national down syndrome society
ndss

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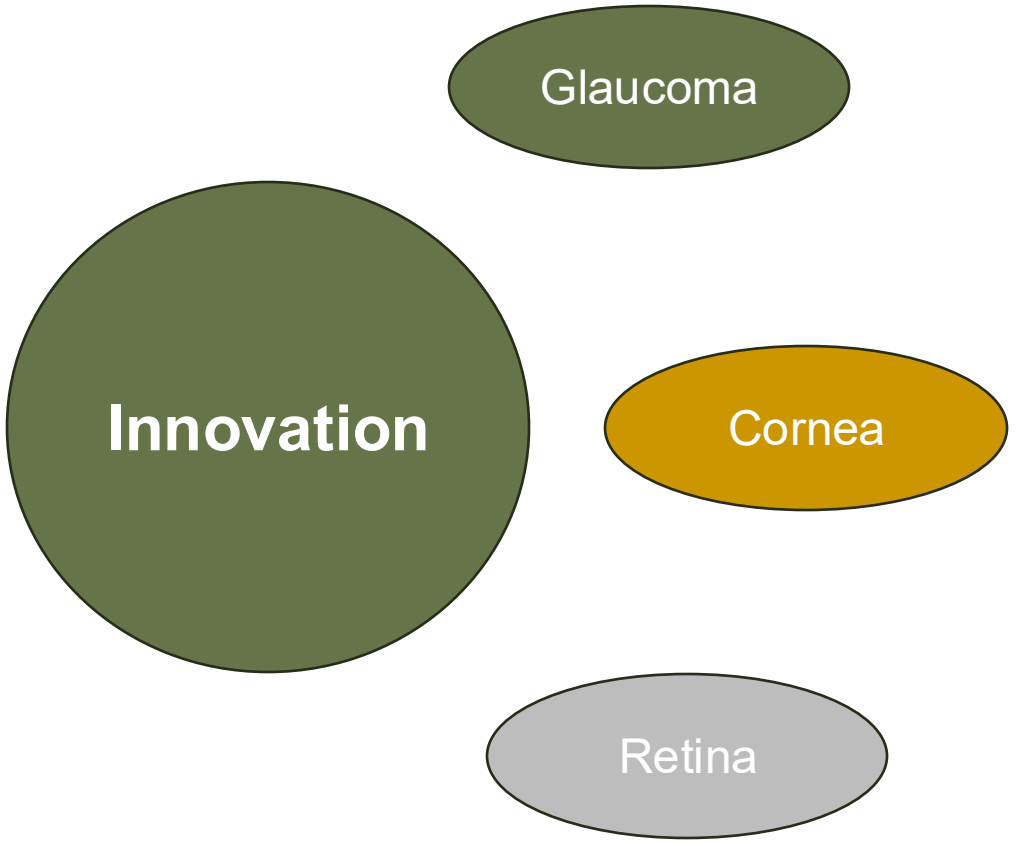
Caring for Bright Eyes: Understanding Eye Health and Keratoconus in Individuals with Down Syndrome

Rutvi Doshi, OD FAAO, FSLS

Global Medical Director, Cornea

Who is Glaukos?

Glaukos is a publicly-traded, ophthalmic medical technology and pharmaceutical company focused on novel therapies for the treatment of glaucoma, corneal disorders, and retinal disease.



Did you know?

