

# CICADA

**NATIONAL  
NEWSLETTER**  
of the Cochlear Implant  
Club and advisory  
Association

VOLUME I

NOVEMBER 1995

## *Why CICADA? Professor Bill Gibson*

In 1985, two young women (Cathy Simon nee Easte and Susan Walters) suggested a meeting to form a support group for the people who had received cochlear implants. They had been the first people to receive the 22 electrode implant in NSW. A number of people had already received a single channel device developed in the USA, but this new implant which had been developed and first used in Melbourne appeared to have some major advantages. Professor Graeme Clark and his team had researched and initiated the project, and Paul Trainor and the engineers in his company Nucleus had combined to produce the commercial product. The first prototype was implanted in Melbourne in 1979 and, over the next few years, several people had received devices in Victoria and had shown excellent progress. NSW was the next state to use the new device.

The first meeting (*of this support group*) was held at the Deaf Society in Cavendish St, Stanmore with the second meeting held at Better Hearing Australia in the old Trades Union rooms in Sydney, during March 1985, and the support group was formed. The writer claims the credit for the name 'CICADA', which he originally decided stood for Cochlear Implant Club And Deafness Association. However, it became quite clear that people with cochlear implants were not Deaf. Indeed the Deaf Groups around the world were opposing the use of cochlear implants which threatened the growth of their organisations. The acronym was altered to Cochlear Implant Club and Advisory Association. In retrospect this turned out to be the perfect description of the organisation.

As the number of people with cochlear implants, now called implantees grew, CICADA flourished. A number of events were held including barbecues and Christmas parties. In 1985, the first Christmas party was held in the backyard of the Gibson's house. The first newsletter was written on my Apple 2E computer and mailed to the 10 implantees and their families. All the prospective candidates gained by meeting and discussing the practicalities of having a cochlear implant with experienced users. In 1987, the first children received implants in NSW and they soon became the focus of the Christmas party.

Nancy Hoffmann who received her implant in NSW lived in Queensland. When Queensland began their own programme she began a CICADA group in Queensland. Next came Western Australia and South Australia. Victoria had had a Bionic Ear Club but recently revitalised their support group and began to use the name CICADA.

There is now a CICADA group in every state of Australia which offers support to cochlear implantees, and there are now over 700 people using cochlear implants in Australia. Although CICADA in each state is autonomous, there is considerable interest in sharing knowledge between the groups. This newsletter represents a landmark in the history of CICADA as the first federal activity begins. This is only possible because of the help of Cochlear Limited who have done much over the years to support CICADA and continue to care about their 'customers' years after the surgery.

*(continued on page 2)*

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Hopefully, the future of CICADA is bright. Soon there will be over one thousand implantees and, maybe, the time will come for a national conference. Would the small group of people who met in that little dark room, within the trades union building, have ever guessed?

*The views expressed in this article are not those of the CICADA.*

Professor Gibson holds the ENT Chair at Sydney University and is the Director of the Childrens' Cochlear Implant Centre at the Royal Alexandra Hospital for Children and the Cochlear Implant clinic at Royal Prince Alfred Hospital in Sydney.

## Editorial Committee:

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## Your CICADA Contacts - State Secretaries

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## Submission Deadline for Articles for 1996

### Issue:

### Deadline:

March

February 9

July

June 7

November

October 4

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# Queens Birthday Honours

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As a member of CICADA I am very happy to congratulate Professor "Bill" Gibson on his receiving the Australian Medal on this years list. This award was for his service to medicine and in particular the field of otology.

Professor Gibson founded the Chair of Otolaryngology at Sydney University and was responsible for the founding of the Cochlear Implant Program in NSW.

I was the third implantee in NSW and since that time, 11 years ago, I have seen the enormous effort he has put into making the whole thing the success it is. Even the name CICADA was created by him.

Of course - all this would not have been possible without the support of his wife Alex who has taken a very active part and who also deserves a medal.

Thankyou Professor & Alex Gibson and congratulations from all of us.

Shirley Hanke - NSW

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## Intrepid Travels

### Those Airport Adventures!

Over the years I have been through a few international airports, and the experiences realised are never identical.

I find that explaining just what a cochlear implant is, and why we cannot\* go through "The Magic Door" can be quite time consuming; some customs officers are mystified and some just do not believe the explanation at all, preferring to believe, I suspect, that I am a new breed of sophisticated smuggler.

