

voice



WDSC 2024
BRISBANE, AUSTRALIA

**Celebrating World Down
Syndrome Congress 2024**



Down Syndrome
Australia

November 2024



WDSC 2024
BRISBANE, AUSTRALIA







Down Syndrome
Australia



Supporting positive change for our community

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Editorial



Hello everyone,

In July this year, nearly 1,000 people from over 45 countries came together for the World Down Syndrome Congress in Brisbane.

It was an unforgettable week of learning, connecting, celebrating and driving positive change for our community.

I was inspired by the heartfelt stories of people overcoming adversities to find meaning in their work, relationships and daily activities.

There were dance and musical performances, art exhibitions and film screenings. We heard from leading medical researchers and politicians, and enjoyed social activities, including a glittering Gala dinner on the final night.

This issue of *Voice* celebrates just some of the incredible events, people and stories that shone over those few days.

I hope it gives those who weren't there a taste of what Congress was all about, and those who were, some fond reminders.

Enjoy,
Nathan

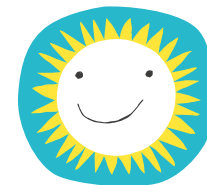


f I've loved Congress. Seeing all different people. Feeling that I'm not alone. **f**

Cameron Gibson, Scotland.

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Message from the CEO



Welcome to this special edition of *Voice*, celebrating World Down Syndrome Congress 2024!

In early July, nearly 1,000 people gathered to learn, connect and honour the

incredible achievements and contributions of people with Down syndrome from around the globe.

The World Down Syndrome Congress is more than just an event; it is a global movement that champions the rights and potential of individuals with Down syndrome. Families, advocates, researchers and professionals came together, united by a shared mission to enhance the lives of people with Down syndrome.

Down Syndrome Australia and its member organisations were delighted to proudly host this landmark event in Australia for the first time in over 20 years.

The theme, “Together We Can: Celebrating Diversity and Inclusion,” resonated right through the Congress, reflecting our collective vision to ensure that people with Down syndrome are seen, heard and respected in every corner of society.

Throughout the Congress, attendees were treated to inspiring keynote speeches, dynamic workshops, and thought-provoking panel discussions. These sessions offered deeper insights into the talents, perspectives and contributions of those with Down syndrome, who were at the heart of the Congress. They were not just participants, they were presenters, performers, advocates and leaders, proudly showcasing their abilities.

In this edition of *Voice*, we’re excited to highlight the key moments of Congress—from the lively pre-Congress social event (where, believe it or not, I found myself in a wig and sunglasses!) to the Self-Advocates Day, the three-day Congress program, and the vibrant social events.

We also spotlight the inspiring personal stories of resilience, creativity and success that remind us of the limitless potential within the Down syndrome community. From heartwarming stories of individuals overcoming challenges to achieve their dreams, to stories of communities rallying together, each narrative is a testament to the strength, determination and joy that define this incredible community.

Of course, an event of this magnitude is no small feat. My heartfelt thanks go to the DSA staff, Board, Member organisations, Volunteers, Patrons, and the Organising Committee, whose tireless efforts brought the Congress to life. Their dedication and hard work helped make this Congress a resounding success.

For those who joined us at the Congress, thank you for making it an event to remember. And for those who couldn’t be there, I hope this edition of *Voice* brings the spirit and excitement of the Congress to you, sparking the same joy and inspiration we all felt.

Enjoy!

Darryl Steff
CEO DSA



DSAN update



Hi, my name's Michael Cox, and I'm based in Brisbane. I've been part of Down Syndrome Queensland (DSQ) for over 10 years. In this time, I was part of the DSQ Advisory

Network where I worked up to being chair. This then led me to become part of the Down Syndrome Advisory Network (DSAN).

All my hard work with DSQ and DSA led me to be able to attend COSP (the Conference of the States Parties to the United Nations Convention on the Rights of Persons with Disabilities) in June in New York city. I was the only Australian representative with a disability who had the chance to give a speech about employment.

I was also a panellist in a discussion, and I talked about how it's important for people with disabilities to be treated with respect, love and kindness in all workspaces. I advocated for everyone to have meaningful work. Employment is important to me for many reasons—from being independent to knowing who you are and having a sense of purpose.

It felt amazing to be onstage having these conversations with other delegates from around the world.

To be honest, I didn't like New York City very much—way too overcrowded, noisy, stinks! It was good to come back to Brisbane, but the experience of COSP was unforgettable and I was happy to be representing Australia and the DSAN and my community

Over this period at DSAN we have been having our monthly meetings, and obviously Congress was a

big part of our discussions. We've also been talking about how we can help create a more diverse and inclusive society.

We want to see society be more accepting of people with Down syndrome and understand that we have important things to contribute. It's also up to people with Down syndrome to take responsibility for what we do and say, and not be lazy or disrespectful.

Most members of DSAN were at Congress. I personally had three main things on. I talked about the Gen Z Project, which I'm doing with the University of Queensland. It's research about the Gen Z demographic of people with disabilities—learning what they want to do with their life and what is important to them. I also did a presentation with Gemma Clarke about healthy relationships. And the third talk I did was about the New York trip.

There were heaps of people from DSAN doing multiple presentations and workshops. The DSAN was involved in the pre-Congress Meet and Greet, where it was great to get to know other people from different countries.

I enjoyed being out and about at Congress, doing the talks, and advocating for people with disabilities.

I also enjoyed being part of the planning. I was part of the sponsorship committee and personally reached out to Bill Shorten and Amanda Rishworth to be involved. They both gave donations, and Amanda Rishworth attended and spoke at Congress because of my email!

That's it from the DSAN. For the rest of the year, we plan to sharpen our agenda items, do more advocacy, and get ready to have a big impact in 2025.

Michael Cox
Brisbane DSAN member

Congress highlights – easy read



Down Syndrome Australia was excited to host the World Down Syndrome Congress 2024.

The Congress was in Brisbane from July 9-12.



Nearly 1,000 people came from over 45 countries.

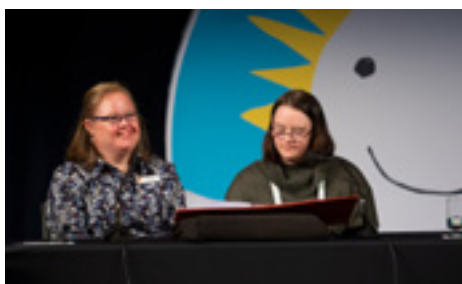
We had a week of presentations, social activities and performances.



Over 120 people with Down syndrome also went to the Self-Advocates Day.



Congress began with an opening ceremony. There was a Welcome to Country, a flag ceremony, and speeches.



The co-chairs of the ceremony were Claire Mitchell and Ruth Faragher. They did a great job!



At Congress, over 200 speakers spoke about:

- health
- education
- family life
- learning new skills
- speaking up for yourself.

It was great to hear the personal stories of people with Down syndrome.



There were also:

- dance and music performances
- film screenings
- art and poster displays.



On the last day, there was a closing ceremony. We heard that the next World Down Syndrome Congress will be in Buenos Aires, Argentina in 2027.



The best part of Congress was meeting friends from around the world.

Congress highlights



Left: The passing of the World Down Syndrome Congress banner to Australia. **Right:** Pulling out the moves at the opening ceremony.



Left: Brazilian-Australian mums embracing their South American culture with Bolivian-born photographer Carlos Biggemann. **Right:** The Honourable Amanda Rishworth, Federal Minister for Social Services, gives a powerful address.