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Eye disease is reported in **60-80%** of people with Down syndrome

Vision affects more than just eyesight

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Learning and development



Vision affects more than just eyesight

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Motor skills: balance and coordination



Vision affects more than just eyesight

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Social connections and presence



Visual challenges can be harder to notice

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Symptoms may not be verbally reported



Vision changes can happen slowly

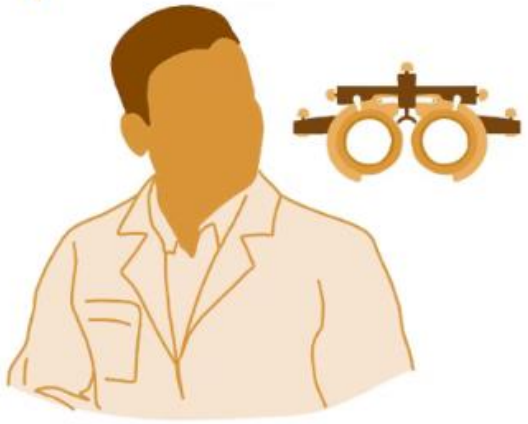


Behavioral changes can be mistaken for developmental or attention issues

Types of Eye Doctors

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Optometrist



- OD (Doctor of Optometry)
- Requires eight or more years of education and training
- Provides comprehensive eye exams, treatment for common eye conditions, and corrective eyewear

Ophthalmologist



- MD (Doctor of Medicine)
- Requires twelve or more years of education and training
- A specialist who performs and treats more complex or severe eye disorders

Common Eye Conditions

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Presbyopia: Loss of the eye's ability to focus on nearby objects



Clear Vision



Presbyopic Vision

Common Eye Conditions

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Nearsighted: Close objects appear clear, but distant objects are blurry



Clear Vision



Nearsighted Vision

Common Eye Conditions



Farsighted

Distant objects are seen clearly, but nearby objects appear blurry

Common Eye Conditions



Astigmatism

Curvature of the eye's cornea or lens, causing blurred or distorted vision at all distances.

