

In 2011, I was diagnosed with Acanthamoeba Keratitis (AK), a rare but sight-threatening corneal disease, caused by an amoeba getting into my contact lens and then into my eye.

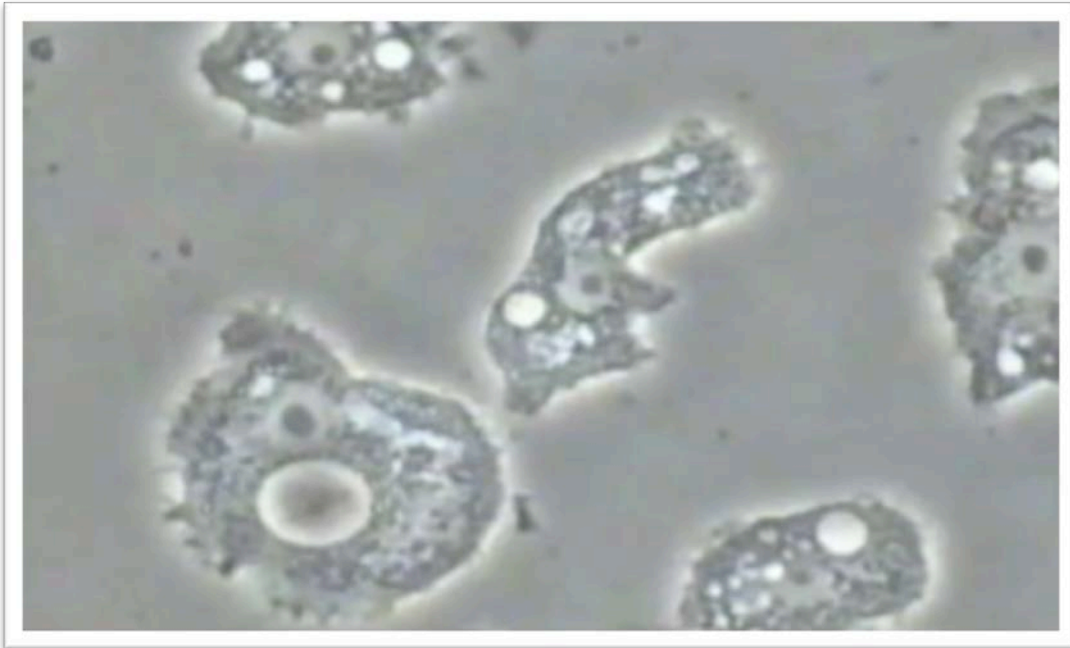


Image courtesy of Dr Fiona Henriquez

I won't go into the full details of what happened to me (it would take too long!) but suffice to say that despite being diagnosed very early, I had a terrible course of disease. First, I was treated with hourly eyedrops day and night but quickly deteriorated to the point where I was in so much pain and so light sensitive I was unable to leave my darkened bedroom.

My active disease lasted for over 3 years and included raging inflammation of my cornea and sclera, repeated breakdown of my corneal epithelium, 2 secondary bacterial infections and huge problems with intraocular pressure.

2 cornea transplants, and a battery of powerful drugs later, I had lost my job, my social life and my confidence, as well as the sight in my right eye.

One of the hardest things I think I found about being ill was losing control –of my own fate and my ability to make my own choices.



I'd always been an independent minded individual, in charge of my own destiny and absolutely driving the course of my life, my relationships and my career. I'd actually just got married- I had a fantastic job which I loved, and we were busily decorating our first house when AK struck.

Unfortunately, my illness arrived and changed everything. That's the thing about getting ill. It stops you from being in charge and you suddenly find yourself in the unfamiliar position of having to submit to others, better qualified than you to decide on the plan for your future.

I was fortunate enough to be treated at one of the best eye hospitals in the country. Under Professor John Dart and the extraordinary team at Moorfields, I had exactly the right mix of excellence and empathy.

But for someone who's used to being the decision maker for themselves, it was really uncomfortable to have to surrender all control and to let the doctors do their thing.



The thing about AK is that it's a very rare disease. And its effects are also extremely severe.

And that meant that even at Moorfields, seeing world-renowned experts in corneal disease, there were just some questions they couldn't answer. Questions like *'why do some lens wearers get this and others don't'* or *'why do some patients respond badly to treatment'* or *'why did I get scleritis'* or *'why isn't there better information about risk factors for AK in the public domain'*, they had to hold up their hands and just say they didn't



know the answers to a lot of these questions.

And frankly, when you hear your doctors say things like that, it makes you feel even lonelier, more isolated and even less in control of your destiny.

I know that this isn't just the case for those affected by Acanthamoeba Keratitis. It's the case for thousands of patients with all sorts of diseases all over the world every day.

We go from being in control of our own lives, to in the hands of others. And sometimes those others don't know the answers either.

