has changed paradigms,³ by establishing surgical procedures prior to keratoplasy.⁴ But there are fundamental differences between elective (non-esthetic) refractive surgery and the therapeutic procedures which should be appreciated.⁵ In fact, refractive surgery aims to improve uncorrected vision while therapeutic procedures aim for visual rehabilitation. Besides such essential part for raising the value of success of surgery, patient education may reduce sorrow from the disease and the overall impact on the society. The idea that lack of information and misinformation may be even worse than the disease has been our philosophy when the June Violet campaign on public awareness on keratoconus was initiated.

The June Violet campaign sums up the previous work, such as the National Keratoconus Foundation (NKCF), which is a program of The Gavin Herbert Eye Institute (UC Irvine) dedicated to increasing the awareness and understanding of keratoconus and promoting advances in research (https://www.nkcf.org/). The goal is to have actions since June until November 10, which is the International Keratoconus Day.

FOCUS ON EYE RUBBING

The Global Delphi Panel of Keratoconus and Ectatic Diseases had unanimously agreed that the habit of eye rubbing aggravates the disease.⁶ It was also agreed that the continuous trauma to the cornea related to eye rubbing may even cause biomechanical decompensation and ectasia evolution in relatively normal patients.⁶ Interestingly, there are already over one hundred articles that point to the relationship between eye rubbing and ECD, including the



Fig. 1: June violet: The keratoconus awareness campaign



editorial by Gatinel,⁷ who has asked the fundamental question: "Eye rubbing: a sine qua non for keratoconus?" Still the statement "sine qua non" (something that is unconditionally essential) may be an exaggeration, we should center on the agreement that eye rubbing is very bad (and may be worse for some patients). We may even teach the patient how to rub the eye in a less aggressive way, again the caruncle as suggested by Carlson.⁸ We should educate our patients and support initiatives as https://defeatkeratoconus.com/. "Don't Rub Your Eyes!" It's a simple message that will prevent vision loss. Please help spread the word!

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Renato Ambrósio Jr, MD, PhD

Founder and Scientific Director, Rio de Janeiro Corneal Tomography and Biomechanics Study Group Adjunct Professor, Department of Ophthalmology, Federal University of the State of Rio de Janeiro Affiliated Professor, Federal University of São Paulo

Director of Cornea and Refractive Surgery, Instituto de Olhos Renato Ambrósio, Rio de Janeiro, Brazil Phone: +552122745694

e-mail: dr.renatoambrosio@gmail.com