ANNUAL REPORT 2021

President's Report

As we reflect on another year of 'living with COVID', I wish to acknowledge and congratulate my fellow board members for a very productive year for CSA. While our family lives, our working lives and our other lives were at times chaotic and far from routine due to the unpredictable nature of COVID lockdowns and restrictions, our board members dutifully continued to show up each month to contribute their precious time and energy into keeping our little organisation ticking over. It's been a tough year, but our board has done some amazing work, as you will see in this Annual report.

Our Outreach service, led by Rob Last and Liz Levesque (and supported by all board directors), continues to provide a valuable link to those seeking information, resources, connection to families and professionals. We have responded to many requests for assistance this year, not only from around Australia and New Zealand, but also from far places around the world, including Asia, Europe and the UK.

Our community have shone the light on CHARGE syndrome through their wonderful stories. While online resources such as our Understanding CHARGE Syndrome course, and Perkins School for the Blind elearning hub and the recently released CHARGE Syndrome book (second edition) (TS Hartshorne, MA Hefner and K Blake) provide a wealth of information on CHARGE syndrome, it seems real stories from those living with CHARGE syndrome resonate more with people. We strive to inspire our community through our stories which celebrate the uniqueness of the individual. Thank you David, Riley, Sarah, Sean, Aimee and Holly for sharing your stories this year. If you have enjoyed reading these stories, we encourage you to share your own story in our future newsletters (admin@chargesyndrome.org.au).

We have significantly advocated for our community, raised the profile of CHARGE syndrome and expanded our networks through participation on several deafblind and disability reference groups seeking to improve outcomes for individuals with CHARGE syndrome and the wider community of people with disabilities. We contributed to a federal government submission to highlight the impact the introduction of NDIS Independent Assessments may have on our community, and we participated in focus groups to contribute to the design of the Australian national disability research agenda. Through these activities, CHARGE syndrome has been placed front and centre in the discussions, and the voices of our community are being well and truly heard in these arenas.

Thank you to our generous fundraisers and donors – we are very grateful for this support. Every cent is vital as it helps support our activities and projects, and keeps CSA ticking along.

In closing, I sincerely thank our board: Vice President Robert Last AM, Treasurer Mukesh Baluja, Secretary Kath Green, Communications Director Louisa Cameron, Education Director Elizabeth Levesque and NZ Director/NZ Treasurer Annette Stocker. I value their contributions, friendship and support. They make my role as President a very satisfying and enjoyable one.

Madelene Rich
President

Connect – Social Activities

Vic CHARGE Family Networks,
26 March 2021, Jells Park, Mt Waverley.

Virtual Community Catch Up
(L-R Rob Last, Ruth, James, Ellen, Madelene
Rich, Nicoleta, David

Inform – Develop Resources

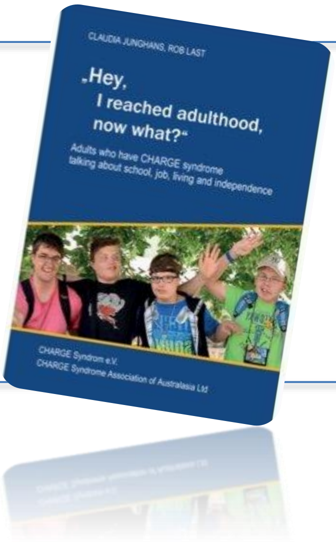
Warrior Welcome Packs
Our Warrior Welcome packs are the initiative of our Communications Director Louisa Cameron. These well thought out packs are designed to let families know there is support available and their new baby is a welcomed warrior of the CHARGE syndrome community. Six warrior packs have made their way to newly diagnosed families this year already and we can see they are making a real impact. Well done Louisa!

