

*Acanthamoeba Keratitis (AK) is a living nightmare in excruciating pain, light sensitivity, isolated from the world, depressed and afraid of the future. Applying 72 eye drops daily for the first 4 days, and then 48 drops for many weeks, causing drop toxicity. Some days you want to give up. Or pull your eye out. (J. Vila Sinclair Spence)*

## WHO ARE WE?

The Global Alliance Against Acanthamoeba Keratitis is a collaboration of diverse stakeholders that includes patients, clinicians, researchers, industry and regulators passionate about preventing this rare but serious disease and improving the outcomes for patients.

## OUR OBJECTIVE:

The purpose of this white paper is to create greater awareness amongst clinicians, researchers, industry and regulators about *Acanthamoeba Keratitis (AK)* to assist in prevention strategies, improved diagnosis and appropriate treatment for patients.

It is our hope that by creating greater awareness about this rare but emerging, devastating eye disease and its many complexities, we highlight the urgent need to mobilise sustained funding of vital research so that the well-being and safety of contact lens wearers and other vulnerable communities is ensured and to improve patient's outcomes.

## OUR GOALS:

Specifically, we aim to:	Because:	This will:
1. Approach AK with 360° perspective including the patient voice	AK patient involvement has resulted in meaningful outcomes	Create awareness and change across clinical practice, patient behaviour and research direction
2. Highlight challenges of <i>Acanthamoeba</i> biology	<i>Acanthamoeba</i> has distinct survival and proliferation properties	Improve use and development of standardized treatments
3. Improve early diagnosis and treatment plans	AK mimics other eye infections delaying diagnosis and increasing vision loss	Increase use of artificial intelligence and imaging in diagnosis, and clinical acumen in treatment
4. Track, educate and prevent AK	AK awareness is low because it is perceived as rare	Provide quicker response to outbreaks and prevention tools

## CALL TO ACTION: RECOMMENDATIONS

- Increased education, awareness and understanding of the impact of AK on patients, as well as their needs and how to best support them during their diagnosis, treatment and beyond.
- Working alongside contact lens manufacturers and other stakeholders to assist in better awareness, education and prevention.
- Greater understanding of *Acanthamoeba* biology and how it causes infection.
- Awareness, standardisation and improvement of diagnostic processes.
- Increased efforts to develop new and improved treatment strategies.
- Better tracking of AK and emerging risk factor identification.

## What is *Acanthamoeba* Keratitis?

*Acanthamoeba* is a single celled organism that can cause infection of the cornea, the clear window in the eye that covers the pupil and coloured iris. The cornea is essential for good vision, and once infected, vision is compromised. *Acanthamoeba* lives in water and soil, feeds on bacteria and has two life-cycle stages, an active motile trophozoite and a resilient dormant cyst. Interchanging between these forms makes it difficult to eradicate in the environment and the cornea.

The main populations who experience AK and who have the greatest risks for AK are contact lens wearers who expose their lenses to water and agricultural workers who suffer eye injuries. Most patients with AK are unaware of these risks as AK is a rare disease and often not discussed.

## How does it occur?

AK occurs when *Acanthamoeba* attaches to the surface of an injured cornea (Figure 1). Once attached, the *Acanthamoeba* migrates more deeply into the eye and feeds on corneal cells. The body's defence system responds with white blood cells entering the cornea to kill the *Acanthamoeba*. Corneal nerve inflammation and redness, swelling, pain and acute light sensitivity occurs. This leads to scarring of the cornea and vision loss, as well as other eye complications.

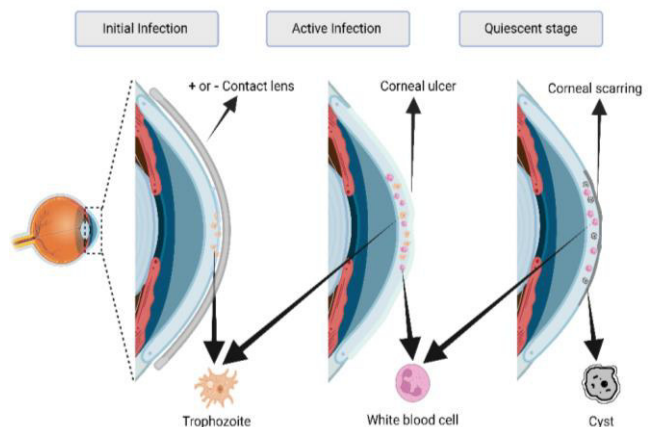


Figure 1. *Acanthamoeba* eye infection process

## WHAT ARE THE CHALLENGES?

### From the patient's perspective

- *Acanthamoeba* causes 5% of corneal infections worldwide<sup>1</sup> yet is disproportionately responsible for over 50% of cases resulting in vision loss. One quarter of these patients lose 75% of their vision after the condition has resolved.<sup>2</sup>
- As a neglected and rare serious disease, patient support is essential but is often not discussed or provided.<sup>3</sup>
- Lack of awareness in contact lens wearers and agricultural workers of the risks from water exposure and eye trauma.<sup>4</sup>

### In the laboratories

- There are limited effective antimicrobial therapies to treat the disease, and so new treatments and drugs are needed.<sup>5</sup>
- The disease course and outcomes also depend on the biology of *Acanthamoeba*, the patient's immune response and the treatment regime, which all require further research.<sup>6</sup>

### In the doctor's rooms

- The clinical picture is like that of other corneal infections, making AK difficult to differentially diagnose.<sup>7</sup> Misdiagnosis occurs in up to 80% of patients.<sup>2</sup>
- Standardised treatment is not available globally.<sup>8</sup>

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