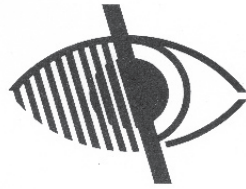


The Partially Sighted Society



Information Sheet

RETINITIS PIGMENTOSA

Retinitis Pigmentosa is the generic name given to a group of hereditary disorders which are characterized by the progressive loss of photoreceptor function (the light sensitive cells at the back of the eye). As yet there is no known cure for this condition although much expenditure has, and is, being put into research.

The clinical features may differ markedly among patients but, in general, the condition affects both eyes to the same extent.

Many individuals are only diagnosed when they experience problems associated with reduced night vision, a characteristic of this condition. A definitive diagnosis is usually provided by an Electroretino-gram (ERG) or an Electrooculogram. These are simple, painless tests which involve the positioning of sensitive electrodes near the eyes, or on the eyelids, which then record the electrical activity in the light sensitive cells at the back of the eye.

The age at which the condition begins, the speed of progression and the extent of ocular damage is often related to the way it is inherited, which is why a good Ophthalmologist will always ensure that full genetic testing and counselling is offered to those affected, and their families if necessary.

Although atypical forms of Retinitis Pigmentosa exist, in general it results in the progressive loss of the outer visual field (what you are aware of around you when looking straight ahead). This may progress to such an extent that the individual is left with only a tiny central area of useful vision. Other individuals experience only minor symptoms which may go undetected until

late in life. A form of atypical Retinitis Pigmentosa exists which results in profound deafness and progressive visual loss - this is known as Usher's Syndrome and accounts for about half of the cases of combined deafness and blindness.

The main difficulty encountered by those with Retinitis Pigmentosa is arranging suitable lighting levels - too bright and the affected individual will experience severe glare problems, too little light and their vision will markedly deteriorate. There is no definitive answer to this problem as it is usually specific to the individual. A thorough low vision assessment will help determine the optimum levels for visual function and provide advice on how to achieve them. Often, affected individuals find that a coloured tint in their spectacles, or in the form of an acetate sheet helps to reduce glare and give the appearance of improved contrast. Occasionally individuals find that some form of magnification is useful but, in general, it is of little benefit as the problem is reduced outer visual field and not reduced acuity.

Many affected individuals find that if their condition deteriorates then so do their mobility skills. They may be able to read the smallest of price labels on shop goods but cannot find the shop! (Although this may seem an exaggerated example, it gives an idea of the problems encountered.) These difficulties can often be helped by support and training provided by the Social Services Mobility or Rehabilitation Officers. This training is often offered routinely following home assessment undertaken after Partial Sight/Blind Registration but if these problems only manifest later, then they can always be contacted for assistance directly at the local Social Services.

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