

**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.

The Australasian CHARGE Syndrome Association Limited is a registered charity with DGR status and all donations are tax deductible.

The Australasian CHARGE Syndrome Association

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Families in CHARGE Newsletter
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Families in CHARGE



Welcome to Your New Newsletter

Hi All

I am writing this in New Zealand, sitting in front of a heater – and there's not even any snow on the mountain yet! Doesn't bode well for when winter really strikes.

Welcome to new members, the Bartlett Family—Paul, Annie and their family (see the story on pg 7). Paul is the director for Tasmania and his son, Raphael, is the first known child in Tasmania diagnosed with CHARGE syndrome.

It has been suggested that the Association needs a slight name change from The Australasian CHARGE Syndrome Association to *CHARGE Syndrome Association of Australasia*. This will make us easier to find in local disability group listings, where we will now appear under 'C' for CHARGE, instead of 'A' for Australasia. A flyer was sent to all members inviting them to a special meeting regarding this important name change and on Tuesday night (26 June) those present voted unanimously for the name change, which will take effect in the near future.

Fundraising events are happening in both Australia and New Zealand. In Victoria, a Fundraising Dinner is planned for 25th August. In New Zealand, a local Repertory Theatre has been booked for one show with proceeds going to CHARGE. In Christchurch each year there is a Charity Bike Ride. Only a small number of charities are selected as recipients and, following a great presentation by Annette Stocker, the Association has been selected as one for next year's ride. Well done! If you have some suggestions for fundraising, please let your director know. We need to constantly raise funds so that we can continue to exist.

We are planning to produce an information booklet on CHARGE Syndrome which will give an insight into the condition and what it is like living with CHARGE. We envisage this being part of our information package that we provide to new families, and also being made available to all the services that families come in contact with when they have a child / young adult with CHARGE Syndrome. A funding grant has been applied for and we are awaiting to hear if we have been successful.

An early notice for the AGM. This is to be held on 23rd October at 7.30pm via phone link up. Details of how to take part will be published closer to the date.

Welcome to our new CHARGE families.

Tricia Gillbanks

The Australasian CHARGE Syndrome Association 2006/2007 Board of Directors
President

Tricia Gillbanks (New Zealand)

Vice President

David McHugh (SA)

Treasurer

Ken Patterson (NSW)

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Paul Bartlett (TAS)

Annette Stocker (NZ)

Ken Patterson (NSW)

Madelene Rich (VIC)

Donna Sperandio (NZ)

You can find your director's contact details on our website: www.austcharge.com.au. Or contact the Association on (02) 9605 8475.

Calendar of Events



29 August 2007

Transition: Moving on to Adult Services, Royal Childrens Hospital, Melbourne, 6.00pm-8.00pm
Register through Felicity or Magda. Tel: 9345 4858
Email: magda.dzierzynska@rch.org.au

25-30 Sept 2007

Deafblind International World Conference, Burswood Resort and Convention Centre, Perth, WA.
Further details contact: Sharon Barrey-Grassick, Senses Foundation or Robin Hamilton (Dept Head, Deafblind Specialist Services) (08) 9473 5400
www.dbconference2007.asn.au

31 October 2007

Transition: Moving on to Adult Services, Royal Childrens Hospital, Melbourne, 6.00pm-8.00pm
Register through Felicity or Magda. Tel: 9345 4858
Email: magda.dzierzynska@rch.org.au

School Funding and Advocating for Adequate Support

The following story was written by Kelsey and Kerry Dalton (New Zealand), highlighting a recent issue they had regarding their daughter, Sarah's, ongoing funding issues in her primary school.

Our daughter Sarah attends Cockle Bay School in Auckland and is mainstreamed with Teacher aide support. This is her last year of primary school. She is ORRS funded (Ongoing and Reviewable Resourcing Schemes), ie high needs. In New Zealand, the Ministry of Education through Group Special Education (GSE), allocates ORRS funding to the most disabled 1% of students, while all schools get a Special Education Grant. This grant is based on the size of the roll and the school's decile rating: decile ratings are determined on the average household income within the school zone, however this does not necessarily reflect the income of the young families attending the school.

