



INSIGHT

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The Official Publication of the Western Australian Retinitis Pigmentosa Foundation Inc.

YOUR EDITOR'S COMMENTS by Rhys Wood

Happy New Year everyone. Welcome to the first Insight for 2009. There's been changes at WARP that you should know about and these will be no doubt explained in this issue. The Foundation remains strongly committed to the raising of funds and awareness of Retinal diseases. To the new staff, I wish all the best. To Vivienne French and Tennille Nathan, thank you for jobs well done. In particular, special thanks to Vivienne who has been at WARP since the dawn of time. All the best for the future.

Recently we lost our friend Bob Daniels to Cancer. Amongst other things, Bob used to edit Insight before me until he had to focus all his energies on fighting the good fight. As I look back at my editorials the earliest I can find is from 2005, so fight he did! There is more about Bob in this issue, but on a personal note can I just say that Bob was a gentleman and an inspirational figure. He was always very interested in what I was doing and always good for a chat. Thanks Bob.

We have lost a lot of experience from our resources through one thing and another but sometimes good things can come from change. Take the Australian cricket team who took a young team across to South Africa and against all the odds managed to win the series in 2 tests. Order has been restored! Anyway, let me take this opportunity to invite anyone with enthusiasm and skills (not necessarily in that order) to step up to the plate and help the foundation. The contact details are in every issue of Insight.

I don't suppose anyone's been listening to Eoin Cameron's show on ABC 7.20? He's been playing songs from my album. It's no big deal... Bye for now.

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REPORT FROM THE PRESIDENT

Welcome to 2009 which I trust has started off well for you all. There have been a lot of changes within the foundation since the last issue of the Insight in December 2008 within the Foundation.

The passing of our Founding and Life Member Bob Daniel was a tremendous loss for his family and the WARP Foundation. Bob, together with Georgie, was a tireless worker for RP over many years. We extend to Georgie and family the Foundations condolences and support during this sad time.

At the end of December Vivienne French our Operations Manager resigned after 19 years with the Foundation. During that time she was a dedicated and hard worker, through her efforts she has left the Foundation in a sound position. We extend to Vivienne our grateful thanks and best wishes for the future.

Jan Wood, Life Member and long time librarian / counsellor, has relinquished her duties. Jan leaves us with a wealth of knowledge in her well documented library on inherited retinal dystrophies. Members will miss their chats with Jan as she was able to pass on information of where retinal research and treatments are at as well as giving comfort and support to the newly diagnosed. We trust Jan will be able to enjoy a well earned rest and we thank her for her valued support over many years.

Marg Lane and Jenny Sage joined us in early February to fill the positions of Operations Manager and Fundraising Coordinator. Both Marg and Jenny have settled in well and are coming to terms with their new duties.

With everything that has happened the commencement for the 2009 RP raffle was rescheduled to the 23rd March and is now underway. Books have been posted out and your help will be greatly appreciated with ticket sales.

The Antique and Collectors Fair for March was cancelled as we have been searching for a new venue. A very promising venue is now being looked at and hopefully we will be holding a Fair later in the year.

The RP Street appeal is set for Friday the 5th June, so if you are able to help for a few hours on the day please call Marg or Jenny to offer your services. The more collectors on the street the more funds in our research account.

I trust you will find this issue of the "Insight" interesting and informative. If you are in the vicinity of the office, please call in and make yourselves known to Marg and Jenny.

Murray Witham
President

Blindness no bar for civic campaigner

BOB DANIEL (Blind community activist)

Born: Kadina, South Australia, 1938

Died: Nedlands, aged 70

"For years, a physical disability in Australia could mean curtailing unrelated expectations. And that was true for farmer's son Bob Daniel, who was born legally blind. Poor eyesight put him at an obvious disadvantage to take over the family farm in South Australia, but he was inexplicably forced to abandon plans to teach history.

