



EYE-Q NEWS

Retina Australia (Qld) Inc.

Quarterly Newsletter - Issue 96
Summer Edition 2011

96 – Summer 2011

CONTENTS

PRESIDENT'S REPORT AND LETTER.....	2
GERARD GOSENS	3
QUEENSLAND NARRATING SERVICES.....	4
RP AND GLAUCOMA.....	4
LIBERATING LABELLER	5
RP FIGHTING BLINDNESS Q & A.....	6
RECIPE	7
2011 NATIONAL GOALBALL	8
BUNDABERG REGIONAL VISIT	9
FINDING IT DIFFICULT TO READ PRINT ..	10
BLIND CITIZENS AUSTRALIA AWARD	10
AMD GENE FACTOR	11
MEET ONE OF OUR MEMBERS	12
QUEENSLAND RAIL.....	13
DISCOVERY CENTRE FOR HEARING & VISION IMPAIRED	14
ESTATE PLANNING	14
MINOR HOME MODIFICATIONS.....	15

DIARY DATES

COFFEE MORNINGS

Brisbane City Library-9:30–11:00am

FIRST TUESDAY OF THE MONTH

(Please note change of day)

Commencing in February
(No Coffee Morning in January)

7 FEBRUARY

6 MARCH

3 APRIL

XMAS PARTY

SATURDAY 10 DECEMBER

11:30 am

New Farm Bowls Club



Mission Statement: To provide information and the opportunity of support to people and families affected by sight loss due to inherited retinal disease. With the support of the Australian community, to raise funds to finance scientific research into the causes, prevention and cure of retinitis pigmentosa and other retinal dystrophies.

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PRESIDENT'S REPORT

It has been a year of change, and I'm hoping we all enjoy a period of grace over the Christmas period to have time to stop and reflect and more importantly reconnect with ourselves and family and dear friends, before the busyness of next year hits us once more.

The Annual General Meeting was held on the 10th September, where we had the good fortune to have Gerard Gossens as the guest speaker. Gerard was inspirational and gave us much to think about when overcoming adversity. (See article).

The new management committee was elected as follows: I was elected President, Rosemary Oldfield Vice President (as well as continuing as Editor of our newsletter), Anne as Secretary and Gerard Mugavin as Treasurer. Rose Fraser and Marg Veltheim continue as ordinary members and our new members are Avril Morgan (our resident Optometrist) and Grant Fraser.

One of the first actions by the new committee was to form a sub-committee called the Social Committee (Rose and Grant Fraser, Bob Logue and Graham Willets), to deal with the multitude of elements involved including coffee mornings, speakers, exploring outings, the Christmas Lunch, raffles and so on. Rose and Grant are driving this and

hopefully this will result in lightening Anne's never-ending workload.

Anne and I attended the Retina Australia Annual General Meeting and Board meeting held in Adelaide on the 14th October, 2011. The Board decided unanimously that the Inherited Retinal Disease Register would be our major focus for funding research for 2012. We previously undertook to fund a three year project enabling our members to be part of this data collection nationally. The hoped for Government Funding for subsequent years didn't eventuate after strong representation by the Board and concerned parties; however there is every hope that this is a short term glitch in the tortuous funding application process.

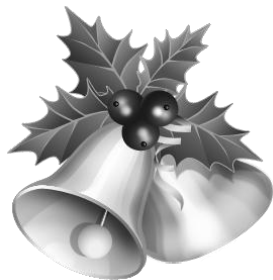
Retina Australia is exploring the possibility of joining the Australian Blindness Forum (ABF) as an associate member, to speak as a strong voice to Government, particularly in light of the recent Productivity Commission Reports on the National Disability Support Scheme and Caring for the Older Australians. The ABF has as its major concern that blindness is kept as a priority within the Health and Disability Systems. We will keep you informed as information comes to hand.

The Retina International General Meeting and Congress are to be held

in Hamburg in July 20012 when it is expected that there will be extensive reporting on significant developments in the areas of gene therapy trials and stem cell treatments for inherited retinal diseases. There are indications that major advances are to be reported at the Congress. It is therefore appropriate to advise that **the 2012 Retina Australia Congress will be hosted by R.A.(NSW) over the weekend of the 20th & 21st October, with the venue being the NSW Parliament House Building, Macquarie Street, Sydney.** United Kingdom based **Professor Robin Ali**, well known for his work on gene therapies and stem cells **will be the Keynote speaker**. Make a note in your diary to try to attend this Congress next October.