I have always found the staff at Australian airports to be courteous, understanding and extremely helpful. In fact, one officer jokingly remarked that he could do with a bionic ear himself to assist him with his work. Such was his fascination.

The worst experience occurred at Wellington airport in New Zealand where I was met with total disbelief and treated like a criminal. I still shudder remembering the treatment of being led into a

room and hand searched. So it was a real surprise to be given 5 star treatment at Beijing airport en route home after an amazing 8 day holiday there. Staff were astonished and curious at the "something foreign" in my head and took it upon themselves to personally escort me through customs, even to be the first to board the plane.

I recently learnt that Beijing has just performed the first two implants in China and this has left me wondering if perhaps this was why I was given the red carpet treatment at their airport!

Shirley Edwards - QLD

\* It is important to read the section on interference in the User Manual supplied with your speech processor.

**Are there any other intrepid travellers out there. We'd like to hear from you.**

# CICADA Get Togethers

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## NSW Starts the Ball Rolling

As our membership steadily grows and becomes more widely dispersed around the country it is more difficult for people to get together and we ask ourselves are we doing enough for all members. So we decided to do something about it.

The idea was for small gatherings outside Sydney to provide greater opportunities for new, old and potential implantees to get the support they need from CICADA. Meetings could be held on Saturday or Sunday every three months at the same location. We have found that smaller groups work best as there is a little less noise and it's easier to get to know people.

Several smaller CICADA gatherings have been held recently as a trial run and we hope that all concerned have enjoyed and benefited from these get-togethers.

We would welcome your suggestions as to suitable venues and times that these occasions could be held.

Sue Walters- NSW

## Lets Have Lunch

Shirley Ryan, of Foster, recently thought it might be a nice idea to get together with other implantees in her area. Sunday lunch was organised at her home and from all reports it was a very successful day.

A big THANKYOU to you Shirley for your thoughtfulness and all the hard work!

## A Spot of Tea!

An afternoon tea was held in June at "Hillview" Turramurra. This gathering was for new and potential implantees to come along and discuss aspects and concerns about the cochlear implant.

A successful afternoon from the reactions of the number of people who attended.

**Contact the Secretary in your state for information about get togethers.**

Thanks to all especially the "old" implantees who came along to lend their experience.

## Messing Around in Boats

A sunny afternoon in September, a beautiful day and we are departing from Man-O-War steps, at the beautiful Sydney Opera House for a harbour cruise. Up the harbour we went and anchored off Clifton Gardens to laze in the sun, chat to new friends and enjoy our afternoon tea.

Thanks to Judy and Doug Wimble for organising the boat for us.

## A Capital Idea

There is a group starting up in Canberra. Welcome - from all CICADA groups. The first meeting is being held at 12md on Saturday December 2nd at Anne White's house, 3 Middleton Close, Gowrie ACT 2904. Please bring a sandwich (tea & coffee provided).

If you miss the meeting you can contact Anne on Ph. 06 291 7788 or her pager service on 016 020 and leave a message of pager no. 016 264 150.

**We would like to hear about your Get Togethers. Send your snippet to your state committee so that we can all hear about it.**

## The National Relay Service

This Service is operated by Australian Communication Exchange Ltd. which was formed as a result of a merger between Deaflink Inc., a Brisbane based organisation which has operated a relay and an outreach program for people who are deaf, or who have a communication impairment and Deafness Resources Australia Ltd, a Sydney based organisation which advises and assists people who are Deaf, or who have a hearing impairment, through the provision of equipment, community outreach and information services.

The Service can be contacted, 24 hours a day, 7 days a week, from anywhere in Australia on 13 25 44 for voice, TTY or computer. For emergency calls and for other Freecall numbers (TTY & ASCII) dial 1800 067 167.

If you would like to receive more information about Australian Communication Exchange, they can be contacted during business hours on (TTY) FREECALL 1800 629 863 or (Voice or computer) FREECALL 1800 067 167. Or write to: Australian Communication Exchange Ltd, 252 Annerley Road, Dutton Park Qld 4102.

For more information and customer advice on the Telecommunication Equipment Access program, call during business hours 1800 808101 (TTY), 1800 066 456 (Voice & ASCII)

### Usher's Syndrome

International researchers have identified the gene that they believe causes Usher's Syndrome. In the Journal *Nature*, the researchers said that this discovery was a step to finding a treatment for the syndrome, that affects about half of those people who are deaf and blind.