Such is human resilience, however, that Bob overcame these setbacks with determination, matched only by a generous nature that saw him become one of the most popular councillors in the City of Stirling, with a community centre named after him in Inglewood.

Robert John Daniel was born in Kadina, 150km north-west of Adelaide, on June 16, 1938, only child of farmer Norman Daniel and wife Mary. Cancer claimed Mary when he was eight but he was barred from her funeral because of his youth. The inability to pay his last respects was a lifelong regret.

Young Bob's vision could make out colours and movement, but little else, and he wore thick spectacles. By the time Bob turned 14, his father accepted that his son was physically incapable of managing the farm in Kulpara and sold up to come to WA, where several relatives had settled.

Bob's intelligence was apparent; he got his leaving certificate from Leederville Technical College and got a prize for book-keeping at City Commercial College before graduating from the University of WA with a Bachelor of Arts in History, poring over textbooks just a few millimetres from his nose. But for whatever reason, which would almost certainly require explanation today, he was refused teacher training, the first of several employment setbacks.

So Bob worked the switchboard for the Association for the Blind. In 1964 he married Georgie Higgins, whose father was foreman in Nannup Road Board. Bob's prospects improved in the next year when he joined AMP Society as an unpaid trainee switchboard operator. Within six months he was full-time member of staff. He memorised 120 telephone extensions, which over time increased to more than 270. Within AMP nationally he was The Voice from the West. After a few years, he passed the Australian Insurance Institute exams; his tests were on tape cassettes and his typed answers in some sections equalled and beat some of the best in the nation.

Through his new-found knowledge, he answered many switchboard queries without transferring callers to specialist staff. His confidence was bolstered by an uncanny ability to match a voice with a name. He retired from AMP after 31 years.

When he went totally blind in his 30's, Bob eschewed sunglasses and a guide dog, and relied on a cane. Although he was active in agencies supportive of his loss of vision, he selflessly delved into community work with minimal personal benefit.

As a member of Inglewood Ratepayers Association for 30 years, he brought local issues to the attention of authorities and was president of the association for six years. In 1989, he ran for a seat on the City of Stirling and became an Inglewood ward councillor for 18 years until ill health forced reluctant retirement in 2007.

For years, Georgie read council minutes to him before meetings. Among his biggest achievement was the rebuilding of Inglewood Community Centre in Beaufort Street, later renamed Bob Daniel Community Centre.

Son Paul recalls his father climbing the roof at home to clear leaves from guttering. On another occasion, Bob placed insulation batts on top of the ceiling, while balancing on roof beams. As well he used to kick a footy and for a while played blind cricket.

Bob Daniel was a founding member of the WA Retinitis Pigmentosa Foundation and first president of the national body, Retina Australia, and was a founding member of the public speaking organisations, Rostrum 31. Such was his community spirit, he was often shaking a collection tin in his lunch hour for various causes he supported and sometimes for unconnected charitable organisations.

As well, he was a star at quiz nights, loved music and was a frequent letter writer to newspapers and caller to talkback radio.

He died on February 7, aged 70, after a long battle with cancer. He is survived by his wife Georgie, two children, Paul and Heather, and seven grandchildren, Jack, Stewart, Alyssa, Shayana, Georgie, Kealani and Coby."



Bob was an active member on the Management Committee of the WARP Foundation for over 27 years as President, Vice President Editor of the Insight and tireless worker. His contribution was recognised when he received a Life Membership of the Foundation.

This article, which appeared in the 5th March 2009 "West Obituaries", has been included with permission from the West Australian Newspaper.

2009 Retina Australia Congress – second progress report.

The Retina Australia Congress will be held in Brisbane, on October 23rd, 24th and 25th, 2009. It will be held at the Royal on the Park Hotel, in the centre of Brisbane.

