



About the National Keratoconus Foundation (NKCF)

NKCF is the world's oldest and largest organization providing resources about keratoconus to patients, their families, the public and eye care professionals. Founded in 1986, NKCF is an outreach service of the Gavin Herbert Eye Institute, the Department of Ophthalmology at UCI Health.

Contact NKCF at 800-521-2524 or info@nkcf.org

To support our activities or learn more, visit www.nkcf.org

About the UCI Program for Down syndrome

As part of the UCI Institute for Memory Impairment & Neurological Disorders, the DS Program offers comprehensive services for children and adults with DS. Available resources include pediatric and adult clinics, a dementia referral program, and several NIH-funded research programs for adults with DS.

Contact the program
at 714-456-8443 or downsyndrome@uci.edu



Down Syndrome
& Keratoconus

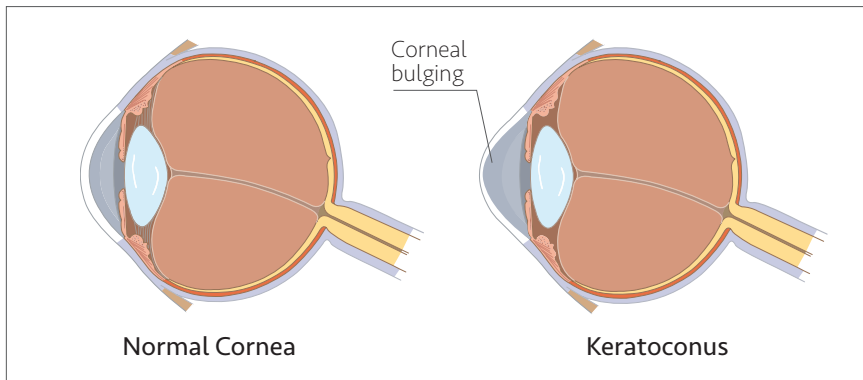


Individuals born with Down syndrome face a multitude of health issues. Eye problems and vision disorders are especially common.

Although somewhat rare in the general population, Keratoconus, or KC, affects between 5–15% of people with Down syndrome (DS) and can impact their ability to function at their highest level.

What is Keratoconus?

KC is a disorder in which the normally clear, spherical shape of the front of the eye (the cornea) becomes thin and distorted. As the disease progresses, the cornea forms a cone-like bulge that impairs vision. Glare, blurred or double images, and halos are common complaints. As the disease progresses, scars can form on the cornea, causing additional complications. KC affects both sexes and usually becomes evident during the teen years. The disease is bilateral (in both eyes), but one eye may be more affected than the other.



How is KC treated?

In the general population, KC is often under-diagnosed because the patient may be told that vision changes are due to astigmatism. Only as the disease progresses, requiring frequent changes in the eyeglass or contact lens prescription, does it become apparent that a medical condition is responsible. For patients with DS, a missed or delayed diagnosis can be even more debilitating. They may not complain about changes in vision until the disease is advanced.

In addition, it is believed that eye rubbing can make KC worse. People with DS often have a predisposition to allergic conditions, causing them to rub their eyes frequently and likely worsening their KC. For these reasons, it is important for caregivers to schedule regular eye exams beginning in infancy, and to screen for KC during the teen and early adult years.

In the mild form, KC can be treated with eyeglasses or soft contact lenses. As the disorder progresses, the majority of cases are correctable with specialty contact lenses. Although it may present a challenge, individuals with DS should be given the opportunity to try contact lenses to improve their vision and provided with adequate support and supervision.

Corneal cross-linking (CXL) is an FDA-approved procedure for treatment of progressive KC, using ultraviolet (UVA) light and eye-drops containing Vitamin B. Although not without possible risks, CXL is a safe, single treatment procedure that takes about an hour and can be performed in a doctor's office.

Candidates for treatment must be able to follow directions, focus on the UVA light during the procedure, and avoid eye rubbing after the treatment. In the overwhelming majority of cases, CXL stops or halts the progression of KC.

Other options

When CXL is not an option, or when patients can no longer tolerate contact lenses or achieve satisfactory vision, a corneal transplant may be recommended. The scarred and misshapen cornea is replaced with a donor cornea. Any patient who undergoes corneal transplant surgery will need to be closely monitored. The outcome for patients with DS who receive a corneal transplant is variable and depends greatly on patient and caregiver compliance.

While KC will not result in irreversible blindness, the visual distortions can lead to a diminished quality of life and affect an individual's ability to function. This is especially true for people with DS who may not complain about their vision, and where poor vision may increase social isolation and make performing daily tasks difficult. Family members should be watchful for signs of a vision disorder, and if KC is suspected, find an eye doctor familiar with the visual problems of people with DS.