Global Alliance against Acanthamoeba Keratitis

WHITE PAPER - OCTOBER 2024

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 360º 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 *Acanthamoeba* biology	***Acanthamoeba* 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.

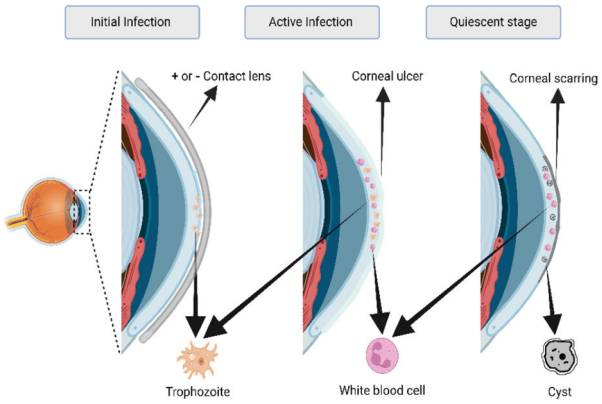

Figure 1. *Acanthamoeba* eye infection process

WHAT ARE THE CHALLENGES?

From the patient's perspective

- *Acanthamoeba* causes 5% of corneal infections worldwide[1] 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.[2]
- As a neglected and rare serious disease, patient support is essential but is often not discussed or provided.[3]
- Lack of awareness in contact lens wearers and agricultural workers of the risks from water exposure and eye trauma.[4]

In the laboratories

- There are limited effective antimicrobial therapies to treat the disease, and so new treatments and drugs are needed.[5]
- 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.[6]

In the doctor's rooms

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

APPENDIX 1 Patient Perspective

The challenges include:

1. **Poor recognition of the patient perspective.**

My Acanthamoeba keratitis (AK) diagnosis at age 15 meant my whole world was disrupted - no swimming, no reading, no traveling. After 17 surgeries, things didn't get much better; I repeated years of high school and learnt to be my own advocate. And now, 6 years later, the effects of AK are even more profound. It is my independence I miss the most. (M. Leitner)

There is a lack of awareness and understanding of AK from the patient perspective making it challenging for those affected to find the correct support and information they need.[3] There is also a lack of appreciation of the impact of AK on all elements of a patient's life.

Recommendations: Signpost all patients to relevant AK support groups.

1. Support groups for orphan/rare diseases like AK play an essential role in sharing personal experiences, compassion, and supporting individuals and families affected.
2. AK support groups offer practical advice on managing the unique challenges of living with AK, including guidance on navigating the complex healthcare system based on non-standardized protocol for treatment, finding what type of treatments are being applied in the different countries, and accessing available resources.
3. These groups also provide opportunities for patients and their families to participate in raising awareness, campaigning and improving outcomes for other patients with AK.
4. Support groups recognize the importance of sharing up-to-date and correct facts through targeted social media groups such as *Acanthamoeba Keratitis Eye Foundation* Facebook, Instagram, TikTok and LinkedIn.

2. **Lack of understanding of AK pain and pain management**

Every tiny light, sound and touch of my face is like a stabbing knife into my exploding eye and head. I feel desperate in a dark universe of endless, excruciating pain. (S. Widmer)

Patients with AK undergo excruciating and debilitating pain. There are many different types of ocular pain however two are most common:

1. ***nociceptive pain*** (i.e. active pain which is acute or reversible) during active infection characterized by throbbing, burning, sharp/shooting, and sensitivity to light.
2. **persistent *neuropathic or neuroplastic pain*** (i.e. pain associated with nerve damage which is often persistent and non-reversible) is described as shooting or aching pain associated with the trigeminal nerve region.[9]

Patients may also experience symptoms like sweating, nausea, tiredness, and rapid heartbeat. Some patients may be prescribed opioids for pain management and can become addicted to them during and after treatment. Some patients opt not to take pain medications due to the fear of addiction, even if their pain is excruciating.

Recommendations: Proper pain management to make the journey less painful and emotionally less traumatic for patients

1. It is crucial to acknowledge that the level of pain is excruciating and debilitating.
2. Patients often feel that their pain is not being taken seriously due to the lack of correlation between their clinical picture and the severity of their pain.

3. Medical experts should listen attentively to patients, refer them to pain management, and consider nerve modulators as a pain relief option. Nerve modulators can help to block both persistent and acute pain.