While we have yet to finalise arrangements with all of the invited speakers, I can advise that the following presenters will be included in the program:

- Professor Elizabeth Rakoczy (University of Western Australia and Lions Eye Institute) who researches in the area of genetic treatments for retinal eye diseases.
- Associate Professor Nigel Lovell (University of NSW) who was a funded researcher. He will speak about vision prostheses.
- Dr Erica Fletcher (University of Melbourne) who researches the possibilities of pharmaceutical treatments.
- Dr Monica Acosta (University of Auckland – an associate of Professor Michael Kalloniatis) Prof Kalloniatis research was also funded by Retina Australia. Dr Acosta and Prof Kalloniatis conduct research into the causes of retinal eye disease.
- Dr John de Roach (Principal Medical Physicist, Sir Charles Gairdner Hospital, WA) who will speak about the Australian Inherited Retinal Disease Register and DNA Bank.
- Tina Lamey (Senior Research Officer working with John De Roach). She will speak of their work studying the genetics of Western Australian Families Affected by Inherited Retinal Disease.

We are negotiating with other presenters, and have begun to arrange sessions of a practical nature for Congress participants. There will be a session focussing on the issues relevant to young people, and a session focussing on mental health, particularly depression, for those affected by retinal eye disease. We will also have a question and answer session with an ophthalmologist.

The program is shaping up to be one which will cater for a wide range of interests. Recently each State organisation of Retina Australia has committed funding to a three-year study involving the Australian Inherited Retinal Eye Disease Register and DNA Bank. Our presenters John de Roach and Tina Lamey will provide the Congress with specific information about the project, and clarify issues for participants.

We expect to be distributing registration forms and more specific details to members around Australia, and in New Zealand, in April.

Be ready to register for the Congress when registration forms become available. Come and join us in the warm Queensland springtime. I look forward to meeting you there.

By: Anne Housego. Retina Australia (QLD)

DISABILITY NEWS

ID Mate talking barcode scanners for the blind and low visioned

Visual Independence announces that grants for the ID Mate talking barcode scanners are available. Applications will close 31 May 2009.

The talking barcode scanner assists the blind and low visioned community by identifying products and items that have or can have a barcode attached. Using an onboard database of item descriptions, the user can hear what an item is by simply scanning the object with ID Mate.

The first grant for 2009 will be for 15 units. The grant opportunity targets those most in need and least able to afford the technology. The criteria allow applicants to receive an income of up to \$10,000 above their Centrelink entitlement.

Application can be obtained by email info@visualindependence.org.au

LOW ENERGY LIGHT BULB



Following recent press coverage about the potential withdrawal of the traditional light bulb, several members with RP have asked whether there are any hazards resulting from the use of Low Energy Light Bulbs.

These bulbs work very much like the long tubular fluorescent lights. The old type of tungsten filament lamp is very inefficient, as only a tiny percentage of the electricity energy that goes in is converted into light. The vast majority is converted to heat, which is why that type of bulb feels so hot. The new bulbs give about four times as much light for the amount of electricity that goes in.

One possible reported hazard with the new bulbs is if you break one, because they contain a tiny amount of mercury. However the amount is so small that you would need to break many bulbs at the same time in a closed room to cause even a slight hazard.

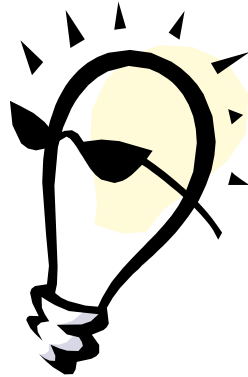
There is a potential problem, with flicker, as with all fluorescent, types, but this is now almost eliminated in the newer versions. This is a problem mainly for people with epileptic tendencies and diseases such as ME.

These bulbs do emit a small amount of ultraviolet light, which could be a problem for people with skin or retina problems but again the amounts are very small. This needs to be considered in relation to the amount you get from daylight. You would need to sit with your face almost touching the bulb (within 2cm) to get the same dose as midday summer daylight. At 30cm (about 1 foot) away there should be no problem at all.

