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Acanthamoeba Keratitis (AK) patient advocate & founder of www.acanthamoebakeratitis.info
and the Acanthamoeba Keratitis Support Group, or 'AK Warriors', on Facebook.

Juliette is originally from Venezuela but has lived in the Netherlands throughout her experience with AK.

A journey I will never forget:
CL + H2O = AK

The beginning

I have been wearing contact lenses for more than 35 years, and had never been told not to shower, swim, wash or store them with water; sadly, this is common for 'AK warriors'.

My journey started in August 2016 when I went swimming with my contact lenses. It took only a second and the free-living amoeba (FLA) got stuck on my contact lens and made its way into my cornea, changing my life forever.

The day after, I felt like something was in my eye and the feeling would not go away, so I removed my monthly contact lenses and tried my glasses. I dismissed symptoms of light sensitivity and fatigue as the result of being a tired mum of two young boys.

Symptoms can manifest within days or weeks so all contact lens users should get their eyes checked whenever they feel something is different with their eyes.

For the next 6 months I wore my glasses most of the time, as each time I wore contact lenses my eye felt like there was something in it. My optician tried me with a variety of different contact lens brands but none made a difference to my symptoms. At the end of February 2017, the nightmare really started and never stopped...

Symptoms worsen after 6 months

I began my day with a pair of contact lenses but within a couple of hours I was struggling with the eye with which I was experiencing symptoms (my right eye); I felt something in my eye that I could not wash away, aching pain and increasing sensitivity to light. Two days later I went to my general practitioner who sent me to the hospital the same day. At the hospital I was misdiagnosed; the optometrist on duty prescribed eye drops for a bacterial infection. Three days later, I experienced no improvement and returned to the emergency department, where an ophthalmologist changed my medication and asked me to come back the following day.

Investigation and diagnosis

For 2 weeks, after 3 corneal scrapings,[1] culture of my contact lens case[2] and many drops, the pain and light sensitivity worsened and the vision in my right eye deteriorated. Eventually, a Confocal laser scanning microscopy (CLSM)[3] was recommended which confirmed I had Acanthamoeba Keratitis (AK), a rare but serious infectious disease of the eye. If not treated adequately and aggressively, AK can lead to loss of vision.[4]

Treatment

Immediately I started non-stop eye drops 24/7 for 4 days. I could not sleep because of the pain and regimen of drops. My sensitivity to light was acute, so I spent my time hidden in a dark room with the windows covered with black plastic bags. The pain was excruciating – I wanted to pull my eye out with a fork. Two weeks into treatment with drops, the eye got worse; the treatment was not working. Upon examination, it was concluded that the amoeba was getting deep into my eye, so I underwent an emergency therapeutic corneal transplant (**Figure 1**).

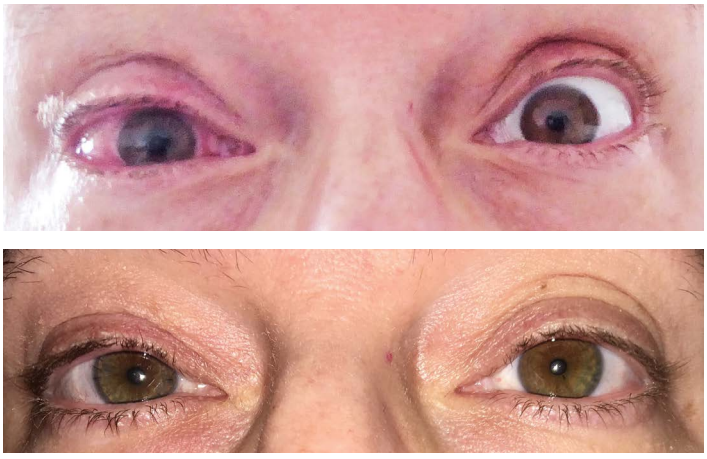

Figure 1.
Juliette before (top) and after (bottom) her corneal transplant

Post-treatment

I now have nerve damage (Trigeminal neuralgia), high astigmatism, light sensitivity, and a cataract. Nonetheless, I am grateful for a quick diagnosis and the timely emergency cornea transplant. Many 'AK warriors' worldwide have shared with me experiences of being misinformed, misdiagnosed, mistreated and misunderstood, and concerns they have a long and painful journey ahead.

Having been a patient of this rare disease, I can say it has been one of the hardest things to go through in my life; AK led to isolation, excruciating pain, loss of vision, guilt, depression, loneliness, fatigue and financial concerns.

Prevention, education and support

Steps you can take to educate contact lens wearers, to prevent AK, and support patients with AK:

Prevention

Educate patients new to contact lenses; do not assume they know and take every visit as an opportunity to explicitly remind them:

- → Never let water mix with your contact lenses
- → Never shower or bath with your contact lenses
- → Never swim with your contact lenses
- → Never touch your contact lenses with wet hands from water
- → Never wash your contact lenses with water
- → Never store your contact lenses in water
- → Never go to the sauna with your contact lenses

Education

AK is a rare disease becoming increasingly common in contact lens users[5]

- → AK is easily misdiagnosed. If patients are experiencing itchy, watery eyes, pain, sensitivity to light, redness, and/or blurred vision, check if their contact lenses have been exposed to water
- → Rule out AK when Herpes Simplex Virus (HSV) keratitis is suspected[6] – do not start on steroids without confirming AK is not present, due to the potential risk of promoting encystment and increasing the number of trophozoites[7] - of 80% of 'AK warriors' misdiagnosed, half were diagnosed with HSV keratitis and given steroids.[8]
- → If an AK diagnosis is confirmed, seek expert advice
- → Contact with water should be avoided for eyes with corneal damage

Support

- → Listen to patient concerns and refer to a general practitioner for pain management and counselling
- → Support groups - refer patients to the Acanthamoeba Keratitis Support Group on Facebook

My purpose as an Acanthamoeba Keratitis Patient Advocate is to educate, raise awareness and support patients by providing a platform where all stakeholders involved in the journey of Acanthamoeba Keratitis – patients ('AK warriors'), contact lens manufacturers, ophthalmologists, optometrists, opticians, cornea specialists, researchers, contact lens users and pharmaceutical companies – can share their knowledge and efforts; as well as prevent contact lens users going through this journey. The sooner AK is diagnosed and treated, the better. By working together, we can make a difference!

For more information please visit: www.acanthamoebakeratitis.info, or to see Juliette speak of her experience, scan the QR code.

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