

CHARGE Syndrome Association of Australasia



**B in  
CHARGE  
CONFERENCE**

**8th – 10th October, 2010  
Fremantle • Western Australia**



**Shining brighter as they grow.**

[www.esplanadehotelfremantle.com.au](http://www.esplanadehotelfremantle.com.au)

**CHARGE Syndrome Association of Australasia Ltd**

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

## **'B' in CHARGE**

The '**B' in CHARGE** Conference of CHARGE Syndrome Association of Australasia is **beeing** held 8 - 10 October at the superb Esplanade Hotel in Fremantle, Western Australia. This is the first time this biennial conference will **bee** hosted in WA.

The conference title, '**B' in CHARGE**', represents a multiple theme, as follows:



David Brown and others have commented there should **bee** a '**B**' in CHARGE - for **Balance**.



**Balance** in CHARGE goes **beeyond** the vestibular sense. There is also a need for balance of education and therapies with daily home life, including time to play! A balanced, holistic approach enables individuals with CHARGE and their families to take control of their daily routine and **bee** in CHARGE.



Tim Hartshorne and others have commented there should also **bee** a '**B**' in CHARGE - for **Behaviour**.



The bumblebee should not **bee** able to fly, due to its physical make-up, but apparently no-one told the bumblebee, as it flies anyway - just as our children with CHARGE should not **bee** able to walk due to missing or malformed semi-circular canals; yet most children with CHARGE eventually do walk, then run, jump and virtually fly along!



So, the **bee** is the perfect mascot for our conference!



With 4 international key speakers and 2 key speakers from the East Coast of Oz, there will **bee** something for everyone. Clinics with the professionals will **bee** offered on the Friday afternoon, 8 October, 2 - 5 pm.



The Social program and kid's activities will **bee** lots of fun too!



And there's more...Based on the highly successful Professional Day held at the World CHARGE Conference in Chicago July 2009, a forum on Friday morning 8 October 8.15 am - 12.30 pm will **bee** targeted at doctors, medical specialists and other professionals involved in the identification and medical treatment of children with CHARGE Syndrome. This scientific forum is not designed for questions or discussion related to a specific individual. All of the presentations will **bee** repeated in concurrent sessions within the conference, to give people with CHARGE, their families and support providers an opportunity to ask questions of an individual nature.

**Please see separate registration form, fees and program on the website.**



The '**B**' in **CHARGE** conference committee is very excited about the opportunity to showcase our beautiful state and wonderful hospitality. We invite you all to what is shaping up to **bee** a wonderful conference experience!

**'B' in CHARGE** Conference Committee:

Sharon Barrey Grassick - Chairperson; WA Director [sbgrassick@gmail.com](mailto:sbgrassick@gmail.com)

Lisa Watson - WA Director [lisa\\_charge@hotmail.com](mailto:lisa_charge@hotmail.com)

Marie Ingley

Jon Ingley

Paul Drok

Shirley Ciccotosto

Sophie Makse

Robin Hamilton

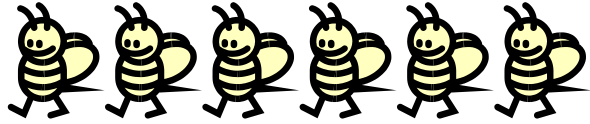
Karen Wickham

Michelle Ranieri

Carly Blenkhorn

Brooke Till

# Key Speakers



## **David Brown**

David Brown is an Education Specialist with California Deaf-Blind Services in San Francisco and has spent many years working with children with deafblindness and CHARGE Syndrome, particularly regarding adaptation to multiple sensory issues. David's enormous contributions to the field have been acknowledged recently through presentation of an honorary Doctoral Degree from Central Michigan University.

## **Tim Hartshorne**

Dr Tim Hartshorne is a Professor of Psychology at Central Michigan University. He is also the father of a 20 yr old son with CHARGE. Tim has been interested in the parent-professional relationship, families coping with CHARGE and the challenging behaviours in CHARGE. His studies have contributed greatly to a better understanding of how CHARGE affects all members of a family.

## **Jeremy Kirk**

Dr Kirk is a paediatrician and long-time contributor to the knowledge base on CHARGE Syndrome in the area of endocrinology and growth. He is Head of pediatric endocrinology at the Diana Princess of Wales Children's Hospital in Birmingham; Associate Professor (Reader) in the University of Birmingham; Council Member of the Royal College of Paediatrics and Child Health; and past secretary of British Society for Paediatric Endocrinology and Diabetes. He has a special interest in growth and gonadal problems and is the Medical Advisor to UK CHARGE Family Support Group.

## **Rob Last**

Rob Last is an Early Childhood Educator, specialising in working with children who have sensory disabilities in hearing and vision. He works for Vision Australia. Rob has developed communication systems to meet individual needs of children with CHARGE syndrome since the early 1990's. He has done longitudinal studies of the progress made by people who have CHARGE Syndrome, beginning in 1993.

## **Kasee Stratton**

Kasee Stratton is a PhD student under Dr. Tim Hartshorne, assisting with the study of behavioral disorders associated with CHARGE; her research has focused on pain and stress in CHARGE.