As some of you already know, I started campaigning for greater awareness of the risk factors for AK shortly after my diagnosis. I guess that was an attempt on my part to get back some control over what had happened. And I seem to remember that's what led me to getting involved in the PSP.

I was invited to join by Fight for Sight, who explained the process and outlined what was going to happen during the session.

At first, I must confess, I was a bit confused.

I obviously wasn't medically trained- so what qualified me to help identify research priorities?

There were plenty of other patients who would have equally valid points of view on how to diagnose, treat and manage corneal and external diseases. What about the other patients who'd suffered other diseases? Wouldn't we all just end up arguing about whose cause was most important?

Wouldn't the doctors in the room just decide that questions around the most common corneal diseases were the ones that should be prioritised? Wouldn't rare diseases like mine get left out, as they always had done in the past? How could I meaningfully contribute to this process, given all of these issues?

So on the one hand, I was confused about what I would be required to do. And on the other hand, I suddenly felt really listened to.

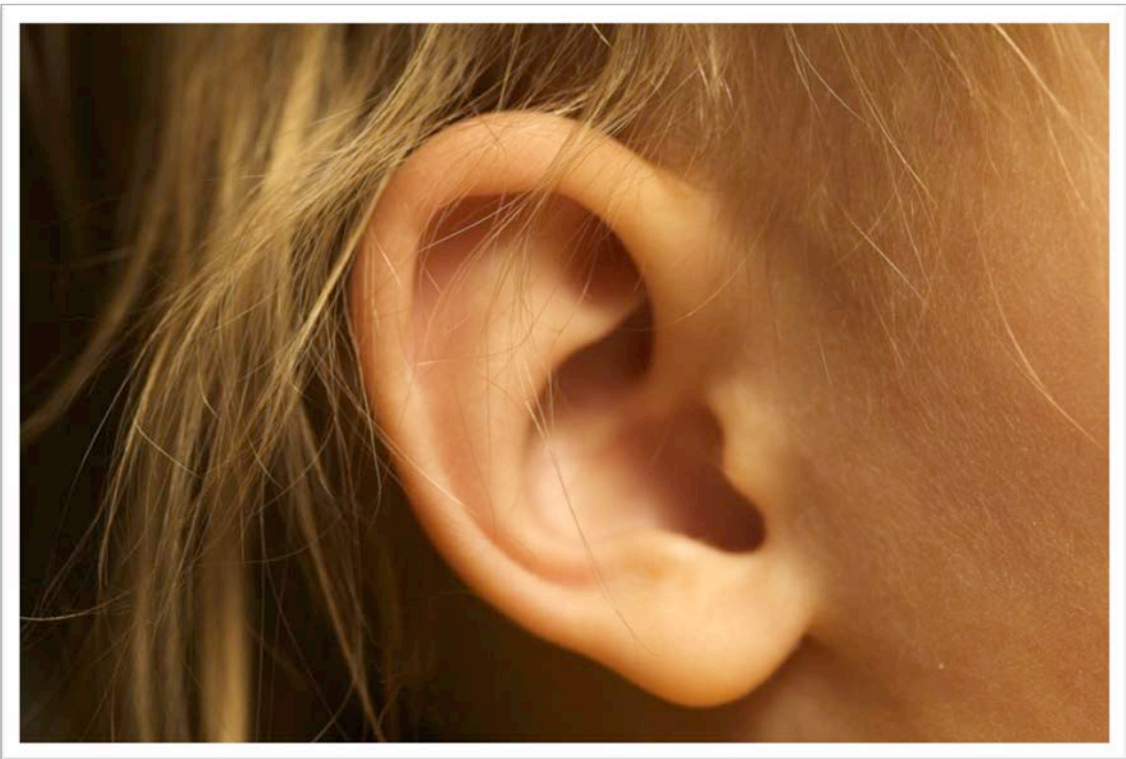


Image courtesy of Travis Isaacs

For the first time since becoming ill, and losing control of my life, and outside of the clinical setting of my own treatment, I was being given the opportunity to recount my experiences, frustrations and hopes about my illness.

And, I was being invited to share those experiences with the very people involved in diagnosing, treating and researching my disease.

I actually don't know why I was surprised when I heard clinicians share the same experiences, frustrations and hopes as I had done.

When you think about it, it's a no brainer. We're all on the same side, after all.

Why not bring together all those affected by sight loss to discuss the things we don't know, the things we wish we could improve and jointly make a plan for our future?

But I think it was the PSP process that helped me realise this.

