



Down Syndrome
New South Wales

Our Newsletter

The Latest from Down Syndrome NSW

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CEO Update



We warmly welcome Sherie Avalos as CEO, who joined us on 9 August. Ten days in and Sherie is busy connecting with staff, forging partnerships with our suppliers, strengthening our strategic relations with our state, territory and national associations and reaching out to our members.

In line with our Strategic Plan, our focus remains on:

- Authentic member engagement across metro, regional, rural and remote;
- Thought leadership and expertise;
- Exceptional governance;
- Supporting systemic, individual and self advocacy;
- Building a strong culture and being an employer of choice;
- Strong brand with dedicated partners to further our mission;
- Financial viability and future growth opportunities.

Sherie joins us from her senior executive role at the National Disability Insurance Scheme Quality and Safety Commission, prior to which she possesses an impressive resume of CEO and senior leadership positions in exceptional disability organisations. Sherie will be connecting with many of you in coming weeks in which we know you will see her passion, strong work ethic and inspiring ideas for our future.



Prior to Sherie's

commencement, Emily Caska filled the role of Acting CEO and Chief Strategy Officer (CSO). Emily is well known to many of our members from her role on our Board as well as her former role many moons ago as our UP! Club Coordinator. Emily remains with us as CSO and is focusing on our strategic plan for the future, our rural and regional engagement strategy, government relations, financial management, training and events, social media, fundraising and partnerships. You'll also be sure to see Emily volunteering at a range of our programs, including UP! Club, Up, Up & Away, events and training – she can't help herself and loves connecting with our members.

None of this is possible without our incredible, hardworking and passionate expert team. In what has been a time of change, we wish to warmly acknowledge our staff, your staff, for all they do and for their reinvigorated dedication:

- Ellen Hester (Administration Assistant)
- Christine Pegram (Administration Officer)
- Miriam Philomena (Behaviour Advice and Professional Training)
- Nikki Hayhurst (Participation and Skills Development Program Lead)
- Sophia Culbertson (NDIS Finance & Administration Support)

And finally, thank you to our members. Your support is unwavering and so powerfully felt.

We look forward to a very bright future with you all, drawing on the past 40 years of our incredible association and adding new expertise along the way.

You can revisit our [Strategic Plan here](#).

Join Us on Socials

Did you know we are on Facebook and Instagram?

We are providing more updates daily and can't wait to connect with you! Your interaction online has been so heartwarming and we can't wait to increase our digital footprint. And the beauty is – when you like, comment, share it brings even more people to our humble little page and organisation which means the world! Keep sharing the (online) love!

You can join us here:

- [Facebook](#)
- [Instagram](#)

We Need Your Photos

Yes, you! With our Annual Report coming up and our increased online posts, as well as the prenatal and corporate packs we are putting together, we are running out of photos to use to showcase our awesome members.

We'd really LOVE it if you could send us photos of you and your family to admin@dsansw.org.au

We'll send you back a consent form to give us permission to use these photos. The more, the better so please send in your photos!

UP!Club Update

UP!Club

Program for adults with Down syndrome aged 18+ years

What an incredible month of fun events we've had and a great month to come!

We've made some cool changes that we'd like to tell you about:

- The UP! Club Program will be released on the third Thursday of every month for the month ahead, in this newsletter (as well as emailed to our UP! Club members);
- We have introduced our new FIT + FUN CLUB run by Sean Bowes, on the third Wednesday of every month. Sean is a qualified PT, owner of Bowes Fitness and Bowes Boxing, former member of the Australian Boxing Team, high performance coach for the NRL, competition marathon runner and qualified primary and secondary school teacher. These sessions focus on physical fitness as well as meditation, breathing and lots of laughs.
- We have launched our new UP! Skill Academy, dedicated to capacity building and skills development in a super fun way! Emily Caska is running these sessions, along with special guests and subject matter experts.

Please note all events and activities are all currently online due to the resulting guidance from NSW Health regarding COVID-19 restrictions and the extended Sydney lockdown. We have so many wonderful events planned for when we can be face to face again. Until then, our jam packed and diverse program has something for everyone!

September Program

It's here and we think it's one of our very best yet!

All of your favourites such as Dance Parties, Coffee and Music, Have Your Say, UP! Club Yourself, Crafternoons plus some awesome new sessions that we'd love you all to attend:

- Celebrity Chef Matt Moran is joining us for a Sunday Cook UP!;

- Olympics Superstar Elka Graham who competed in the 2000 and 2004 Olympics is joining us to talk Olympics, Paralympics and have a dance with us;
- We are visiting Rome from the comfort of our own home with our Virtual Tour of the Vatican Museum;
- Emily Caska is doing a fun session in our UP! Skill Academy on goal setting, accountability and things to look forward to in this difficult time;
- Sean Bowes is back for another epic Fit and Fun Club session;
- And so much more!

