CURE BLINDNESS
AUSTRALIA

FREQUENTLY ASKED QUESTIONS

WHAT ARE THE SYMPTOMS OF RP?

One of the earliest symptoms of RP is “night blindness” where there is difficulty seeing at night and in dimly lit places. This is accompanied by a progressive loss of peripheral vision (side, upper and lower), leading to “tunnel vision”. Frequently, in time, central vision also deteriorates.

WHAT CAUSES RP?

The death of photoreceptor cells in the retina is responsible for the symptoms of RP. A defective gene that fails to have the essential balance of proteins produced to keep photoreceptor cells healthy causes this. Over 100 gene defects have been recognised and so far research scientists have isolated over 30 defective genes causing forms of RP.

Is there any treatment?

There is no medical treatment to date...but world-wide research and studies are growing strong with positive results. In the foreseeable future, gene therapy may make it possible to substitute a healthy gene for a defective one.

IS ONLY VISION AFFECTED?

Yes, in most cases. However, syndromes combining RP and one or more other problems affect a minority. One example is Usher’s Syndrome, in which deafness accompanies RP.

Does “night-blindness” mean a person has RP?

No, in some cases night blindness does not represent any significant eye disease.

HOW QUICKLY WILL I LOSE MY SIGHT?

Progression of RP can vary from person to person. It is important then to be evaluated by a specialist eye physician. For some, the loss of sight is slow and there may be only a small loss over perhaps ten years or more. Others have periods of rapid loss, often with years in between with no apparent decline. Some will have poor vision since childhood or teens; for instance, they probably experienced difficulty with ball games or getting about at dusk. Classically the outer fringes of vision are affected initially, causing apparent clumsiness and an inability to see at dusk. In other cases the central vision may be affected first, causing difficulty in detailed work such as reading and identifying colours.

LIVING WITH RETINITIS PIGMENTOSA?

The first and hardest step towards living positively with a disability is accepting it. Accepting that you have RP will not be easy. You may go though periods of despair and of feeling resentful, bewildered or even angry. Adjustments are made and coping mechanisms help to live with the condition. Learning to adapt and having a positive attitude governs the type of life you and your family will share from day to day. Never write yourself off, with effort you will not miss out on many of life’s enriching experiences. Anything that you can do now you will be able to do with a more severe vision loss with training.

Help with coping mechanisms is available through your local Retina Australia branch or Guide Dog Associations around Australia.

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HOW CAN I HELP A FRIEND OR FAMILY MEMBER?

Try not to be overprotective, either as a parent or a spouse but observe what he or she can do without help. Listen to any suggestions such as how to arrange the house, keeping the floor clear of objects, not moving the furniture around too often, shutting cupboard doors and never leaving doors half open. When out, try to give warning of unexpected hazards such as steps, sloping pathways, uneven surfaces and doorways.

If you are the one with RP, attempt to explain how much you can do without assistance. Ask for help when it is needed; explain the type of help needed. Directional help is often useful i.e. 2 steps to the right and a step forwards. Learn how to be a 'sighted guide' correctly. The family that is always tense and over protective can be morale destroying. Sighted members of the family may need constant reminders not to leave things in your path, with time they will come to understand the degree of vision loss that you have.

Adjustments need to be made at varying times. Both the person affected by RP and the family need to patiently understand the adjustments necessary. Living with a disability can be hard for the other members of the family too. The affected person can do much towards making life happier by explaining to those around how they can best be helpful.

Remember that RP is a progressive disorder and that, consequently, the needs of a person with RP will change from time to time. It is often difficult for members of the family to understand that something, which was helpful five years ago, may be of little use today.