Homai, the Auckland School for the Blind, is now only a transit school i.e. children go for 12 weeks to learn Braille. Our local Special school is about 30 minutes away and therefore comes under another region's budget. ORRS funding is distributed regionally, the money is combined at the local office of GSE and then gets reallocated by that office. Most years Sarah has received approximately 15 hours a week. Our school board has given an extra 5 hours a week, some of it from the SEG grant. The school and I have worked together to make the most of these hours: with parent help by me, banking hours when Sarah is unwell or in hospital, taking her out during school time for swimming lessons etc.

In 2007, our local GSE office said they would cut the hours of all ORRS students at Cockle Bay School. However, I later learned that they ran out of time at the meeting to even discuss Sarah and so cut her hours in Term 1, saying they would meet again later in the year, probably to make further cuts.

The school asked the Ministry of Education for a review of all the children. They met with the parents and asked for our approval to go to the media and also asked if we were willing to contribute financially to teacher aide hours. My husband, Kerry, and I felt somewhat obligated to do this as we want Sarah to continue being mainstreamed and would need teacher aide support for learning at a Year 6 level. We donated money for Term 1, meaning Sarah would have her teacher aide from 9am to 2pm every day.

Another parent and I approached the PTA re fundraising for Teacher aide hours in the school. A comment was made that if we give money to "these" children then that would mean there is no money for the chess club or the rugby team. I wanted to point out that this money wasn't funding an extracurricular activity that my child chose to participate in! It was clear from the discussion that we had 99% of the school community's support, so I decided to keep my mouth shut.

The Media circus: the school contacted a local newspaper that did a story on the 6 children; from this the school received some donations of money and time including interest from the local branch of the Masons. Then the *Sunday Star Times* (a NZ wide newspaper) phoned the school saying they had information that the government were planning to under-spend by \$23 million in special education, they wanted to put a face to this story, and did the school have a child who had been dealing with GSE for years. Only one – Sarah, as the other children are in the junior school.

Just when the caterpillar thought the world was over, it turned into a butterfly.

Proverb



Photo: *The Eastern Courier*, Auckland, NZ

The reporter read me her final draft and it seemed OK, but what was later published was quite different. There was no mention that Sarah had CHARGE Syndrome, rather graded her abilities by age e.g., physically like a 7 year old. All that mattered to Sarah was the photo and she was pleased with it, although she wondered why the one where she posed like a supermodel wasn't used!

Next, the *New Zealand Herald* rang the school as they were to do a feature on the same issue and wanted photos of the children. We asked that they not use Sarah as she had been in the *Sunday Star Times* and another article in the *Eastern Courier* about Starship hospital (see above photo). I had to explain to Sarah there was such a thing as too much fame! The *New Zealand Herald* article was much better reporting. The government by now had come back about the 23 million saying it was a "forecasting mistake".

In the meantime, we had our review with GSE. Four, yes 4, consultants came to the school, observed the children, spoke to the principal and teachers and we, the parents, would get a ½ hour meeting with them. This, they said, was our one chance to tell our child's story. All I kept thinking was the wages the Ministry of Education pays for them to spend this time at school would easily cover the money we were asking for to pay the Teacher aides. Bureaucracy at its best!!