Left: Down Syndrome Australia board director and Congress organising committee member Claire Mitchell with Congress patron the Honourable Dame Quentin Bryce AD CVO. **Right:** Congress co-chairs, Angus Graham, OAM and Rhonda Faragher, AO



Left: A group shot of the DSA health advocates. **Right:** One of the film and interviewing crews proud of their work.



Left: The crowd getting up for a boogie at the Congress closing ceremony. **Right:** The dance floor at the Congress closing dinner



Left: Sherry Hogan Foundation scholars with their leadership certificates. **Right:** Fun and laughs at the Congress closing dinner.

Congress highlights

Cameron Gibson and Kirsty Lockhart came all the way from Scotland to be at Congress. They are part of Down Syndrome Scotland, and run a popular program called TeenZ Space, which runs regular social activities for teenagers with Down syndrome. We caught up with them for a quick chat.

Tell us who you are and where you're from.

"Hi I'm Cameron. I'm from Monifieth, Scotland."

"And I'm Kirsty, I'm from Dundee."

What is TeenZ Space all about?

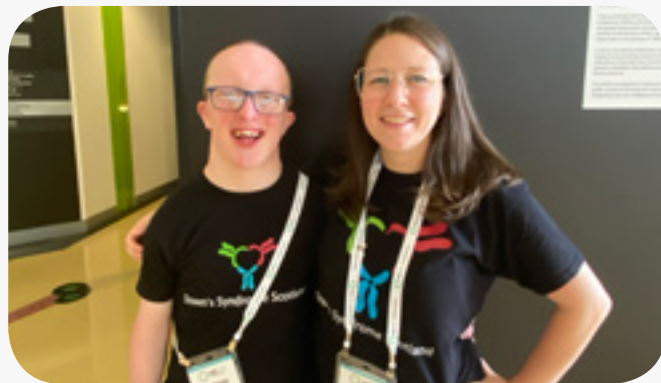
Cameron: It's a place to have fun and we do lots of talking.

Kirsty: We do a lot of talking at TeenZ space. And no topic is off limits. We really prioritise having fun, but at the same time we do talk about some heavy stuff.

The emphasis is on being social, making connections. We do a mix of in-person and online get-togethers. We don't talk about mental health that much but everything we do and talk about contributes to good mental health. So we talk about our feelings, and it's a very safe space.

We heard that you make a Zine?

Kirsty: Yes! People who are part of TeenZ Space send in photos, "I went to this event, I went on holiday and saw this." It's low-fi, black and white, done on the home computer, but full of all the fun things people are doing.



Sounds like a great community, what was one of your recent events?

Cameron: We had a karaoke disco night at a pub in Stirling, it was packed. I sang, so did my dad. My dad used to be in a band, toured all over the States."

Incredible! And how is your experience of Congress going?

Cameron: I love it. Seeing all different people. Feeling that I'm not alone.

Kirsty: It's been completely out of this world. I really can't believe that Cameron and I are here. It's been so inspiring seeing all these people with Down syndrome being so authentically themselves, and so confident. This morning we were really moved watching David the singer. We were really rocking out to that. I got the impression Cameron that you were getting inspired, hatching some songs in your head.

Cameron: Yeah!

Alexandre Ott from Switzerland chaired the Wednesday morning session on Advocacy and Social Inclusion. He told us how it went:

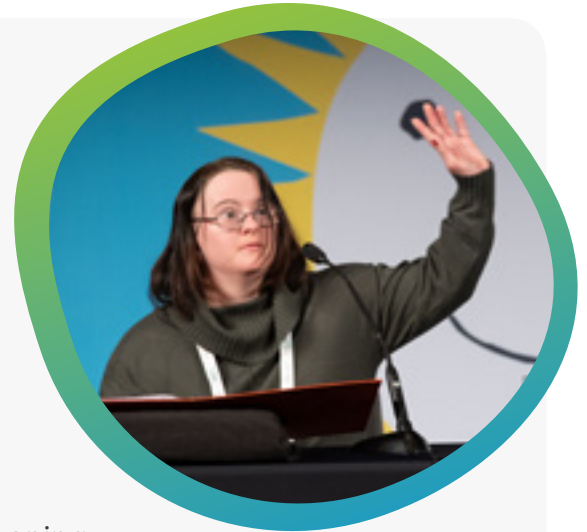
ff Today went really good. I introduced the speakers. I wasn't nervous. I practiced two times. I did a little bit of speaking at the UN for World Down Syndrome Day this year because I live near Geneva. I spoke in English and French. My mum taught me English! **ff**





Ruth Faragher was one of the Congress co-chairs for the opening and closing ceremony. We caught her the day before the official Congress launch to ask how she was feeling. Here's what she told us.

Everyone is arriving now and I've just been learning about filming and interview, which was interesting. I like to learn something new every day. I'm chairing the opening event of Congress with Claire Mitchell, and we're also doing the closing of Congress. We have a script. We will be welcoming everyone, acknowledging Country and telling people what's happening. I'm feeling like I just want to enjoy it. I'm not a really excitable person. I just do it.



Braydon Lack was part of the poster event at Congress, where people exhibited information and stories on big, illustrated posters. Attending from the rural town of Clifton in Queensland, Braydon's poster was titled "Farmer Wants a Life". Here's what he had to say about it:



It starts with me on the farm, doing farm work. I didn't have many friends. We farm beef and grains. And then I got involved in the NDIS, and that's where I got more connections and social outings, so I'm not lonely anymore. Now I've got a life. The NDIS helped me a lot. We have lots of social activities: basketball and touch football. I graduated in a two-year program on learning and technology, run by Down Syndrome Queensland. So I do all these things now. I'm still on the farm, but now I have lots more other things to do. That's my favourite thing to do on the farm, harvesting. Also I go on holidays, I went to Tasmania.

I was expecting Congress to be inspiring and interesting, but I underestimated it, just the global context on this whole thing is really amazing. In fact, what's really grabbed me, and I've welled up a lot, is the self-advocacy. I didn't realise how many people with Down syndrome were here to share their successful stories, or just to share something, with one another, it's been incredible to witness.

Karlee Rawkins

Joseph Blake is from Hamilton, New Zealand, and he presented on the new S18 swim classification in Australia and NZ for athletes who have Down syndrome or an intellectual and physical disability. We caught up with Joseph for a quick chat after his presentation.

I heard in the talk that you qualified to swim for New Zealand at the Virtus Global Games in France last year?

Yes, Virtus is an international competition for elite athletes with an intellectual impairment. It has a classification called I12 for athletes with an intellectual and physical disability. I got to swim and compete for medals against other athletes with Down syndrome.

How did that make you feel?

It made me feel really included, to swim with people with the same passion as me at a competitive level.

How long have you been swimming for?

Since I was six. Ever since then I've loved it, and I still love it today.

You also talked about the new S18 classification for swimming in Australia and New Zealand. What does that mean for you?

It means greater inclusion. It means we are competing with everyone who have the same interests and passions for water sports. The S18 is



the same as I12 classification, so it means people with intellectual and physical disability can swim at that competitive level.

How did you feel presenting today? Were you nervous or calm?

It was a mix of both. I was trying to just relax and enjoy what I was doing at the time. It was my first time public speaking, and I intend on doing more. I would like to be a voice of change, and to inspire others to share what is important to you.

How is your experience of Congress?

Being here is so important, it feels really amazing to know you are not alone, you can get support wherever you are.



Speaking out

Leigh Creighton is a Newcastle-based disability and human rights advocate, passionate about sharing his experience as a person with Down syndrome. He regularly speaks at events and on panels across Australia. We sat down with him at Congress to hear about his motivational speaking.



When did you first learn about standing up for your rights and speaking up?

