

**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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# Families in CHARGE



Welcome to Your New Newsletter

## CHARGE Conference 2008 Christchurch, NZ 160 days to go!

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

Dear Families,

The countdown is on: 160 days (approx) to go until our 2008 New Zealand CHARGE Conference. Kim Blake (Canada), Tim Hartshorne (USA), David Brown (USA), Rob Last (Australia) will be in attendance and clinics held on the Friday prior. This conference will cover several topics of great interest to families and professionals alike.

The Board of the CHARGE Syndrome Association of Australasia would like to advise its members 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. We urge you to seek further financial assistance from other organisations and agencies within your local area and community (see page 5 under How To Obtain Financial Assistance for some suggestions). If you would like to apply for the conference subsidies through the Association, please contact our newly appointed Family Liaison Officer, Marie Patterson, Tel: (02) (02) 9605 8475, Fax: (02) 9605 8759. Email: [marie-anne@hotmail.com](mailto:marie-anne@hotmail.com).

We are creating two new books on CHARGE syndrome and need your input. Contributions are being sought from individuals with CHARGE syndrome, their families, friends and professionals to help us create books which will be worthwhile, relevant, up to date and informative.

David McHugh  
 President

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

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 Annette Stocker (NZ)

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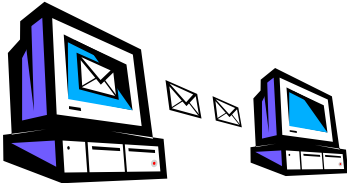
*You can find your director's contact details on our website: [www.austcharge.com.au](http://www.austcharge.com.au).*

## 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.chargeysyndrome.org.nz/charge2008/index.html>

## Newsletters via Email

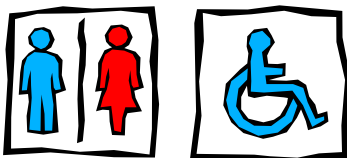


If you would prefer to receive this newsletter via email and to help keep our costs down, please send your request to:

[ctos@teksupport.net.au](mailto:ctos@teksupport.net.au)

Newsletter is also  
 downloadable at:  
[www.austcharge.com.au](http://www.austcharge.com.au)

## National Toilet Maps



Have you wanted to organise a get-together in a park somewhere, but wasn't sure what toilet facilities were available for the disabled? Then next time, visit the National Toilets Map website to find out what's available where. This website includes a list of parks throughout Australia which have disabled toilet facilities.

[www.toiletmap@gov.au/toilet](http://www.toiletmap@gov.au/toilet)

*Life does not have to be perfect  
 to be wonderful.*

Annette Funicello

## Computer Magnification Software

By Madelene Rich

### ZoomText® and MAGic®

There are several software packages for the vision impaired which provide computer magnification, and which offer far more superior capabilities than the Windows accessibility options. ZoomText® and MAGic® are two packages which I have recently trialled and have found them to be excellent in their application. Both programs come in a basic and standard version, with the more expensive version offering 'speak out loud on screen text'.

Both programs offer fully integrated magnification (up to 36x) and screen reading programs enhance, enlarge and read aloud everything that is on the computer screen, including websites, email and documents. There are enhanced mouse pointers and cursors, plus the ability to change the background colours to improve contrast, and several other features. The software readily operates in programs already running on your system.

The standard version is approximately A\$550. Trial copies of both programs are available through the following companies.

ZoomText      Contact: Quantum Technology      **Tel: 1300 791 777**  
**[www.quantumtechnology.com.au](http://www.quantumtechnology.com.au)**  
*Request a trial CD of ZoomText®*

MAGic          Contact: Freedom Scientific  
**[www.FreedomScientific.com](http://www.FreedomScientific.com)**  
*Download a trial copy of MAGic®*

## Victorian News

Your Directors: Rob Last, Madelene Rich

### Post School Options 'Exploring the Possibilities'

#### *Post School Options For Young People With A Disability*

A new resource guide from VALID for young people with a disability and their families. This guide has information and advice on transition from school to the world of higher education, training and employment, and specialist and community based options.

Published by VALID and supported by Dept of Human Services, the guide is available for download at

[www.valid.org.au](http://www.valid.org.au)

## NSW News

Your Directors: Ken Patterson, Lisa Donnelly

Julia Patterson (daughter of Ken and Marie) represented Macarthur Disability Services (MDS) and joined some 2,000 other entrants in competing in the Community Challenge walk on 9th March. The 6 km walk was completed by Julia in 1 hour and 20 minutes.