[View our September Program](#)

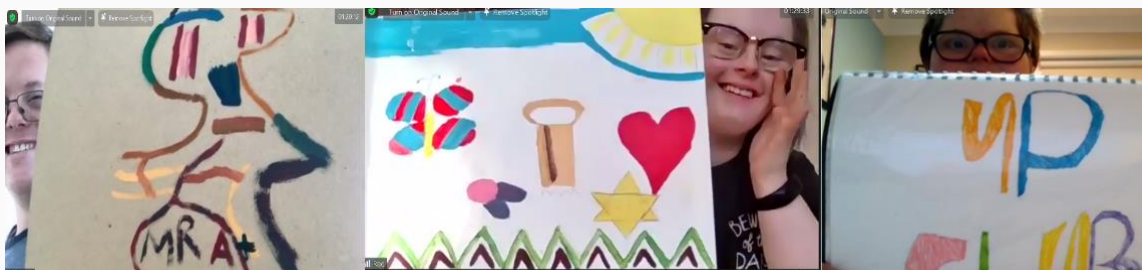
Staying Connected

Due to the extended stay at home orders, we added 11 extra Zoom sessions to the July program, bringing more craft, exercise, trivia, music and dance to the lounge rooms of our UP!Clubbers. We have been using our contacts to invite special guests to join us for our Coffee Clubs and Dance Parties too!

Please let us know any 'star connections' you may have, we would love to invite them to join us online and share their stories with our UP!Clubbers about their skills and talents.

Here are some photo highlights:

Crafternoons: full of creativity and fun! We love seeing your talents!



Yoga Skills with Bec from A Sound Life



Health Talk with Jayden, Personal Trainer volunteer from We Flex



What is a cool down/stretching?


Again, exactly what it sounds like - cooling the body down to what it was like before exercising.

Like what?

- Stretches!
- Slow walk

- Childs Pose
- Cobra
- Door Stretch
- Hamstrings
- Hip Flexor/Hamstring
- Couch Stretch
- Froggy
- Neck
- Sitting Stretch
- Cat – Dog
- Worlds Greatest Stretch
- Pretzel
- Arms



UP!Club Yourself Planning Session with Nick, Ruth Tara and Nikki



20 July, Special Guests Peter Kelly and Michael Craig, AFL Umpires



31 July Christmas in July Special Guests, Home and Away actors
Luke Jacobz and Patrick O'Connor



We still have awesome sessions for August so if you want to check out the program or book in for something between now and the end of this month, [check it out here](#).

For all things UP! Club, contact us at: Nicola.Hayhurst@dsansw.org.au.

Up, Up & Away Update

Up, Up & Away

Program for children with Down syndrome aged 4-17 years

Up Up and Away – Survey

It's up to you: What kind of activities would you like us to create for this program?

[Please help us to shape future events by clicking on this survey link and having your say.](#)

Up Up and Away – Cooking Workshop

We had such a great time at our workshop on 10 July! Look at Hannah's perfectly baked muffins! Yum!



 Down Syndrome
New South Wales

Apple & Cinnamon Muffins

For Teens with
Down syndrome
aged 13 - 17

Free online event



Let's Cook online with M
from Kids Love to Cook
Saturday 10 July
1:00pm- 2:00pm



- Online cookery workshop
- Hands on sensory based
- Recipe supplied for you to follow along at home in real time
- Siblings can join in the fun too

Up Up and Away – Relaunch October 2021

We are busy planning to boost our Up, Up and Away Program to bring you more of what you want enabling you to have fun, connect with each other, share information and learn new skills or improve on existing skills.

You talk, we listen! Drawing on your valuable feedback, we will be launching our new Up, Up and Away Program in October and can't wait to share it with you all!

Prenatal and New Parents Update

Passion, expertise and advocacy to give all children and parents the very best start.

Our Strategic Priority

In line with our Strategic Plan launched in March this year, the critical area of prenatal and new babies is a high priority for DS NSW. We are working hard behind the scenes with Miriam Philomena who holds so much passion and expertise in this space, as well as with our members, to frame up an optimal, evidence based, person centred approach to ensuring DS NSW is by your side from the very beginning. We look forward to sharing more with you soon!