I started in a program and found my own voice and learned to get on stage and speak. I became a peer mentor and motivational speaker, advocating for people with Down syndrome and mental health advocate.

What is a peer mentor?

As a peer mentor, I teach people from other organisations to learn to speak up for themselves. It makes me feel great helping other people to be their own self-advocates.

What tips would you give to people who are keen to become an advocate?

First and foremost, you've got to find your own voice. Speak naturally. Speak compassionately and help others along the way to promote their own voice. I've started a self-advocacy group down where I live and it's really important for those people to have family and other support people to help them speak up.

What do you hope to do in the future?

I want to become an author and write my own book. I want to work towards the United Nations speak. I always wanted to go around the world doing TEDx talks. I want to be a well-known Down syndrome advocate. I want to advocate around the world. It's very important to make my nieces and nephews very proud of me.

What do you want people to know about people with Down syndrome?

Don't ever put people down. That's something I don't like. Don't ever put people down. Always lift them up.

What do you wish people knew about people with Down syndrome?

They bring the gift of love. They bring their own self. I wish that one day, people with Down syndrome can rule the world.

What are some misconceptions about people with Down syndrome?

That they're always happy. But on some days, they're not happy. Sometimes it comes from mental health, comes from depression, anxiety. I just want people to be able to do things freely, to make their lives better.

What negative experiences have you had as a person with Down syndrome?

When I'm out in the community, I get called a lot of bad language—retarded and spastic. Bullying. It makes me really upset. It makes me vulnerable to see people go through that.

What changes would you like to see to improve life for people with Down syndrome?

We should be treated like human beings, like everyone else in this world.

WDSC self advocacy forum wrap-up

Down Syndrome Australia's Senior Advocate Rachel Spencer shares some of the key takeaways from the pre-Congress Self Advocacy Forum which took place on July 9 2024.

The World Down Syndrome Congress Self Advocacy Forum attracted over 150 adults with Down syndrome from around the world.

Countries represented included the UK, Europe, USA, Canada, Germany and Indonesia, but by far the largest contingent was the Australians!

Our Sherry Hogan Foundation scholarship awardees attended and contributed to the conversation. Their leadership skills were on show with four of the five giving individual presentations during the day.

As the Congress Over 18 Sub Committee Co-chairs, Ruth Faragher and I gave an introduction and acknowledged traditional owners, self-advocates and family advocates who have paved the way for our rights and inclusion, along with the Sherry Hogan Foundation for their support.

The scene was then set by Roy McConkey and Pat Clarke, talking about rights, the Convention on the Rights of Persons with Disabilities, and the history of this pre-Congress event. It was noted this is the biggest event of its kind to date.

We broke into small groups and had discussions led or supported by table hosts – mainly DSA and our State and Territory staff members and some volunteers. We discussed:

- Good things in our lives
- Things that could be better

Each group shared some of their key points, and the facilitators explained how both the good things and things that could be better in our lives are our human rights.

After a social lunch, Robin Gibson and Nathan Rowe from DSA led an open mic session. Everyone had a chance to introduce themselves and share something about their life or something they hope to get out of Congress. It was a big hit!

During this time, subcommittee members collated key issues and ideas the groups had spoken about. Some regular themes and emerging issues were evident, including:

- Friendships – meeting new people
- Making my own decisions
- Speaking up and self-advocacy opportunities
- Being safe and no bullying
- Independence – moving out and having my own home
- Parents and families – being listened to
- Intimate relationships – boyfriends, girlfriends and getting married
- Respect – increasing awareness and decreasing discrimination
- Mental health – feeling good about yourself and less depression
- Employment – getting a job, being paid fairly and having good support in the workplace
- Support – better government support and better support workers.





After landing on these key areas, people were then asked to vote on their top three, using an inclusive method that saw everyone get involved. Nothing like arming people with three green stickers to have their say!

While all issues and ideas raised are important, the standout areas were:

- Relationships; friendships and intimate relationships, including same-sex or gay relationships
- Independence; having my own home, independence from family and making my own decisions
- Mental health and its importance for overall health
- Speaking up, self-advocacy and leadership
- The importance of world issues including the environment

So many people reflected on what a great opportunity it was to share, listen, and learn.

The pre-Congress Meet and Greet, held the day before, also sponsored by Sherry Hogan Foundation, had provided the opportunity for attendees to meet new people and catch up with old friends. It also allowed people the chance to enjoy some fun activities, including some singing and dancing!

These two events were a highlight for many people with Down syndrome at Congress. We highly recommend future Congresses and other DSA- or DSI-led events to consider running similar programs, no matter how big or small.

Thanks again for the support of the Sherry Hogan Foundation and the involvement and enthusiasm of all our self-advocates – current, new and emerging. We look forward to people with Down syndrome continuing to learn about and claiming their human rights.

Self advocacy forum – easy read



We had a World Down Syndrome Congress Self Advocacy Forum on July 9 2024.



150 adults with Down syndrome joined from countries around the world.



The Sherry Hogan Foundation scholars gave presentations during the day.



In the morning, small groups got together to talk about:

- good things in their lives
- things that could be better.



After lunch there was an open mic session.

This is a time where everyone gets a chance to introduce themselves.



People also had a say about the issues that are most important to them.



The most important areas were:

- Relationships: friendships and close relationships, including same-sex or gay relationships
- Independence: having my own home, independence from family and making my own decisions
- Mental health
- Speaking up, being a leader
- World issues and the environment



We look forward to people with Down syndrome continuing to learn about their human rights.



Adventures in advocacy, with my heart leading the way

During Congress, we sat down with a number of extraordinary humans to hear their stories and ask questions about their advocacy. Charlotte Woodward was one such guest. She is an American sociologist who presented at Congress on her experiences undergoing heart surgery and advocating to prevent transplant discrimination for people with disabilities. Here is some of what Charlotte shared with us.

All of us in all our wonderful diversity can make the world a better place—not just for those of us with Down syndrome, but for everyone.

I like to think that it's my heart that has helped lead me through life, with a desire to promote inclusion, acceptance and advancement for people with Down syndrome.

Although we may live many, many miles apart, in many different parts of the world, there are things we all share and have in common. We all have hopes and dreams and desires. We all want to feel we belong, and we all want to be included.

When I was born and they told my mum that I had Down syndrome, she did not know what that meant. She had never encountered anyone with Down

syndrome before. Today, there is much more inclusion, but still not nearly enough. Many people have never met or interacted with a person with Down syndrome, so stereotypes persist.

I consider my mission to dispel those stereotypes and to invite others to meet and include people with Down syndrome and other disabilities in all walks of life. We should all try within our hearts to see the essential humanity and inherent value and worth of others. If together we do that, the world will be a better place for all of us.

Within minutes of my birth, doctors told my mum I would likely never learn to read or write and that when I was older I would probably end up working in a sheltered workshop. If only those doctors could see me today! Thankfully, my mum did not take the doctor's words to heart. She became determined to do her very, very best to help me learn as much as I could, which has resulted in me becoming a lifelong learner.

I learned to read and write at a very young age. I might add, in fact, reading and learning are my very favourite things to do. I hope to have some of my original stories published one day. In the meantime, I am the first person with Down syndrome in the United States to have an article published in a medical journal. I have also co-authored several other articles in medical journals. I have written other articles about Down syndrome and disability that have been published as well.

I have been a successful student in preschool, elementary school and middle school, and have been included in general education all those years.

After graduating high school, I became involved in my local Down syndrome advocacy group and later joined its board of directors. Through this group I met



members of the National Down Syndrome Society (NDSS) and was encouraged to apply for a job there. I was initially hired as the community outreach associate and worked with another amazing colleague who are here at Congress. For the past two years I have worked as an education programme associate.