2. Profound psychological challenges

AK took my vision, my profession, my hobbies, my familiar appearance, my energy and gave me a daily routine with medication, side effects, eye appointments full of anxiety and lost hopes. (S. Widmer)

AK is not only a physically painful disease, but it can cause great mental distress. In addition to the primary symptoms of eye pain, light sensitivity, and blurred vision, patients may experience a range of psychological symptoms that can further impact their mental health and quality of life.[10]

Depression: The constant pain, sleep disturbances, and isolation can leave patients feeling helpless and hopeless, leading to depression, side effects of drugs and potential addictions.

Anxiety: *Dealing with a disease like AK made me insecure, not only about my eye, but also about myself. With that, I developed social anxiety as well. (M. Leitner)*

Patients may worry about losing their vision or their eye, not being able to work and provide for their family or missing out on day-to-day activities. In some countries, AK is not a recognized disease by many insurance companies leaving patients to cover the costs of management.

Social Isolation: *Felt disconnected from the outside world. Felt none of my friends would understand my condition, so I basically hibernated or for a better word, vegetated. (M. Castle-Genn)*

Due to pain and light sensitivity, patients isolate themselves in a dark room in their homes, leading to social isolation.

Post-traumatic stress disorder (PTSD): *Through all the traumatic surgeries at a relatively young age, PTSD came fairly soon. It grew from fears of never leaving the cycle of surgery and doctor appointments and manifested in nightmares. (M. Leitner)*

As a result of the traumatic experience of dealing with the infection, patients with AK may develop PTSD. The way they were treated, misdiagnosed, type of treatments and the procedures used to treat them can result in flashbacks, nightmares and avoidance behaviours related to the experience. Many patients are scared to shower/swim even without wearing contact lenses.

Recommendations: The management of psychological symptoms will improve patients' overall well-being and journey.

1. Patients with AK require proper care and support for both their physical and mental health and may may require assistance from a mental health professional.
2. Compiling data from patients' lived experience can help create a critical care roadmap which can be followed by caregivers. This will assist with standardized diagnostics, treatments, and mental health care, ensuring equitable healthcare globally.

APPENDIX 2 *Acanthamoeba* biology

The challenges include:

1. ***Acanthamoeba* are found mainly in water and soil and their numbers are set to increase and expand geographically with climate change.**

Around a third of domestic taps, showers, lakes and recreation water facilities are contaminated with *Acanthamoeba.*[11] Increased numbers are associated with increased water temperatures, pollution and flooding and are likely to increase with climate change.[12]

2. **Trophozoites transform into resilient cysts that support survival in the environment and in the eye (Figure 2).**

This biological resilience enhances *Acanthamoeba's* success in initiating and sustaining infection in *Acanthamoeba* keratitis (AK). Even when the active infection is resolved, cysts can lay dormant in the eye and reactivate at a later time (even up to 31 months after AK has resolved).[13]

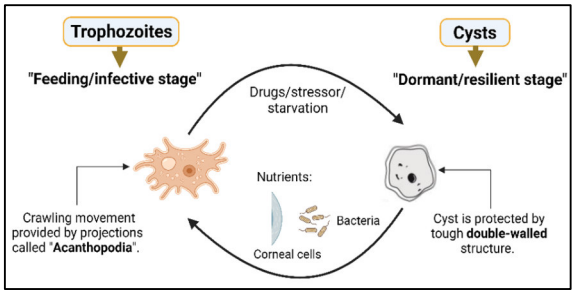

Figure 2. *Acanthamoeba* life cycle

3. ***Acanthamoeba* hosts microorganisms that exacerbate the infection in the cornea.**

Acanthamoeba not only transports these microbes to the eye, but it also enhances their ability to evade the eye's defences and makes them more resistant to antimicrobials. The associated microbes may also cause more severe AK.[14]

4. ***Acanthamoeba* are not classified consistently between laboratories/researchers hampering linking types to outcomes.**

There are different naming systems which can be based on several genes in the DNA structure or the shape and size of *Acanthamoeba*. As genetics influences the ability to cause infection, increase severity, and evade treatment, inconsistent naming is not supporting advances in clinical treatment.[6]

Recommendations:

A global biobank would facilitate better understanding of the biology of *Acanthamoeba* and their microbial cargos and develop strategies to overcome its unique survival and disease mechanisms.

