

Living with Keratoconus: A Journey of Resilience and Hope

My name is Mary Okutoi Anyera from Eldoret Kenya. Keratoconus, or KC as it's commonly known, entered my life like an uninvited guest when I was just 17. Diagnosed with a severe case in both eyes at 29 years now, the condition has been a formidable challenge. Yet, through this journey, I've discovered an inner strength I never knew I had and a community of support that has been my guiding light.

My initial symptoms were subtle—slight blurriness and a peculiar distortion in my vision. I dismissed it as simple eye strain from too many hours in front of screens. But as the months passed, my vision deteriorated rapidly. The world around me became a mosaic of blurred shapes and colors, making even everyday tasks increasingly difficult, and reading, which I've always loved, turned into a frustrating chore.

The diagnosis of keratoconus came after a series of eye exams and consultations. It was a relief to finally have a name for what I was experiencing, but the reality of living with KC soon set in. Since then, I have only used glasses for treatment, sporadically due to financial constraints, and currently, I am without glasses or insurance. This leaves me in a daunting predicament, with limited access to proper medical care and little support from those around me. Some local doctors are unfamiliar with my condition, making it even harder to find the right treatment.

Without insurance or financial means for treatment, I had to become my own advocate. I reached out to local and international organizations dedicated to eye health. The National Keratoconus Foundation (NKCF) became an invaluable resource, offering information and connecting me with others who were navigating similar journeys. Through online support groups, I found a community of individuals who understood my struggles and offered practical advice and emotional support. Knowing I wasn't alone in this battle made a world of difference.

Despite these challenges, I have explored every possible avenue for help. I visited local eye clinics and university programs, hoping to find sliding scale fees or financial assistance. Though my search for specialized contact lenses or advanced treatments continues, the journey has taught me the importance of persistence and resilience.

One of the most profound lessons I've learned is the importance of self-advocacy. Living with keratoconus has taught me to be proactive in managing my health and to never underestimate the power of community. I've become more vocal about my condition, sharing my story to raise awareness and encourage others to seek help and support. I remember going to a certain eye clinic and the doctor did not know what to say. My dad who had accompanied me looked so crushed that I had to tell him it was going to be alright. The awareness of kc is simply low especially in rural areas where i come from and it is thanks to the internet that i have the information that i have.

World KC Day is a reminder that we are not defined by our conditions, but by how we rise to meet them. It's a day to celebrate the resilience and strength of everyone affected by keratoconus—from patients and their families to the dedicated professionals working tirelessly to find better treatments and solutions. I know that Sub-saharan Africa has a long way to go but it is a step by step thing.

As I continue my journey, I remain hopeful for advances in research and treatment. I look forward to a future where keratoconus is more easily managed and understood, especially for an african child. Until then, I'll keep pushing forward, inspired by the incredible resilience of the KC community and driven by the hope that our combined efforts will lead to a brighter tomorrow for all of us.