## **George Williams**

Dr George Williams is a childbirth and parent educator who served as the Director of Newborn Intensive Care Unit at the Children's Hospital in Sydney. He has appeared on national radio and television and has contributed to many media publications. George has a particular interest and expertise in diagnosis of CHARGE Syndrome.

# 1. CONFERENCE



A: Full Weekend		B: Saturday Only		C: Sunday Only	
Includes: Friday, Saturday and Sunday Daytime Events Lunches and Morning & Afternoon Teas (Sat/ Sun) Child Care for Members		Includes: Saturday Daytime Events only Lunches and Morning & Afternoon Teas (Sat only) Child Care for Members		Includes: Sunday Daytime Events only Lunches and Morning & Afternoon Teas (Sun only) Child Care for Members	
Members	\$295*	Members	\$160*	Members	\$160*
Non-Members	\$325*	Non-Members	\$190*	Non-Members	\$190*

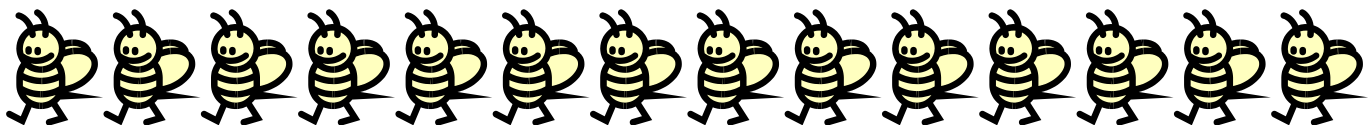
\* Price is per Adult attending conference sessions.

\* Information regarding how families, who must be members, can seek funding support to attend this conference is now available on the website. Membership of CHARGE Syndrome Association of Australasia is free.

# 2. OPTIONAL EVENTS



A: Meet & Greet	B: Conference Dinner
6:30PM - 8:30PM Friday Evening A light finger-food supper will be provided Bar Available (at own cost)	From 6:30 PM Saturday Evening Surprise Guests! Bar Available (at own cost)
Adults \$25.00 Children (5 – 15 yrs) \$10, Under 5 free	Adults \$60 Children (5 – 15 yrs) \$25, Under 5 free



# 3. ADDITIONAL INFORMATION



## Accommodation

We have secured a block of bookings at the conference venue, Esplanade Hotel in Fremantle. This is an excellent 4 ½ star hotel which we have negotiated at the discounted price of \$220 per night for a standard room. This is the recommended accommodation, as it is a very good rate for this area at this time of year. Please book directly with Esplanade Hotel at [www.esplanadehotelfremantle.com.au](http://www.esplanadehotelfremantle.com.au) Be sure to say you are with the CHARGE Conference to obtain the discounted rate.

There is alternative accommodation within 5 - 15 minutes walk of the venue, eg. Quest Harbour Apartments is close by; however, these are townhouses with toilet and bedrooms upstairs and a step going down into living area. [www.harbourvillage.property.questwa.com.au](http://www.harbourvillage.property.questwa.com.au)

Additional information regarding accommodation will be available on the website soon, or go online and Google Fremantle accommodation. As our conference is during the school holidays in WA, we suggest you book accommodation as soon as you possibly can.

## Airport Transfers

The Esplanade Hotel is located approximately 45 minutes drive from the Domestic airport. Taxi costs will be expensive, around the \$75 – \$80 mark. However we have negotiated rates with a bus company familiar with children with high needs, including lifting equipment if needed for wheel-chairs, etc.

Please make your booking directly with Brian Gibson at mobile: 0437886324 or [bbjm@inet.net.au](mailto:bbjm@inet.net.au) and mention any special needs, eg. Lifting equipment, when making your booking.

Prices as follows (per trip one-way to and/ or from Airport - Fremantle or vice-versa)

- 1-3 per Car \$ 55 (includes GST)
- 4-10 Mini-van \$66 ( includes GST)
- 10- 30 \$110 ( includes GST)

## Childcare

Childcare is available and included in the registration fee for Members. This will be staffed by childcare professionals, volunteers and a number of trained nurses. Lunches and morning/ afternoon teas will be provided for the children.

## Perth and Fremantle

There are a wide variety of exciting activities available in these cities and the surrounding region. Details will be available closer to the time.

## Friday afternoon ‘Clinics’

‘Clinics’ are opportunities for individuals with CHARGE and/ or their families to meet individually with professionals; clinics must be pre-booked with Conference Registration. Access will be on a first-in, first-filled basis, and will be confirmed by 15 September 2010. Every attempt will be made to accommodate individual preferences, but availability is limited.

## Meet and Greet

This will be held on the Friday evening and is designed to give everyone a chance to catch up with old friends and make a few new ones. A selection of nibbles and non-alcoholic drinks will be provided, with alcoholic drinks available for sale at the bar.

**Note:** There are no spelling mistakes or typos in this form...the **bees** are

intentional. There will **bee** a prize for delegates who can tell us how many **bees**

there are in this document! Silly? **Maybe.**