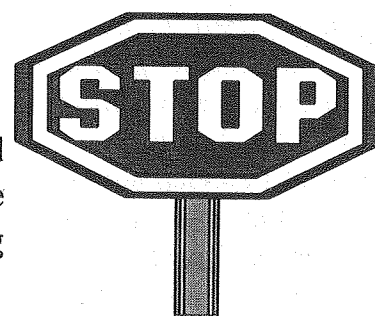
Dr Karen Steel, a geneticist at the Medical Research Council in Britain, said "In the very long term, we hope (to be able to treat it)".

Gene therapy, the correction of a person's genetic make-up was only one possibility. "If you understand why a retina is deteriorating at the molecular level, you might be able to do something to stop it," she said.

Reuters

### Lost in Space

We've heard recently that people have been swapping processors.



### Danger! Danger!

*Warning! Warning!*

This is not a recommended practice and Cochlear advise us that using Maps designated for another implantee may in fact cause overly loud sound sensations to be experienced which may lead to further damage of the auditory nerve.

## Insurance

Over the past few months, two speech processors have been lost. This has highlighted the importance of insuring the speech processor and headset against loss and theft. The device can be insured independently, or included as a personal or specified item under your House and Contents Insurance.

The current value of the new Spectra 22 speech processor (plus headset) is \$7,620.

To obtain insurance contact the insurance company which covers your house and contents, explain what you would like to include on the policy, what it is for and how it is used. If the person you are speaking to is unable to assist, ask to speak to the Contents Underwriter.

## News From Victoria

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### **Congratulations from CICADA Vic on the inauguration of the National Newsletter.**

Last year, in Victoria, the support groups of the various hearing disabilities joined together to form the Hearing Disabilities Support Groups (Vic). Representatives from Menieres Support Group, Tinnitus Association, Acoustic Neuroma Association, CICADA (Vic) and Better Hearing (Vic) meet every 3 months to exchange information and ideas, and discuss problems affecting each group.

The first combined venture was for fund-raising, and a great deal of time and effort went into organising a Fair (held in November '94). Other groups associated with hearing impairment also joined in; altogether 10 groups were involved. Plans are underway for a repeat in March '96.

The second combined effort, held recently during Deafness Awareness Week, was a seminar for GPs and audiology students. The aim of the Seminar was to pass on advancements in diagnostic techniques and treatment, and to explain how the support groups work in helping people to cope with their problems and in realising that they are not alone. Over 50 people attended. Papers were presented by eminent professors and surgeons, followed by a 5 minute explanation from a relevant support group member.

CICADA (Vic) has achieved much by being a part of this combined group and its activities, giving us a platform to speak on the benefits of cochlear implantation, and awareness of other hearing disabilities.

Currently there are over 50 financial members of CICADA Vic.

## The Parents Support Group

The Parents Support Group began in Melbourne, when the first children were implanted here. Support is offered to families who are considering this options for their children and a chance to discuss with other parents who have had similar experiences, and understand the concerns inherent in this decision-making process. Once the children are implanted, there is the opportunity to meet with other families, in a relaxed social setting.

Recently we have made contact with the adult group, CICADA, hoping to make our voice stronger in lobbying for the needs of all implantees, in particular our children.

If you would like more information about the support group contact Anne Neame on 03 9763 5709 or Leonie Duncan on 03 9887 3607.

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### **Need to Practice?**

Try using the recorded message information service available from Telstra.

Here are a few suggestions to start with:

Time	1194
Weather	1196
News	1199

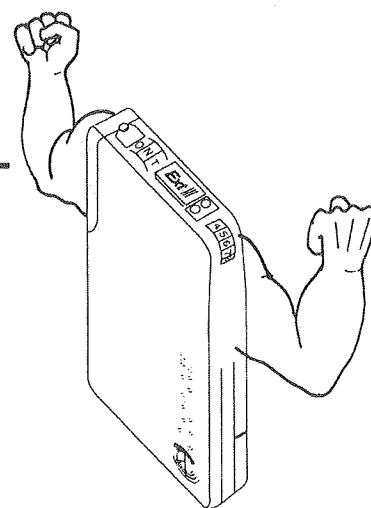
Listen to someone speaking on the phone without actually having to answer them!!!

### **Did you know???**

**That there are now nearly three hundred people in Australia using the Spectra 22 speech processor.**

# Processor Power!

NiCad batteries are long-life rechargeable batteries, which require special care to optimise their life span. Correct treatment of these batteries will ensure maximum use time between recharging. Here are some tips and guidelines for using the Panasonic or other appropriate rechargeable batteries.