> *We received our welcome pack today and are very grateful to have this community's support. Reading the welcome letter made us happy and also a little emotional.*

Donations
A call out for donations to our pack resulted in financial donations (thanks **Built** and **Jamic Group**) and a generous supply of 15 beautifully handmade blankets from the amazing folk at *Crochet and More (Australia)*. These financial donations and blankets, made with oodles of love, will ensure we have plenty of Warrior Welcome Packs ready to send to families as soon as they contact us.

CHARGE
SYNDROME
AUSTRALASIA

Hey, I reached adulthood, now what?
In collaboration with our friends from CHARGE Syndrom e.V. (Germany), this book focuses on adults with CHARGE syndrome talking about school, jobs, living and independence. Developed by Claudia Junghans and our very own Rob Last, it features stories from people with CHARGE syndrome from around the world including Australians Ellen Howe, Belinda Arnell, Sean Rich and New Zealander Sarah Dalton. Available for download from our website.


CLAUDIA JUNGHANS, ROB LAST

„Hey,
I reached adulthood,
now what?“

Adults who have CHARGE syndrome talking about school, job, living and independence

CHARGE Syndrom e.V.
CHARGE Syndrome Association of Australasia Ltd

Inform – Raise our Profile

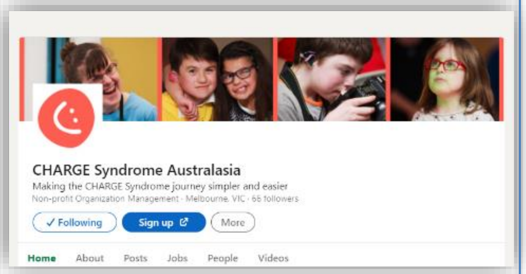
Meet our smiling C

We embrace the one human quality that is true to us all: uniqueness.

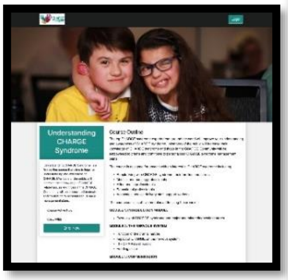
We rolled out our new logo in 2021 and updated our communication networks. The bright and cuddly smiling C is welcoming; it embraces diversity, is full of hope, is selfless and always energetic in its endeavours. We love our new branding.

Thanks to the team at **Made Simpler**.

CSA is now on Linkedin!


CHARGE Syndrome Australasia
Making the CHARGE Syndrome journey simpler and easier
Non-profit Organization Management · Melbourne, VIC · 66 followers

Coming Soon! Understanding CHARGE syndrome course in French and German for release in 2022. Huge thanks to Chris Parker for his ongoing support of this resource that continues to be a very useful learning tool.



Fabulous course. It clarified many things for me that I was puzzled about, especially behavior.

Germany: CHARGE Syndrome e.V. **France:** Cresam

Donors and Fundraising

Thank you to our major donors for 2021 for their generous donations.

Matchworks SA
Ellen Howe
Dean

Jamic Group
Built

Grill'd Matters
Crochet and More Australia

Inspire – Share our Stories

We shared inspirational stories from our community:

David's story

Holly's story

Riley's story

Sean's story

Sarah's story

Advocacy – Creating Better Outcomes

NDIS Independent Assessments
CSA was one of 13 national deafblind organisations who contributed to Able Australia's submission to the Joint Standing Committee on the NDIS Parliamentary Inquiry into Independent Assessments in relation to people with deafblindness. The federal government received 376 submissions from organisations and individuals. Able Australia's submission was led by Dr Meredith Prain - you can read it here (scroll to #318). Thank you to members of our community who contributed their lived experiences to this submission so as to highlight the significant impact this initiative may have on people with CHARGE syndrome.

In July 2021, Senator Reynolds announced that the introduction of Independent Assessments would be put on hold – for now.

Advocacy – Growing our Networks

We increased our networks by participating on reference groups aimed at improving outcomes for individuals with disabilities in particular deafblindness and vision impairment.

