

FACE THE FACTS

An optician claims to have developed a treatment for face blindness, but as Richard Shrubbs found out, finding the scientific research to back it up is hard

On June 17, 2011, the BBC reported that 'an optician in Scotland has developed what is claimed to be the first ever effective treatment for face-blindness'.

If true, this could revolutionise the lives of sufferers of face-blindness, where the sufferer cannot see a whole face, or sees a distorted version of a face. But for a treatment to gain credence requires independent trials – and this takes time.

The clinical name for face-blindness is prosopagnosia. For the child who experiences it, it will mean that they cannot recognise their parents' faces and this impacts on bonding and most social situations. Prosopagnosia is a condition that affects many people with autism. According to the website www.prosopagnosiaresearch.org 'as many as one in 50 people may suffer from developmental prosopagnosia.'

The condition is not wholly confined to people with autism. People who are not autistic can develop the condition or acquire it after suffering a head injury.

To counter prosopagnosia, optician Ian Jordan uses specially-developed light tests to assess the patient and find out at what wavelength of light they see faces. He then gives tinted lenses to the patient so that they can see faces. This treatment is available – free on the NHS. Jordan has trained five other opticians across the UK in the technique and families can book an appointment for an assessment without having to travel huge distances.

'The lenses I have developed help most people with the developmental condition, though a much lower rate of those with acquired face blindness,' says Jordan. He suggests his lenses help 90–100% of those with developmental face blindness.

A major breakthrough such as this should make the news, and it has. However, with such claims you must seek independent confirmation. In my own research about this I have no reason to believe that Jordan is some fly-by-night, 'what I cannot find is any independent

and recent research into the product, and so cannot find balance to his claims.

Put simply, it, for example, leaders in autism research had insight into this product and were singing its praises – or even confirming that it works in many cases – I could walk away and extol the virtues of the orthoscopic lens technology. A number of sources in the UK were approached for this article and could offer at best a general interview but nothing about this specific product.

Finding information

In seeking help for a condition associated with autism, practitioners and parents alike should do the legwork in finding out about a product. The highest form of scientific research is the double-blind randomised controlled trial (RCT). A large group of participants will be invited to test the product; the more the better for statistical significance. Two groups of patients are given a product, one a placebo or similar therapy of known outcome, and the other the real thing. Neither patient nor administering practitioner knows what is being given to the patient. The patient is tested for their response to the product, all in the belief that they have received the clinical version, and they report their responses. With those suffering prosopagnosia some will see faces, and others won't. Some non-clinical product users will see faces as 'placebos'. The result will indicate the efficacy of the product among those using the clinical version.

Dr Gina Gomez, director of autism research at the National Autistic Society (NAS), says: 'Finding treatments for autism can be a minefield. There is often little independent research backing up the claims of people who develop them.'

'More research is required across all treatments for symptoms associated with autism. Evaluation of such treatments is very expensive and this may well be a barrier to the good ones getting recognition in the medical community.'

Gomez was asked to discuss the

orthoscopic lens treatment but could not comment specifically.

Jordan says that he has done some post-reviewed work into the effects on the brain of his lens in face-blindness cases. 'Electroencephalograph (EEG) testing on 50 patients wearing these lenses showed a 1,000 fold increase in ATP [adenosine triphosphate] in the temporal cortex of the brain.' He reveals that neurons in the sensory area of the brain are far more active when the lenses are worn. Jordan doesn't know why this change takes place and doesn't venture to make claims as to why. The work shows promise but he is pretty much a one man band in researching the whole area of treatments.





For more information

- Prosopagnosia explained: <http://prosopagnosiaresearch.org/index/information>
- A simple explanation of orthoscopic lenses can be found at Norville Opticians of Cirencester: www.norville-opticians.co.uk/orthoscopes.asp
- Research Autism: www.researchautism.net
- AOA appraisal of Irlen lenses: www.aoa.org/x5418.xml

Evaluating treatments

Gomez recommends the website www.researchautism.net as a sound tool for those trying to evaluate the efficacy of a treatment for themselves. Set up by the NAS, it sets out to 'carry out high quality, independent research

into new and existing health, education, social and other interventions. Its goal is the 'improvement of quality of life and outlook for the individuals affected and those around them.'

The site should be a first port of call for those looking at a new treatment;

but it contains no information specific to orthoscopic lenses. It makes suggestions that colour filters can help with dyslexia and that Irlen lenses and filters can help with other conditions, but that is all.

Irlen lenses are the precursor to Jordan's orthoscopic lenses. Different people appraise them differently and Jordan says they are now discredited. The American Optometric Association (AOA) describes wide, non-repeatable variation in their efficacy. Where some RCTs found that they seemed to work in one way, others found they worked in another, and no one could repeat the trials exactly and find the same results.

Such variation in results calls the therapeutic benefit of Irlen lenses into question. If you can't repeat a trial and obtain similar results then you cannot ascertain the therapeutic benefit statistically across a wide spectrum. With multiple RCTs finding wildly different things, you can only say that such a treatment works in some cases but not all, and you won't be able to quantify how many people could benefit beyond those trialled.

"How do you RCT someone's face? It either does work or it doesn't," says Jordan. "I will seek RCTs in future as the product gets more widely used." He is disparaging of Irlen lenses for reasons similar to those described by the AOA. Jordan says his product is repeatable and works.

Researching this product, one feels that such a treatment should be tested independently and more widely, on the basis that it shows promise. There are a number of treatments out there that may be described as 'snake oil remedies' made by quacks but in my opinion this does not appear to be one of them.

However, thanks to the quacks and sharks, a potentially good remedy such as this would benefit from independent evaluation, to help practitioners and families of people with prosopagnosia evaluate the product for themselves. ■

BBC (2011) *Optician in Ayrshire Tackles Face-Blindness*. July 17, 2011. Available at: www.bbc.co.uk/news/uk-scotland-glasgow-west-13807268 (accessed February 2012).

About the author

Richard Shrubb is a freelance journalist.