Congratulations Julia!



# New Zealand News

Your Directors: Tricia Gillbanks, Annette Stocker, Donna Sperandio

## Central South Island Charity Bike Ride

The Central South Island Charity Bike Ride was held Feb 29-March 1 2008. Over 150 riders took to the roads of South Canterbury to raise money for six charities and this year the CHARGE Syndrome Association was lucky enough to be one of the benefactors. Our introduction was made via Mark Taylor who is a Valuer at DTZ, an international property company. For the last four years, Mark has taken part in the charity bike ride putting his body and mind on the line raising funds for many charities. Mark works with Annette Stocker, (Vice President of the Association) in the Christchurch Office of DTZ. Mark put the CHARGE Syndrome Association's name forward after meeting Annette's daughter Aimee and learning more about the CHARGE syndrome and the Association.



Rider's shirt showing sponsors and supported charities for this year's event. CHARGE logo is to the right.

Prior to the race, the two South Island Directors Annette Stocker and Donna Sperandio enjoyed an evening with the riders at the final briefing on the Wednesday night preceding the race. Annette and Donna where they presented information on CHARGE syndrome and were able to mingle with bike riders, volunteers and organisers.

On the first day of the race, the riders were split into groups depending on rider ability. Each group of riders was given a name and this year they were Grey Mice, Green Frogs, Purple Cows, Yellow Ducks, Brown Bears, Blue Elephants and Pink Rabbits.



The course started in Timaru with Day 1 ending in Kurow after 120 kms. Day 2 commenced in Kurow and ended at Lake Tekapo after another gruelling 133 kms. Day 3 finished back at Timaru some 111 kms from Tekapo.



Annette Stocker (Vice Pres.) and Donna Sperandio in their hot pink 'Thank You' tee-shirts.

The final race results saw the Grey Mice being the faster group but were closely chased by the Green Frogs (there seemed to be a bit of rivalry and a fair amount of testosterone flowing in these two teams). Donna and Annette were invited to attend the Saturday night dinner and welcome the riders back

from their long journey. To say thank you to the riders and organisers the girls made special shirts. Donna gave a wonderful thank you speech to the organisers, volunteers and riders. Donna and Annette were asked to hand out the thank you certificates to the Green Frogs and the Frogs all got a kiss. Over \$120,000 was raised for the various charities this year, with a possible \$9,000 to be donated to the CHARGE Syndrome Association. We would like to thank all the sponsors, riders, supporters, volunteers and all those involved in this hugely successful event. We hope to be involved again in the future.



Annette Stocker and Mark Taylor after the race, receiving his thank you drink and an ice pack (you can guess where the ice pack was to go!)

## CONFERENCE 2008—170 Days To Go! (approximately)

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

### I'm Putting Myself in CHARGE 3-5 October 2008, Christchurch, New Zealand

#### Conference Subsidies

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. After some recent fundraising success (see the New Zealand Bike Ride story in this newsletter) and generous donations received, we have managed to keep the conference costs to a minimum this year. 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. We urge you to seek further financial assistance from other organisations and agencies within your local area and community (see page 5 under How To Obtain Financial Assistance for some suggestions). To apply for the conference subsidy through the Association, please contact our Family Liaison Officer.

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

#### Registration Papers

Conference registrations forms have been posted to all members of the Association. If you did not receive one, or if you are not a member but would like to receive a conference registration form, contact: A. Stocker: [t.a.stocker@xtra.co.nz](mailto:t.a.stocker@xtra.co.nz). Or <http://www.chargesyndrome.org.nz/charge2008/index.html>

#### Speakers

Dr. Kim Blake (Canada), Tim Hartshorne (USA), David Brown (USA), Kasee Stratton (USA), Rob Last (Australia), George Williams (Australia), James Townshend (NZ).

#### Clinics

Pre-booked professional clinics with Tim Hartshorne, David Brown, Rob Last, Neil Heslop and Donna Sperandio, will be held on Friday afternoon followed by an evening meet and greet session from 6.30pm. If you are interested in attending these clinics, you will need to fill out the relevant information on your registration form and return it to the committee.

#### Conference Schedule

Saturday's program includes family stories, George Williams' review of CHARGE over the last 25 years, a session on endocrinology by Dr. Kim Blake, updates on CHARGE Syndrome research, projects undertaken by the Board, families living with CHARGE, stress in children with CHARGE and a one hour session by Tim Hartshorne. A group photo at 6.15pm will be followed by the conference dinner and silent auction. Sunday's program begins with David Brown exploring transition to adulthood and independence for individuals with CHARGE, followed by a grief workshop. Prior to lunch, break out sessions will cover a range of interesting topics with several options to choose from. The afternoon sessions will include panel discussions and a young adults panel.