Common Eye Conditions



Symmetrical Eyes

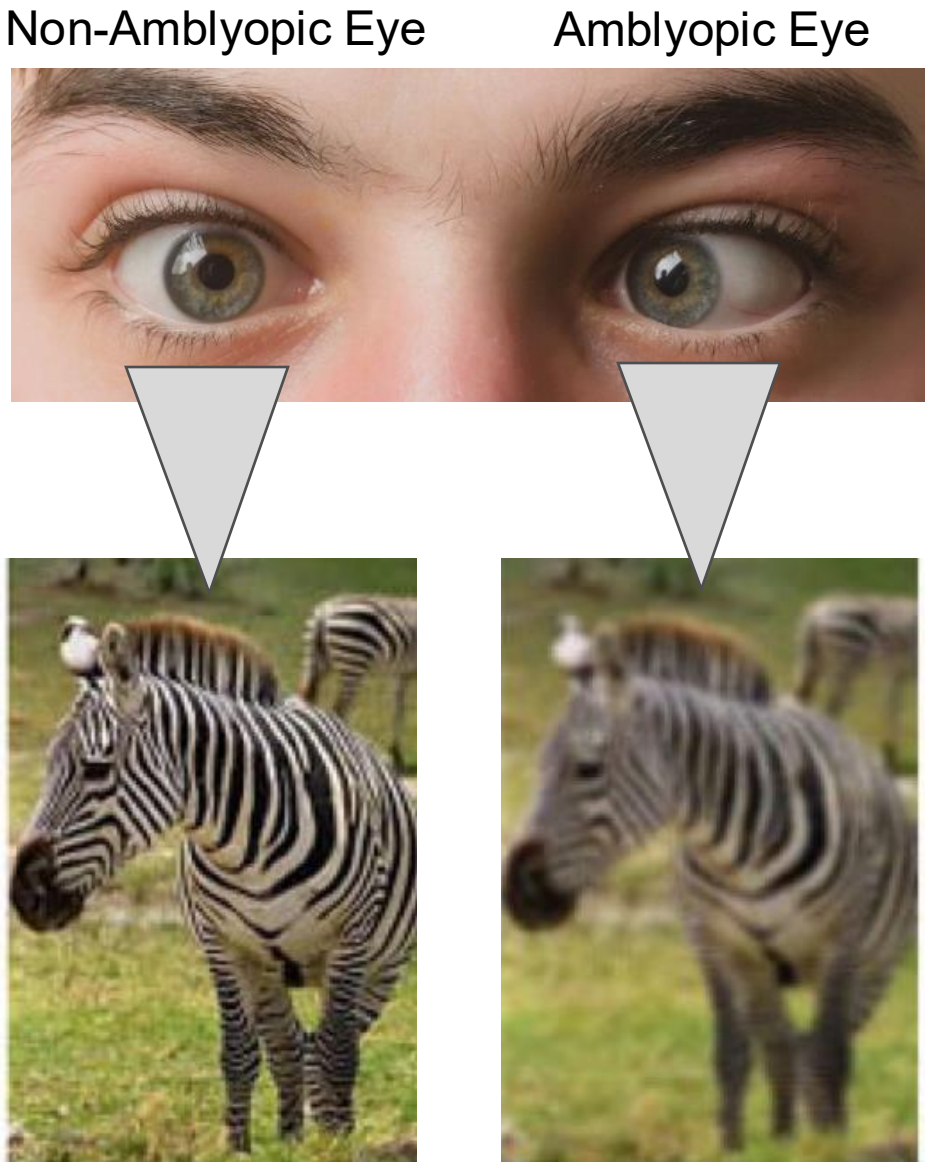


Strabismus

Strabismus

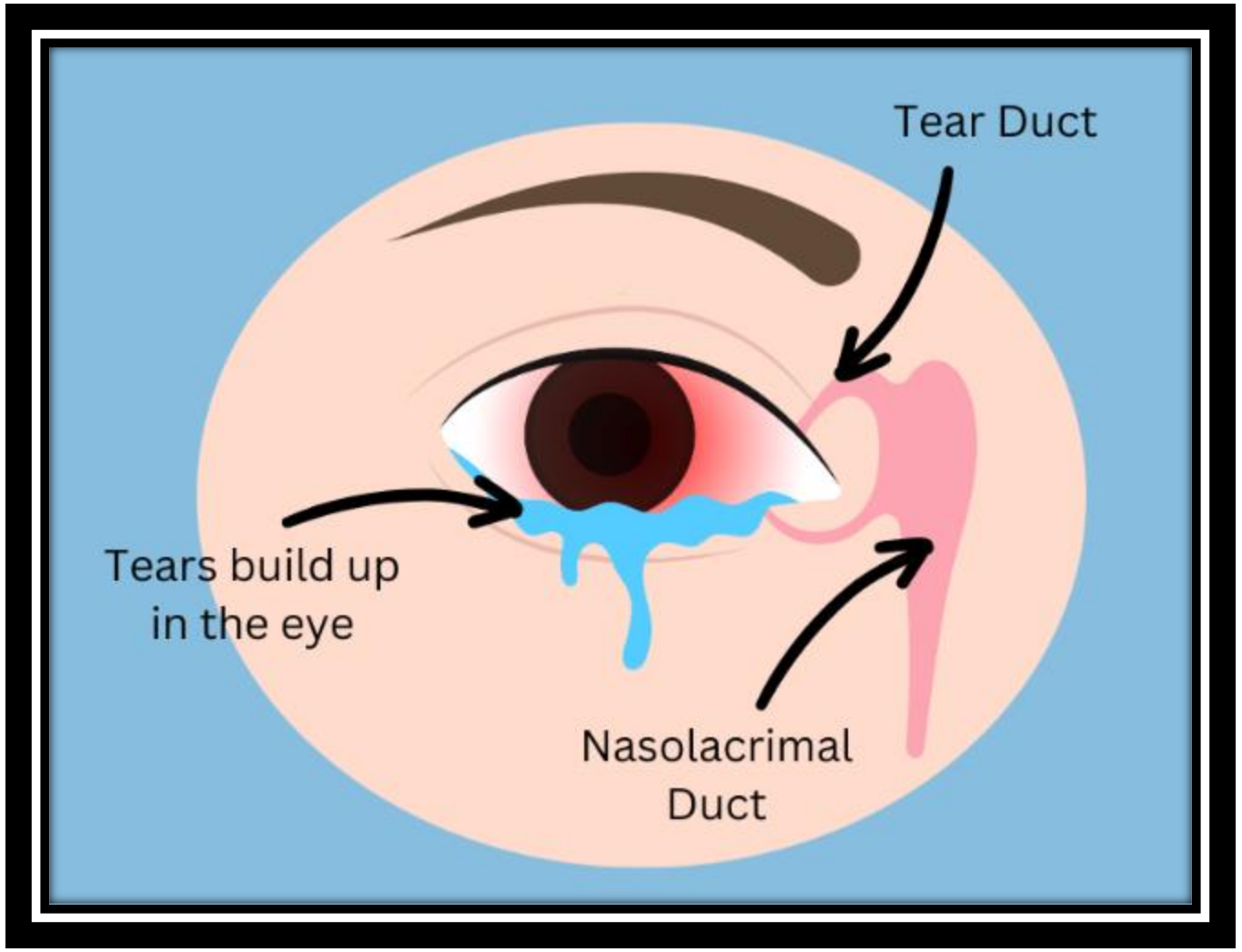
Commonly known as crossed or wandering eyes, is a disorder where both eyes do not align properly or look at the same place at the same time.