Deafblind Information Australia

Able AUSTRALIA SensesWA DBA Deafblind Australia

Deafblind Information Australia (DBIA) Project
CSA is one of a consortium of community representatives and service providers contributing to the development of the DBIA website to ensure it is accessible and easy to navigate for people who are deafblind and that it provides current, up to date information on deafblindness, such as CHARGE syndrome.

Networks: Senses WA, Able Australia

DEAFBLIND WORKING GROUPS

Deafblind Working Groups (Australia and New Zealand)
CSA joins key stakeholders on several working groups aimed at improving services and resources for deafblind children and those who support them. It does this by raising issues relevant to deafblind children, identifying and exploring ways to address key gaps in research, and improving and increasing training for professionals in the field.

Working Groups: DB Childrens; DB Centre of Excellence; DB Research; DB Training

Networks: UsherKids Australia, Victorian Deaf Education Institute, Parents of Deaf Children, NextSense, Children's Tumour Foundation, Eyes and Independence Able Australia, Blind and Low Vision Education Network NZ, Education WA, Senses WA, Education Queensland, Aurora School, Schools SA, South Pacific Educators of Vision Impairment, Cortical Vision Impairment Australia

GUARD COLLABORATIVE AUSTRALIA

GUARD Collaborative Australia – Community Advisory Group
GUARD is a coalition of peak bodies - Genetic Support Network Victoria, Genetic Alliance Australia (NSW), Syndromes Without A Name (SWAN Australia) and Genetic and Rare Disease Network (WA). CSA joins the community advisory group (CAG) to represent the voice of people living with genetic, undiagnosed and rare disease which will in turn inform GUARD's important work in awareness raising and advocacy for this community.
Networks: Genetic Support Network of Victoria, Genetic Alliance NSW, Syndromes Without A Name (SWAN), Genetic and Rare Disease Network WA

PVI ALLIANCE AUSTRALIA

Paediatric Vision Impairment (PVI) Alliance Group ensures equality and equity in education, community participation, healthcare, future medical treatment and research for children diagnosed with vision impairment. Developing a *Profile of Need* tool for families listing therapists involved at different life stages of a child with vision impairment.

Networks: Cortical Vision Impairment Australia, Batten Disease Australia, Independent Pathways, UsherKids Australia, NextSense, Cataract Kids Australia University of Melbourne.

Advocacy – Research Opportunities

Education and Training

CSA continues to benefit greatly from the expertise of our Education and Training Director Dr Elizabeth Levesque. Liz is relentless in championing CHARGE syndrome through her work with teachers of the deaf and blind/low vision. She participates on key working groups in the deafblind field sharing her valuable expertise and experience with professionals working with our children. Through Liz’s connections, CSA has grown networks with researchers, allied health and mental health experts with an interest in multisensory impaired people.

Trial Clinical Service for People with CHARGE Syndrome

CSA collaborated with audiologist Donella Chisari to establish a CHARGE clinic similar to the vestibular clinic she operates at University of Melbourne. Donella plans to research vestibular issues with young adults with CHARGE syndrome and several members of our community volunteered to take part in the initial testing stage.

We are also liaising with the Head of Audiology and Speech Therapy department at University of Melbourne regarding training audiologists in specialised assessment and treatment techniques for children and adults with CHARGE syndrome.

CHARGE Syndrome Community Consultation – National Disability Register Agenda

CSA aims to get CHARGE Syndrome on the Australian disability research agenda. A call out to our community to participate in focus groups being run by Royal Children’s Hospital Melbourne to help shape the National Disability Register Agenda for the next 10 years resulted in a remarkable response from 10 of our families participating out of a total of 50 people all together. This fantastic contribution significantly raised the profile of CHARGE syndrome with researchers. Families generously shared their views on what is important in their life, how we can improve the lives of people with disability and what research is needed. The most important issues identified in the focus groups were:

- Disability attitudes, awareness and inclusion
- Disability representation – consult and engage those with lived experience
- Get the right services at the right time – access, coordination, integration
- Self-advocacy, choice and person-centred practices

A huge thank you to those families and individuals who participated. Your valuable time and lived experiences are very much appreciated.

