

Blind Faith: Mariya Moosajee

INTERVIEWED BY EYE NEWS

In light of the BBC releasing *Blind Faith: Do genetic eye disease 'treatments' work?* earlier this year, a documentary which follows BBC journalist Ramadan Younes as he investigates practitioners who falsely claim to have 'treatments' for genetic eye disease, Eye News spoke with Professor Mariya Moosajee, a Clinician Scientist and Consultant Ophthalmologist in genetic eye disease at Moorfields Eye Hospital, UCL Institute of Ophthalmology and the Francis Crick Institute, London. The documentary can be found here:

<https://www.bbc.co.uk/programmes/p0f8vnvm>

How would you describe the overall response to this story from the UK-based ophthalmic community?

There has been a damning response from our sight loss community. Many have expressed feelings of shock, being horrified, appalled and angry at the level of exploitation. Interestingly, when we hosted the live viewing of the film at UCL, almost half of the patient audience admitted to having explored similar bogus treatments with no improvements in their vision. This was a major breakthrough as most patients do not admit to these endeavours as it can make them feel somewhat embarrassed, going against NHS medical advice.

But it's important to bear in mind we have global access through the internet and live in a diverse community, where friends and relatives reside abroad and may want to share alternative approaches that could potentially help.

We are not entirely immune from such practices in the UK. Although our NHS have world-leading experts who work according to the latest evidence-based medicine and have a well-regulated ethical framework for research and clinical trials, patients may choose to visit private doctors who can go unregulated.

A key example of this was the case of ophthalmologist Bobby Qureshi, who was the director of the London Eye Hospital and was offering telescopic intraocular lens implant surgery for AMD, at a cost of £24,000. The Macular Society, another leading UK sight loss charity focused on macular disease, submitted a complaint to the GMC in 2017 after receiving more than 50 telephone calls complaining about Mr Qureshi. The Society was concerned that Mr Qureshi had cheated patients and was operating on people inappropriately. He was struck off the GMC register in 2019.

We will be using *Blind Faith* as an educational resource for patients who ask about these rogue treatments. From my own experience, I am contacted at least one-two times a week by patients asking if certain therapies could work and if they are legitimate. I have seen hundreds of patients who have travelled to various international centres claiming their intervention is a cure for RP. None had seen any improvement, some a deterioration, some with visible and permanent scars from unnecessary surgery.

In an article published by Retina UK, they state: 'There is only one therapy available in the UK, specifically for people living with the genetic diagnosis of RPE65. More information about Luxturna.'



Professor Mariya Moosajee

Does this form of treatment, or its promise, break any law you know of? And if not, what are the implications of such a practice being allowed to continue?

I can only speak for doctors in the UK. We take a Hippocratic oath, which states that we will abstain from all intentional wrong-doing and harm. These bogus treatments are not based on ethically-approved clinical trials which have been designed and powered accordingly. They claim it will restore or improve sight, which we know is not the case at present. The GMC will have strict rules about misleading patients about their prospects for improvement and I would encourage any patients who have been put in a similar position to speak up. Since the viewing we have already managed to avert some UK-based patients considering travel abroad for stem cell therapies.

“ Patients must discuss any treatments they come across with their ophthalmologist before embarking on what could be an unethical, unsafe, costly and potentially harmful procedure ”

Blind Faith investigates a US-based doctor, Jeffrey Weiss, but to what extent could, or is, this false-promising treatment practised in the UK?

As far as I am aware, it is not available in the UK. There are several commercial human retinal progenitor cell trials underway, one of which, run by Reneuron, is recruiting patients in Oxford, but they have the necessary ethical approval in place and this is a research study with no claims that it will work.

There is another intervention being suggested as a treatment in the private sector in the UK: transcorneal electrical stimulation (TES) with OkuStim – they claim it is the only available topically applied treatment for retinitis pigmentosa with clinically-proven safety and efficacy. OkuStim therapy can slow the disease and progressive loss of visual field.

Although there have been several studies with variable outcomes, all have concluded that much larger and long-term studies are required to establish whether this is really of benefit. The company Okuvision state that: “the clinical data from the various studies do not yet provide a consistent picture of clinically relevant long-term effects.” So claims this is a ‘treatment’ may be too soon and this procedure has not been adopted by the NHS.

What measures could be enforced to validate future trials / treatments from those that are disingenuous?

This is a global issue and it is very difficult to regulate physicians in other countries, that is the responsibility of the local governing medical body, and I would urge anyone researching this topic

further to speak to someone from research and development as they will know more about the regulations. In the UK, we need national ethical approval and clinical trial authorisation from the Medicine and Healthcare Products Regulatory Agency (MHRA, an executive agency within the Department of Health and Social Care) for a Clinical Trial of an Investigational Medicinal Product (CTIMP). All trials should be externally audited to ensure they are adhering to their protocols.

To conclude, in light of this story, what precautionary advice can you offer those seeking treatment to retinitis pigmentosa or other related sight issues?

My take home message is this: patients must discuss any treatments they come across with their ophthalmologist before embarking on what could be an unethical, unsafe, costly and potentially harmful procedure. Please watch this documentary and share with others. And finally, alert your doctor, ophthalmologist or sight loss charity helpline if you feel something is not quite right.

FURTHER READING

1. BBC News. *The doctors selling bogus treatments to people facing blindness* (2023).
<https://www.bbc.co.uk/news/world-64838936>
2. VisualEyes with Bhavini. *Blind Faith – The truth uncovered! (please read, watch and share)* (2023).
<https://visualeyeswithbhavini.wordpress.com/2023/03/21/blind-faith-the-truth-uncovered-please-read-watch-and-share/?fbclid=IwAR0vw40Vov8iEc80IsWP eY6a5NsmtD-9Bq5-bIEJLsc5IGFb9n8YVRH4aeg>
3. BBC News: The Documentary. *Blind faith: Do genetic eye disease ‘treatments’ work?* (2023) [audio].
<https://www.bbc.co.uk/programmes/w3ct59r0>