All things considered, it seems that the new low energy bulbs shouldn't present a problem to our members. However if you do find them less bright than the old type, you can use a higher wattage bulb and still use much less electricity than the old type.

In Australia the old type of globes are being phased out from 2009 and completed by 2014.

BY Selwyn Higgins, British RP Society



No one ever hurt their eyesight looking on the bright side of life.

Surgical risk factors related to vision loss

Interruption to the eye's blood supply during surgery may be a risk factor for post-operative visual loss (POVL).

A paper entitled 'Postoperative visual loss: A review of the current literature' examined studies of non-ocular POVL.

It found that the duration of anaesthesia, time spent in the prone position and the amounts of intravenous fluids given during surgery were factors in determining the risk of vision loss.

The review was written by Dr Molly Filbert from the University of Illinois Eye and Ear Infirmary. It showed that POVL is as high as 4.5 per cent in cardiac surgery and 0.2 per cent in spinal surgery.

Recommendations for reducing the incidence of POVL include careful collection of preoperative history; avoidance of compression of the eye, abdomen or chest in patients lying prone; and correction of anaemia or hypertension.

Emerging Treatment Stabilizes Vision in People with Dry AMD

BBC Inside Out London speaks exclusively to blind patient, 73-year-old Ron, who is one of just three people in the UK to have been fitted with a "bionic eye" enabling him to see for the first time in 30 years. Ron had the experimental surgery seven months ago at London's Moorfield's eye hospital and has since been making good progress.

Ron who lost his sight in his forties due to Retinitis Pigmentosa now has the ability to see flashes of coloured light and dark. His treatment is part of an international trial carried out by an American company called Second Sight and he is one of the 18 patients across the world taking part in the experiment.

Over the past few months Ron has been learning how to use his new bionic eye. He is beginning to recognise objects and follow road markings like white lines.

The bionic eye means that Ron is now regaining his independence and is able to carry out normal everyday tasks such as sorting the washing.

Ron: "They said let there be light and there was light. For 30 years I've seen absolutely nothing at all it's all been black but now light is coming through.

"It gives me grades of bright light to black and anything in between. I can actually sort out white socks, grey socks and black socks." It has made a huge difference to his wife Tracy's life too.

She says: "He can do a lot more now than he could before, doing the washing, being able to tell white from a coloured item. I've taught him how to use the washing machine and away he goes. It's just the ironing next."

The treatment works by implanting a small electronic receiver at the back of the eye. Light from an image is captured by a video camera on the patient's glasses. The camera sends the signal wirelessly to the receiver on the outside of the eye. The message is transferred to the implant on the retina which stimulates the optic nerve and sends the image to the brain.

Consultant ophthalmic surgeon Lyndon da Cruz, who carried out Ron's operation, says a huge step has been made towards restoring people's sight.

Gregoire Cosendai from Second Sight, the company that designed the bionic eye, says that within 50 years people like Ron will probably be able to read and in the future people with retina implants could have better vision than normal sighted people.

Lyndon da Cruz: "Certainly for blindness I think the step has been made. I mean a stable device is interacting with the retina and people are starting to get visual stimuli. That first step is often the hardest step because that's a proof of principle step; it shows it's feasible that it's actually happening."

Ron adds: "It's a great privilege and an honour I think to be able to take part in an experiment such as this hoping that the outcome is going to be able to bring sight to people like myself that are completely blind."

FROM THE OFFICE DESK

Hello to all readers.

It is a new year and a new look at the RP Foundation in Stirling Street, Perth.

As some of you will know by now our Operations Manager Vivienne French has left the Foundation and gone off to pursue other ventures. I thank Vivienne for leaving such a stable environment for me to move into. Tennille has also moved on and thanks to her for her services while working with RP.

Jan Woods has decided to leave RP after many years of volunteering as our Librarian and her services will be missed. We thank Jan for her service to the RP Foundation.