#### Conference Price

Full Weekend—\$250\*, one day only—\$150\*

(\*prices quoted are in New Zealand dollars and are for conference attendance only. These prices do not include other expenses such as accommodation, optional events (such as meet and greet on Friday evening), transport etc. For full conference program, prices and registration, please contact Annette Stocker: [t.a.stocker@xtra.co.nz](mailto:t.a.stocker@xtra.co.nz) or go to <http://www.chargesyndrome.org.nz/charge2008/index.html>)

#### Registration Closing

All registrations must be made and paid for by 1st August 2008.

## How To Obtain Financial Assistance to Attend a Conference

The Board of the CHARGE Syndrome Association of Australasia has limited funds available to assist families (i.e. full members of the Association) to attend this year's conference and are offering conference subsidies. These subsidies will not cover all the expenses involved in getting you and your family to the conference and we encourage you to seek further financial assistance through other services and sources. To apply for a conference subsidy through the Association, please contact our **Family Liaison Officer—Marie Patterson** **Tel: (02) 9605 8475, Fax: (02) 9605 8759. Email: marie\_anne@hotmail.com.** We also encourage you to seek further financial assistance from organisations and agencies within your local area and community. To support you in this, we offer the following ideas:

### Who to Approach

- Lions, Lionesses, Rotary, Soroptomists; Variety Club, Very Special Kids, Starlight Foundation, Ronald McDonald Charities
- Local Council, Mayor or your Local Member of Parliament
- A guide to government community grants throughout Australia can be found at [www.apf.gov.au/library/intguide/sp/spgrants](http://www.apf.gov.au/library/intguide/sp/spgrants)
- Commonwealth Carer Respite Centre 1800 059 059 (Australia)
- Centrelink (Disability Officer) 13 2717 (Australia)
- Grants LINK <http://www.grantslink.gov.au> (Australia)
- Our Community [www.ourcommunity.com.au](http://www.ourcommunity.com.au) (Australia)
- Grant Search [www.grantsearch.com.au](http://www.grantsearch.com.au) (Australia)
- **New Zealand Specific**—Visit your local Disability Resource Centre, Internal Affairs Department or Library and access the Fundview programme. Fundview is an extensive computer program which lists all NZ funders – what they fund for and the closing dates etc. It is a free service. If you have Maori ancestry (or Aboriginal as they may have same scheme) you can approach your tribe as they all have funds available. Check out [www.fundraiseonline.co.nz](http://www.fundraiseonline.co.nz).

Try to think outside the square when it comes to your local community. Consider your **school community** and **local church**. Raise funds by holding a **sausage sizzle** at a large hardware chain, a neighbourhood **garage sale**, a **trivia night** or **fun run**. If you work in a corporate environment, hold a special day like a **loud shirt / bad hair day**. Approach **local art groups** or other special interest groups which raise funds from time to time but have no specific nominated charity. Consider approaching the **local newspaper** with your story. **Local theatre companies** sometimes allow people/groups to sell tickets for an evening performance and you get to keep the profits which could be \$600 – 700. Contact your case manager who may know of '**one off**' packages of financial support being offered (or if you don't have a case manager, contact a support agency in your area and speak to their Family Services Coordinator). Speak with your child's medical specialist who may also be able to offer assistance.

### How to Write a Letter Requesting Financial Assistance

When contacting organisations, obtain all relevant contact details (address, telephone number etc). Your letter should include the following:

- The first paragraph should explain the reason why you are writing the letter
- A brief explanation of CHARGE Syndrome (information is available on our website [www.austcharge.com.au](http://www.austcharge.com.au))
- A brief explanation of your child's diagnosis
- A brief description of the conference program and describe the benefits that you and others will gain from attending. It is not only vital that you learn more about CHARGE syndrome, but it is an important opportunity for you and your child/family to meet with other families and children with CHARGE syndrome)
- A photo of your child
- A complete budget of costs and an indication of an amount you are requesting from the organisation

Consider including a letter from a medical specialist who can verify your child's disabilities and your need to attend. Finish the letter with an invitation for them to contact you, or advise that you will contact them in the next few days. Follow up with a telephone call a week later. If you do receive financial assistance, then immediately write a letter of thanks to the organisation. After the conference, it is important to follow up with the organisation to inform them of your conference experience and to again thank them for their contribution.