I love my career with NDSS. I just learned that when I return from Australia, I'll transition to the position of programme associate. It means I will become even more involved in policy and advocacy, health and wellness, community engagement and employment-related issues.

At university I pursued a degree in sociology, which is the study of social life. I believe that majoring in sociology would help me to work towards structural and systemic change, including the passing of

FF I consider my mission to dispel those stereotypes and to invite others to meet and include people with Down syndrome and other disabilities in all walks of life. We should all try within our hearts to see the essential humanity and inherent value and worth of others. If together we do that, the world will be a better place for all of us. **FF**



legislation that will benefit those with Down syndrome. I had to write a research proposal for a potential research study. It was titled *In Their Own Words*, and explored identity in a Down Syndrome community.

I was born with a significant heart condition which would require surgery to correct. Had I been born prior to the late 1980s, doctors may have refused to provide lifesaving surgery due to my Down syndrome diagnosis, which was sadly common in the United States. I am very thankful that medical care was an opportunity. I ended up needing four open heart surgeries: three as a baby and one when I was 10.

As I grew, my heart struggled to support my body. As the struggle worsened, my cardiologist determined that I needed a heart transplant and if I didn't, I would die. Fortunately, my transplant team considered me a candidate for this lifesaving procedure and on

January 30th, 2000, I was given a very, very healthy new heart. I'm so very, very grateful for the generosity of my heart donor and her family, and for the willingness of my medical team to give this lifesaving gift.

“Too often people with disabilities are denied lifesaving transplants because of institutional bias and prejudice in the medical field against people with intellectual and developmental disabilities.”

As I learned more about this issue, I began to work hard towards ensuring that right for everyone with Down syndrome and other intellectual and developmental disabilities. The result is a federal bill called The Charlotte Woodward Organ Transplant Discrimination Prevention Act, which “expressly prohibits healthcare providers and other entities involved in matching donated organs with recipients from denying or restricting an individual’s access to organ transplants solely on the basis of the individual’s disability, except in limited circumstances.”

The congressional committee has voted in favour of this bill, and the next step will hopefully be approval by the House of Representatives before being sent to the Senate and signed into law.

Those of us who are born with Down syndrome want to have the chance to become involved, caring and contributing members of society. Our family, friends and allies already know the enormous positive impact we make on the world. We urge the world to accept us for who we are and to welcome the many contributions we make.

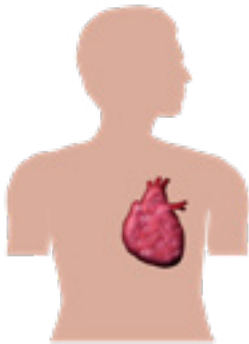
I'm still very grateful for the passion within my heart that has led me to a life of advocacy and adventure. I'd like to encourage all of you to act fiercely. People with disabilities, including those who Down syndrome, have the right to be proud of who they are, to be treated with dignity and respect, to participate in and to enjoy all that life has to offer and to be included just like anybody else.

Adventures in advocacy – easy read



Charlotte Woodward from the United States spoke at Congress.

She talked about having a lifesaving heart transplant.



Sometimes people with disabilities miss out on lifesaving transplants.



Charlotte has a university degree in sociology.

She is the first person with Down syndrome in the United States to write an article in a medical journal.



There are now laws in the United States named after Charlotte.

The laws help to make sure everyone can get an organ transplant.



Learning to interview

Andrew Denton was part of the Film Group at Congress, which involved asking people questions and recording them. We asked Andrew about his experience.

Voice: What has your experience of Congress been like so far?

Andrew Denton: Lots of learning about Down syndrome. People are sharing their stories and experiences. It can be heart-warming and emotional.

Voice: And you've been doing quite a bit of interviewing. You joined the film crew and did some training to begin with. What did that involve?

Andrew: I did training with Dean and Alyssa in June. We learned how to do it with our phone, very simple and easy. They were experts. We did more training when we got to Congress. And we've been grabbing people here and asking them their story, about their life and job, and recording them.

Voice: What questions do you like to ask?

Andrew: A bit of a mix of serious and funny.

Voice: What do you enjoy about interviewing?

Andrew: I've been watching a lot of people on TV and I thought I want to get into the interviewing and maybe make it into a real job. I like hearing people's stories. They have a recording studio here and they interviewed me.

Voice: So you've been behind the camera asking the questions and in front of the camera answering the questions!

Andrew: Both, yeah!

Voice: It sounds like you've found something in interviewing that you'd like to do after Congress?

Andrew: Yes, really enjoy it and want to keep doing it.



Andrew's interview with Roy McConkey, Emeritus Professor of Developmental Disabilities at Ulster University, Northern Ireland.

Andrew Denton: Hi my name is Andrew Denton, and I'm from Perth, Western Australia. I have a guy from the United Kingdom, from Northern Ireland, it's Roy McConkey.

Roy McConkey: Hi Andrew, nice to be with you.

Andrew: My question to you is, how many people have Down syndrome in your country?

Roy: It's a similar proportion to the numbers in Australia. We reckon that every 1 in 6 people who have got the label "developmental disability or intellectual disability" have Down syndrome. So, if you like, there are probably 1500 people with Down syndrome in Ireland, because we have about 8000 people we know of with development or intellectual. That's counting babies right up to some very old people.

Andrew: Alright, that's pretty good. So the biggest question is how will you stop the bullying? How will you stop people bullying people with Down syndrome?

Roy: It's a difficult question Andrew, as you well know. Everybody with Down syndrome or some sort of intellectual disability, at some point in their life, gets bullied. In fact, you could say anybody growing up gets a bit of bullying. I remember getting bullied a bit, not physically, but I wouldn't get picked for the



teams. Nobody wanted me to join. That was a bit of emotional bullying. To say "Oh well, that doesn't matter, I'll walk away from those people because they're not being kind to me" is hard to do if you're seeing those people every day, but it does make you a bit stronger, and then you can start saying to them, "How would you feel if I called you those names?".

Andrew: That's true.

Roy: Once you get more confidence in yourself, you realise words can't really hurt you, and you might be able to face them right on. If you need help, talk to an adult, parents, teachers, anyone who looks after you. Sometimes people are afraid to admit that they're getting bullied because they sometimes blame themselves for it, but that's wrong. They haven't done anything, it's the other people who need to change, and their attitude needs to be different.

Andrew: Very true. That's it! Good, thank you!





Teaching Raji

Raji Renshaw is a 15-year-old actor, dancer and model with Down syndrome. He presented at Congress on the films he's made, and his love of performance. Raji's teacher and mentor, Odette, also presented, and shared her experiences of educating Raji at a small-town Steiner school in the Northern Rivers of NSW. Here is some of what Odette had to say in her presentation, as well as a small Q & A we did after with Odette, Raji and Raji's mum Karlee.

Odette:

I feel very fortunate to have met Raji when he was four years old, when his mum Karlee was looking for an education pathway for him that was inclusive and supportive. We embarked on a journey together through the Steiner school in the small regional town where we lived, and I became passionate about making his learning experience as accessible and inclusive as possible.

The school curriculum matched Raji's interests: lots of music, art, craft, performance, dance, sport, public speaking, and lots of camps and excursions. All classes were inclusive with Raji, and I would break down the lessons for him as necessary— scaffolding, modifying and differentiating the curriculum to suit Raji and his learning pace. This was something I found came very naturally, and a true calling.

I also worked one-on-one with Raji so that literacy and numeracy were highlighted in each learning capacity.