I hope you and all those who are so important in your life have a wonderful festive season; that there is no repeat of the horrors of last summer (floods & cyclones), and that you are filled with joyful experiences and happy memories.

Jan MacLean



GERARD GOSSENS

Gerard Gossens delivered an inspiring talk to us following our meeting on 10th September 2011. Gerard is congenitally blind and keen to break down misconceptions about blindness. Throughout his life he lives by the motto 'Success is the journey, not the destination'.

When growing up, Gerard learned about being blind and being different. He recounted his love of running and hitting every goal post when training as a teenager. Gerard says that things will change. It depends on your window of attitude being crystal clear and not having a muddled perception.

Gerard's list of achievements also includes running 2000km from Cairns to Brisbane and from Port Douglas to the Gold Coast five times over five years. Climbing Mt Everest has also proved challenging. Apparently we are born with three fears: falling, isolation and noise and all other fears are learned. Gerard also excelled in *Dancing With The Stars*. For this, he used ginger to overcome motion sickness!

He is now in training for the marathon run in the 2012 Paralympic Games and is special projects officer at Vision Australia. What an inspirational record of triumphs!

QUEENSLAND NARRATING SERVICES

By Kirsty Wedderburn

Queensland narrating services first started as a tape recording association in November 1967 for people who enjoyed tape recording they were called Queensland tape recording association (QTRA). In May 1968 they started recording books for the blind especially for blind students then it extended in 1969 to recording for the handicapped as well. In 1973 they changed their name to Independent tape services for the handicapped... They are now called Queensland narrating services which is a not for profit organisation helped by volunteer narrators that supply alternate formats for people who have print disabilities. They provide recreational novels to the libraries in CD, cassette and mp3 for standard audio equipment. They have been providing audio services for primary to post graduates for over 40 years for them to be able to have their text books, lecturer notes, tutorial readings and any other source materials for them to have independent access to information.

The cost is individually based.

They are open from 9am – 2pm Monday to Friday you can contact them by phone on (07) 3324 0004. Email qns@qns.net.au website [www.qns.net .au](http://www.qns.net.au) or PO Box 1383

4151 Coorparoo DC Queensland there is a criteria you must meet to be able to use their services.

RP AND GLAUCOMA

Avril Morgan, 22/09/2011

The subject of an RP sufferer with high pressures in the eye, most likely to be glaucoma, arose recently. The situation involved an active, elderly person with longstanding severe vision impairment from RP. I understand from a third party that this means no light perception. High eye pressures were diagnosed by her optometrist. The decision whether or not to consult an ophthalmologist for further glaucoma assessment/treatment was unclear, as she has no perception of light. Glaucoma treatment will not restore any of her lost sight, however it will minimise any further damage to the sensitive nerve fibre layer and ganglion cells of her retinas. It is the photoreceptors (rods and cones) that are affected in RP, not the ganglion cells. Glaucoma treatment most commonly involves eye drops used regularly, but sometimes laser treatment or surgery may be necessary. Given the current trends with research on RP treatment, it may be possible, in the future for ganglion cells to somehow be used to restore the function of the damaged photoreceptors and deliver some

sight to RP patients. Although this particular lady is elderly and has no light perception, there may be a possibility for RP treatment in the future... As glaucoma treatment is non-invasive, it would make sense to consult a retinal specialist for further advice. This case highlights the importance of regular optometrical/ophthalmological reviews for all people, regardless of their existing eye condition and state of visual impairment.

LIBERATING LABELLER

Report from Evelyn

I thought my World had changed when I bought my PenFriendT but the new Touch Memo has improved even on that.

The Touch Memo comes with 120 labels which are tactile with raised edges, it also comes with 60 washable labels which can be sewn onto clothing which I think is great, at least I'm now able to co-ordinate my tops and slacks without help. There are also small plastic tags which you can add a label to. These are good for threading an elastic band through so household products, food items and even food in the freezer can be identified. I would have liked more of the plastic tags but these can be bought. I've sewn labels to my slacks but for skirts and tops I've used the tags. I tied the tags securely to coat

hangers and when I take a top or skirt from the wardrobe I leave the hanger out. I wash tops after each wearing and put it back on the same hanger when it's dry. I can think of so many uses for these tags that I'll definitely order more. A CD is in the pack and it's very clear and simple so setting up is a breeze. It also comes with its own adaptor so it can be charged (for 2 hours) either from a power point or from a PC. The only fault I've found is that the USB port cover comes off and needs to be carefully placed so it doesn't get lost, I put a piece of cellotape in a handy spot and place the small cover on it. The Touch Memo is smaller and neater than the PenFriend and has a nice musical tone, I put my shopping list on a label but another neat feature is that I can play the list back without accessing the label and I find that a huge plus. The price is \$149 and I think it is well worth the price. I should add though that the sew-in labels cannot be used in a tumble dryer or ironed so it's best to sew it to a size label in the garment.



