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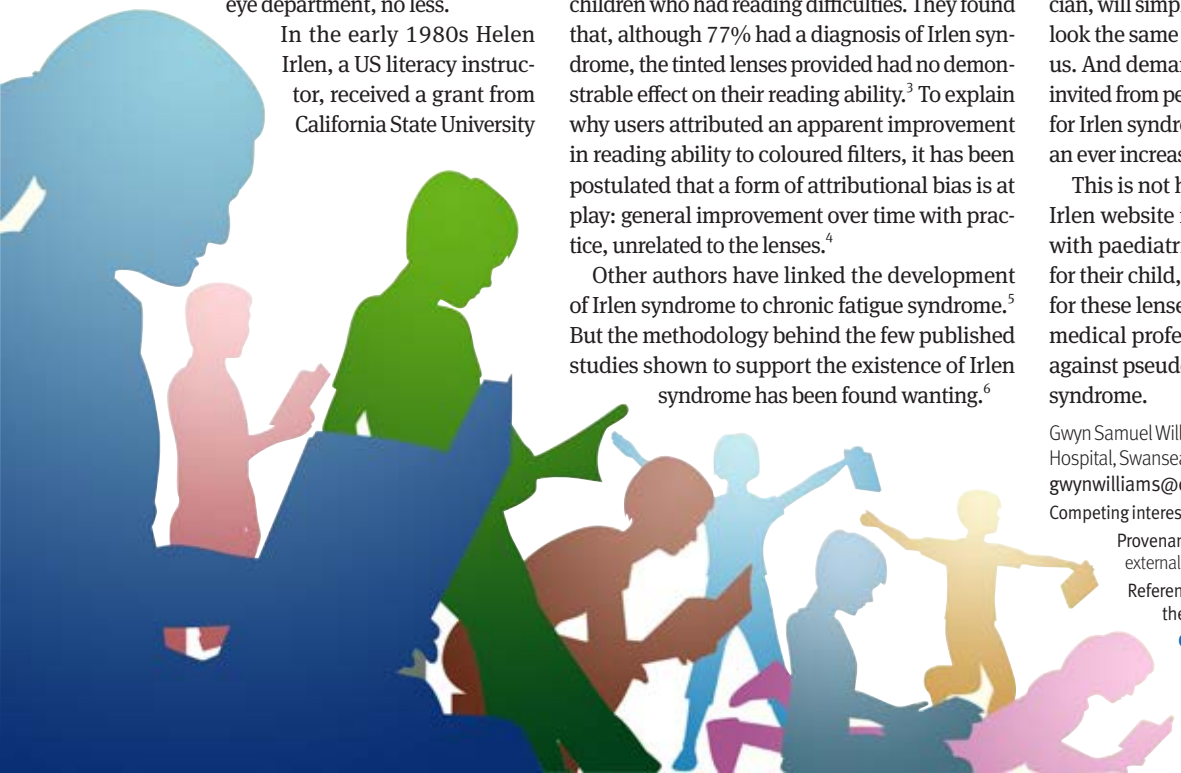
Irlen syndrome: expensive lenses exploit patients

So called scotopic sensitivity syndrome, or Irlen syndrome, is being promoted to patients who are then sold products to improve their reading speed—but they have no published evidence of efficacy, says **Gwyn Samuel Williams**

Her mother asked, "Well, doctor? Does she have Irlen syndrome?"

"Irlen syndrome?" I stifled my discomfort: I hadn't heard of this seemingly common eye disease despite recent revision for my final postgraduate ophthalmology exams. The mother recognised that the ophthalmologist did not know what this condition was—"just like the support group woman said would happen." She took some literature from her handbag with barely disguised contempt, and her young daughter continued attempting to dismantle the slit lamp as I scanned the leaflets.