Luckily, as I sat for an hour waiting for my meeting, our Resource Teacher Vision passed by and informed me that one of the consultants had previously worked at Homai so knew about CHARGE. Furiously, I scribbled out my first bullet point: *how much do you know about CHARGE syndrome?*

Thank God for Tim (Hartshorne), David (Browne) and Rob (Last)! I was quoting them left, right and centre, handing out papers with highlighted relevant information. One of the first responses I received was "Oh, (in surprise), you've prepared something for us!" Hmm, this being the one chance I had to advocate for my child, funnily enough—I HAVE!! I also quoted Dr Warwick Smith who wrote a paper on medically fragile children being pioneers in mainstream education. I said this applied to Sarah and as such I would not let her be an experiment in "how low can the funding go". So the end result: an extra ½ hour a week in funding and a report that said Sarah receives more funding than most high needs children in our area.

The report noted however, that Sarah's full inclusion in her education at her local school was remarkable and there was a difficulty in identifying a group of children to provide a comparison for Sarah. Also the complexity of her disability is not immediately apparent and the observation data needs to be considered alongside CHARGE syndrome information. While it was a heart breaking and gut wrenching experience, I can say I was proud to talk about Sarah and her strong willed determination, firstly to survive all the medical hurdles and then to achieve academically in mainstream education.

Did you enjoy this story? Perhaps you have one to share? We would love to publish it in the next issue of *Families in CHARGE*. If so, contact Madelene Rich ctos@teksupport.net.au, PO Box 256 Seaford, Vic, 3198

CHARGE Across Europe 2008

A 7,000km walk to raise awareness of CHARGE syndrome

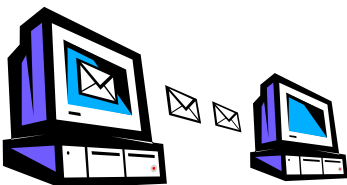
CHARGE Across Europe is a 7,000km walk taking place over 2 years across mainland Europe, from the northernmost point in Norway to the southernmost point of Greece.

Ruan, Tina and their beautiful Belgian Sheperd Akela will be walking this distance to raise awareness of CHARGE Syndrome. By doing so, they wish to build a foundation for future projects and create a better understanding and tolerance for people who are affected by CHARGE syndrome.

The walk will be through Norway, Finland, Russia, Estonia, Latvia, Lithuania, Poland, Ukraine, Hungary, Romania, Bulgaria and Greece staying between the longitudes 20°East and 30°East.

To follow their journey visit: www.expedition-earth.com

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

Greetings from Manila

A warm hello to all from a very warm Manila! Yes, it is the hottest summer we've had having temperatures up to 38°C and also very humid.

But as the heat rises, so does our marvels with our little CHARGER Giuliana. From where we left off (conference in Sunshine Coast last year), lana has gone through so much. In November, her CT scan reveals that aside from having incomplete inner ear structure, she also had unilateral choanal atresia. This was the reason why her feeding is poor because she can breathe only through her left nostril. Fortunately, the closure of the right nostril is membranous only and so she had an operation to repair this last January. The surgery was successful and she recovered well, though having a plastic tube for 6 weeks to keep the nostril open. There was a dramatic improvement in feeding and in no time, she gained weight immediately.



However by some stroke of faith, just two weeks after removing the plastic tube, lana showed the same symptoms as when her nostril was closed. True enough, the doctor found out after scoping that, the newly repaired nostril's hole is closing up again! She was scheduled for another surgery in April but was postponed in May, as she was hospitalised for a week due to pneumonia.

One week before her 2nd surgery and during a routine check-up with the ENT, a miracle happened. The doctor was astounded to see that the closed nostril is now open! The doctor was in disbelief as this is as she said, very unlikely to happen. Miracle or no miracle, we are very happy and thankful for it.

lana turned one May and she is doing very well. She was declared no longer a cardiac patient since December 2006, eyesight improved from 700/800 grades to 300/450 grades and kidneys and urinary tract normal. Physically, she has improved tremendously as well due to her regular PT and OT sessions. Our biggest challenge remains her hearing. But we are very patient. We'll have her tested again to see if she still needs hearing aids or proceed to schedule her cochlear implant.

We hope to see you all again at the 2008 conference.