DS NSW Meeting with NSW Health

Earlier this month, Emily Caska from DS NSW and Amelia and Charlie Burfitt attended a meeting with NSW Health to discuss the need for fair, equitable, evidence based and lived experience information to be provided to expectant parents of children with Down syndrome. This initial meeting forms an ongoing series of meetings between DS NSW and NSW Health to work together to achieve a range of priorities, including:

- Upskilling of GP's, obstetricians, maternal clinics, nurses, social workers, counsellors and health workers with up to date, evidence based information on Down syndrome;
- Provision of fair, balanced and evidence based information to all expectant parents in NSW at the earliest time possible to enable informed decision making;
- Connections with new babies with Down syndrome and their parents in a more robust way, with a focus on early contact, individualised support and partnering with parents at the same stage of this wonderful journey;
- Partnering with other organisations and individuals who already provide incredible services and supports in this space to strengthen their impact.

Information and Support Update

We are available to you, for all your information and support needs.

Change to Office Hours

With Covid, we have changed the hours for incoming calls to our office. We will now be accepting incoming calls Monday to Friday between 10am and 2pm. Never fear, outside these hours you can still call and leave us a message and you will hear back from us very soon afterwards. We are here with you, every step of the way.

We are also looking into an online appointment booking system which will enable our members to pre-book dedicated information and support sessions with our wonderful expert team.

Employment Program Update

Our new program supporting adults with Down syndrome to be work ready with individualised support.

Launching in November 2021

We were recently successful in receiving a grant through the Information, Linkages and Capacity Building (ILC) Grants from the Australian Government to provide employment support to people with Down syndrome. We know this is an important goal for many of our members and we are passionate about the employment space. We are currently working on the structure of this program and will provide more information in our next newsletter!

Julie Cromer Library Resource Centre Update

Our comprehensive library of resources ranging from books, articles, DVD's and more on Down syndrome, intellectual disability and all topics of interest to our members, schools, organisations and the community.

Library Reinvigoration Project

We are currently working with the incredibly talented and passionate Julie Cromer, Maie Barrow and Jo See to reinvigorate our library. This includes updating our catalogue, implementing an online search and loan function, transferring resources to online versions and growing our library which is touted as the biggest collection in the Southern hemisphere – what an achievement! We are deeply passionate about our beloved library and acknowledge the incredible volunteer work of Julie, Maie and Jo See. We can't wait to relaunch this very soon – watch this space!

COVID-19 Updates

The Pfizer vaccine has now been approved for those aged 12-15 years.

In addition, 12-15 year olds who have underlying medical conditions have been added to the 1B Group which will allow them to access the vaccine immediately.

To book a vaccination appointment, you can do so via the [Service NSW website](#). You can also check your vaccination eligibility on the [Department of Health's Vaccine Eligibility Checker](#).

Northcott, a disability service provider near our office, has a vaccination hub open. Jump online via the following links:

- [First dose clinics](#)
- [Second dose clinics](#)

Community Events

In this section, we share with you community events our members might be interested in attending! With lockdown affecting all of us, we aim to share lots of accessible, relevant and free events to support you all.

If you have any community events you'd like to share with our members, feel free to email us: admin@dsansw.org.au

Down Syndrome ACT Online Fun Science Workshops

Every Friday from August 27 - September 17, from 10.30am to 12pm

Join this FREE world class program for young adults with intellectual disability! Created by PhD Candidate Vanessa de Kauwe, come along and develop your science skills and meet new people! Increase observational skills;

Develop rational thinking skills;

Learn about the world we live in; and

Make some mess and have some fun!

Every Friday from August 27th - September 17th (4 weeks)

Places are limited. Registration closes August 25th

Contact Gemma for further information and registration community@actdsa.org.au 02 6290 0656

Accessible Film Studies Program

Bus Stop Films is heading to the Blue Mountains to deliver its award-winning Accessible Film Studies Program for people living with disability in partnership with the Blue Mountains City Council.

The classes are aimed at older teens and young adults living with a mild to moderate intellectual disability. The Program offers a film school experience as

well as literacy, social and work ready skills, and is a fantastic post school option. Additional screen industry excursions, masterclasses and professional workplace opportunities are offered through the Program.

Mentored by passionate professional filmmakers, students create amazing films of the highest artistic quality, many which have won multiple awards and screened in festivals all over the world.

The program fees can be funded through a participant's NDIS funding.

To get you in the mood the team is hosting Free Taster Workshops at the Blue Mountains Cultural Centre.

Registrations to the workshops are essential.