RP FIGHTING BLINDNESS Q & A

(18/08/2011)

Q. Is gene therapy effective for treating autosomal dominant forms of RP?

A. You can still use gene therapy to treat the RP, but you wouldn't necessarily be replacing the missing gene. If you increase the amount of normal protein in the dominant disease, it will offset the effect of the mutant protein. Also, you can use gene therapy to deliver a DNA or RNA sequence to cause suppression of the dominant gene. Gene therapy is a little more complicated in dominant RP, but still possible.

Q. In the term autosomal dominant, what does autosomal mean?

A. The disease is carried on the chromosome that is not the sex chromosome.

Q. I have RP and have been diagnosed with early cataract, also. Cataract surgery has been mentioned to me by my doctor, but I understand that this can cause swelling and damage to the retina. With the advent of gene therapy and stem cell therapy, I wouldn't want any damage done to my retinae. Should I pursue cataract surgery? Is there any harm done by delaying cataract surgery?

A. Every case needs to be taken on its merits. It is important to have regular check-ups every year or two. Leaving a cataract will not do you any harm. There is no point in removing a cataract unless it is causing a clinical problem e.g. if you have constricted visual fields and the cataract is obstructing your central vision. Various tests can be done to determine the level of difficulty as a consequence of the cataract and the level of difficulty as a consequence of the RP. Swelling at the back of the eye is called cystoid macular oedema. This can occur as a consequence of RP anyway, but also after cataract surgery. If it is unable to be treated with medication, it does have an impact on the remaining visual field that is left. In summary, all of the symptoms, signs and risks have to be considered in the case of cataracts.

Q. How blind does a person have to be for inclusion in the retinal implant trial?

A. The person has to be unable to orient themselves in a room. This means perception of light or worse. When the retinal implant becomes available not just as a clinical trial, but as a treatment, it is expected that the limit will be lowered. Then it can be offered

to people to whom it will make a difference.

Q. I have fairly advanced RP. How does one go about establishing what their gene type is?

A. You start by being referred to a specialist clinic, where there are individuals who do genetic testing. A family history is taken and the type of RP established. Details such as age of onset and rate of progression are recorded. From all of this, an indication of gene type can be ascertained.

Q. Is the success of the experiments with retinal implants determined by the technology or the condition of the actual retina itself?

A. The success is determined by the positioning of the chip. If the chip is underneath the centre of the retina, there is a higher likelihood of getting a good outcome. The state of the retina is important too. If the retina overlying the chip is healthy and the connections to the brain are intact, there is a higher chance of a positive outcome. Some retinæ appear healthy when examined, but later prove to have a poor blood supply and are therefore less conducive to a good outcome with the retinal chip.

(British RP Society)



Cranberry and Mustard Glazed Turkey

Ingredients

- 1 whole turkey
- 3 tablespoons cranberry jam
- 1 tablespoon whole grain mustard

Method

1. Bake the turkey covered with foil in the oven on 190°C or gas mark 5
2. While the turkey is cooking, prepare the glaze. Mix the cranberry jam and mustard in a bowl until well combined.
3. Half an hour before the turkey is cooked, remove the turkey from the oven and remove the foil. Brush the glaze generously over the turkey.
4. Return to the oven uncovered and cook for a further 30 minutes.

2011 NATIONAL GOALBALL

On the 29th of September the Queensland women's and men's teams left for Sydney to participate in this year's 2011 Goalball Nationals. We had the opening ceremony Friday morning with all teams Queensland, New South Wales, Western Australia, Victoria and the Barbarian's team which was made up of legends of the game. The Queensland Women's team won all of their games which won them a spot in the semi-final, the game was against Western Australia and what a game we won 10 – 0. We were then in the grand

final, Queensland against NSW it was a close game with Queensland winning 5 – 4 the NSW girls gave a good fight and it was a hard game to win. The Queensland Women's team are now a finalist for sporting wheelies team of the year. The Queensland men's team also won gold in their grand final against Victoria; they did extremely well all weekend. For more information about Goalball Queensland, please contact Sporting Wheelies Sports Program Coordinator on (07) 3253 3333 or go to <http://goalball-qld.webs.com/>.