Best Regards, George and Michee Cadhit

Western Australia News

14th Deafblind International World Conference
25th-30th Sept, Burswood Convention Centre, Perth, WA

World Wide Connections
Breaking the Isolation

CHARGE Syndrome Special Interest Group
Thursday 27th Sept 2pm-5pm
9 papers on various topics relating to CHARGE Syndrome

For the full program go to: www.dbiconference2007.asn.au

New Zealand News

Your Directors: Tricia Gillbanks, Annette Stocker, Donna Sperandio

CONFERENCE 2008

Christchurch, New Zealand

3-5 October

I'm Putting Myself in CHARGE

Plans are well underway for the next Australasian CHARGE Syndrome Conference to be held in 16 months' time.

Start planning now.

Visit <http://www.chateau-park.co.nz/> to view the accommodation and conference facility or Google Earth Placemark: Chateau on the Park.kmz

Behaviour Research 16+ Young Adults with CHARGE Syndrome

University of Western Sydney is conducting research on behalf of the Australasian CHARGE Syndrome Association. The research is surrounding behaviour issues, in particular challenging behaviours of young adults, 16+, with CHARGE Syndrome. Requests to families to participate in this research were posted in May.

If you received this request, please return it to the Association with your intention to participate as soon as possible. If you did not receive a request, but would like to participate, please contact the Secretary

PO Box 91, Glenfield NSW 2167

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

Refurbished Computers for Sale

WESLEY RECYCLING

24 Upward St Leichhardt, NSW
02 9572 3200

Wesley Recycling receive donations of preloved computer hardware which they then refurbish for sale to not-for-profit organisations and health card holders.



Software is installed free and all software is registered with the parent company.

This offer is available Australia-wide. Outside NSW, you will need to provide and pay for your own transportation costs.

Discount Qantas Airfares – Nican



If you have a Carer Concession card, you can apply for a 10% discount on Qantas airfares for you and the person with the disability. Restrictions apply, such as discounts are not available on all flights, you must travel at the same time as the person with the disability and there is an application fee.

Application form and further information is available at www.nican.com.au.

What If

What if he could hear?
I could tell him my deepest secret.

What if he could talk?
He could tell me a funny joke.

What if he went to high school?

He could help me with my Maths.

What if he was "normal"?

He could introduce me to his friends.

What if?

*By Laura Mandeville,
sister to Robbie.*

*A single sunbeam is
enough to drive away
many shadows*

St. Francis of Assisi

In Search of Behavioural Phenotypes

Tim Hartshorne

Unusual behaviour is often associated with genetic syndromes. And so it is not surprising that children with CHARGE syndrome express unusual behaviours. Sometimes the behaviours of individuals who have genetic syndromes are lumped into psychiatric categories such as autism, or obsessive-compulsive behaviour. As an alternative, many of us have become interested in identifying the truly unique features of these behaviours that are associated with different syndromes. The identification of a behavioral phenotype helps us to focus in on the specific and unique behaviours of a syndrome. A behavioural phenotype is “A pattern of behaviour that is reliably identified in groups of children with known genetic disorders and is not learned.” (Harris, 1995). In other words, if a person shows this unique kind of behaviour, that is almost diagnostic of the syndrome. If they behave in that way, they probably have CHARGE.

Do we have a behavioural phenotype for CHARGE? That is what some of us have been working on. I believe we are making progress. This is what we have developed so far:

While working on the CHARGE behavioural phenotype I was struck by certain commonalities I was observing in the behaviour of the mothers. I began to wonder if in truth there might be a unique behavioural phenotype for the CHARGE mother. After careful research and analysis, I believe that I can answer that in the affirmative. Here is what I have learned about the CHARGE Mother Behavioural Phenotype:

CHARGE Mother Behavioural Phenotype Tim Hartshorne

1. Above average cognitive functioning, and near genius when it comes to baffling medical terminology.
2. Persistently focused on advocacy for her child.
3. Experiences little need to be socially appropriate when facing difficult professionals.
4. Repeats things over and over because the professionals need extra reminders.
5. May experience sensory meltdowns after school meetings and medical appointments.
6. When confronted with difficult professionals may lose behavioural control.
7. Professionals may have a hard time getting them off track and shifting their attention to irrelevant perspectives.