Raji is naturally very musical, and it took some time to find the right music teacher to fit the role. Class plays were where he shone, and now being on stage is becoming a career for him that he has always dreamt of. This is something I encouraged in Raji from the beginning of his learning journey, and when Raj refused his lessons or to learn scripts, I promptly reminded him of his dreams.

Raji became well-liked in our school community. His class peers were very supportive, and we each felt lucky to grow and learn with him.

School camps were Raji's highlight, from mountain hikes and beautiful beaches to snow fields and even remote islands, he loved it all. These required lots of preparing and planning to ensure Raji was fully included and supported.

When Covid lockdowns came into our world, we had to again become brave and rewrite a learning program. Whole class Zoom lessons didn't suit Ra, so I quickly set up our own learning space via 1:1 Facetime lessons, and we discovered this worked really well for him.

It has been so effective that when I had to move interstate, we continued our regular online tutoring lessons, and to this day, Raji is thriving. He is a word wizard and a unicorn number cruncher, and we study all kinds of topics, interests and learning subjects.

We sat down with Raji, Odette and Karlee after the presentation.

Voice: Thanks Odette for the incredible presentation. Why did you feel this was something people needed to hear at Congress?

Odette: It's such an important story to share. Raji's education didn't come without its obstacles, but we dug in our heels, and had very loud voices, and demanded changes so that Raji could enjoy the education that he and everyone with a disability deserves. We just made it happen, and others can too.

Voice: Raji, what was it like to hear your teacher and mentor share her experiences of your learning journey?

Raji: I like it a lot. It was very special. I love Odette.

Voice: You seem to have built an incredible relationship?

Odette: I love Raji. He really does feel like family to me, and that will be forever—right throughout our lives.

Voice: What was it like for you Karlee as Raji's mum, watching him receive this wonderful learning experience from Odette?

Karlee: I've been incredibly grateful for Odette, because it took a lot of effort, passion and extra hours to make sure Raji was educated, otherwise he would have slipped through the system. This was a tiny regional town, and they've never had a child with Down syndrome. It was such a new experience for so many teachers there, they didn't know what to do and

What a journey it has been, with its ups and downs, obstacles and breakthroughs, tears and laughs, frustrations and pure delights. Raji has had an amazing school life so far, and I have found my true educating career.

As Raji goes on to attend his high school years, he will have a little team—that's us—advocating and consulting so his new educators can give him the best of his high school years that he deserves. We have learned not to ever give up, to be the strongest advocates, and to demand that everyone deserves and is capable of an education with a positive experience. We feel very proud of each other.

didn't bother. It was Odette who single-handedly took it on and made sure he could read and write and is still tutoring him. I'm just so incredible grateful for this gift that she's given Raji. She's our angel.

Voice: What advice do you have for parents of children with Down syndrome when it comes to getting their child the education they deserve?

Odette: If you find someone who is the right fit, do everything you can to keep them. A lot of schools and OTs suggest that teacher aids should rotate, although that's changing now. They used to think having the same aid fostered too much dependency on that person. Working in a Steiner school where it's encouraged to have the same teacher right the way through, that helped.

Also, no one wanted to put their hand up, but I was there for the ride. And I think it's benefitted both of us in many unexpected ways.









A new mum's experience of congress

We hear from Jess from the Gold Coast about attending Congress with her one-year-old son, Ollie, who has Down syndrome.

Ollie is our first child, and Ollie and I have been here at Congress the whole time.

We've made lots of friends. Ollie makes friends everywhere he goes. I feel like it's been beneficial for a lot of the young adults here to meet Ollie as well. They've been so drawn to him.

I've learned a lot; there's been lots of informative speakers.

It's also really nice to see how so many people with Down syndrome are fitting into society—with their work, their social connections, living independently. It's great to see the possibilities there are for Ollie.

I feel the world is more inclusive now compared to when I was a child. I had a friend at school who had Down syndrome, and I remember then the classes were segregated, so I had a friend one year, and then the next year I didn't. I'm glad that's changed.



It's been nice speaking with a lot of the mums who have walked my journey already. Now that I've connected with them, if I have questions down the track about schooling or raising a child, I've got them to bounce things off as well.



Being a photographer

Carlos Biggemann is a New Zealand-based photographer with a passion for capturing landscapes. He chaired two sessions at Congress, exhibited his photos, and spoke on the topic "How does it feel being a photographer?" Carlos spoke with us about his background and photography.



I'm half-German from both my parents and was born in the heart of Bolivia in a city called La Paz. When I was ten years of age, I moved with my family to Sydney, Australia and lived there for nearly four years.

My dad was offered a job which took us to the region of Otago in New Zealand. I have lived in Otago for 18 years now, half of my life, so it is my home.

Photography is a career that I am so passionate about. I have been taking photographs for ten years. I have a certificate in digital photography.

I love to take landscapes, but also many other kinds of photos, from the delicacy of foods, the adrenaline of sports, the forms of buildings, the eyes of people because through the eyes we see the souls.

I would like to work as a freelance photographer one day. I think with perseverance and love, one of my dreams can possibly come true.

I am here at Congress with my camera, and I just follow it. So I have volunteered to take photos and I am enjoying capturing all the presentations.

This is my second Congress; my first was in Glasgow in 2018. I am enjoying this one very much and meeting lots of people. A group of Brazilian mums just came up to me because I was speaking Portuguese, and it was wow, incredible. They were so surprised!

I speak Spanish, English and Portuguese. Half of my family lives in Brazil, that's why I speak Portuguese.

It is incredible to be here with more than 40 cultures from around the world in one room.

You can visit carlosbiggemannphotography.com to learn more about his work or follow [carlos.biggermann](https://www.instagram.com/carlos.biggermann) on Instagram.

A tribute to Sir Robert Martin

Cindy Johns from People First New Zealand presented a touching tribute to the self-advocacy pioneer, Sir Robert Martin. Here are some of the messages she shared.

I have known Sir Robert for about 35 years and have worked alongside him for the last 15 years in my role as National Manager of People First NZ. Sir Robert was one of the founding members of People First NZ and went on to become a Life member. For the last ten years, I also assisted him through his nomination and election to the United Nations Committee on the Rights of Persons with Disabilities (UNCRPD), and then led a small team of assistants as he undertook his role as a committee member.

I want to start by sharing a little about Robert's early years. This comes with a warning as some information may be difficult to read.

Robert's early years were hard. He was brain damaged at birth and from the age of 18 months, was sent to various institutions. He mainly lived in the Kimberly centre, which was a large institution for children and adults with learning disability. Recently, a Royal Commission enquiry into abuse in care has exposed New Zealanders to the horrors of Kimberley—horrors which Robert experienced.

As a child, he became a ward of the state and experienced foster care—another bad experience. He went to a school for boys in the South Island for a time and to another institution near his hometown of Lake Alice when he was a young teenager. Throughout this time, he returned to his family home, but never for long.

At age 15, Robert got out of the large institutions and moved into a 50-bed hostel for people with learning disability. Again, he experienced and witnessed violence and abuse, and it was here that he first started speaking up for rights. He saw things that he thought were wrong and spoke up about them.

Working on a farm run by the disability service, he saw a staff member being treated unfairly, and called a strike and encouraged other workers to down tools. They demanded to talk to the bosses to put things right, and it worked. Robert was fast becoming a leader, to whom others listened and followed.

The service saw Robert's potential and he became employed firstly as a support worker and then as a self-advocacy advisor.

During this time, he also took on roles with Inclusion International and started travelling the world talking to people about self-advocacy and other disability rights issues. In 2008, he retired from paid work and devoted himself to community.