Nicole Esdaile, Rachel Henderson, Meica Jayne Christensen and Kirsty Wedderburn

BUNDABERG REGIONAL VISIT

Jan MacLean

On the 2nd of September 2011 Anne & I visited Bundaberg to hold a meeting with our members in the Bundaberg / Wide Bay area. The meeting was held at the Burnett Bowling Club and eleven members attended. The members shared their personal history and discussed many humorous experiences of their vision journey. It was a privilege to be part of this, where thoughts and ideas were discussed and questions were hopefully answered.

After lunch, everyone was invited to attend a coaching session on how to

play lawn bowls. Two coaches, the Qld. Blind Bowls State Coach and a coach from Bundaberg introduced seven of our members to the game. Those who participated on the day enjoyed the experience and showed signs of wanting to learn more about the game.

As a result of this interest a meeting was held with three coaches from Burnett, who hope to pursue this 'come and try day' with the vision impaired and are happy to coach the group on Sunday afternoons provided there are sufficient numbers.



Budding Bundy Blind Bowlers' Day

PUBLISHED BY RETINA AUSTRALIA (QLD) INC.

ARE YOU FINDING IT DIFFICULT TO READ PRINT?

Tactile literacy tutoring by distance mode

Braille and Moon are two forms of tactual literacy which serve the same functions as print. Queensland Braille Writing Association (QBWA) offers tutoring in Braille and Moon to adults who are blind or have low vision, regardless of where they live in Queensland.

There is no waiting list, as each learner works at his or her own rate.

The program is managed from Braille House, Annerley. Enquiries about this program should be made by phoning 3848 5257, preferably on Monday or Friday between 12:30 and 2:30. At these times there will be a tutor available to answer questions and deal with applications.

Once a student is accepted QBWA will supply instructional materials as required.

Cost?

Tutoring is free but a charge of \$70 is made towards the cost of materials.

In order to make progress a student will need to spend at least two hours a week on this program. It is best to have frequent short practice sessions.

Support?

Tutors will respond to requests for clarification of any aspect of the instruction. Distance students may ask for help by phone within the hours mentioned above.

Tutors will provide support by phone, email and post. Contact QBWA if you are interested 3848 5257

BLIND CITIZENS AUSTRALIA 2011 DAVID BLYTH AWARD

RECIPIENT PATRICIA STILLMAN'S ACCEPTANCE SPEECH

Patricia Stillman, who is a founding member of Retina Australia (Queensland) is the recipient of the 2011 Blind Citizens Australia (BCA) David Blyth award.

Patricia's acceptance speech is summed up as follows.

She is currently on the women's branch committee of BCA and has been involved in the blind community for 25 years. When first diagnosed as legally blind, Patricia couldn't find anywhere to go. This led to her being involved in BCA from the early 1990's.

Patricia states that BCA is a mainstay and permanent part of the blind community. There are services and supports obtained through BCA that wouldn't exist otherwise. She wants to encourage others to be involved in BCA, who work with local, state and national governments to change

things and have things improved. For example, the availability of audio descriptions in movie theatres and on DVDs, taxi numbers on the outside of taxis and the companion card. The BCA women's branch cookbook project which has been in progress for four years is now being produced in braille, audio and electronic versions.

Patricia wants to keep working with Queensland Vision Initiative who has a website for optometrists and ophthalmologists to access low vision resources in their area. She is also keen to express the peer support, motivation and information obtained from attending a BCA convention.

BCA has done so much for the blind community and Patricia is proud to be a part of that. She states that advocacy is needed in the blind community for services for visually impaired and blind persons in rural and regional areas.

The Management Committee would like to congratulate you as the recipient of this prestigious award. What a wonderful advocate you have been for the blind community. Well done!

AMD GENE FACTOR

The Foundation Fighting Blindness reports that in a research paper published on October 6, 2011, Dr Hendrik Scholl from the Wilmer Eye Institute at John Hopkins Hospital

and an international group of scientists identified a faulty defence mechanism in age-related macular degeneration (AMD). This is a mechanism that protects against damage from oxidative stress, which will present a new target for scientists to develop better treatments for AMD.

In 2005, a person's risk of developing AMD was found to be significantly increased by particular variations in the gene Complement Factor H (CFH). It was known that CFH was involved in controlling the part of the immune system that fights off infection and other pathogens, however the specific action of CFH was yet to be determined.

