

Live Strong, CHARGE On!

13th Biennial CHARGE Syndrome Conference

Conference Report

What a superb conference weekend we have just experienced in Melbourne! On behalf of the conference committee Rob Last, Belinda Arnell, Elizabeth Levesque and Louise Adams, we would like to thank everyone who attended the 2018 CHARGE Syndrome conference: delegates, speakers, volunteers and exhibitors Abbott, Conexu Foundation, Guide Dogs Victoria and Able Australia. Hosting conferences supports our vision of improving the quality of life for children and adults with CHARGE syndrome and I believe this year's event met that vision incredibly well.

It was wonderful to renew acquaintances and welcome many new families and professionals into the Australasian CHARGE syndrome community. 139 delegates from around Australia, New Zealand, United States and Indonesia helped make this one of the largest conferences we have hosted. We welcomed Nancy Salem-Hartshorne to her first Australasian CHARGE syndrome conference, joining Tim Hartshorne, David Brown, Daniel Choo, Kim Blake, Kasee Stratton-Gadke, Daniel Gadke and George Williams this year. Our program covered topics such as ENT and audiology, pain and stress, update on CHARGE, vestibular dysfunction, multidisciplinary assessment, behaviour, feeding and gastrointestinal issues, teenage and adult medical issues, social relationships and puberty and development. Students from Tim's (3) and Kasee's lab (4) and OT students from Monash University (2) presented research posters.

We learned about government funding for Australian people with disabilities from Donna Shaw (VALiD) and Amanda Greenfield chaired a separate session for New Zealand families. Kathy Dean shared her family's journey into distance education and Marea Howe and Kathy Bodycoat presented on financial and legal issues. I was deeply moved by Hannah's story told so beautifully in words and pictures by her mum Heather and sister Kristen. Our Young Adult Panel, chaired brilliantly by Belinda Arnell, was funny, inspirational and informative. Mia, Mitchell and Cameron gave us a small insight into their life journey so far and each of them have the world at their feet as they transition into the next stage of their lives.



Club CHARGE

I wish to personally acknowledge and express my utmost gratitude to Club CHARGE coordinators Jodie Mutimer, Tracey Palmer and their volunteers Louise, Pat, Luke, Nat, Jane, Kathy and Leanne. Jodie and crew had one goal in mind for Club CHARGE: that our children would have an awesome conference experience. What we saw at Club CHARGE 2018 was outstanding: a team of dedicated, empathetic and knowledgeable volunteers caring for our children while we attended the conference. Saturday's excursion was a huge day with lots of smiles and every person on that bus had an amazing time. Sunday's onsite activities were well planned with a variety of things for the children to do which were stimulating, educational and interactive.

There was plenty of quiet space as well with relaxing activities for those who needed it, and more physical activities with balls, balloons and hip hop dancing for those needing to burn energy. Our children had a wonderful opportunity through Club CHARGE to connect with their peers, make friends, enjoy themselves, smile, laugh and play together. What Club CHARGE has achieved is truly remarkable and will be hard to replicate. I congratulate and thank Jodie and her dedicated, professional, highly energetic team of volunteers who helped make Club CHARGE 2018 an awesome experience for our children. And fittingly, we celebrate the work of these amazing volunteers as National Volunteers Week comes to an end (21-27 May) – thank you Ellen Howe for making me aware of this.

Evaluation

Tell us what you think - did conference 2018 meet your expectations? Please take the time to complete your conference evaluation [online](#). We aim to create relevant, informative and worthwhile conferences for our Australasian CHARGE syndrome community and your evaluation is important in our planning process for 2020. Help us make a conference you will want to attend.

Save the Date! 14th Biennial CHARGE Syndrome Conference 2020 – Hobart 3-5 April

On behalf of the Board, I am thrilled to announce our 14th biennial conference will be in beautiful Hobart, Tasmania in 2020. Kylie Moore (Tasmanian Director) will lead the conference committee and is already making some great plans.

Board Report

After five years as President, Lisa Russell has stepped down from this position and will continue as Queensland Director. During her tenure, we have seen the development of a new logo, website and Facebook group which supports our aim of raising awareness. Lisa and Dean have hosted several annual Golf Days in Queensland to raise funds for our conferences and have made connections in the local community which has also



resulted in funds being received. The board wishes to thank Lisa for her leadership, passion and dedication to the CHARGE Syndrome Association of Australasia. We also thank Dean, Billy and Eddie Russell and acknowledge that those on the board are partners and parents first and foremost and we thank you for the support you gave Lisa as well.

I am very proud to take on the role of President of the CHARGE Syndrome Association of Australasia. I was a Victorian Director from 2000-2008, when I resigned to commit more time to my family. I now have the capacity and energy to contribute to the board and this role.

We have raised the profile of CHARGE syndrome and multi-sensory impairment significantly in the lead up to and after our 13th biennial conference.

On Thursday 24 May, Kasee Stratton-Gadke, Dan Gadke and Tim Hartshorne along with their seven students toured the Royal Children's Hospital, met with psychology department staff and Murdoch Childrens Research Institute researchers. Many thanks to Alice Morgan at RCH for helping coordinate the excellent agenda for the day. We now have good connections with the psychology department at RCH and look forward to building on this.