Irlen syndrome, also known as "scotopic sensitivity syndrome," was being publicised by a company called the Irlen Institute based in California. It sells expensive filtered lenses to people with vague collections of symptoms who tend not to trust eye professionals. I gave an honest assessment of what I thought: that the company's literature seemed intent on selling worthless bits of coloured plastic at exorbitant cost and without the backing of any credible evidence. Mother and child left the clinic. But it was not long before another patient inquired about Irlen syndrome—soon followed by a staff member from the eye department, no less.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In the early 1980s Helen Irlen, a US literacy instructor, received a grant from California State University to set up an adult literacy programme. The website of the company she founded in 1983 (www.irlen.com) notes that she undertook "in-depth research" into why some adults learnt to read more quickly than others. She published very little of this research but concluded that special tinted lenses could solve the problem. A review of the evidence in 1990 showed that, in all likelihood, these lenses were not useful in developing reading skills, and the literature even questioned the very existence of the condition.[1]

> I performed the Irlen website's "self test" and was surprised to find that I may indeed have Irlen syndrome—but, trying different answers, any combination with three "yes" answers gave that result

Indeed, "scotopic sensitivity syndrome" is a misnomer, implying that symptoms occur in dark conditions in which colour vision plays no part. But despite this, the Irlen organisation has spread to 46 countries worldwide, with nine clinics in the United Kingdom. The prevalence of Irlen syndrome has been estimated to be as high as 20-34% using such loose criteria as "voluntary use of a coloured overlay," so these clinics have plenty of potential work.[2]

In a recent study, diagnosticians certified by the Irlen organisation examined a cohort of schoolchildren who had reading difficulties. They found that, although 77% had a diagnosis of Irlen syndrome, the tinted lenses provided had no demonstrable effect on their reading ability.[3] To explain why users attributed an apparent improvement in reading ability to coloured filters, it has been postulated that a form of attributional bias is at play: general improvement over time with practice, unrelated to the lenses.[4]

Other authors have linked the development of Irlen syndrome to chronic fatigue syndrome.[5] But the methodology behind the few published studies shown to support the existence of Irlen syndrome has been found wanting.[6]

I performed the Irlen website's "self test" to see if I had this condition. Many of the vague symptoms in the checklist might have indicated closed angle glaucoma, cataract, or several other recognised eye conditions. Another test considered whether headache symptoms could be a result of Irlen syndrome, and an "in-depth test" promised to explain "how Irlen syndrome impacts your life." I was surprised to find that I may indeed have Irlen syndrome—but, trying different answers, any combination with three "yes" answers gave that result.

Patients with a reading difficulty, or with a genuine undiagnosed ophthalmic disorder that may be amenable to proper treatment, are being misled and exploited by Irlen practitioners. Articles in the popular press and in online communities such as Mumsnet are generally supportive and uncritical of the scientific validity of the Irlen method and treatment.

The Irlen website states that only Irlen centres can provide the correct colour tint for the lenses and that other specialists, including every optician, will simply not do. Even coloured lenses that look the same will not work, the website assures us. And demand is so high that applications are invited from people to attend courses in screening for Irlen syndrome, so that the centres can be fed an ever increasing list of clients.

This is not harmless. The testimonials on the Irlen website include anxious parents battling with paediatricians over the correct treatment for their child, and patients are beginning to ask for these lenses to be provided on the NHS. The medical profession must be united in its stand against pseudoscientific nonsense such as Irlen syndrome.

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EDITORIAL, p 6

NO HOLDS BARRED Margaret McCartney

"Case finding" in dementia is full of fudge

The UK dementia czar, Alistair Burns, agrees that population screening for dementia lacks evidence of benefit.[1] Therefore, the NHS has not contracted general practitioners in England to "screen" for dementia, but rather to use "case finding" among groups of patients who are thought to be at higher risk of dementia. [2 3]

What's the difference? After all, approved NHS screening programmes offer their services only to defined subpopulations. Notably, the classic text on screening does not distinguish case finding from population screening in terms of the need for scrutiny or evidence base.