Victorian News

Your Directors: Madelene Rich, Rob Last

Major Fundraiser for Victoria—All Proceeds to the Australian CHARGE Syndrome Assoc.

Dinner Dance

Saturday 25th August 2007

Band, Silent Auction, Raffles, Door Prizes

Somers Yacht Club, Somers

\$50 per head—Get in quick! 150 tickets ONLY

A major fundraiser will be held at the Somers Yacht Club located on Western Port Bay. The use of the venue has been donated by the Club, dinner will be prepared by a local chef and a band will provide music during the evening. Volunteers will be providing the food and bar service. Paul and Jodie Mutimer (parents to Thomas and Sophie) and Rob Last (Victorian Director), with a band of local people, will be coordinating this great night. It will be a wonderful opportunity to raise funds for the Association and great for families to come together and socialise.

Contact: **Rob Last 03 5983 2675**

Tasmanian News and Raphael's Story

Welcome to our newest member and newly nominated Director for Tasmania, Paul Bartlett. Paul and his wife Annie are proud parents to Raphael. As far as we know, Raphael is the first child with CHARGE syndrome diagnosed in Tasmania. Welcome to the Bartlett family and following is Raphael's story so far.

My name is Paul Bartlett and our third child was born on 18/3/2006. We already had names selected for a girl or a boy and so we instantly knew what to call him. Raphael Shalom Bartlett came into the world with raspy, gurgly breathing (stridor), a crooked mouth and a funny ear but that didn't stop us from instantly loving him.

Everyone told us that a lot of babies have stridors and facial palsy and that we could probably expect it to clear up in a few days. After a few days he still had the same little peculiarities and people's comments turned to "it will probably clear up in the first few weeks". After a few weeks the predictions turned to "a few months" but by this time another problem had come to the surface. Before he was three months old we visited a paediatrician because he wasn't putting on weight fast enough. Then we were referred onto an ENT and barium swallow x-ray in the same day. Back then I thought - naively - that having three medical appointments in one day was probably some kind of record.

More work ensued over the following months looking for the reason that he was not putting on weight and trying different things to get Raphael to gain weight, culminating in final success with placement of an NGT (NasoGastric Tube) to supplement his feeding by mouth. During this time we had an echo cardiograph that looked for vascular rings around his oesophagus. There wasn't one, but it found a small ASD (Atrial Septal Defect) to add to his list of problems. His osteopath, who was trying to therapeutically resolve his facial palsy, noticed a difference in Raphael's eyes which was ultimately diagnosed as being a microphthalmus (small eye) with a large coloboma of the optic disc and retina. Later, a trip to an audiologist revealed that Raphael had hearing problems and the list of issues was beginning to form a small mountain of reports and letters detailing Raphael's problems.

Eventually, an MRI was performed on his head and chest to try to find out what was going on inside him. The anaesthetic gave him a rough time but no permanent damage was done. The MRI revealed yet another problem with his vestibular semi-circular canals (which provides a sense of balance). This was enough for the geneticist to make the diagnosis of CHARGE syndrome for Raphael. He indicated to us that this was a very rare condition and according to his database this is the first case in Tasmania.

Researching on the web for any information on CHARGE syndrome, we came across information that seemed to match other issues that we had noticed in Raphael but previously had not considered them to be important. We found excellent sources of information from the CHARGE Syndrome Association of Australasia, the CHARGE Syndrome Foundation (US), the CHARGE Syndrome Listserv (US) and CHARGE Family Support Group (UK). Their websites, published documents and parent contributions have given us excellent sources of information and platforms for questions to our medical consultants.