On Friday 25 May, David Brown, Daniel Choo, Nancy Hartshorne, Kasee Stratton-Gadke, Dan Gadke, Tim Hartshorne and Kim Blake, along with students, Dr. George Williams, Rob Last and my son Sean presented at a special medical symposium on multi-sensory impairment at Monash Health Translation Precinct. Situated on the Monash Children's Hospital site at Clayton, the symposium was attended by 45 medical professionals (see stats below). With the support of Dr. Robert Roseby (Head of Medical Specialties, Director of Education, Monash Children's) and Dr. Phil Bergman (Head of Paediatric Endocrinology and Diabetes at Monash Health) the symposium was widely promoted Australia-wide through their professional networks generating local, regional and interstate interest.

Whilst the symposium came under the banner of 'multi-sensory impairment' we still raised the profile of CHARGE syndrome as presenters made reference to CHARGE syndrome throughout the day. The seminar room was at capacity and delegates were engaged, interested and passionate about learning more about multi-sensory impairment and CHARGE syndrome. A NICU nurse remarked that this symposium changed the way she thought about CHARGE syndrome. Nurses in NICU see our children at their most fragile and very rarely do they get to meet these babies again. It was incredibly satisfying to hear her say that the symposium 'opened my eyes' and 'made me think more positively about CHARGE syndrome' as the presentations spoke to 'the whole child' and they heard from a young adult with CHARGE syndrome talk about his life. How wonderful that this NICU nurse has been enlightened this way and can



incorporate her newfound belief in the important work she does with babies in NICU.

On Monday 28 May, we hosted an education symposium at Victorian Deaf Education Institute which was also live streamed. A highly valuable session, we saw this as another great opportunity to reach Australasian professionals who work in the educational field supporting individuals with CHARGE syndrome. Many thanks to Elizabeth Levesque, General Manager of the Institute for coordinating this incredible day at VDEI for us.



Conference Papers

Speaker papers from all events and a link to VDEI live stream will be available on our [website](#) from **Monday 4 June 2018**.

Thank you to our photographers Wayne Neal and Paul Bartlett for capturing wonderful moments from the conference weekend. We will be uploading these photos to the website for everyone to enjoy.



Thank you to The Ian Potter Foundation for providing funds to enable us to bring our seven international speakers to Australia and Department of Social Services National Disability Conference Initiative for funds to assist families to attend.

In closing, it was an absolute pleasure for me to meet each attendee at this year's conference and to know a little bit about each of you. Our Australasian CHARGE syndrome community is vibrant and strong and I look forward to getting to know everyone a little bit more over time.



Madelene Rich
President, CHARGE Syndrome Association of Australasia



Statistics

Multi-Sensory Symposium

Registrations: 45. Speakers: David Brown, Daniel Choo, Nancy Salem-Hartshorne, Kasee Stratton-Gadke, Dan Gadke, Kim Blake, Tim Hartshorne, George Williams, Rob Last, Sean Rich.

Attendees: registered nurses/clinical nurses/medical officer/maternal child health (13); paediatricians (4); paediatric dentists (2); occupational therapist (8); speech pathologists (5); physiotherapist (3); dietitians (2); psychologist (1); social worker/mental health clinician (1); teacher of the deaf-early intervention (2); doctor (1); behaviour support consultant (1)

Conference

Registrations: 165. Speakers: David Brown, Daniel Choo, Nancy Salem-Hartshorne, Kasee Stratton-Gadke, Dan Gadke, Kim Blake, Tim Hartshorne, George Williams, Chloe Stevenson, Lauren Chanter, Heather Flynn, Kristen Sellings, Kathy Dean, Marea Howe, Kathy Bodycoat, Donna Shaw, Amanda Greenfield, Belinda Arnell, Mia Barbutto, Cameron Gillbanks, Mitchell Dean, Mandy Nolan.

Students: H. Ripple, M. Anderson, K. McCulla and M. Ferrigno (Bulldog CHARGE Syndrome Lab, Mississippi State University). S. Brown, A. Weatherley and S. Muhn (CHARGE Syndrome Research Lab, Central Michigan University)

Attendees: 130 Australia, 18 New Zealand, 10 United States, 3 Indonesia, 15 professionals, 20 speakers, 43 families (new families 16, new individuals 64), 13 volunteers, CHARGE individuals 28 (0-16yrs [16], 16+ [12]), 13 siblings, 10 students, 4 exhibitors (Abbott, Guide Dogs Victoria, Able Australia, Conexu Foundation), 2 Auslan Interpreters, 1 support worker.

Victorian Deaf Education Institute

Registrations: 55 (plus an online audience). Speakers: David Brown, Nancy Salem-Hartshorne, Kasee Stratton-Gadke, Dan Gadke, Tim Hartshorne.

Students: H. Ripple, M. Anderson, K. McCulla and M. Ferrigno (Bulldog CHARGE Syndrome Lab, Mississippi State University). S. Brown, A. Weatherley and S. Muhn (CHARGE Syndrome Research Lab, Central Michigan University)

Attendees: Teachers of the deaf, teachers of blind and low vision, mainstream teachers, deaf educators, psychologists, audiologists, speech therapists, OTs, family counsellors and education support staff.