



Families in CHARGE

CHARGE SYNDROME

- C** coloboma of the eye
- H** heart defects
- A** atresia of the choanae
- R** retardation of growth
- G** genital defects
- E** ear defects and hearing loss

Please contact us for information on CHARGE Syndrome, such as brochures, videos, handbook, literature, parent support or to make a donation.

CHARGE Syndrome Association of Australasia Ltd is a registered charity with DGR status and all donations are tax deductible.

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Families in CHARGE Newsletter
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Welcome to Your New Newsletter

CHARGE Conference, 3-5 Oct 2008 Christchurch, NZ 60 days to go!

<http://www.chargesyndrome.org.nz/charge2008/index.html>

Your Conference Committee Members: Annette Stocker, Tricia Gillbanks, Donna Sperandio, Chris Maslin, Shirley O'Shea, Helen Smith

Payment of Conference Registration Fee

Payment of the Conference Registration fee can be made direct to the New Zealand CHARGE Association Bank Account. If you wish to make payment direct to this bank account please contact Annette Stocker at t.a.stocker@xtra.co.nz. Please include all your contact details.

Conference Subsidies

As detailed in our Autumn newsletter, the CHARGE Syndrome Association of Australasia holds conferences on CHARGE Syndrome every two years throughout Australia and New Zealand. The Board endeavours to provide informative, worthwhile and enjoyable conferences to its members and interested families and professionals who want to keep abreast of CHARGE syndrome.

From past conference feedback, we understand how important it is for families to attend our conferences because it is an extremely important event in their lives. For some families, it is their only opportunity to meet with others who are well versed in CHARGE syndrome and for children to meet other children.

The Board would like to advise that it has limited funds available to assist families (i.e. full members of the Association) to attend this year's conference.

We understand that for some families, financial constraints make it difficult to attend conferences and, to support this need, the Association is offering assistance in the form of conference subsidies. These subsidies will not cover all the expenses involved in getting you and your family to the conference, but this financial assistance may be the difference between you going and not going.

To apply for the conference subsidy through the Association, please contact:

**Family Liaison Officer—Marie Patterson Tel: (02) 9605 8475
 Fax: (02) 9605 8759. Email: marie_anne@hotmail.com**

CHARGE Syndrome Association of Australasia Ltd 2007/2008 Board of Directors

President David McHugh (SA)	Vice President Annette Stocker (NZ)	Treasurer Ken Patterson (NSW)
Secretary Nicole Tebble (NSW)	Assistant Secretary Madelene Rich (VIC)	Family Liaison Officer Marie Patterson (NSW)
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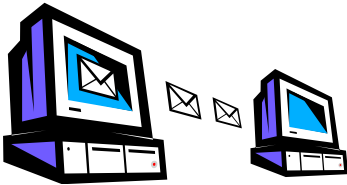
You can find your director's contact details on our website: www.austcharge.com.au.

Calendar of Events



3-5 October 2008
CHARGE 2008 Conference,
I'm Putting Myself in
CHARGE, Christchurch New
 Zealand, Conference
 Committee: T. Gillbanks
 tricianz@xtra.co.nz
 Or view the program at:
<http://www.chargesyndrome.org.nz/charge2008/index.html>

Newsletters via Email



If you would prefer to receive this newsletter via email and to help keep our costs down, please send your request to:

ctos@teksupport.net.au

Newsletter is also
 downloadable at:
www.austcharge.com.au

*The only way to avoid
 being miserable is not to
 have enough leisure to
 wonder whether you are
 happy or not.*

George Bernard Shaw

NSW News

Your Directors: Ken Patterson and Nicole Tebble

Resignation of Secretary

It was with regret that we accepted the recent resignation of our Secretary Lisa Donnelly. During the past seven months, Lisa has provided a great deal of support and input to the Association as our secretary. Unfortunately due to family circumstances, Lisa has had to resign from this position. We would like to thank Lisa and her family for the contribution she was able to make to the Board and its members and we wish her and her family all the best.

Appointment of Secretary and NSW Director

We would like to introduce Nicole Tebble. Nicole has taken up the position of Secretary and Director for NSW following the resignation of Lisa Donnelly. We look forward to having Nicole on the Board and we also look forward to knowing a bit more about Nicole and her family in our next newsletter.

Major Scam

On 12th May 2008 there was a major breach of access to our austcharge email address. An email was sent to several of our members with the subject line: "I need your help".

This was a scam email purporting to be from a 'Marie' in Nigeria, requesting financial assistance. Several members were alerted by this and contacted the Association concerned by what they thought was an email from Marie Patterson.

We were able to get confirmation that Marie Patterson was in Sydney and not Nigeria and that this email was a scam. We immediately contacted those members who have email addresses and who we believed had received this scam email, and advised them of it. Our website coordinator rectified the situation that same day.

NSW TO GET COMPANION CARD FOR CARERS

The Companion Card currently operates in Victoria, Tasmania, Western Australia and will be introduced into NSW from mid to late 2008. The Companion Card allows people with a severe or profound disability, who require attendant care for the rest of their lives, to participate in community activities and events without discrimination. It allows the person with the disability to take a carer on public transport and to events for the price of a single ticket.