Common Eye Conditions



Amblyopia: Also known as "lazy eye," is a common childhood condition where one eye experiences blurred vision and the other eye has normal vision, but the brain only processes the normal vision.

Common Eye Conditions



Tear Duct Abnormalities
Blockages or structural issues in the tear drainage system that prevent tears from draining, causing constant tearing, discharge, and infections.

Common Eye Conditions



Cataract

A common age-related, progressive clouding of the eye's natural lens, located behind the iris. By disrupting the lens, it scatters and blocks light, causing blurry vision, glare, and faded colors.

Common Eye Conditions

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Clear Vision

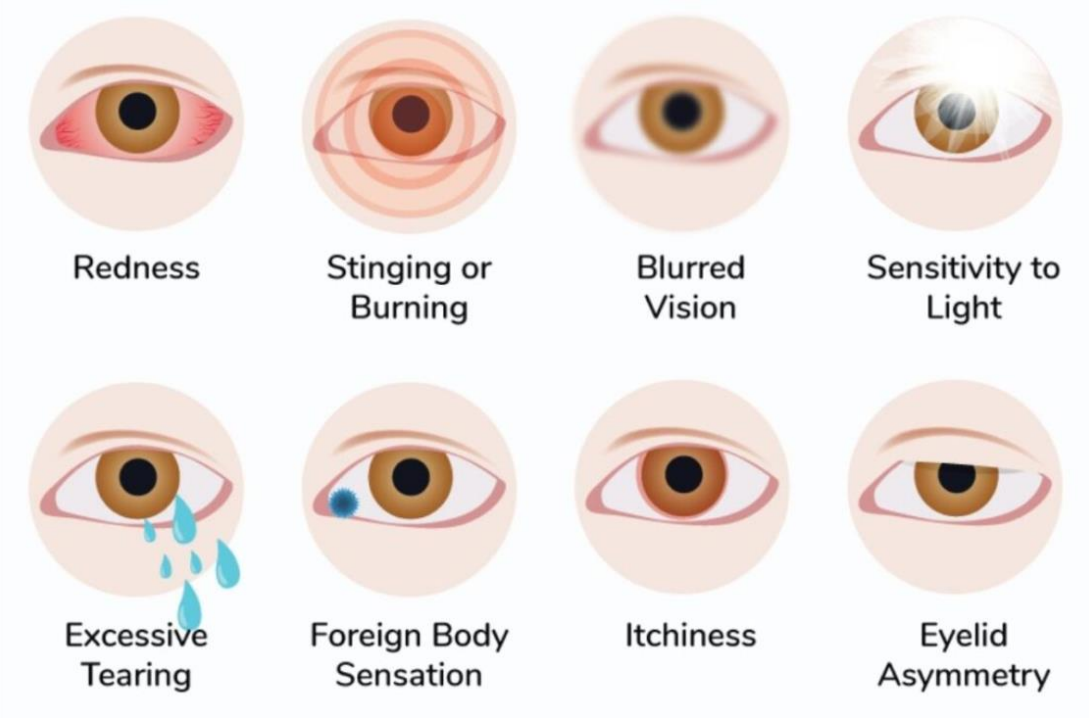


Glaucoma

Glaucoma

A group of eye diseases that damage the crucial optic nerve, usually due to high fluid pressure inside the eye

Common Eye Conditions



Dry eye

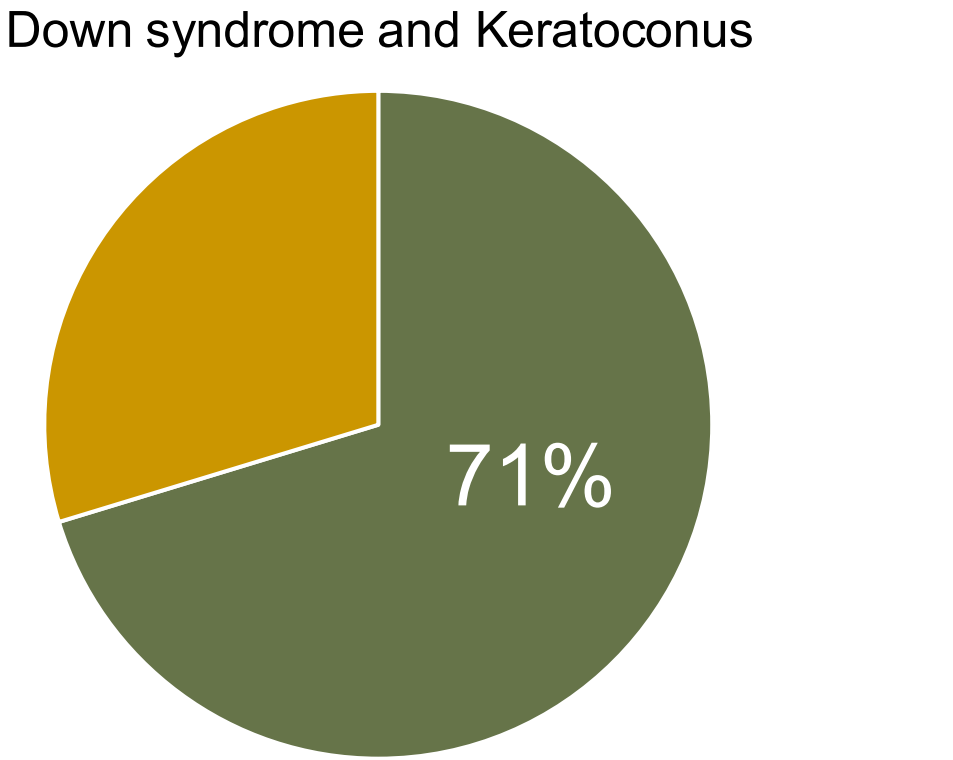
A common, chronic condition where the eyes do not produce enough tears or the tears evaporate too quickly, causing insufficient surface lubrication.

Keratoconus, often referred to as “KC,” is a progressive eye disease in which the cornea weakens and thins over time, causing the development of a cone-like bulge and blurry or distorted vision.