As you will gather from the above information RP in Stirling Street has two new faces taking over the running of the office and we have Murray Witham spending a few weeks in the office teaching the new staff and assisting with advice and knowledge to any newly diagnosed patients that call into the office or telephone.

Jenny Sage is our new Fund-Raising Coordinator and I have taken on the roll of Operations Manager.

Previously I have been working in politics and before that owned and ran my own business with a partner. I come from a business background and have the honour of being a WA Telstra Small Business winner in the past. I have two grown children living in Melbourne.

Jenny comes from a retail background and is doing a wonderful job working with the collectors and organising the Raffle. (More on the Raffle Later) Jenny, her husband and two grown children live at Brigadoon and Jenny loves the quiet country life she has away from the office. Jenny works Monday – Wednesday 9.00am to 4.30pm.

We have a great bunch of collectors at present and we thank them for the wonderful work they do.

Obviously with such staff changes in the office things are a little different but we are endeavouring to fit in with everyone's requirements and make the transition as smooth as possible.

By: Marg Lane

WHAT'S HAPPENING ON THE SOCIAL SCENE?????

LAMONT'S

*The WA Retinitis Pigmentosa Foundation in conjunction with Lamont's, bring you...
Food & Wine Conversations with Kate Lamont*



A six course sensational seasonal menu with wine matching. A rare opportunity to discuss the recipes and their ingredients with Kate. Discuss how to match food and wine; what works, what doesn't and what you can do to modify recipes to suit the style of wine you like to drink.

"Don't miss this fabulous evening"

When: Tuesday, 26 May 2009

Time: 6.30 pm for a 6.45 pm start

Where: Lamont's, 11 Brown St, East Perth

Cost: \$99 per head (all inclusive!)
Limited seats available, so book early!



Bookings Essential: Call Pina Faliti-Smith on 0419 906 206
or Email: pinaandsean@dodo.com.au
Proceeds support the WA Retinitis Pigmentosa Foundation

HELP US TO FIGHT BLINDNESS

Courage doesn't always roar. Sometimes courage is the little voice at the end of the day that says I'll try again tomorrow.



ENTERTAINMENT BOOKS

2009/2010 Books will be launched mid May 2009. We are hoping once again to sell a lot of books. These are a great way to fundraise, so please get in contact with friends and family and take their orders now ! (**Order Form on next page**).

We have been promised the book will have many wonderful new inclusions this year.

SELLING FOR \$65-00 THIS IS GREAT VALUE

You only need to use the book a couple of times to make it worth while – so please ask around and get those orders in. There are bonus vouchers for early orders.

DON'T MISS OUT



WE ARE HAVING A BALL !!

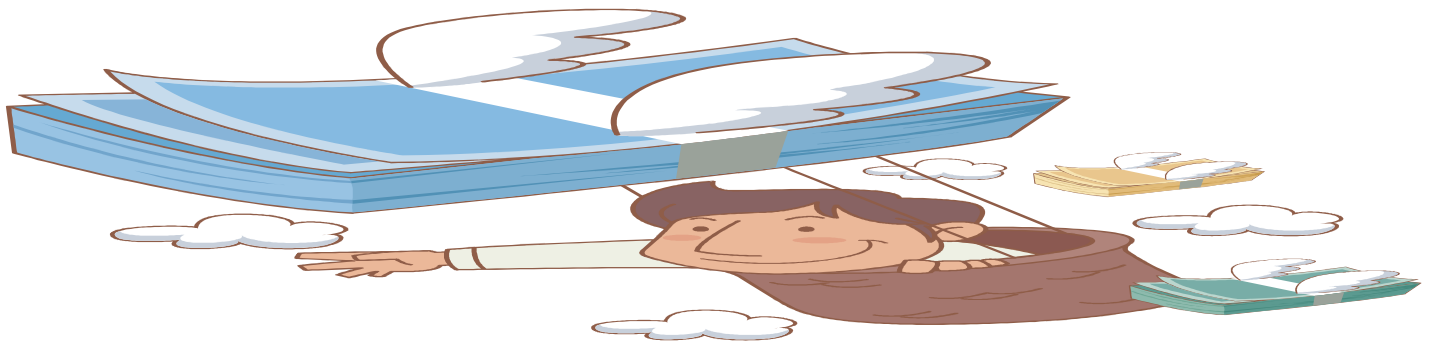
Start practising those beautiful dance steps and get your toes tapping as we are having a Gala Fundraising Ball.

