**Guide dogs Victoria's Perceptions June 2018:**
**a newsletter for professionals working with people with vision loss**

# **Spotlight on Retinitis Pigmentosa -** **a common form of degenerative vision loss affecting children and teens into adulthood**



This issue of Perceptions focuses on Retinitis Pigmentosa (RP) – one of the most common forms of inherited vision loss, that can start to manifest in childhood and degenerates to near total vision loss in adults.

Because of its early slow manifestation, patients can often experience lingering grief and anxiety on their journey towards acceptance. Often people with RP often wait to seek help, until vision is reduced to the point of effecting their ability to be safe and function with day to day tasks. This can result in a loss of independence, employment and isolation. Learn more in this newsletter about RP and its impact, and your role in getting patients the early help that can maximise low vision and develop strategies to be safe in any environment.

Your role is important. Encouraging patients with RP that it’s never too early to seek support can help them greatly, as they are more prepared to transition through declining vision. A referral to a support agency like GDV for low vision orthoptist advice to maximise functional vision, is a first step that can make a huge difference.

Of course, the ultimate aim of science is to look for a way to prevent or ‘cure’ the vision loss caused by RP. The Centre for Eye Research is a GDV partner that is currently recruiting for RP patients to join its Bionic Eye research. If you know of someone that may be appropriate, check out the details at the end of this newsletter

As always, any comments, suggestions or requests for articles are always welcome. You are welcome to forward this email on to your colleagues and members of your networks who can subscribe to our newsletter directly at www.guidedogsvictoria.com.au.

Warm Regards

Shelley Pannier

Client Services Manager

Remember:

* Refer online, via the ‘Request a Service form’ on [www.guidedogsvictoria.com.au](http://www.guidedogsvictoria.com.au/).
* We always welcome your feedback, comments and contributions. You can contact us on info@guidedogsvictoria.com.au

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**Dates for the Diary**

Regional Information Sessions**:** Free information sessions with morning or afternoon tea covering the locally available services provided by GDV. Come and meet some local practitioners, have a look at some technology, meet a Guide Dog and see if we can offer you something new to help your patients and clients. No bookings necessary. Further info 1800 804 805.

* Thursday 28th June, at Glenroy RSL, 186 Glenroy Road, Glenroy, from 2-4pm

**Acquired Brain Injury and Vision loss – Professional’s Workshop**: run regularly by Guide Dogs Victoria. 2018 Sessions:

* 5th July
* 25th October

For further information or to express your interest email info@guidedogsvictoria.com.au or call 1800 804 805.

**Low Vision Orthoptist Assessments:** available for any patient or client with a diagnosed uncorrectable vision condition. They will receive a functional vision assessment and some strategies for reading/lighting/glare etc, plus access to an ongoing program if they require. GDV is registered with NDIS to provide Orthoptic assessment and equipment recommendations.

We will be running these assessments all over Victoria throughout the coming year, but you can also arrange a bespoke information session for your staff, or a low vision orthoptist clinic for your patients, at a time & date to suit you by contacting info@guidedogsvictoria.com.au

We offer various programs to people experiencing vision loss from information sessions through individual programs, peer support and group programs. You can refer any of your patients to explore these programs, by advising them to email info@guidedogsvictoria.com.au, or call 1800 804 805.

**All about Retinitis Pigmentosa (RP)**

Retinitis pigmentosa (RP) is the name given to a group of conditions that involve a breakdown and loss of photoreceptor cells in the retina (light sensitive tissue that lines the back of the eye). This breakdown and degeneration of the retina is also called Retinal Dystrophy. ‘Retinitis’ means inflammation of the retina and ‘pigmentosa’ is associated with the discolouration of the retina, visible on examination. (A list of references and further reading can be found at the end of this article).

**What causes RP?**
It is thought that one child is born with RP in approximately every 3,000 births in Australia. RP results from an imperfection in a tiny gene that causes an incorrect protein to be supplied to the retina. Over time this causes photoreceptor cells (rods and cones) to die and hence the progressive loss of vision.

Although it is a genetic disorder and can be inherited, it is important to recognise that RP can strike in a family with no known history of it.

**How is RP diagnosed?**

RP can be diagnosed through the examination of the retina using an ophthalmoscope (a tool that allows for a wider, clearer view of the retina). This tool will generally reveal abnormal, dark pigment deposits that streak the retina if RP is present. Other tests include electroretinogram, visual field testing and genetic testing.

 An image of a retina showing the tell-tale dark pigment affecting the peripheral vision.

**How does RP affect vision?**

Symptoms of RP typically appear in childhood and often children show signs of difficulty navigating their way in the dark (nightblindness). Other symptoms may include taking an abnormally long period of time to adjust to changes in lighting and find bright lights uncomfortable, (photophobia).

There is a progressive loss of the visual field (peripheral vision), to eventually very narrow tunnel vision or complete sight loss, but this can affect different people, in different ways. Some people experience significant vision loss in early adulthood whilst others retain central vision into late adulthood. However, most individuals with RP will eventually lose a large amount of their sight.

**Things to look out for in patients**

People may describe having difficulty:

* Reading
* Driving
* Walking (unassisted- may fall over objects)
* Recognising faces and objects

As people’s ability to complete daily tasks and their mobility decreases, they report;

* Frustration
* Low confidence
* Depressive symptoms
* Poor mental wellbeing; and
* Low levels of general happiness in life

Typical to RP is denial and a sense of grief. Often the person will try to continue functioning in excess of their ability, from fear of losing the independence they have always enjoyed. It is important to be aware that RP can produce significant isolation and depression.