A sample letter based on the above information can be found on our website [www.austcharge.com.au](http://www.austcharge.com.au) under 'How To Obtain Financial Assistance' to Attend a Conference. This **sample letter** is intended **to be used as a guide only** and we suggest you **modify it to suit your own circumstances** and needs. In the event of more than one person applying to the same organisation, the request will be viewed much more favourably as an individual request rather than if it appears to be a reproduced letter.

## Two New Books on CHARGE Syndrome

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

The CHARGE Syndrome Association of Australasia is producing two new booklets on CHARGE syndrome; two very different books with complementing themes.

The first book has the working title '**Why I Am Me. All about CHARGE syndrome**'. This book is aimed at children and young adults with CHARGE syndrome, their siblings, families and friends. Many children with CHARGE syndrome are asked by their siblings and friends questions such as what it is like having CHARGE syndrome or why they are different. This book will help address these questions by telling the story of CHARGE syndrome through a conversation between two children, one of whom has CHARGE syndrome. The characters are based on our kids logo and the focus of the book will be on the abilities of children with CHARGE syndrome rather than the differences.

The second book is aimed at adults and has the working title '**Living with CHARGE Syndrome**' and will replace our existing Australasian manual (gray/yellow cover) that is now very much out of date having been originally created in 1997/1998. This book will not replace, nor will it attempt to recreate, the excellent American manual on CHARGE syndrome, which is an extensive, informative reference guide for families and professionals alike, and is available free online at [www.chargesyndrome.org.au](http://www.chargesyndrome.org.au). Instead, this new booklet will contain accurate information, in an easy to read format, ie layman's terminology. It will explain the CHARGE acronym and the 4 C's, recent genetic findings and will cover a range of issues such as early intervention, communication, endocrinology, deafblindness, siblings, transition to adulthood, and more! It will also include links for further information (such as the American manual online), services, support, websites etc.

#### How You Can Help Us Create These Books

These two books will not happen without your input. We are looking for contributions from individuals with CHARGE syndrome, their families and professionals who are familiar with CHARGE syndrome. Your contributions will assist greatly in ensuring these books are very relevant with helpful information and advice. There are two ways you can help us.

#### 1. Compete a Questionnaire for our Children's Book

The following questionnaire is for the children's book and is directed to the individual with CHARGE syndrome.

1. What is your favourite activity? What do you do for fun/enjoy doing most? *We aim to show a balance of activities.*
2. What do you dislike the most? What is your least favourite activity? *This question aims to show the barriers as well as the routine everyday experiences that CHARGE families have so readers can relate to and also learn from.*
3. Do you have any photos of you having fun (like in question 1) or doing difficult things (like in question 2)? Or in a special CHARGE t-shirt? *Please send us a copy. Don't send the original. Label each photo clearly so we know who you are and what you are doing in the picture. Remember: only send us photos that you are happy for us to publish in the book.*
4. What question do people ask you most often about CHARGE?
5. What info about CHARGE would you like to tell people without CHARGE? Or would like to see in the book?
6. What can your teacher do differently to support you and help you learn more effectively?
7. What can healthcare professionals do differently to support you more effectively?
8. What can your friends/extended family do differently to support you more effectively?
9. If you feel different, what makes you feel different?
10. How does feeling different make you feel? *(Sorry that's a tongue-twister!)*

#### 2. Submit an Important Tip, Snippet or Suggestion for our Adults Book

As an individual with CHARGE syndrome, or as a parent, sibling, family member or professional who knows a lot about CHARGE syndrome, do you have an important piece of information which you would like to relay to others, such as someone who is just beginning their 'living with CHARGE' journey, or passing information onto others who are at a similar stage to you. Here are examples of some suggestions received.

- *Seek and establish respite early as this will set the pattern for later years.*
- *Early intervention with therapists and educators should begin immediately following diagnosis.*
- *Keep a journal from the earliest possible time in hospital. Just to remember dates, and which doctors said what, and when to go for reviews etc. I didn't start to keep a journal until our child was 2 and half years old and I've forgotten a lot of what happened in the early days because I was overwhelmed. Now I take it to every appointment so when doctors ask me questions I can look it up fairly quickly and not go through the hospital's 7 volumes.*

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

Tel: (02) 9605 8475 Fax: (02) 9605 8759 Email: [austcharge@hotmail.com](mailto:austcharge@hotmail.com)