He began campaigning for his role on the UN Committee in 2014, and learned how to promote himself, which was quite hard for him, but with a bit of coaching, he did it—mainly by being himself. He made people think, laugh and cry. And he made people vote for him.

“ He began campaigning for his role on the UN Committee in 2014, and learned how to promote himself, which was quite hard for him, but with a bit of coaching, he did it—mainly by being himself. He made people think, laugh and cry. And he made people vote for him. **”**





This all led to the historical moment where he got elected in June 2015—the first person in the world with a learning disability to be on the Committee on the Rights of Persons with Disabilities or any United Nations Treaty body. His election went global. His was a win not just for him but for people with learning disability around the globe.

Robert took his role as committee member very seriously. He prepared well, and he worked hard. He said yes to everything and didn't want to miss a thing. He saw the role as leading the way for others and often said, "I may be the first person with an intellectual disability on this committee, but I certainly do not want to be the last one."

In 2020, Robert was honoured with a knighthood by the New Zealand government. He was, as always, humble, and he was proud. It was an amazing moment when the Governor General took her sword and knighted him.

Robert left a huge legacy. He was brave, and spoke a lot about the harm of living in institutions, often sharing his personal story to make others think differently. He took every opportunity to promote Article 19 of the Disability Convention: living in the community with the rights, service and support of everyone else. He was very proud to say he lived with his wife in a house, on a street with a letterbox, like everyone else.

This quote by Robert sums it up.

“Persons with disabilities have the right to feel like they are part of their community and be seen, not segregated. That means participating in activities like art, culture, sports and relationships. Just like everybody else.”

Sir Robert Martin – easy read



One of the top presentations at Congress was about Sir Robert Martin.

He was a disability rights advocate who passed away earlier this year.



Sir Robert Martin was born in New Zealand with a brain injury.

He grew up in places that abused him or did not take care of him.



As he grew older, Sir Robert started to stand up for his and other people's rights. He became a leader who other people listened to.



He was the first person in the world with an intellectual disability to be on the United Nations Committee on the Rights of Persons with Disabilities.



In 2020, the New Zealand government made Sir Robert a knight.

He made an important difference and people all around the world will remember his work.

Taking the stage

Rachel Parker from Western Australia reflects on her experience of presenting at Congress and listening to others share their stories.

My name is Rachel and I'm from WA, near Perth.

WDSC was a great experience for me, I really enjoyed meeting people from lots of different countries and listening to their stories. Learning about Sir Robert from New Zealand was important.

It was fun to be with my friends from WA and we all enjoyed going to the Bus Stop films and the Congress Dinner.

I volunteered to be part of the film crew and that was really great—I've never done something like that before and I like trying new things.

On Friday I gave a presentation about my Journey of Learning. I talked about my life at school and what I do now. I have two jobs, one at a school and the other at a dental clinic. I work independently, with no support



and catch public transport to get there. I also spoke about my hobbies like swimming, going to the gym, knitting and competing in ballroom dancing.

My family were so proud of me for talking in front of other people and I am proud of myself too!

At the Congress I learned about what other people do in their life and heard about some things I might like to try, like supported holidays and living out of home. Some speakers were really good and I think I would like to improve my public speaking skills.



Making society more inclusive for disabled people



Alastair McEwin AM is a disability and human rights consultant, and the former Disability Discrimination Commissioner at the Australian Human

Rights Commission. He presented at Congress on making society more inclusive for people with disabilities, and was kind enough to share some of his key messages with *Voice*.

A bit about me

I was born profoundly deaf into a hearing family. I was taught in a mainstream school with teachers of the deaf supporting me. I was taught by speech pathologists how to speak like hearing people. I learnt sign language later in life.

I have worked in human and disability rights for nearly 30 years. I have worked in the non-profit, legal, government, corporate and professional services sectors.

And for those of you from South Australia, I am a fourth-generation Port Adelaide Football Club member.

My two recent roles

I have been Australia's Disability Discrimination Commissioner at the Australian Human Rights

Commission, and Royal Commissioner with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

I held those two roles for over seven years.

The Disability Discrimination Commissioner protects the rights of people with disability in Australia and promotes the United Nations Convention on the Rights of Persons with Disabilities.

A Royal Commission is an independent, formal public inquiry into a significant issue, including widespread social issues.

What I've been told by disabled people

In my roles, I have heard from many people with disabilities about their needs and desires. They have told me they want to:

- Go to school.
- Get a job.
- Live in a safe home.
- Get high quality health care.
- Get the train or bus or plane to places.
- Spend time with their family and friends.
- Go to the movies or theatre.
- Go to the pub.
- Go out and about in the community.
- Play sport.
- Travel.
- Sing and dance.

When I look at that list, I think – well, that's what everyone wants to do.



What needs to change to make society more inclusive of disabled people?



Four things:

- 1 Visibility
- 2 Disability Leadership
- 3 Attitudes
- 4 Phasing out segregated settings



Visibility

This means being visible and out in the community.

We heard a lot about the lack of visibility of disabled people in the Disability Royal Commission. And we heard a lot about the negative and devastating life-long consequences when disabled people are kept invisible from society.

Disability Leadership

Good leadership is demonstrated by those who are willing to challenge the status quo and see disabled people as part of the diversity of our community.

It is those leaders who will have an impact on attitudinal and cultural changes that we need to see for a more inclusive society. And when those leaders make room for disabled leaders we will see a more inclusive society.

Attitudes

As a Commissioner, I have learned that attitudes change when people with every kind and severity of disability are visible, present and meaningfully participating with non-disabled children and adults on a day-to-day basis, in every setting in the community, starting with the earliest years.

I have also learned that everyone relating together, disabled and non-disabled – as classmates, neighbours, co-workers, friends and acquaintances, can become a growing group of informal and effective watchdogs – calling out violence, abuse, neglect and exploitation.

Phasing out segregated settings

We know devaluation and 'othering' of disabled people lies behind a long history of segregation of those people in Australia.

The continued presence of segregated settings is a significant barrier to reform. We need to continue to phase these settings out across schooling, employment and other mainstream institutions.



Together we can: make disabled people visible, have disability leadership, change attitudes and phase out segregation.





Bridging the digital divide

Jess Wilson is the CEO of Good Things Australia, an organisation giving people the confidence and skills they need to use digital technology. They have been working with Down Syndrome Australia to create resources about online safety.

One in four Australians are considered “digitally excluded” and Good Things Australia works to help close that divide.

For the past two years, Good Things Australia has been working with Down Syndrome Australia to help people with intellectual disability be safe online.

In the next part of the project, the two organisations will recruit and run a group of “Digital Champions” with intellectual disability who will teach other people how to use their phones, email and the internet safely.

The CEO of Good Things Australia Jess Wilson was one of the speakers at Congress, and we spoke to her after her presentation.

We began by asking her what the “digital divide” is all about. She explained that it is “the difference between people who can use technology to participate in our world and those who can’t.” It can be caused by three things:

- 1 Not having access to a laptop or a phone because they live in a remote part of Australia and don’t have connectivity to get online.
- 2 The expense of purchasing a phone or computer and being connected to the internet.
- 3 Not having the ability, skills and confidence to navigate the online world safely.

As Jess says: “It’s really important to have all three of these things to be able to get online safely and confidently”.

Here are some other key messages that Jess shared:

It is essential that everyone can get online because so much of life happens there, such as: education, getting a job, telehealth, dating. “The ability to be able to connect online, in multiple ways is a real part of inclusion today in our society. That’s why we call it digital inclusion,” she says.

Parents are an important part of helping their children get online safely and should be part of their children’s online activities. “Make sure you’re participating and having conversations about these things,” says Jess. “I know kids really love playing computer games so one of the best ways is to actually play alongside your kids to understand what’s going on. If it’s a game that’s online, where there are people commenting or other people around, it’s important to know what’s going on.”