The Companion Card can be presented at participating organisations where cardholders will not be required to pay an admission fee for their companion who is providing attendant care. Participating organisations will recognise all Companion Cards, which share common visual identity and security features.

To apply for a Companion Card go to www.companioncard.org.au and locate your state website, or Tel: **1800 650 611**. Eligibility for the Companion Card is based on the needs of the person with the disability.

Order of Australia Medal Awarded to Our Marie

Marie Patterson was nominated for and awarded an Order of Australia Medal in the Queen's birthday honours list this year. This is in recognition of the many hours, days, weeks, months and years of voluntary service Marie has given to the CHARGE Syndrome Association of Australasia, for which the Board and all its members are truly grateful. Marie continues to provide this voluntary assistance to the Association as its Family Liaison Office and we believe Marie is a much deserved recipient of this OAM. Marie was overwhelmed to receive the award and has received many messages of congratulations.

'Thank you all for your congratulations, BUT I MUST SAY, this award might have my name on it but it is for the CHARGE Syndrome Association of Australasia and EVERYONE who has contributed to it over the past 20 years (since the small and intimate meeting held at RIDBC to the teleconference calls now held each month with directors throughout Australia and New Zealand); each and every family and professional deserves this award. Without the support, encouragement and dream of all concerned it would not have been awarded. Believe me I will take every opportunity to bring CHARGE syndrome into the public eye, and as they say 'keep the dream alive'. Having some input into the lives of those affected with CHARGE syndrome and their families is enough reward for me. We are all after the same thing and that is to ensure our kids have the best possible chance of living the life they can. Thank you all.

Marie Patterson

The following article appeared in the Campbelltown-Macarthur Advertiser News on 11 June 2008.

Special mum rewarded

BY JESSICA MAHAR—Campbelltown - Macarthur Advertiser News, 11/06/2008

Mother of three Marie Patterson was awarded an Order of Australia Medal on Monday for her service to the community through the CHARGE Syndrome Association of Australasia. The Glenfield woman's daughter, Julia, was one of the first children in Australia to be diagnosed with the syndrome.

Each letter in the name Charge stands for a typical symptom of the syndrome.

C stands for coloboma of the eye, H is for heart defects, A is for atresia of choanae, R is for restriction of growth, G is for genital malformations and E is for ear malformations.

Since diagnosis Mrs Patterson and her husband Ken have worked to help other familiesas well as organise conferences with international experts.

The disability affects one in every 30,000 children, Mrs Patterson said. "Julia was diagnosed in 1991, aged 4," she said. "We were told 'here are the three lines in a book that we know about it' and we thought that's not on, there's got to be more information. We've become enriched by being involved with other parents who are like us – we've met a lot of really great people."

Children with Charge Syndrome usually have at least four of the six characteristics, with growth and hearing common issues.....Julia defied the odds to become a happy adult.

Mrs Patterson said her daughter was now working in Narellan through help from Sunnyfield, which finds work for people with disabilities.

"She's very independent in lots of ways but still needs 24-hour supervision because she might over-fill a cup or four litres of milk will end up with chocolate Qwik in it.

"It's been a rewarding experience." Mrs Patterson said the award was an honour and a "humbling experience".

"Without the support of family and friends I wouldn't have been able to do the 25 years that I've done.'



Mitchell's BAHA (Bone Anchored Hearing Aid)

Mitchell Dean – BAHA Candidate (Bone Anchored Hearing Aid)

A BAHA is a surgically implantable type of hearing aid (made by Entific Medical Systems and owned by Cochlear Ltd) that works by bone conduction, that is, sounds are transferred through the bone to the cochlear, by mechanical vibration. The BAHA comprises a titanium fixture (3mm or 4mm) which is implanted into the skull bone behind the ear, an abutment which is attached to the fixture and a processor (20mm x 10mm). The titanium fixture is screwed into the skull and is left to bond with the bone for at least 3 months before the abutment is attached in a second operation. Finally, the processor is simply clicked on to the abutment. Conventional hearing aids can continue to be used after the first operation and prior to fitting of the processor. After the processor is attached hearing aids are no longer required as the ear canal is no longer needed for the reception of sound.



The processor contains a miniature air bag which receives sound and vibrates the abutment and fixture which in turn transfers to the cochlear. The advantages of a BAHA over a conventional hearing aid for those with bone conduction thresholds lower than aided thresholds include:

- Improved hearing thresholds;
- Clearer sound;
- No hearing downtime during ear infections;
- No difficulties with mould fittings;
- Improved aesthetics.

A Google search of “bone anchored hearing aid” produces many useful websites including a baha users support site (www.baha-users-support.com/) and for a video of the operation at Hartford Hospital in the U.S see www.or-live.com/HartfordHospital/1864/event.rnh.cfm.

Background

Our youngest son Mitchell was born with CHARGE syndrome in November 2000. He came home after 17 weeks in the RCH Melbourne. He had oesophageal atresia which was corrected by surgery at 3 months of age. Amongst other things he suffers from profound hearing loss in the left ear (110 db at 500Hz – 80db at 4000 Hz) and severe hearing loss in the right ear (95db at 500Hz – 75 db at 4000 Hz) both of which measured with air conduction testing.