When: April 2010

It will be a wonderful, glittery occasion and we hope to make it an annual fund raising event so be ready. More detail next Insight.

RAFFLE RAFFLE RAFFLE !!

If you can sell a couple of books it would be really appreciated. Remember all the funds raised go to helping with research and helping to make life a little easier for people with RP. If you are able to do a day or two selling tickets at a shopping centre please get in contact with Jenny 9227 7810 and see what we can arrange. If you have a local shop or business that will take a book please let the office know and we will get a book out and arrange for collection before the raffle draw.



Please get involved and help make the job of fund raising a little easier on everyone. A big **"thank-you"** to those who have already offered to sell a book or two.

*****NEWS*****NEWS*****NEWS*****NEWS*****NEWS*****



HOT OFF THE PRESS

We have a new venue for the
"GOLDEN WEST COLLECTORS FAIR"

WHERE: UWA, MOUNTS BAY ROAD, CRAWLEY

WHEN: 10th and 11th OCTOBER 2009

Spread the news !

Do you have a great fundraising idea that we can use? We would love to hear about it or have you work with us to make it a bigger and better function.

Do you have a business (big or small) and would like to place an ad in our Insight magazine? For a small fee we can arrange ½ or full page ads. You will be getting your message out there and helping RP at the same time.

Are you hatching or matching or just wanting to share some great news with other readers? Let us know and we will spread the news. Good jokes also very welcome.

WANTED

COLLECTORS FOR STREET APPEAL FRIDAY 5TH JUNE 2009

Please contact the office and offer to shake a tin for an hour or two
Ph: Jenny or Marg on 9227 7585

Stifling an urge to dance is bad for your health – it rusts your spirit and your hips.

Vision Australia's Dickinson Literary Award Winners Announced

10 March 2009

With more than 80 entries across six categories the standard of writing is exceptional and we are sure that you will appreciate the literary excellence demonstrated. Each winning author will receive a \$500 gift voucher from Vision Australia's Equipment Solutions. Second place getters will each receive an audio book kindly donated by Vision Australia Audio Books.

Both these winners have RP. What a remarkable talent for two young gentlemen.

First place: WASP / Author: Hugh Caldwell (VIC)

Chapter One

"James closed his locker, slung his bag over his shoulder and started to walk away. One more week of Yr 8. Underneath thinking this, he was thinking about what everyone else was thinking and talking about these days, WASP. WASP was a war waiting to happen. The initials stood for War Against Sighted People, something the blind people had created by trying to get equal rights.

James and his friends said that blind people were sightless and therefore useless, and teased them whenever they got the chance. Down the corridor, Mark was putting his things in his locker, by coincidence, Mark was blind.".....

Second place: Abisthort / Author: Hugh Caldwell (VIC)

"The Elthemadons were the most intelligent race in the universe, and worshiped any kind of great intellect, their god's name was Abisthort, and they decided to make a physical representation of their god in the form of a gigantic computer.

And so they went to work, the plan was to give him all the knowledge in the universe, but have him able to think for himself, rather than be a huge voice activated set of programs.".....

Honorable Mention: Raining blood / Author: Christian Caldwell (VIC)

"Ivy was running as fast as she could through the dark, silent jungle, the trees and plants just a blur as she sprinted passed them. Unexpectedly, there was a large, air-shattering roar, she looked up and saw a gargantuan creature advancing towards her, it stood eleven feet tall, it had large arms with dragon-like talons for hands which held a large double-bladed axe. She had heard of this creature, it was called a 'Moku-Oni', an earth demon. It stared at her with its large, yellow, pupil-less eyes, growled as black saliva dripped from its jagged teeth.".....