Know how to block and delete someone if something doesn’t feel right about that person.


Jess says: “When things feel a bit unsure, talk to somebody. And then work out how to delete and block”.

Set up an online dating profile with a parent or trusted supporter who knows you well.

This is a person who can help make sure the profile has the right things in it. They can also help check that a potential match is a good match. “On those dating sites, it’s important to be really careful about who you check and match with. A support person can help you see whether they are really the right kind of match for you. If you do find somebody online, make sure you take interactions really slow before connecting face to face”.

Learn more by undertaking the ‘Bridging the Digital Divide’ online course.

Down Syndrome Australia and Good Things Australia developed this course together. It is free and accessible here:

 <https://goodthingsaustralia.org/learn-resource/intro-to-online-safety-online-course/>

Jess says: “There are four modules: Introduction to online safety; Connecting safely with others; How to use email; and How to do video calls. We’ve also developed some conversation cards that will help people with Down syndrome and the people around them to have conversations about being online”.

Music, art and dance at congress

One of the highlights of Congress was the spectacular array of performances and art exhibitions. People with Down syndrome took to the stage to sing, dance, and even perform magic, while others showcased their painting and photography at the Congress marketplace and art exhibition.

Weng Jia Ying, dancer Singapore

Weng Jia Ying is part of the Diverse Abilities Dance Collective in Singapore. She and several other dancers came down to perform at Congress and lead workshops in movement and dancing.

“We performed a dance called Confluence,” she says. “It was a big stage. We performed with dancers from Maya Dance Theatre too. It went very well.”

“We rehearse many times, and remember the steps. This dance I really like so I put more practice and effort in. It make me happy to dance with everyone and to teach people to do the movements. This dance was directed by Kavitha Krishnan.”



“It make me happy to dance with everyone and to teach people to do the movements.”



“I use my ability to be the best that I can be.”

David Waldie, singer-songwriter Brisbane, Australia

David Waldie performed his new album “Speak your truth” with his singing and guitar partner Kate Fletcher-Becroft.

It was a bright, humorous and intimate show, with lyrics like “see me for who I really am” and “I use my ability to be the best that I can be.”

David is a passionate performer who sings from his heart. He has a big, powerful voice and his tunes are catchy and honest.

Ned Middleton, artist Castlemaine, Australia

Ned Middleton is a dancer and artist living in regional Victoria. He exhibited his fun, vibrant, pop art throughout Congress and presented on the topic "Connecting with community through creativity."

"Hi, my name is Ned Middleton and I went to the WISC in Brisbane.

I did a presentation with my art mentor extraordinaire, Toby, about my painting practice and the other things I do in my hometown of Castlemaine, central Victoria. Things like: my radio show about the TV show *Glee*, my job at a local brewery and pizza place, and things I do for fun like my dance class.

I took a painting of Brisbane band Savage Garden with me to the Congress to show people what kind of an artist I am. I am a music painter. I paint different bands, singers, and music video clips because that's what I'm interested in.



The gala dinner was fun at the end of the Congress. I liked the DJ doing a mix up of different artists.

I enjoyed staying in the apartment in Brisbane and eating out and meeting new people."

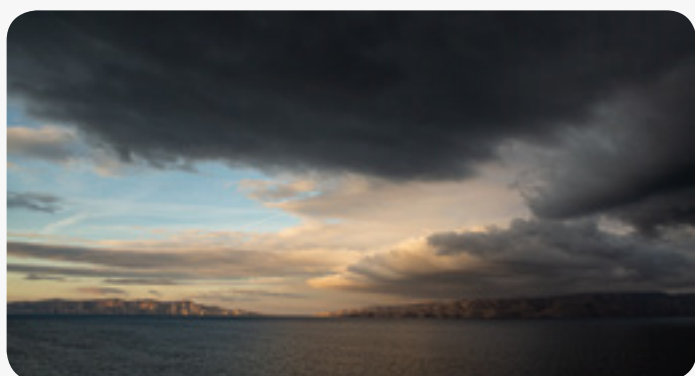


Zac Chester, artist Melbourne, Australia

Zac Chester is a 38-year-old artist from Melbourne. His works are expressive of his loving and vibrant spirit. Zac exhibited his art throughout Congress, and sold some of his pieces at the marketplace.

"I loved meeting people at Congress, showing them my art and telling them my story. I am an entertainer, a world traveller and an artist," says Zac.





**Carlos Biggemann, photographer
New Zealand**

Carlos exhibited his beautiful photography through Congress, and also presented about his life and experiences as a photographer.



**Keziah Glenane, photographer
Ballarat, Australia**

Keziah loves to capture the beauty of Ballarat. She shared her photography and art products at the Congress marketplace.



**Marissa Matthews, ballerina
NSW, Australia**

Marissa performed classical ballet on stage, giving us a glimpse of her passion for dancing.