Board Of Directors as at 20 December 2021

President - Madelene Rich

Madelene Rich has substantial not for profit knowledge and experience having held several Executive Assistant roles in this sector. She was CSAA Secretary from 2000-2008 and in 2018 led the Melbourne organising committee for the 13th Biennial CHARGE conference. She was elected President in 2018. Madelene's adult son Sean has CHARGE syndrome.

Vice President - Robert Last AM

Rob Last is a retired Teacher of the Deaf and Early Childhood Educator and worked with a number of children in the 1980s when CHARGE syndrome was relatively unknown. He was instrumental in establishing our group in 1988 and coordinated the first CHARGE syndrome conference in Australia. His expertise is in early communication and the importance of meaningful communication systems. In 2018, Rob received an Order of Australia Award for significant service to children who are deaf, deafblind, or have low vision, and their families, particularly those with CHARGE syndrome.

Secretary - Kath Green

Kath Green comes from various corporate roles within the finance sector and is keen to give back to the community through volunteering opportunities. She has an interest in the not for profit sector and is completing a Diploma in Business. In addition to the Secretary role, Kath provides project management support to special projects.

Treasurer – Mukesh Baluja

Mukesh Baluja comes from a corporate sector and is currently working as Commercial Manager. He has a proven track record of partnering with Board and Senior Management to deliver financial and business objectives and gains great satisfaction from establishing structured finance processes and systems that deliver clarity of data and enable non-finance leaders to understand and utilise financial information. He has been involved in voluntary services with other not for profit organisations for over 25 years alongside his usual day jobs. Mukesh wishes to contribute to the welfare of community and will assist in strengthening CHARGE Syndrome Association of Australasia's financial processes and systems. Mukesh became a board member in 2021.

Director NZ - Annette Stocker (Installed November 2019)

Annette rejoined the board in 2019 as she found she had more time to dedicate to supporting the aims of the Board and our New Zealand families. Annette comes from a corporate background and brings her professional expertise and acumen to this role and is strongly committed to connecting families and raising awareness of CHARGE syndrome throughout New Zealand. Annette Stocker resides on the South Island of New Zealand with her husband Tony and two children. Her daughter Aimee has CHARGE syndrome.

Director - Dr Elizabeth Levesque

Elizabeth Levesque is General Manager of the Victorian Deaf Education Institute. She has taught in the deaf, deafblind and multi-sensory impairment fields for several decades. Liz has a strong interest in communication and language development of children with CHARGE syndrome and is a passionate supporter of self-advocacy for children with CHARGE syndrome and other complex conditions.

Director – Louisa Cameron
Louisa Cameron is a human-centred designer, with a marketing degree and masters in human-computer interaction. She designs digital interfaces in the health industry. Her daughter Lillian has CHARGE syndrome and Louisa is passionate about making digital health services easier for everyone to use.

Director - Emily McDonald (Resigned January 2021)
Emily will represent the needs of our community in WA and NT (and currently SA). She is an Occupational Therapist and Deafblind Consultant at Senses Australia. Currently, Emily is completing the Master of Disability Studies (Sensory Disability) at Macquarie University/RIDBC. Emily works with individuals with deafblindness across the lifespan, and is passionate about supporting individuals with deafblindness, including CHARGE syndrome, to live full, happy, independent lives.

CHARGE Champions
Kelsey Dalton (NZ)
Ellen Howe (NSW)
Kylie Moore (Tas)
Belinda Arnell (Vic)

CHARGE Assist
Rob Last (Vic)
Elizabeth Levesque (Vic)
Melissa Evans (WA)
Kerrie Weaver (QLD)
All board members

Supporters
Phil Jones (FCA), Auditor, CABEL Partners, North Sydney NSW 2060
Phil Herborn and Louisa Cameron, Made Simpler, Sydney, NSW.
Michael Paphazy
Marea Howe