Why this is important to the DS Community

- People with Down syndrome have a much higher risk of keratoconus than the general population
- Studies suggest prevalence ranging from 5–71%*
- Often develops earlier and progresses faster



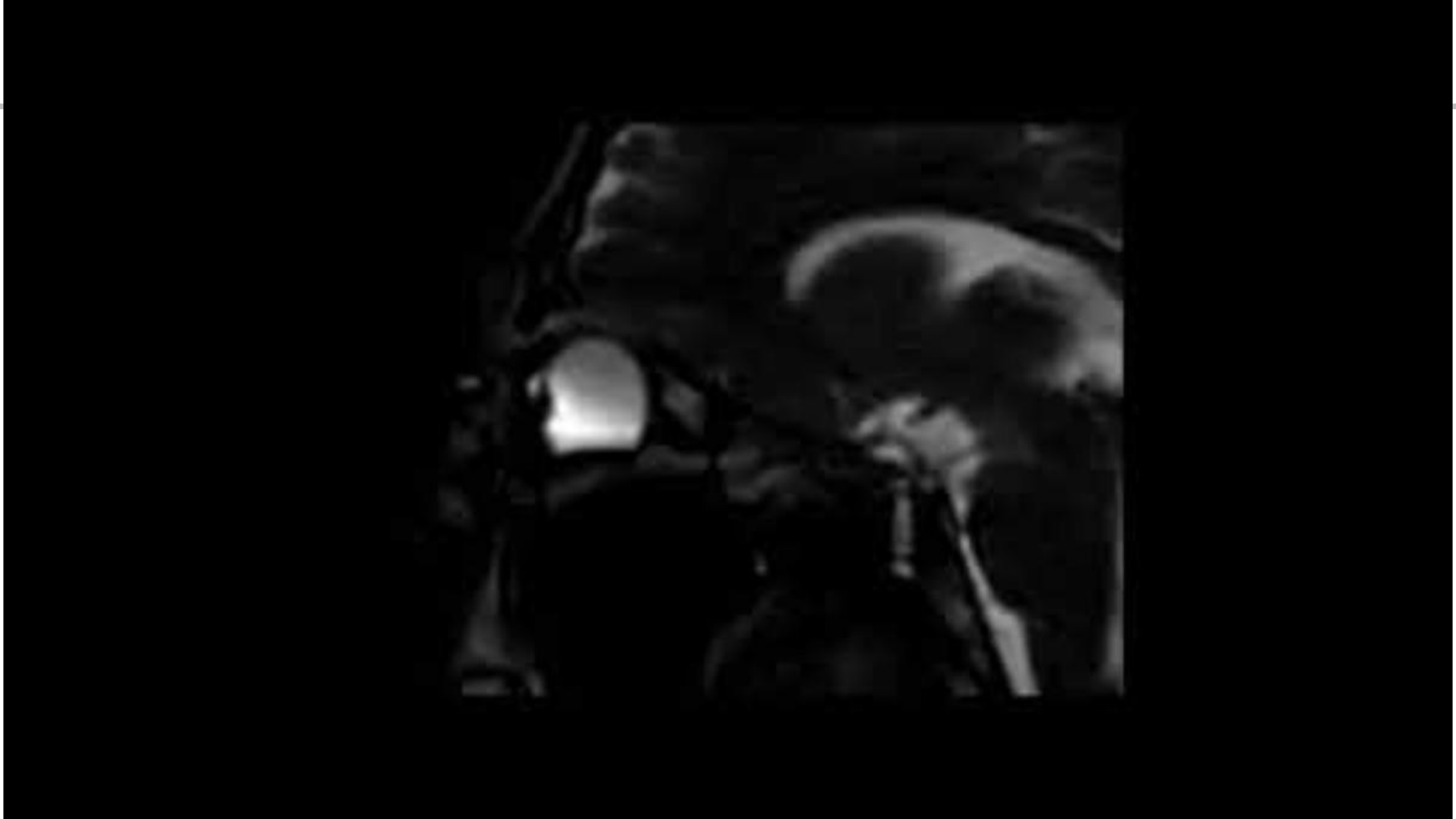
The reported prevalence in people with Down syndrome ranges from 5.5% to 71%, depending on the study and screening method. KC was already advanced at the time of diagnosis in most patients, 24% already had corneal scarring.