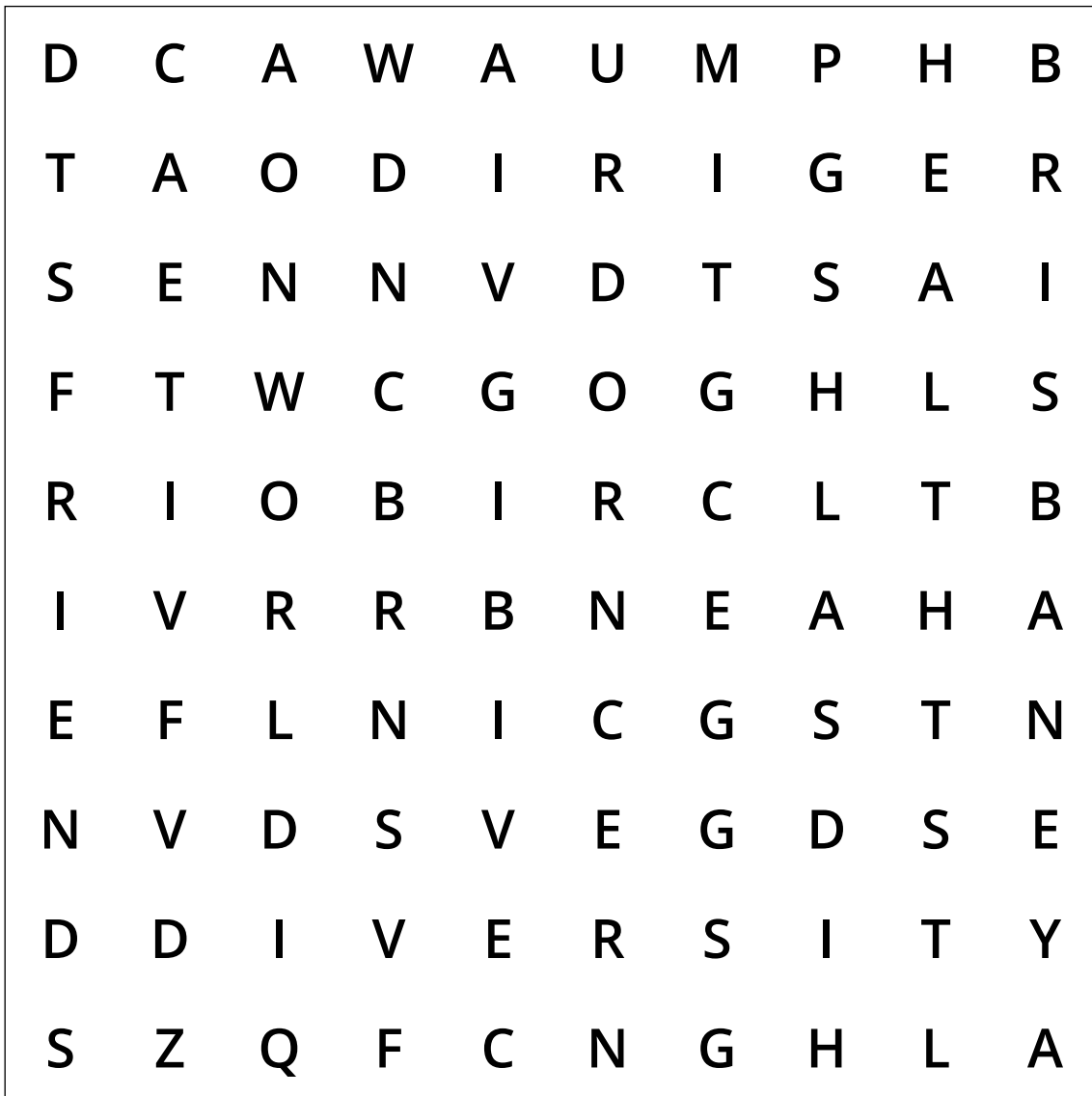


**Jerry Richter-Nguyen, magician
Wai'ala, Australia**

Jerry is a martial arts champion and magician! He presented at Congress on the intersection of his two passions.

Congress find a word

Can you find the ten words listed below? They could run in a straight line down, across or diagonally.



Diversity

Congress

Advocate

Dancing

Art

Stories

Brisbane

Friends

Health

World

Our voice



Australian Capital Territory

ACT Down Syndrome & Intellectual Disability has had an exciting few months!

In July we attended World Down Syndrome Congress in Brisbane. Office staff Charlotte, Gemma and Shannon, along with a Canberra contingent of around 50-plus members, attended workshops and events and met people with Down syndrome and their families from all around Australia and the world.

Our members with Down syndrome also attended a self-advocate program and a fabulous afternoon of drinks and entertainment at a pub on South Bank. Thank you to everyone who made the journey to Brisbane for this fantastic event, and we look forward to the next World Down Syndrome Congress in 2027 in Buenos Aires, Argentina.

In July we announced that we have become the ACT member of Inclusion Australia. Inclusion Australia is the national peak body for intellectual disability and we look forward to working alongside them and their state and territory members to help create a more inclusive Canberra.

In August we hired six new staff with intellectual disability to create our Advocacy Reference Group funded by the ACT Government. This group will develop and deliver supported decision-making training for Canberrans with intellectual disability. This group will also work with various ACT Government departments to test and review new easy read materials.

Shannon Kolak

CEO ACT Down Syndrome & Intellectual Disability



Queensland

The second half of 2024 has seen full capacity take up of our Continuing Education Program and Skills for Independence Classes. Pleasingly we were successful with continued Queensland government funding for the Possibilities Pathways Program to support our employment work.

Our fundraising events have two highlights for October. Step Up in Townsville will be a fabulous community event and at the end of October in Brisbane we have a Gala Dinner. The Gala Dinner will raise vital funds and showcase some the talents of our members!

The Support Services Team have been exploring different mediums for information gathering and sharing. A revamped Advisory Group will commence in late October. New audio resources in "bite" sized durations are being developed and planning is underway for Disability Action Week – with the theme 'Accessible Communication, connect, include, empower'.

The Education Services Team have been busy delivering individual school-based consultations, a Professional Teaching Cluster meeting on Transitions as well as Professional Development workshops. A current focus of the Education Services Team is to work on trying to build connections with kindergartens in the Torres Straits.

I look forward to sharing our 2025 services and events with you in the next edition.

Chris McMillan

CEO Down Syndrome Queensland





South Australia

DSWA CEO Cassandra Hughes visited the South Australia community in August, meeting with 27 families, and 11 stakeholders, and travelling to a variety of locations both across Adelaide and rural SA.

Recruitment for a person to work on the ground in SA, with support from the WA team, will commence shortly.

During the August visit there was great conversation around the needs of the community and the desire to have an association to support members across their lifespan. We're continuing to work on this outcome, and SA families can expect a survey in their inboxes shortly.

The SA Info Service continues to provide support to families with resources, phone and video support calls and referrals to other parties.

The DSA Resource Hub provides a large range of resources across all age groups and topics.

Families have received pre- and post-natal diagnosis information, new parent resources, information on Down Syndrome Regression Disorder, and education sector support.

Cassandra Hughes

CEO Down Syndrome WA



Tasmania

The last few months have been a blast for Down Syndrome Tasmania!

Our board jumped into strategic planning, and it was a whirlwind of creativity and teamwork. We've set some goals to guide us over the next three years, focusing on empowerment, support and building connections within our community. We're super excited about the positive impact these plans will have on our members and their families!

At our recent AGM, we loved connecting with everyone and sharing our vision for the future. After chatting about our plans and the year that was, we headed out for a fun mini golf day! There was friendly competition, lots of giggles, and it was the perfect way to celebrate our amazing community. We can't wait for more fun events like this!

Now, we're gearing up for Down Syndrome Awareness Month, and we're ready to celebrate in style! We're excited to gather at Zoo Doo for a day filled with fun, laughter and connection. It's the perfect chance for our members and their families to enjoy a wonderful day together.

Stacey Jackson

EO Down Syndrome Tasmania



Victoria

It's been a big six months for DSV. Not only did we host StepUP! Melbourne in October, but we also supported the community in Geelong to celebrate with their own StepUP! event too.

Both events were well-attended, fun celebrations. We appreciate the commitment of all who attended, as well as the event donors, partners and volunteers. We especially want to thank Carer Gateway Merri Health, our new sponsor in 2024 for their support of StepUP! Melbourne.

StepUP! is a huge part of our October Down Syndrome Awareness Month activities that this year also included nearly thirty MyTime events across Victoria to thank and pamper our valued carers as part of National Carers Week. These MyTime events were made possible through the generous assistance of Carers Victoria and Clark Rubber.

The DSV Five Peaks Challenge took place in November, with 16 intrepid hikers taking on Mt Kosciusko and four other nearby peaks, raising funds to enable the continued advocacy and support of people with Down syndrome in Victoria. A remarkable effort by all involved!

We also had a healthy contingent of DSV staff and Advisory Network members attend the World Down Syndrome Congress in July, ran a Members Engagement Survey in October and released our Annual Report for 2023–2024.

For more information, visit our website at downsyndrome.org.au/vic.

Dan Payne

CEO, Down Syndrome Victoria



Western Australia

The past few months have been full of exciting events and activities, including the World Down Syndrome Congress, which many WA families attended.

It was fantastic to see the camaraderie and friendships built over the days and events of Congress, and our adult members shining on stage, giving presentations and taking on the dance floor.

Down Syndrome Regression Disorder (DSRD) continues to be a key focus for DSWA. We are supporting families across Australia and supporting the introduction of new DSRD resources on the National Resource Hub. More than 40 families have now completed the pilot research, and we are in continuing conversations with research organisations about future DSRD research. We enjoyed a brilliant presentation from Dr Santoro in August, with 127 registrations.

The DSWA Family Support team continues to support higher than usual new members, holding Key Word Sign workshops, new parent morning teas and our regular twice weekly playgroups.

The future focus for our team is securing funding to support the work we do to improve the lives of adults living with Down syndrome, particularly when it comes to capacity building, housing and future living arrangements.

Cassandra Hughes

CEO, Down Syndrome WA





voice

The Journal of Down Syndrome Australia

Volume 12, Issue 2 ISSN 2203-3580

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