

Series editor: David Taylor

## Five years of surveillance

**M R Stanford on behalf of the British Ophthalmological Surveillance Unit Steering Committee**

### The British Ophthalmological Surveillance Unit

The British Ophthalmological Surveillance Unit (BOSU) has now been in existence for 5 years and has been actively involved in the surveillance of rare ophthalmological disorders for most of this time. It is now an appropriate time to consider what relevance it has to practising ophthalmologists. The unit was set up to facilitate national surveillance of rare conditions that were either important for the public health or whose natural history or management was of clinical or scientific interest to the ophthalmological community as a whole. The system of active case ascertainment is well known to be the most effective way of gathering information in these types of studies<sup>1</sup> and is used in a number of medical subspecialties in both the United Kingdom and abroad, most notably by paediatricians on whose model the unit is based.

The BOSU currently actively surveys 1062 ophthalmologists. This number is made up of 828 consultants and senior lecturers, 156 associate specialists, and 78 ophthalmologists in the Republic of Ireland, all of whom have clinical autonomy. Over the past 12 months 342 have maintained a 100% response rate by returning all report cards, while only 72 (7%) have failed to return a single card. The response rate has risen steadily since the inception of the unit and is now consistently more than 70%. There is still quite a marked variation in this response with South and West, Scotland, and Northern Ireland regions being the best responders (over 85%), but even in other regions the rate has slowly improved. In the early days it was probable that unfamiliarity with the system, particularly the need to report even when no case had been seen, accounted for this. Our current reporting rate is now equivalent to that achieved by other surveillance units (neurological, gastroenterology), but we aim to improve this to a consistent rate of better than 90% in the future. This is what is routinely achieved through the Paediatric Surveillance Unit and is certainly possible in ophthalmology as shown by the current rate in Northern Ireland (>90%).

In terms of output the unit has now aided 15 separate studies leading to seven peer reviewed publications and 24 reports to national meetings. Although this output is somewhat low, it is largely accounted for by the types of studies being run rather than from a lack of scientific or clinical value of the studies themselves. For instance, major studies relating to visual loss in the non-amblyopic eye or the incidence of stage 3 retinopathy of prematurity, required the collection of a cohort of patients and then longitudinal follow up in order to achieve their aims and it is only now that the final reports are being produced. The unit has endeavoured to encourage studies that have immediate impact for the routine work of the ophthalmologist as well as more esoteric studies. The data gathered from the postoperative endophthalmitis and expulsive haemorrhage following cataract surgery surveys should reveal the current incidence of these complications with implications for clinical governance, informed consent and the development of guidelines.

**Busy ophthalmologists can and do regularly contribute to this epidemiological exercise, and the benefits of the scheme are readily apparent**

The study of other conditions such as *acanthamoeba* keratitis and acute retinal necrosis will not have the same immediate impact, but monitoring current trends in the incidence of these diseases is important to the public health. Finally, the studies of diseases such as sympathetic ophthalmia and adnexal lymphoma have aided research into their pathogenesis (the relevance of HLA genes in sympathetic) and classification (the formulation of new histopathological criteria to assess prognosis in adnexal lymphoma). Two applications of active case ascertainment that were originally anticipated to be suitable to be run through the BOSU have yet to be put into practice.<sup>2</sup> These were the identification

of patient pedigrees in uncommon genetic disorders and the recruitment of patients with rare disorders (such as fungal keratitis) for randomised therapeutic trials.

It is also a time to reflect on the practicalities of running a surveillance unit among ophthalmologists. A recent survey of participating ophthalmologists run by BOSU concluded that the scheme was felt to be worthwhile by the large majority. The principal difficulty to participation was being unable to trace a patient's details at some point after the initial report. This is not a new problem in any surveillance system and will inevitably contribute to underascertainment, a problem that can only be truly resolved by external validation and capture/recapture analysis. Another concern was the lack of feedback given by the individual research groups and poor dissemination of their findings. This has been and will be resolved by greater feedback in newsletters, presentations at national meetings, and through peer reviewed publication. Finally, the initial enthusiasm for lengthy questionnaires by research groups has now been tempered by the realisation that they are unlikely to be filled in. Accordingly, questionnaires are now limited to four pages, with greater support being given to those even shorter.

The BOSU is the only surveillance system in ophthalmology in the world. The success of active case ascertainment as carried out by the unit is reflected in the knowledge that other subspecialties (paediatrics, neurology, gastroenterology) each have their own units, all of whom contribute to their own communities. In the first 5 years we have shown that even hard pressed and busy ophthalmologists can and do regularly contribute to this epidemiological exercise, and the benefits of the scheme are readily apparent. The BOSU is aware that participating in the scheme requires a monthly commitment (or more when reporting a case), but the existence of the unit should prevent the arrival of questionnaires which fit the "rubbish in/rubbish out" model of research.<sup>3</sup> It is to be hoped that the unit will be able to continue its work and provide a model that could be used by our colleagues overseas. In the future, the adoption of similar schemes by other countries will lead the way to international collaboration and encourage the use of identical protocols to enable simultaneous or sequential collection of data on rare ophthalmic disorders. This will allow the detection of environmental and genetic influences in the pathogenesis of such conditions.

## ACKNOWLEDGEMENTS

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## VIDEO REPORT.....

Thixotropy: a novel explanation for the cause of lagophthalmos after peripheral facial nerve palsy



**Figure 1** The online video shows two patients with a peripheral facial nerve palsy. The degree of lagophthalmos can be observed following gentle closure of the eyelids before and after stretch of the upper eyelid on the affected side.

One of the major complications of a peripheral facial nerve palsy (PFP) is the occurrence of corneal ulceration due to lagophthalmos—that is, incomplete closure of the affected eyelid. It is widely accepted that lagophthalmos after PFP is directly caused by paresis of the orbicularis oculi muscle (eyelid closure muscle). Yet, some of the signs and symptoms, which may be observed in patients with PFP cannot be explained by paresis of the orbicularis oculi muscle alone. First of all, gentle closure of the eyelid, as for example occurs when a person falls into sleep, is completely brought about by inhibition of the tonic activity of the levator palpebrae muscle (eyelid opener muscle).<sup>1</sup> Secondly, upward and downward saccadic lid movements, accompanying saccadic eye movements, are mainly due to modification of the tonic activity of the levator palpebrae muscle. Finally, the downward and upward smooth pursuit movements of the lids are again secondary to alterations in the level of activity of the levator palpebrae muscle. If these above mentioned movements of the lids are not caused by the orbicularis oculi muscle activity, what is then the reason that patients with PFP are unable to perform these movements properly? Furthermore, gold implantation in the affected upper eyelid or injection of the botulinum toxin into the levator palpebrae muscle is helpful in closing the affected lid, while no modification of the orbicularis oculi activity occurs with these treatment modalities.

As the orbicularis oculi and the levator palpebrae muscles have a reciprocal antagonistic activity,<sup>1</sup> we hypothesised that stiffness of the levator palpebrae is the cause of lagophthalmos. In a recent paper, we reported on the positive effect of stretch of the levator palpebrae muscle on lagophthalmos in a group of patients with PFP.<sup>2</sup> In the video report we present two patients showing the effect of our intervention on lagophthalmos.

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The full text video report can be viewed online at [www.bjophthalmol.com](http://www.bjophthalmol.com).