1. Without a clear connection between patient outcome, drug susceptibility in the lab and appropriately named species/genotypes of the *Acanthamoeba* causing the infection, it is hard to determine if the varying outcomes between patients is due to the types of amoebae or other factors, such as the microbes they are carrying.
2. Advanced techniques such as genomics (analyzing DNA), proteomics (studying proteins), metabolomics (examining cell metabolism) and assessing the microbes carried by *Acanthamoeba* should be used to clarify the relationship between disease outcomes and treatments.

APPENDIX 3A Clinical Diagnosis

The challenges include:

1. **Misdiagnosis is common and associated with 5x increased risk of vision loss[2].**

I saw nine ophthalmologists in 4 months before being diagnosed. Awareness of this condition is paramount - imagine, my journey may have had a different outcome. (M. Castle-Genn)

Because *Acanthamoeba* Keratitis (AK) is rare and accounts for only 5% of the cases of corneal infection, in up to 80% of AK cases, clinicians misdiagnose AK as more common forms of keratitis[15] particularly Herpes Simplex Keratitis. This delays and can initiate incorrect treatment, including the use of steroids.

2. **The gold standard diagnosis is traumatic and only 50% sensitive[7]**

I underwent a corneal scraping procedure on the same day I was admitted to hospital. It was particularly painful because the anaesthesia had not taken effect when it began, and I was too frightened to speak up. (M. Leitner)

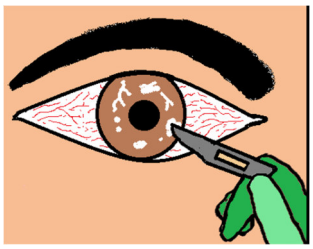

Figure 3. Corneal Scrape

Corneal scraping (Figure 3) to obtain a sample for microscopy and culture (growth in the laboratory) is the gold standard for diagnosing and differentiating AK from other infections like bacteria. However, culture has low sensitivity and long turnaround time (up to 10 days) to make a diagnosis.[7] Polymerase chain reaction (PCR, a genetic-based test), has demonstrated better and faster results (a few hours).[16] However, false positive PCR results have been reported. The sample collection varies between clinics and the analysis is lab dependent. An imaging technique called *in vivo* confocal microscopy (IVCM) can visualise *Acanthamoeba* cysts and can be more reliable than other diagnostic techniques but requires trained staff and is not available in all centres.[7]

Recommendations:

1. **Clinician network providing peer support and sustained awareness of AK.**

A high index of clinical suspicion is crucial and because AK is commonly associated with a recent history of contact lens wear encountering water or ocular trauma, people with any such history should be considered as possible patients with AK. Rarity of the condition could be demystified with a clinician network providing cases and virtual grand rounds.

2. **Invest in new technology and improve standardisation.**

My corneal culture and my PCR test both came negative last week. Then we did a confocal microscopy which confirmed I had AK. (AK Warrior)

IVCM can correctly identify that *Acanthamoeba* is causing the disease about 80% of the time, however IVCM cannot detect the difference between live and dead organisms (i.e. active vs quiet/resolved disease). IVCM also requires highly trained personnel and expensive instrumentation which are not available at all clinical centres. Recent advances are incorporating artificial intelligence (AI) for AK diagnosis.[17] An AK PCR international external quality assurance scheme is now available[16] and Sydney Eye Hospital has developed a culture protocol animation available on YouTube. These initiatives are currently siloed and will benefit from promotion through the Clinical Network.

APPENDIX 3B AK Treatment

The challenges include:

1. No universally licensed treatments or accepted treatment protocols

I had 3 options with a 50/50 success rate, so I chose enucleation, as I wanted to be rid of the torturing pain and the constant stress this placed on me and my family. I am now free. (M. Castle-Genn)

Currently, hourly, mostly unlicensed antiseptics/disinfectant eyedrops are the first-line therapy for *Acanthamoeba* keratitis (AK). These include polyhexanide biguanide (PHMB), chlorhexidine, brolene and hexamidine and it is common for patients to have to use more than one type of drop at the same time. The first and only approved therapy (0.08% PHMB, Akantior, SIFI Pharma) is available only in limited markets.[18] In 50% of patients additional therapy is required, including surgery.[19] When treatments fail, corneal transplantation (keratoplasty), amniotic membrane transplantation, conjunctival flap, glaucoma, cataract surgeries or eye removal (enucleation) might be necessary. In some uncontrolled cases, an oral anti parasitic drug (miltefosine, Impavido) is prescribed off label[20] and requires anti-nausea management and a high fat diet. This drug often results in a severe inflammatory reaction a couple of weeks after initiation which needs to be controlled with steroids. Painkillers and immunosuppressive drugs might also be prescribed. Management varies widely between clinical centres as there is no standardized treatment.