So the number of appointments started to grow. Adding to the early intervention and therapy appointments came a bunch of tests to look for the other known potential problems with CHARGE syndrome. Three appointments in one day was no longer a record for us and it was becoming the norm. To date our record number of appointments in one day is eight.

I tell Raphael's full story on a blog. You can find it at <http://raphaelincharge.blogspot.com/>



Hints and Tips for Sourcing Funding Grants

Conference 2008 in New Zealand may sound like a long way off but it's never too soon to look at how you are going to fund your way there. When sending an application to a prospective sponsor, include a personal letter explaining why you are seeking funds and what it will mean for you and your family to attend the conference; include information on CHARGE Syndrome (go to www.austcharge.com.au or <http://www.widerworld.co.uk/charge/whatis.htm> and use the information on line); include a photo and story about your child; budget of costs requested. Following are just a few ideas for sourcing sponsorship or funds to attend the conference or for other specific needs. If you have had success with other organisations, please let us know.

- Rotary, Lions, local church groups. Variety Club, Very Special Kids, Make a Wish Foundation.
- Your local council member or member of parliament.
- Your child's medical specialist/s (they may belong to an organisation that provides funds for conference attendance).
- Grants link (Australian Government website) www.grantslink.gov.au.
- Lotterywest (Western Australia) www.lotterywest.wa.gov.au/grants.
- Have your story published in your local/national newspaper and ask for donations.
- Run a trivia or quiz night, or a sausage sizzle.
- If you work in a large firm, hold a special day such as Loud Shirt Day or Coloured Hair Day and ask for a gold coin donation.
- Approach a local theatre company and sell tickets for an evening performance and get a cut of the profits.

New Zealand Specific

- Visit your local Disability Resource Centre, Internal Affairs Department or Library and access the Fundview programme. Fundview is an extensive computer programme which lists all NZ funders – what they fund for and closing dates etc. It is a free service.
- If you have Maori ancestry you may be able to approach a specific organisation for support.
- Visit www.fundraiseonline.co.nz.

Family Assistance Fund: Information for Families

DADHC (Department of Aging, Disability and Home Care) provides and funds a range of services, programs and resources to support families to care for their child or young person with a disability. In 2005, the Department introduced the *Supporting Families Care for Children and Young People with a Disability Framework* which aims to provide a broad range of supports for children and young people with a disability and their families. One of the new programs developed under this framework is the *Family Assistance Fund*.

The *Family Assistance Fund* aims to increase family wellbeing and strengthen the capacity of families to provide ongoing care for a child or young person with a disability in their home. Through the fund, small amounts of discretionary funding are provided directly to families to help them address needs that cannot be met through the standard range of services or other funding. The primary purpose of this fund is to support the work that case managers are doing to assist families.

To be eligible for the Family Assistance Fund your child or young person must be **under 18 years old** and **currently receiving a service from DADHC or a DADHC funded service**. If you are unsure if services you receive are funded by DADHC, please contact your DADHC Regional Office. Please note: eligibility does not automatically mean a family will receive support through the Family Assistance Fund. All applications are considered by a panel and the number of families able to be assisted is dependent on funding availability for the region. Please see the Family Assistance Fund Fact Sheet for more information at <http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Services+for+families.htm> or families should contact their case manager or DADHC regional/area office.

Centrelink \$10,000 Ex-Gratia Payment

In a recent interview on a Melbourne radio station, Prime Minister John Howard had granted the family of a young blind boy a one off payment of \$10,000. This decision was based on the fact that the parent was receiving a Carers Allowance but had been rejected for the Carers Pension. A review is now underway to assess if other families and parents are eligible for this one off payment. An overall review of the Carers Pension and the eligibility criteria is underway but you need to register your interest with Centrelink.

Simply call them on 132 717 and register your intent to claim. You need to be receiving the carers allowance and have been rejected for the Carer's Pension.