When Mitchell was 5 months old he was fitted with external body aids which were subsequently replaced with conventional hearing aids. For a number of years Mitchell's aided audiograms have indicated left ear readings of 80db at 500Hz – 50db at 4000Hz and right ear readings of 60db at 500Hz – 50db at 4000 Hz.

Whilst Mitchell learnt and used Auslan he has always expressed a preference for oral communication and has been content to use hearing aids.

During the last 7 years of testing by Australian Hearing Mitchell has consistently recorded bone conduction thresholds of 20db. Recently it was recommended that Mitchell undergo testing at the Eye and Ear Hospital in Melbourne to further explore his bone conduction threshold. During that testing the use of more sophisticated equipment confirmed the bone conduction threshold at 20db for the right ear and at about 60db for the left.

As a result of the low bone conduction threshold for the right ear, and deterioration in his left ear of about 10db since birth, we were advised to strongly consider a BAHA for Mitchell's right ear and, possibly, at a later stage one for the left. We were provided with a BAHA on a velcro head band for a 14 day trial. The band was attached around his head whilst positioning the BAHA processor to rest against the side of his skull behind his right ear.

The trial showed significant improvements in the clarity of sound Mitchell received and the distances over which he could hear conversation and other sound. Usually, Mitchell can hear conversation in a quiet environment at a distance of one metre. Whilst wearing the BAHA Mitchell was able to hear in the same environment at a distance of 10 metres. Mitchell told us that "the toilet was very loud" when he flushed it whilst wearing the BAHA and heard his footsteps in the house and birds in nearby trees for the first time.

On 26 May 2008 Mitchell had two 3 mm fixtures implanted by a Melbourne surgeon recommended by Cochlear Ltd. In children the preference is to implant two fixtures so that if one fails a second implant operation is not required. The operation involved an overnight stay but was without incident. His second operation is scheduled for October. These operations are available both publicly or privately with a reduced waiting period.

We look forward to Mitchell receiving the many benefits that are available to him by this procedure and we hope that he enjoys a whole new world of sound!

Mark and Katherine Dean

BAHA (Bone Anchored Hearing Aid) - What Is It?

The BAHA is an implanted hearing device, which works by skull vibration. The vibration produced by the device is transmitted to the fluids in the cochlea stimulating the inner ear and providing the sensation of hearing.

A titanium screw (abutment) is surgically implanted into the skull, more precisely into the mastoid bone (behind the ear). This abutment integrates with the bone overtime and eight weeks after the surgery a small sound processor (hearing aid) is clipped onto the abutment transmitting the sound to the best functioning cochlea. The abutment remains permanently on the skull while the sound processor can be easily attached and removed by the user, as required.

Cochlear implant and BAHA are both implanted hearing devices but there are fundamental differences between the two contraptions:

- The BAHA is suitable for those who have a mild to moderate hearing loss due to external or middle ear defects with a fairly normal functioning cochlea in at least one ear.
- The cochlear implant on the other hand is used to 'replace' a non-functioning cochlea for those who have a severe to profound hearing loss mostly due to a defect in the cochlea itself.
- The BAHA mechanically stimulates the cochlea while the cochlear implant electronically stimulates the hearing nerve.
- Cochlear implant candidates are those who cannot benefit from conventional hearing aids due to the severity of their hearing loss.
- BAHA candidates do not have severe hearing losses but they cannot wear conventional hearing aids due to chronic ear discharges, allergic reaction to the hearing aid plastic mould, malformation of the pinna or ear canal, amongst others.

More recently, the BAHA has also been used for total deafness in one ear with normal hearing on the opposite ear, also known as single sided deafness (SSD).

Two New Books on CHARGE Syndrome

'Why I Am Me. All About CHARGE Syndrome' & 'Living With CHARGE Syndrome'

As detailed in our last issue, we are producing two new booklets on CHARGE syndrome; two very different books with complementing themes. **'Why I Am Me. All about CHARGE syndrome'** will be aimed at children and young adults with CHARGE syndrome, their siblings, families and friends. The second book is aimed at adults and has the working title **'Living with CHARGE Syndrome'. WE NEED YOUR HELP!** Please complete the questionnaire and/or submit an important piece of information. We have had some fantastic contributions so far, but we desperately need MORE!

QUESTIONNAIRE

What is your favourite activity? What do you do for fun/enjoy doing most?

What do you dislike the most? What is your least favourite activity?

What question do people ask you most often about CHARGE?

What info about CHARGE would you like to tell people without CHARGE? Or would like to see in the book?

What can your teacher do differently to support you and help you learn more effectively?

What can healthcare professionals do differently to support you more effectively?

What can your friends/extended family do differently to support you more effectively?

If you feel different, what makes you feel different?

How does feeling different make you feel? (*Sorry that's a tongue-twister!*)

IMPORTANT TIP, SNIPPET OR SUGGESTION—What piece of advice can you give? Please include your name and contact details.

Please send all contributions to **CHARGE Syndrome Association of Australasia Ltd**
PO Box 91, Glenfield NSW 2167