To read the whole stories above, please refer to the website - <http://www.visionaustralia.org.au>

Here's an easy way to **Raise Money** for the **Retinitis Pigmentosa Foundation** **with very little effort!**

Imagine raising money for The Retinitis Pigmentosa Foundation with relative ease...

By changing your printer cartridge supplier you can now raise money for the Retinitis Pigmentosa Foundation. It's quite simple. Let me explain...

**For every Premium Plus cartridge you purchase from
Quality Printer Cartridges
\$5 will be donated to the Retinitis Pigmentosa Foundation
on your behalf***

Your cartridges are an ongoing commodity that you use daily. **This offer makes your fundraising easier and your donations will continue without you having to lift a finger.**

You will feel great knowing that by using **Quality Printer Cartridges** you are helping with the care and cure of people living with retinitis pigmentosa.

Quality Printer Cartridges already supply the Retinitis Pigmentosa Foundation with top quality, value for money printer cartridges. Not only do we manufacture a superior quality cartridge, but we also plant a tree for every order that contains a Premium Plus cartridge!

All you need to do is call **Quality Printer Cartridges** on **(08) 9408 1740** and quote the code: **CHAR007** or simply mention that you would like your donation to go to the Retinitis Pigmentosa Foundation when placing your order for the first time.

You will see how much has been donated from each of your orders as these details are noted on your invoice.

Feel free to ask others to join in and choose **Quality Printer Cartridges** to assist with their cartridge needs (photocopiers, faxes, printers). Just be sure they mention the code word: **CHAR004** to ensure their donation is recognised.

Thank you again for your constant support and fundraising efforts. If you have any questions regarding the above offer, please telephone one of our helpful team members on (08) 9408 1740 during office hours.

It's the friends that you can call up at 4 a.m. that matter.

WESTERN AUSTRALIAN RETINITIS PIGMENTOSA FOUNDATION INC
Suite 2, 251-255 Stirling Street, Perth WA 6000
Ph: (08) 9227 7585 Fax: (08) 9227 7842
Website: www.retinitispigmentosa.com.au

MANAGEMENT COMMITTEE:

President	Murray Witham	9390 2507H	withamm@inet.net.au
Vice President	Ron Fisher	9397 6525H	ronf@dodo.com.au
Vice President	Pina Faliti-Smith	0419906206	pina.falitismith@synergy.net.au
Treasurer	Sean Smith	0413560848	FTI@foxgold.net.au
Secretary	Leonie Woolley	93791040H	woolleyleonie@hotmail.com
Committee	Joy Witham	9390 2507H	withamm@inet.net.au
	Tom Quinn	9467 3666	tomquinn@amnet.net.au
	Robyn Hollier	9272 8727H	colinrobyn@optusnet.com.au
	Colin Hollier	9272 8727H	colinrobyn@optusnet.com.au
OFFICE STAFF:			
Operations Manager	Marg Lane	9227 7585	warpf@inet.net.au
Fundraising Coordinator	Jenny Sage	9227 7810	rpfundraising@inet.net.au

WARP FOUNDATION
 2/251-255 STIRLING STREET, PERTH 6000

POSTAGE PAID AUSTRALIA

Help support the WARP Foundation in its work by sending this coupon, with your donation to:
WARP Foundation 2/251-255 Stirling Street, PERTH WA 6000
 All donations will be wholly for the support of research and those over \$2 are tax deductible.

Mr/Mrs/Ms _____

Address _____

Please find enclosed my: Cheque/Bankcard/Visa/MasterCard/AMO for \$ _____

Card Number _____/_____/_____/_____ Expiry Date _____

Or to make a regular monthly donation place a cross in this box and the amount as given above will be debited from your credit card as specified.