## What Batteries Can I Use in The Speech Processor?

Disposable:

Alkaline

Rechargeable:

Nickel Cadmium (NiCad)

Nickel Metal Hydride (NiMH)

Batteries must have a **minimum** of 1.5 and a maximum of 1.8 volt output. (*This is written on the side of the battery*).

**DO NOT** use batteries containing Lithium.

## Treat Your Batteries Well and Keep Them Going Strong!

Please follow the procedures for battery use set out below and disregard those currently contained in the patient manual.

Batteries should be **flat** (ie the "M" light blinking) before being recharged.

**How Do I Know That The Batteries Are Flat?** If the "M" light is blinking once per second then the batteries are too flat for use in the speech processor and require recharging using the approved Cochlear Hi-Energy NiCad Charger.

**Why?** Placing partially flattened batteries into the charger may lead to overcharging of the batteries. Overcharging batteries **will** reduce battery life and effective usage time.

**How?** The safest and most effective way for discharging or flattening the battery is by leaving the processor switched ON near a noise source eg., a TV or radio, with the sensitivity set on maximum (number 8) until the "M" light begins to flash.

**DO NOT** flatten the batteries any further by placing them in a torch or other appliance.

**CAUTION:** *Placing them in another appliance could overflatten the battery. Overflattening may cause the battery polarity to reverse and may also cause chemical changes that shorten battery life.*

### **Recharging Your NiCad Batteries**

Batteries require charging for a **minimum of 6 hours** to ensure they are fully recharged.

**How Do I Know That They are Recharged?** The red light turns to green after 6 hours has elapsed. The charger does not measure the charge state of the battery. Therefore once a battery is in the charger and recharging has commenced **DO NOT** interrupt the cycle. The green light indicates that the full recharging cycle has been completed.

Following this method will avoid partial charging or overcharging of the batteries. Overcharging can be as detrimental to batteries as overflattening.

All NiCad batteries have a limited life span. Following these instructions will ensure the maximum possible life from each battery.

### **Other Hints For Longer Life:**

Store batteries in a cool dry place.

Protect battery terminals from being shorted against metal objects (eg., coins, keys etc) by storing in separate plastic bags.

Date or number batteries with a marker pen to ensure old and new batteries are not confused and any problem batteries are easily identified.

## **Not Like Ducks to Water!**



We have recently heard that a few speech processors have gone for a swim.

Now that summer is approaching we thought that we might remind you that speech processors haven't learnt to swim just yet. If they do go for a 'dip' then just rinse them in fresh water immediately, then in alcohol - even a bottle of Johnnie Walker Black Label is less expensive than replacing the processor.

As they are not waterproof, this can be an expensive pastime. To avoid splashes and spills, put the speech processor upside-down in a snaplock bag before it goes into the pouch or harness. This also keeps sand out of the processor when you visit the beach.



# Letters from our readers



"Yes, the The U.K. Government is now funding Cochlear Implant Clinics. The National Health Authority is broken up into Area Health Authorities. The local Health Authorities in which patients reside are being asked to pay for upgrading of their processors. It is not yet known whether all local Area Health Authorities' will comply, but it is considered that the response will be uniform eventually."

Extract from a letter from Betty Brett - Victoria.

*We would like to include some letters and stories from children in our newsletter or any matters concerning the child implantee and their families.*

*If you are willing to contribute please forward any material to your Editorial Committee member.*

Nancy Hoffman tells me you are starting a National CICADA magazine. What a great idea!

One suggestion - could it have a section/page where patients are able to write in with questions to the audiologists at Cochlear. I have noticed this in the international magazines. I think it would be a good way

to share information with patients. Also patients often like to give(sic) information from Cochlear itself.

Just a thought!

June Young  
Director of Audiology  
Mater Hospital, Brisbane

"My implant's the best thing that ever happened to me, as I am now sometimes picking up some sounds long, before normal hearing people.

The biggest surprise is I am picking up the rhythm from music, as I couldn't hear that before".

Extract from a letter from Sean Sewell from NSW.

I started out with the W.S.P., then went on to the M.S.P., now I have the Spectra 22.