**Importance of diagnosing RP early and rehabilitation.**

# It is important to diagnose RP early so that those effected have the best opportunity to learn how to use their remaining vision to navigate environments and continue to complete daily tasks. Outcomes are generally better the earlier people learn these skills – they WILL need them later on.

There are a number of services and devices available for people with vision loss such as special lenses that magnify the central vision and eliminate glare, computer programs that read texts, portable lighting devices and closed circuit televisions.

Orientation and mobility (O&M)

Generally people with RP travel slower and are 5 times more likely to have a mobility related incident due to the narrowing visual fields. O&M will look at strategies for navigating an environment safely. This may include learning the white cane, developing visual scanning skills, learning to use technology for mobility eg GPS. Some client’s with RP may want to explore Guide Dog Mobility.

Occupational Therapy

Explore technology for reading text, safely managing cooking skills, identifying colours, shopping etc

Orthoptist

Provide education on understanding changes in vision and how to maximise a person’s use of functional vision. This may involve the use of magnification or minification, glare control, lighting and contrast.

Peer support and career preparation are also important. Young people with RP find it very valuable to talk to people going through a similar experience, and often if they are from outside their family there is less guilt and mixed emotion. Support in planning and future-proofing career options for eventual sight loss help to build confidence for the road ahead, and inject more security into a changing situation.

Guide Dogs Victoria practitioners are highly experienced at supporting people with RP and their families, throughout their journey. From initial concerns, through ongoing functional vision assessments and decreasing peripheral vision, we are here to help. We are More Than Dogs – providing Occupational Therapy, specialist children’s services, Orientation & Mobility, technology advice and peer support options. All of our services are provided at no cost (unless the person can access funding in which case we would request to utilize this where appropriate).

If you have patients you are concerned about, refer them now via [www.guidedogsvictoria.com.au](http://www.guidedogsvictoria.com.au), or 1800 804 805. One of our friendly practitioners will call them to discuss their situation, and they are under no pressure or cost implications. It might be the turning point they need, and your referral really could change their life.

**References and further reading:**
 http://www.retinaaustralia.com.au; Psychological aspects and depression in patients with retinitis pigmentosa, Moschos et al. European J Opthal Vol. 25 Issue 5 | Sep-Oct 2015 | pp. 373 - 462, e75 - e102); Relative Difficulties of Daily Living Tasks with Retinitis Pigmentosa, Latham et al. Optometry and Vision Science: March 2017 - Volume 94 - Issue 3 - p 317–328); Coping strategies, vision-related quality of life, and emotional health in managing retinitis pigmentosa: a survey study (Krithika Anil, Gulcan Garip) 2018: BMC Ophthalmol. 2018; 18: 21.

**Do you have a patient with Retinitis Pigmentosa or Choroideremia, who may want to be involved in the Bionic Eye Research by Centre for Eye Research Australia (CERA)?**



(Image: Centre for Eye Research Australia logo, purple and orange graphic eye shape)

CERA are currently inviting people who have been diagnosed with retinitis pigmentosa and would like to register their interest in a study that has been designed to understand the disease process and determine which people may be able to be helped with a retinal prosthesis or bionic eye implant.  They are looking for people who have vision loss (only able to distinguish light and dark) from retinal degenerations, such as retinitis pigmentosa or choroideremia.

If you are interested in the receiving more information about the study, please contact maria.kolic@unimelb.edu.au**.**

To keep updated with research with in CERA, please visit [www.cera.org.au](http://www.cera.org.au/)**.** People with vision loss are also able to register their details with CERA via the **‘Clinical Trials Web Sight’** link and be a part of the database.

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**Client Case Study: David’s RP Journey**

David was diagnosed with RP (Retinitis Pigmentosa) in 1987 at the age of 15. Passionate about all things on wheels, with the dream of driving cars and riding motorcycles within his grasp this was a particularly cruel blow.

Initially David’s night vision seemed to be the only area he had real difficulty with, so he proceeded to obtain a driving licence.

There were numerous close calls and David by his own admission kept on driving longer than he really should have, not wanting to accept ‘the inevitable’. He voluntarily gave up his license in his mid-twenties. He was still successfully able to read the eye chart at Vic Roads but knew his peripheral vision and night vision were both dangerously limited.

David’s remaining useful functional vision faded by his early thirties and he now has minimal residual light and dark perception – he can tell day from night but that’s about the extent of it.

David accessed Orientation and Mobility support through Guide Dogs Victoria, initially learning to use a long cane. In 2007 he became the recipient of Guide Dog “Merlin”. He hasn’t regretted the transition from long cane mobility to Guide Dog mobility as for him, it takes a lot of the stress and anxiety out of navigating busy and often hazard filled environments.

Now with his second Guide Dog “Zinnia”, David travels from Ballarat to the Docklands every day for work. He has a busy and fulfilling job and family life and wouldn’t live any differently. Whilst he is philosophical about his RP, he wishes he had got help earlier. He feels he would have been more prepared for the journey to come, and building his long cane skills earlier would have enabled him to access a Guide Dog earlier.

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For **clients of all ages,** Guide Dogs Victoria offers so much More than Dogs:

* **Low vision orthoptic service** to educate clients and monitor vision issues, assist in making the most of declining vision, assess for magnification/tech aids to assist vision
* **Specialist Occupational Therapy & Assistive Technology advice** to support daily living skills
* **Adult and Child Mobility Service** to support safe independence at home and in the community, including Victoria's only specialist **Acquired Brain Injury Mobility service** for people experiencing low vision or blindness.

 

1800 804 805

www.guidedogsvictoria.com.au