



# Violet June: The Global Keratoconus Awareness Campaign

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Received: June 17, 2020 / Published online: July 22, 2020  
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**Keywords:** Corneal ectasia; Crosslinking; Intracorneal ring segments; Keratoconus

## Key Summary Points

This editorial highlights advances in keratoconus management and the Violet June Campaign for creating awareness about the disease.

Refractive surgery has led to tremendous advances in diagnostic and therapeutic technologies, which have improved our ability to treat different conditions, such as keratoconus and ectatic corneal diseases. Different

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paradigms were broken [1], and paradoxes were established regarding when, how, and why to indicate surgical procedures in these patients [2]. This progress is related to the fact that the prevalence and incidence of such diseases have increased, related to the higher diagnostic sensitivity of multimodal corneal imaging, and also due to environmental or genetic factors [1, 2]. For example, a study involving tomography with rotational Scheimpflug (Pentacam HR, Oculus, Wetzlar, Germany) by Torres-Netto et al. found a 4.79% prevalence of keratoconus in a prospective study involving 522 pediatric patients (average age,  $16.8 \pm 4.2$ , ranging from 6 to 21 years) in Riyadh, Saudi Arabia [3]. This contrasts the classic prevalence of 54.5 per 100,000 inhabitants reported in 1986 [4]. It is important to recognize that treating diseased corneas for vision rehabilitation is a whole different world from elective refractive procedures aiming to reduce the dependence on optical correction from spectacles or contact lenses [5]. In such a scenario, the education of patients and their families is fundamental to achieving success. In addition, understanding the disease and the rationale for the treatment enables patients to make conscious decisions and to have realistic expectations.

Patient education is a central part of all doctor-patient interactions. Patients have to understand precisely why any intervention is performed and the role they have to play. In

some circumstances, a simple message may have a significant impact on the natural history of the condition and even on the outcomes of the treatment. In the case of corneal ectatic diseases, eye rubbing is a terrible habit. While it is hard for this message to make an immediate impact, partly because the consequences are not immediate or obvious, repeated trauma to the cornea may cause the development of corneal ectasia and also accelerate keratoconus progression. This is serious, and if we can help people avoid it, we should. We, eye care professionals, all need to work together to make our message stronger and more impactful. We need to make it part of our cultural legacy.

The evidence that supports this statement is the Global Delphi Panel of Keratoconus and Ectatic Diseases, in which all experts unanimously agreed that continuous trauma to the cornea caused by patients rubbing their eyes can cause biomechanical decompensation and the development of ectasia, even in patients without the primary disease [6]. Nonetheless, there is a difference between telling patients with keratoconus not to rub their eyes and advocating to patients with normal corneas not to rub their eyes at all—after all, habits are hard to break.

The understanding that the habit of eye rubbing aggravates the disease is hardly a new opinion. In 2009, Carlson wrote a provocative article entitled, “Keratoconus: Time to Rewrite the Textbooks,” in which he proposed eye rubbing caused damage—and that some ways of rubbing the eyes were more harmful than others [7]. When you look at patients rubbing their eyes, you will see that they all employ different contact methods, apply different pressures to the lid, and the duration, motion, lid location, and even derived benefit may be remarkably different between patients. Therefore, some ways of rubbing the eyes are safer than others. If a patient presents with ocular allergy, we can teach them to rub their eyes against the caruncle, with low intensity and no pressure against the eye globe. This action still satisfies their urge to rub the eye and relieves the itchy sensation. Gatinel recently asked this fundamental provocative question: “Eye rubbing: a sine qua non for keratoconus?” in a recent review article

[8]. In Gatinel’s view, keratoconus is primarily a mechanical and behavioral disease in which sleeping position plays a prominent role as well by triggering some rubbing and reducing the corneal resistance over time [7]. Nevertheless, using the term ‘sine qua non’—something that is unconditionally crucial—may be an overstatement. The two-hit hypothesis, as proposed by McGhee, provides a conscious balance considering the combination of an underlying genetic predisposition or susceptibility combined with external environmental factors, including eye rubbing and atopy [1].

## EDUCATION, EDUCATION, EDUCATION

Educating patients about the potential risks and benefits of surgery and managing their expectations after procedures such as cross-linking and intracorneal ring segment implantation is a real need and an obligation when treating keratoconus patients. Nevertheless, communicating with a broader public is a much different challenge, with a different skill set and much higher costs. Considering the possible impact if people in general start to recognize the risks of and avoid eye rubbing, or even learn to rub safely, then we may decrease the suffering that ectasia causes and the burden it places on society.

The Violet June (Fig. 1) is a public awareness campaign that started in Rio de Janeiro, Brazil, in 2018. The motivation for starting this project was the evidence in daily practice that the lack of information or the misinformation about the disease may cause more suffering than the



**Fig. 1** The Violet June Global Keratoconus Awareness Campaign @ 2020, logo

disease itself. Therefore, the goal has been to raise public awareness about keratoconus, including the dangers of eye rubbing. It made a significant impact at the time, but there are always more people who need to hear the message. This message will need to be continuously repeated until it becomes a cultural legacy. It is a constant battle. But it is a battle in which we are starting from a good position. The Violet June campaign built on the efforts of international organizations such as the National Keratoconus Foundation so that we have traditionally kept activities for promoting awareness for Keratoconus Day on November 11. We have an educational website as a resource <https://www.violetjune.com.br/>. Our campaign required coordination and energy, but it did not require reinventing the wheel. We know that it is having an impact, that it is saving sight and helping patients and their families. This is in agreement with the aphorism: “To cure sometimes, to relieve often, and to comfort always.”

In 2020, the Violet June is back as expected for a continuing campaign. While 2020 was anticipated as the year of ophthalmology because 20/20 represents “normal” distance visual acuity, we now know that the year will be marked by the COVID-19 pandemic global crisis [10–12]. In this scenario, the message of not rubbing the eyes may have further relevance because of reducing the risk of coronavirus contamination [9–12]. While we learn how to adapt to the “new normal,” the month of June 2020 may also mark the return to normality. Finally, the beautiful color violet may represent healing and transformation, which are relevant for the difficult times we all are experiencing. Colleagues, please consider joining this effort to raise more awareness about keratoconus and eye rubbing. Happy Violet June ...

## ACKNOWLEDGEMENTS

**Funding.** No funding or sponsorship was received for this study or publication of this article.

**Authorship.** All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, take responsibility for the integrity of the work as a whole, and have given their approval for this version to be published.

**Disclosures.** Renato Ambrósio Jr. is a consultant for Oculus, Alcon, Zeiss, Mediphacos, Essilor, and Allergan. He is also the President of the International Society of Refractive Surgery (ISRS), and a member of the journal’s Editorial Board.

**Compliance with Ethics Guidelines.** This article is based on previously conducted studies and does not contain any studies with human participants or animals performed by any of the authors.

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