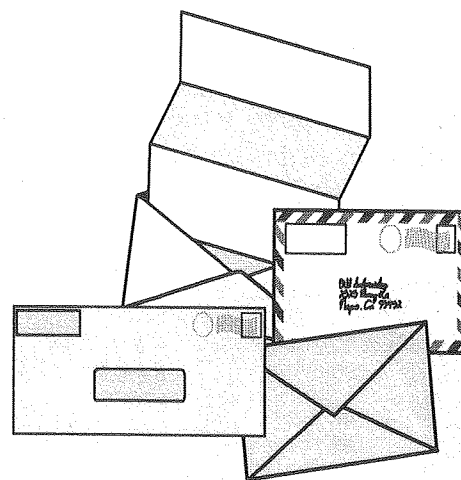
It has been a fascinating seven years for me, with each processor better than the previous one. I think to myself "can this possibly get any better for me?" My perseverance these past seven years has paid off for me, to be able to do my own phone calls, business or personal, it is

incredible, to hear and understand everything that is said. No more three way phone calls for me!

A few months ago I was at a local club and in the auditorium, where they were playing bingo. I closed my eyes and listened to the caller (good clear words) to see if I could understand what he was saying. Would you believe it, I got them all right!

Two weeks ago I went to bingo with another friend and just played one card at a time, since I have never played before, and not knowing how I would go. It was great! The caller went fast and I kept thinking, "I wish he would slow down", but as I kept playing I got used to him. I'm so pleased with myself (bragging?) for handling it so well that I'm off to bingo again.

Carol Cullen - NSW





## WHAT'S HAPPENING?

### IT'S CHRISTMAS TIME AGAIN!

#### Queensland:

Christmas dinner is on Wednesday 6th December from 7pm at 'Kim Thanh West End' restaurant, 93 Hardgrove Road. A Thai banquet for \$15 and B.Y.O.

R.s.v.p: Katie:TTY/V 07 3399 5770;Nancy:TTY/Fax 07 2878 1174.

#### New South Wales:

The Christmas party is being held on Sunday 10th December from 12 noon to 4pm at St Joseph's College, Mark St, Hunters Hill. The cost is \$10/p or \$20/family.

R.S.V.P. Ph. 02 438 3422 Fax. 02 438 5556

#### Victoria:

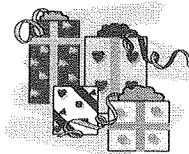
Our Christmas Get-together will be held on Saturday 2nd December from 2pm, at The Bionic Ear Institute, cnr. Lansdowne & Albert Sts., East Melbourne. Dr. Robert Cowan, Deputy Program Leader of the Advanced Bionic Ear Project will be our guest speaker. He will be happy to answer any questions afterwards. At 1.30pm, a short AGM is planned, we need nominations for Office bearers as all positions will be declared vacant.

#### South Australia:

The Christmas Break-up will be held at our President Kaye Halliday's home, Leawood Park, Gawler River on Sunday December 3rd at 12noon. There will be pony rides for the children, Father Christmas will be there plus lots of surprises for everyone. As in the past the meat and tea & coffee will be provided with each family to bring a salad and a sweet, B.Y.O. drinks.

To the young implantees & their families we extend an invitation for you to join us for the Christmas Break-up and to any other of our meetings which are held bimonthly in the B.H.A. meeting rooms, Wakefield St. Adelaide.

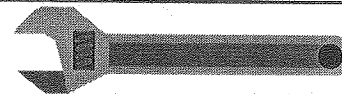
You will all be very welcome.



#### New Zealand

Our Kiwi counterparts recently celebrated the first anniversary of their newsletter - **The Cochlear Implant Newsletter**. The membership of their group has grown to approximately 45. A treasurer was recently appointed to ease the growing workload of the two editors, one of whom lives in the North Island while the other lives in the South Island. The group meets informally every few months, in both islands.

## Ordering spare parts



**Did you know that you can now order your spare parts directly from Cochlear?**

**And to make it easier for you Cochlear now has Bankcard, VisaCard and Master Card facilities.**

**The insert page is the order forms for the spares. You can use this as a guide when you phone us with your order or you could photocopy it and fax it to us. Your order can be shipped to you in just a few days.**



**Do You have any QUESTIONS we could answer?**

# Quota to the Rescue

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## *Gift to the CCIC*

Pat O'Hara has been a long time supporter and friend of the Children's Cochlear Implant Centre in NSW. And now due to her hard work and untiring efforts the centre is to be the recipient of a donation of \$US25,000 from Quota International.

This money has been given to enable the CCIC to employ a part time Clinical Psychologist to do research into the possible psychological, emotional and cognitive damage in the many children deafened by meningitis.