FREE Taster workshop 1: Monday 10th January 2022 10.00am - 12noon

FREE Taster workshop 2: Monday 17th January 2022 10.00am - 12noon

FREE Taster workshop 3: Thursday 20th January 2022 10.00am - 12noon

For more information and to register:

<https://www.busstopfilms.com.au/programs/>

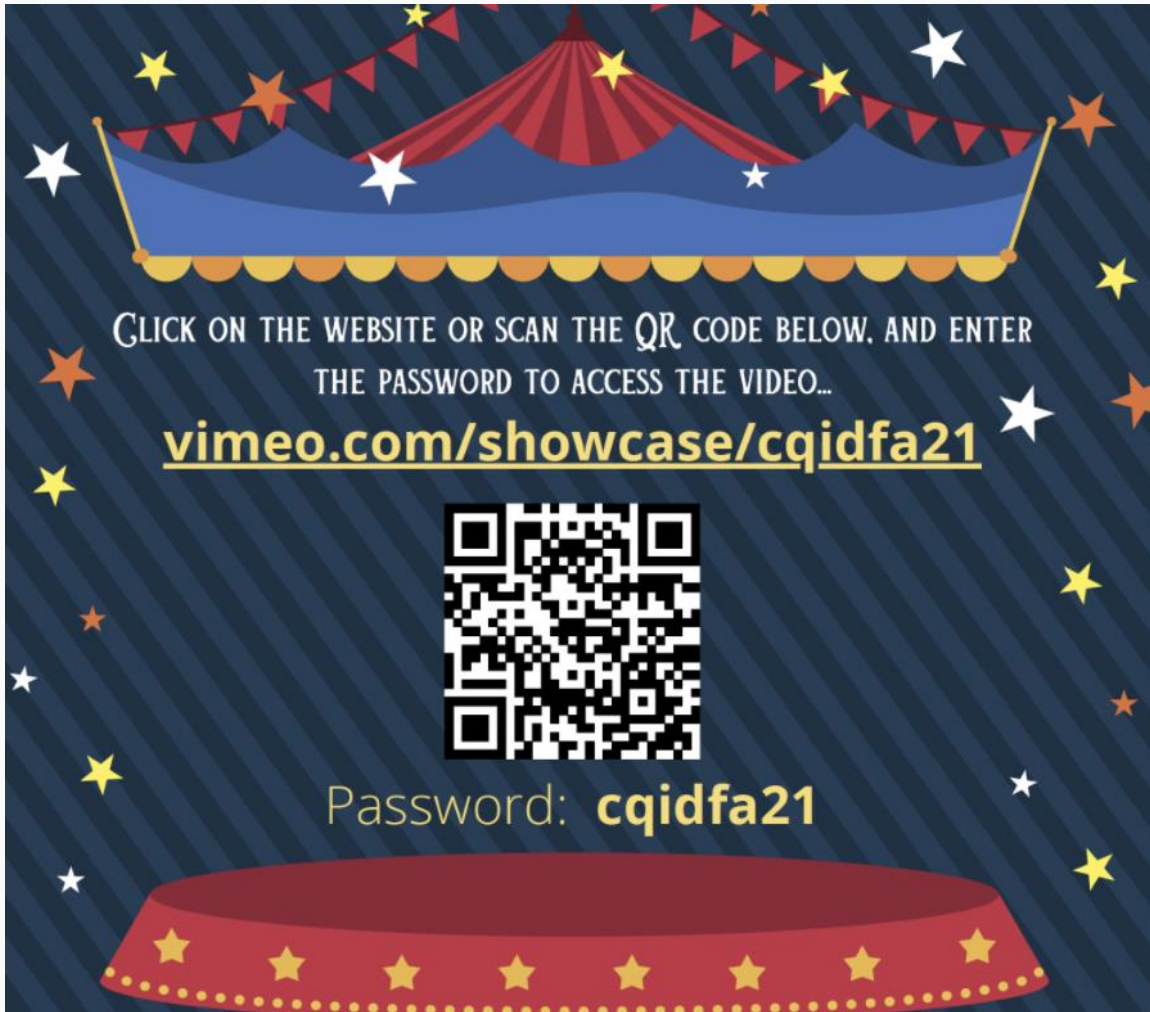
2021 Circus Quirkus Online Show

To help keep the families and clients you work with entertained during the lockdown, the Immune Deficiencies Foundation Australia is thrilled to offer free unlimited and on-demand access to its annual 2021 Circus Quirkus Online Show.

You can access the video online:

<https://vimeo.com/showcase/cgmelb21>

Password: cquidfa21



New Site: Paper Wings

People living with a disability and their families can share, learn and connect on the unique new website, Paper Wings – developed by leading social justice organisation Social Futures.

Paper Wings showcases the personal stories of people who have experienced the changes, challenges and triumphs of life with a disability. Check it out at: <https://paperwings.socialfutures.org.au/>



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