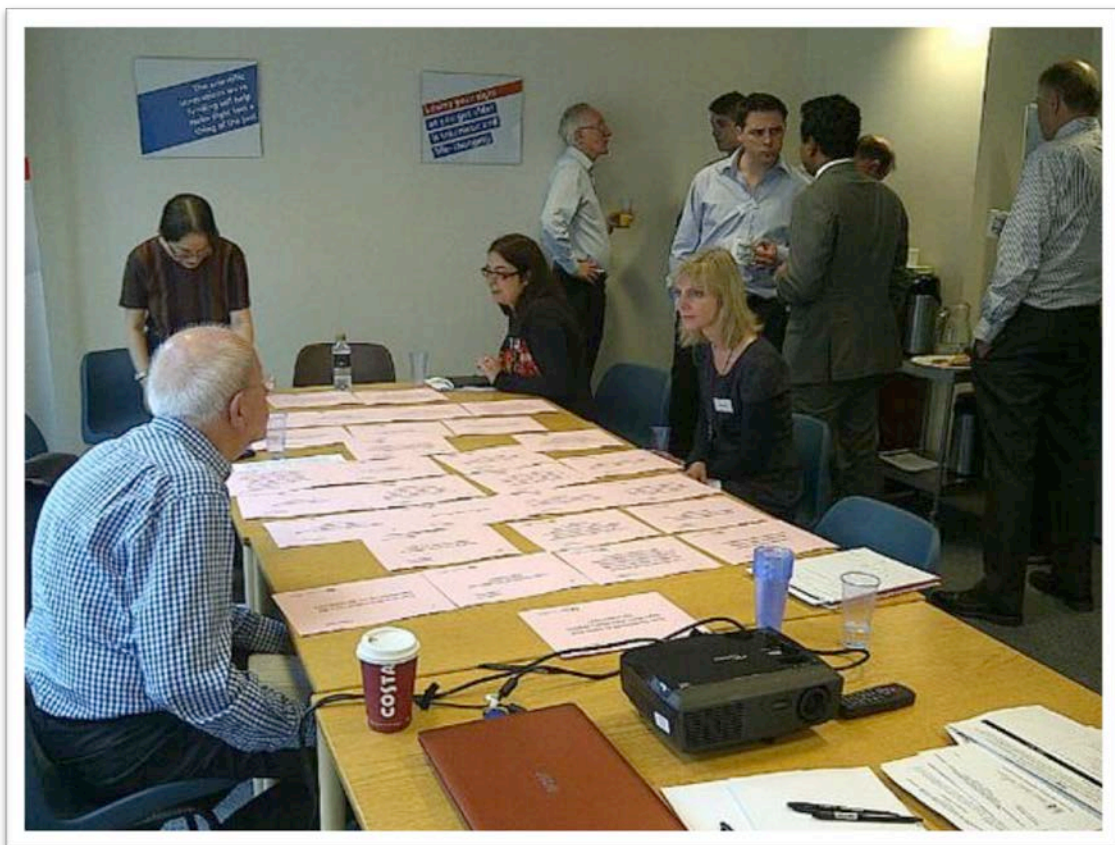


Image courtesy of Katherine Cowan

The interesting thing about the process was that we all were biased. Naturally, of course.

There were patients like me who had no knowledge of any other corneal disease except their own. There were professors who had dedicated their life's work to a particular field of study and treatment. There were parents who wanted to articulate things on behalf of their children, affected by vision loss.

But we were all treated as equals, all working together towards something important.

Somehow, and with some expert facilitation, listening to each other and with this sense of equality, we managed to work collaboratively towards our top10 (or I think in our case, 11 –we just couldn't leave the last question out).

And somehow, that gave me a sense of control back.

It didn't just make me feel listened to, it made me feel like I'd done something important, impactful and meaningful.

Something that might make a difference. Something that might prevent others from going through what I had been through.

It was a hugely uplifting and optimistic experience. And one that I'm hugely grateful to have been a part of.

There's lots of talk in the health sector in general about Patient Power.

Patients are being encouraged to step up and claim their rights, behave as consumers even, exercising their right to choice and the right to complain.



And whilst this is all very empowering and can well lead to improvements in individual outcomes or experiences, I think that the PSP gave me an opportunity to be heard in a different way – and I think in an equally powerful, or maybe even a better way.

Looking back on it now, there was something very interesting about the PSP process – something which put us all in the mindset to behave as citizens, – empowered and with agency, recognising that we were contributing to something that was being done for the collective good, not just our own self interest.

In many ways, I think the PSP set me on a new course. Since being involved I have continued to campaign for greater awareness of risk factors for my disease. I've also worked with the Moorfields team to create a proper patient support network. I've authored essential patient information on AK that didn't exist when I was first diagnosed, and I've become a lay reviewer for the NIHR.

I honestly believe much of this only happened because the Sight Loss and Vision PSP made me feel I had a voice, and a contribution to make.

So thanks to Fight for Sight, for involving me. And I hope you see that its impact has extended way beyond the top 10 priorities list.

I just wish that other initiatives in the sector were as forward thinking as the PSPs. I think then, we'd start to see what it really means for patients to truly feel involved in the healthcare system.

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