This research should prove invaluable when predicting future outcomes for children who have had meningitis and are to be candidates for a cochlear implant.

A very BIG thankyou to Pat and Quota International for their wonderful generosity and for all the support they have given over the years to hearing impaired children and adults.

Susan Herridge - CCIC

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## *Queensland Quota*

Recently the Queensland Quota Club held a fashion parade showing the wonderful and practical clothes of media personality, now designer, Ita Buttrose. Ms Buttrose donated her time for the function and all proceeds went to the Mater Misericordiae Childrens Implant Program.

There is another child somewhere in Queensland learning to listen thanks to the generosity of Quota.

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## The National Working Party on Captioning (NWPC)

The NWPC, a group of captioning consumers comprising both state delegates and organisation representatives, was formed in 1991. The NWPC has successfully lobbied for progressive increases in the amount of captioning, and for the transmission of American-style captioning which already exists on imported programs. Currently the NWPC is campaigning vigorously for captions on the news and current affairs programs.

State delegates act as information channels between captioning consumers, the NWPC and TV Networks; organise public meetings, visits to TV stations, and give talks at schools, seminars and meetings. If you have ideas or general questions about captioning, please contact your local delegate or the NWPC (contact details below).

If you want to have a particular program captioned, or wish to make a complaint about poor captioning transmission, it is better to contact the TV stations directly. Your state delegate has a list of TV networks in your state. NWPC State Delegates: (Note; TTY numbers can be accessed through the National Relay Service on 132544)

ACT- currently vacant - see Chairperson  
NSW - Emma Fisher. Fax 02 99697487  
NT - Keith Smart. Tel/fax 089 81 5450  
Qld - Nancy Hoffman (Chairperson).  
TTY/Fax 07 38781174, Fax 07 33592173  
SA - Gaye Lyons. TTY/Fax 08 263 6054  
Tas- Diane Hodgetts. TTY 002726569,  
Fax 002 73 2406  
Vic - Phil Harper. TTY 03 9650 6786,  
Fax 03 0654 2868  
WA - Marissa Cooper, TTY 09 344 8092

Nancy Hoffman - Qld

# Do you watch television?

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Did you know there are captions on page 801 of Teletext?

That big "S" sign you see at the start of some television programs and promotions doesn't mean the program is in stereo, or has a high sexual content - it means it is captioned. Printed program guides indicate captioned programs with a S or S\* (for 'Supertext').

Current programs include The Bill, Bordertown, Absolutely Fabulous, Backchat, Frontline, Gardening Australia, Four Corners, Waiting for God, GP and various children's programs on the ABC; Blue Heelers, Home Improvement, Home and Away, Talk to the Animals and Superman on the 7 Network; Burke's Backyard, Getaway and Sale of the Century on the 9 Network; and Beyond 2000, Neighbours and The Nanny on the Ten Network, plus various Sunday and Wednesday night movies on all channels. Many Open Learning programs are also captioned.

Captioned videos are available through your local library. Ask the library to order them for you on inter-library loan.

Captions can be useful for helping to learn how to hear again. Be warned though, sometimes it is necessary to shorten the captions to fit the page, although the 'flavour' of the program is not altered. Captions are also good for lip-reading practice. An occasional bonus (?) is that you can lip-read swear words which have been removed from the sound-track!

You can access TV captions with either a Teletext TV, Teletext VCR or a stand-alone decoder (only available second-hand now). Teletext VCRs enable recording of captions; most Teletext TVs do not. Captioned videos can be viewed with an ordinary VCR and TV because the captions are "burnt" onto the tape.

The Australian Caption Centre, the national non-profit organisation which produces most of the closed captioning on television in Australia, will send you an Information Kit on request. Their address is:

Australian Caption Centre  
Level 4, 187 Thomas Street  
Haymarket NSW 2000  
tel: 02 212 5277  
TTY: 02 212 3129  
Fax: 02 281 2198

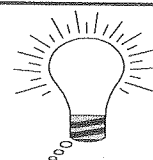
## *Childrens Poster*

This wonderfully bright and colourful poster has been created for children and the young at heart and depicts children at play.

The limited edition poster by artist Sharon Moore is being offered at \$5.00.

To place your order, please call Margaret Sutcliffe at Cochlear on 02 428 6547 or fax 02 428 6352.

**Bright ideas!**



Do you have any wonderful ideas you would like to share with everyone?