2. Inflammation and its management are a double-edged sword.

I had four corneal transplants. As I am still very young, my body rejects all the transplants and when 20 years old, I had to start taking Cellcept next to my regular medication. (M. Leitner)

Steroids are often used to control pain caused by AK inflammation as well as post-transplantation. However, steroids increase the activity of *Acanthamoeba* and if used without anti-*Acanthamoeba* drugs, as in those patients who are misdiagnosed, vision and in some cases eye loss occurs.[2] Steroids also cause side effects like glaucoma which may themselves go on to cause vision loss. Immunosuppressive drugs like Cellcept may be prescribed, which are unsafe during pregnancy.

Recommendations:

1. **Support drug discovery and classification systems for drug sensitivity / resistance in non-responding cases**.

Standardised drug efficacy screening and reporting on microbial break points will be essential for developing patient care treatment plans. The use of robotics will eliminate lab-to-lab potential biases and for drug discovery this will allow several thousands of chemical agents to be screened in a robust manner compared to the low-throughput methods currently used. The need to assess and develop new therapies on the encystment or fully mature cysts, and potentially aggregates of *Acanthamoeba* may need to be adopted.

2. **Delphi consensus study to determine global standard of practice.**

As with diagnosis, peer network support would facilitate better management, but efficiency will be ensured with a Delphi consensus study with experienced clinicians to develop treatment guidelines. This process supports clinician decision making as well as patient care.

APPENDIX 4 Regulations and Public Awareness

The challenges include:

1. **Nearly 90% of AK cases can be avoided but because it is severe and perceived as rare, avoidance techniques are not discussed.**

India has the highest number of new cases per year at 15.2 per million individuals, primarily due to farming accidents, where soil dwelling *Acanthamoeba* establishes infection in a damaged eye.[21] In high-income countries, over 85% of AK occurs in contact lens wearers.[6] *Acanthamoeba* attaches to or gets trapped behind the contact lens, generally through water exposure (such as during showering or swimming) or inadequate lens disinfection.[22]

2. **There is no mandatory reporting system for AK despite its severity.**

Three major AK outbreaks in contact lens wearers have occurred in the last 30 years and all were detected by researchers at large hospitals, but after a delay, as AK is rare.[22] British Ophthalmic Surveillance Unit surveys were conducted for two of these outbreaks but after they had been contained. Similarly, this occurred with the Centers for Disease Control and Prevention (CDC) in the USA.

Recommendations:

1. **Global Contact Lens Safety Week**

AK is a largely preventable disease, if awareness of risk factors was greater. Research undertaken in 2016 by the UK's General Optical Council (GOC) found that 1 in 3 contact lens wearers were unaware of the risks of showering in lenses and 1 in 5 unaware of the risks of swimming in lenses. Attempts have been made to drive public awareness of contact lens safety through awareness campaigns, but these have not had widespread support and investment. An opportunity exists for a global collaborative effort to raise awareness, supported by all key actors across the system, from manufacturers to prescribers, those who treat infections and the patient community. Examples of successful campaigns include the adoption of an AK patient designed #nowaterwithcontacts symbol for contact lens packaging, removal of water imagery in contact lens promotions and health behaviour change programs (Figure 4)[23] however these need to be universally adopted by contact lens manufacturers.

Figure 4. No Water Contact Lens Label

2. **A real-time global monitoring system with AI, patient and clinical reports**

While regulators have adverse event reporting systems, they are not tailored to patient reporting or eye infections. Furthermore, most AK cases in low-income countries are not medical device related. In this initiative, AI screening of X, Facebook and LinkedIn posts as well as active patients and clinician reporting in a custom app, would allow quick mobilisation to identify risk factors to decrease outbreaks/patient risks.

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