In 1968 Wilson and Jungner defined "selective screening" in their seminal World Health Organization report "for the screening of selected high-risk groups in the population. It may still be large-scale, and can be considered as one form of population screening."[4]

Meanwhile, they describe case finding as "that form of screening of which the main object is to detect disease and bring patients to treatment."[4]

The original text on screening does not distinguish case finding from population screening in terms of the need for scrutiny or evidence base

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A 2008 review of the work highlighted the need for "scientific evidence of screening programme effectiveness" along with "quality assurance, with mechanisms to minimize potential risks of screening" and a need to "ensure informed choice, confidentiality and respect for autonomy."[5]

WHO has described the search for tuberculosis among high risk populations as case finding.[6] Asking patients about memory problems when they have no related symptoms is, however, very different from a doctor taking note and acting on symptoms or signs of possible memory loss.

There is a lack of an agreed, formal definition of case finding. The dementia case finding programme is a form of population screening. The term case finding is being used when, to all intents and purposes, population screening is taking place—but without the evidence that would have enabled its approval as a screening programme.

Case finding, as used contemporaneously in the NHS, is full of fudge. The hunt for dementia can't be called a screening programme because it would not meet the standards of the UK National Screening Committee.[7] But call it case finding and suddenly there's no need for evidence that it protects the public against false positives and negatives—or society from the injustice of more resources directed towards the least unwell. This can't be right. We need a definition to include science and ensure accountability.

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BMJ BLOG OF THE WEEK Liz Wager

Research integrity—how can institutions balance discipline and support?

The suicide of Yoshiki Sasai is both tragic and shocking. Sasai was deputy director of the RIKEN Center for Developmental Biology, and a co-author of reports in *Nature* on the phenomenon of "stimulus-triggered acquisition of pluripotency" (or STAP), which were retracted. Although Sasai was not accused of misconduct himself, he was criticised in an institutional investigation for failing to check the data produced by his more junior colleague, Haruko Obokata.

I have been following this case closely, and have had several people ask me what I thought about it. As the investigations were still under way then, and the team attempting to replicate the findings had not yet reported, I declined to comment on whether this was fraud or honest error on those occasions. However, I did praise the institution's prompt and apparently thorough investigations. I also said that I thought it was a good thing the case was getting so much media attention, but now I am not so sure.

I remain convinced that secrecy is unhelpful, and that institutions should be open about cases of suspected and proved misconduct. Too many cases have been ignored or covered up, with fraudsters encouraged to leave quietly and seek another job, while whistleblowers are silenced.

I also believe that public debate is important, and that society needs to understand the pressures placed on researchers and the problems that occasionally arise. Serious misconduct is—fortunately—rare, but denying its existence is both naïve and unhelpful.

But the tragic death of Dr Sasai reminds us that transparency and scrutiny must be accompanied by support for the individuals affected. A few months ago, I spoke to the dean of a major west European institution about its policy of not releasing the names of individuals found guilty of misconduct to the media, even though affected journals were informed, and therefore this information was available in retraction notices.

He emphasised the dual responsibility of the institution not only to investigate (and rectify) misconduct, but also to protect its employees. In the case we were discussing, there had been extensive media coverage and the researcher was considered at risk of suicide (showing that this cannot be considered a peculiarly Japanese problem). I was impressed by this approach combining both discipline and care.

Society needs to understand the pressures placed on researchers and the problems that occasionally arise

I will continue to call for greater transparency around research integrity, and, until that is the norm, will welcome informed debate. But this sad story from Japan should remind us of the harmful effects that such debate may have, which we should try to minimise. As with so many aspects of misconduct and integrity, it's a difficult balance, but one that research institutions should strive to achieve.

Liz Wager is a freelance medical writer, editor, and trainer. She was the chair of the Committee on Publication Ethics (COPE) (2009-2012)