Dr Scholl's research group found that CFH led to the creation of a protein that deactivated a harmful by-product of oxidative stress called malondialdehyde (MDA). Oxidative stress occurs when there is a surplus of damaging by-products, like MDA in our cells, caused by aging, unhealthy eating habits, smoking and other environmental stressors that our bodies can't deal with and neutralize. Healthy living offers some control over oxidative stress, but to conquer the genetic factors that expose us to oxidative damage, a drug or biological therapy is needed.

This recent development allows a clearer target for helping to prevent and treat AMD at its core origin.

**MEET ONE OF OUR MEMBERS:
A CONVERSATION WITH
DOROTHY O'BRIEN**

Growing up in Hughenden, I wanted to be discovered by a talent scout. I wanted to sing. We still sing along in the car, to country music.

My parents were my father, who was a drover and was away a lot, and my mother who was at home. There were nine children. My mother was involved with the church and the CWA.

As a child I played on the streets with the neighbourhood kids. Our home was thirty minutes' walk from the centre of town. We ran home from school each lunch time.

My family now is made up of my husband Fred, my three sons, six grandchildren (including two step-grandchildren). They all live on the north side of Brisbane.

I have lived at Bribie Island for thirteen years. At age fifteen I moved to live in Burpengary, and met Fred there. We lived in Highgate Hill for twelve months, and Cairns for thirty years.

My first job was in a clothing factory in Caboolture. I was sixteen years of age. I stood at a high bench, clipping threads of newly-sewn Can't Tear Em work clothes. I worked in other factories in the Brisbane area, before and after I was married.

My favourite job was in a caravan factory, after the birth of my first child. I went to the Murrumba-Star Caravan factory as a machinist, to sew curtains and cushions. However I finished up working with fibreglass to build the caravans, spraying and shaping fibre and resin in a team of fifteen to twenty people. It was a dirty job.

Something that people may not know about me is that Fred and I follow country music. We go to the Tamworth Music Festival, and other bush venues.

My secret skill is crocheting blankets. I have continued to do this even after I lost my sight. Once I get started, I just crotchet round and round.

In my spare time I listen to talking books, which are sent by Vision Australia.

My link to Retina Queensland came about after I lost my sight. My sister Val, who also has RP as well as glaucoma, knew about Retina Queensland, and had some information. I joined RAQ in 1998, and met Graeme Ferguson.

I became aware of my vision impairment early in life. I had vision problems as a child, and wore glasses from the age of twelve. I had a field test when I was twenty-six and was diagnosed with RP. My eldest brother may have had night vision problems.

I am supported by my family, Guide Dogs, and Vision Australia. I did my white cane training with Guide Dogs, and obtain my audio books through Vision Australia. When I asked Guide Dogs about a local support group, Tahir offered to find a venue, and help me get started. I started the Bribie Island Vision Support Group. There were eight or nine people at the first meeting, and it is still going strong. I have two nieces who are very supportive.

The upside to vision impairment is you don't see some of the ugly side (such as rubbish) or awful things. Everybody's beautiful.

The thing which most frustrates me is not being able to choose a can of food from the cupboard or read a packet. I have not had the chance to learn about a hand held scanner.

The question which I am most often asked is "Can you see anything?" or "How much can you see?" I have been asked, "How do you make a cup of coffee?"

A book which resonates with me is the first book (on tape) which I received from Vision Australia. It was "Master of the Game" by Sidney Sheldon. My son told me that it was good, and I still remember it.

In five years' time I hope to still be able to do what I am doing now.

QUEENSLAND RAIL

Queensland rail has services set up for customers who may need assistance while catching the train. These services provide us with options of an emergency push button help phone which is situated in Core Zones on station platforms, in addition to the emergency help phones there are multiple emergency phones available on board all Queensland Rail interurban rail services. The Help phone buttons are located near the doorways in every carriage and throughout the carriage in some newer trains. Activation of the help phone will put the caller in direct contact with the guard or driver who can arrange an appropriate response.

You can also text on 0428 774 636 or phone 3606 5555 or TTY 3606 5800 and a Queensland Rail Passenger Service Officer will respond promptly to your detailed request for train and platform assistance, station accessibility or timetable information.

These services are available 24 hours 7 days a week. If you need any other information call Queensland Rail on 13 16 17 from 7.15am till 5.30pm (EST) Monday to Friday.