*Outcomes of Corneal Collagen Crosslinking Under General Anesthesia in Down Syndrome Luis C. Barrientos, BS, Ryan Frisbie, MD, Jennifer L. Jung, MD, Lauren Mehner, MD, MPH, Casey Smith, MD, Rebecca G. Edwards Mayhew, MD, PhD, Ronald Wise, MD, Emily A. McCourt, MD, and Michael A. Puente, MD Cornea. 2025; 00:1-5.

Eye Rubbing

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Blurry Vision/Difficulty Seeing at Night

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Simulation of Keratoconus Patient Vision. Creative Commons Attribution-NonCommercial-ShareAlike 3.0 Unported License. Changes have been made to the original image. Times Square image by Spreng Ben (CC BY-NC-SA 2.0)

Frequent Headaches



Family History of KC

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Frequent Prescription Changes

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Sensitivity to bright light or glare

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Squinting



Ophthalmologists should screen all patients with Down syndrome for keratoconus

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Topographer: Takes a picture of the surface of your eye to detect potential subtle changes of the surface of the eye.



Tomographer: Measures the thickness of the cornea at different locations. It can be especially valuable because it can detect KC before the cornea starts to form a cone shape.



The biggest concerns

KC is a progressive disease, meaning it will get worse overtime. If not diagnosed, keratoconus can lead to significant vision loss which can not be restored.



How to treat KC

- Corneal cross-linking is the only FDA-approved treatment to slow or halt the progression of keratoconus

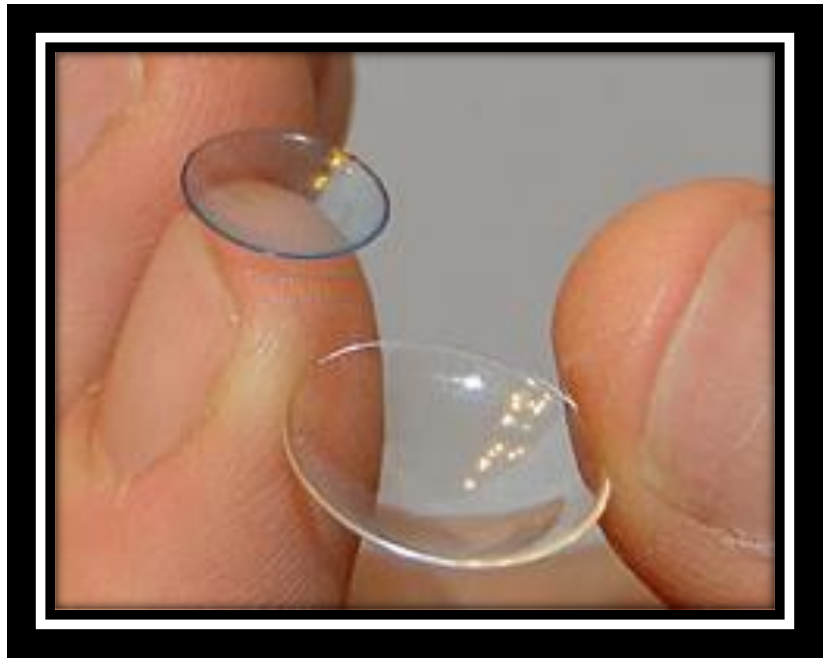
- For people with Down Syndrome, the corneal cross-linking treatment can be done under general anesthesia

- Corneal transplant is also a potential treatment for severe cases, but this is largely not an option for people with down syndrome. Only 12.5% of patients were even eligible for transplant. Uncontrolled eye rubbing, and high complication rates make transplant essentially contraindicated for individuals with Down syndrome.

Long-term vision management

Corneal cross-linking is not approved to help long-term vision management. It is likely that glasses or contacts will be needed.





Importance of Routine Eye Exams

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In Summary

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Questions about Eye Health and Keratoconus

Thank You!