DISCOVERY CENTRE FOR HEARING AND VISION IMPAIRED

During a recent visit to Adelaide to attend the AGM for Retina Australia Anne and I were given a conducted tour of South Australia's Guide Dog Association's Discovery Centre. The Centre is an educational centre designed for the fully sighted and hearing to experience some of the challenges of the vision and hearing impaired.

There are 9 exhibits developed to educate and provide information to the general public about sight and hearing impaired in the community. The centre primarily caters for school children and community groups.

Visitors are given masks to wear to simulate the result of macular degeneration and cataracts while they progress through the 9 education stations. All exhibits rely on the use of touch and hearing.

The emphasis of the program is to demonstrate what can be done rather than focus on the disability. For example one exhibit requires shooting a basketball through a hoop with the message that despite sight or hearing loss players can still perform this skill.

Guide Dogs South Australia also offers rehabilitation services for hearing and vision impaired.

Another primary function of the Association is to breed and train Guide Dogs. During our afternoon tea break we were privileged to be able to view the latest litter of puppies destined to be trained as guide dogs in the near future.

ESTATE PLANNING

Wills

On 8 September 2011, at RAQ's coffee morning, the guest speaker was Nash Te Ua, who is the state manager for wills at the Public Trustee of Queensland. Some of the issues discussed were that there are thirty offices in Brisbane and surrounds and sixteen regional offices between the Gold Coast and Cairns. The Public Trustee provides a free service for the writing of wills and these can be reviewed as often as necessary at no cost. We were informed that the will kits which can be bought at post offices, often do not meet legal requirements and people should consider consulting a solicitor or the Public Trustee for the writing of wills.

Long gone are the days when a percentage fee was charged for the administration of a will. In this day and age, only a fee for service (hourly rate) is charged (for example the administration of an uncomplicated, reasonably straightforward will, when the person is deceased, will

cost between \$3000 and \$4000 approx.). By administration, this means that the Public Trustee organisation attends to all the legal requirements, achieving probate and finalisation of the estate.

If you should have a will, it is advised that the will be revised every year, as changes do occur. If your will is with a solicitor, it would be useful to ask if they also administer the will (i.e. notify all the relevant bodies such as utilities, bank, superannuation etc.). The reason this is important is that you may find that you have to do all of this yourself.

Enduring Power of Attorney

There are two sections of an enduring power of attorney. One is for financial matters and the other is for health matters (otherwise known as an Advanced Health Directive).

Financial Matters

Under the financial section, a doctor will often decide when a person is no longer able to make financial decisions and you can state who you would like to help you with this.

Personal Health Matters (Advanced Health Directive)

This form is for identifying your personal requests (e.g. not wishing to be resuscitated) and appointing a trusted person to make health decisions on your behalf.

The Public Trustee is able to assist people with making and witnessing an enduring power of attorney for a competitive fee. They are also able to make home visits for those who are incapacitated.

MINOR HOME MODIFICATIONS— HOME AND COMMUNITY CARE PROGRAM

The Home and Community Care (HACC) Program provides services to frail older people and younger people with a disability through a range of basic support and maintenance services designed to help people remain living at home.

One of the services that HACC provides is minor and major modifications to assist people to continue living safely at home.

The minor home modifications program helps fund small, low-cost aids and equipment that improve your home's accessibility.

Minor modifications include:

- customised bed blocks
- bed board
- bath seats
- chair platforms
- hand-held showers
- non-slip treatment
- grab rails and hand rails
- step modifications and step ramps

- shower curtain rods and screen removal
- door wedges
- light switch and power point relocation.

How much do I contribute?

You will pay for the materials and the HACC program will pay for the cost of labour.

Further information

Please contact your local Community Health Centre or

Website:

<http://www.qld.gov.au/disability/adults/home-modifications/>

Contact on 1800 052 222

REMINDER LIST

* **Membership Renewal**

So far only 75% of members have paid their 2011-12 membership

~ Please don't forget to pay ~

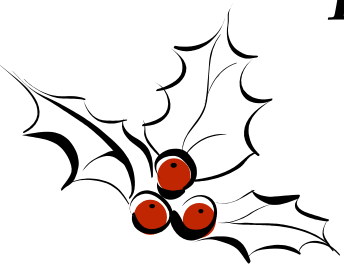
* **Xmas Party**

Saturday 10th December

* **New Day for Coffee Mornings**

First Tuesday of the Month

*The Committee
wishes all the
RAQ members
a Merry Christmas
and a
Happy New
Year*



The deadlines for the quarterly newsletters are
15th February,
15th May,
15th August and
15th November

**Next Issue
Deadline for articles is
15th February 2012**