



Down Syndrome
New South Wales

Our Newsletter

The Latest from Down Syndrome NSW

Happy New Year! Our First Newsletter for 2022

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CEO Update



Happy New Year! I hope you have stayed well over the holiday period and are ready for an exciting 2022. The weather was a little ordinary, but I hope you got out in the sunshine when it was out. I was lucky to get away for a couple of weeks and enjoy the sun in Forster with my family.

The team have been busy planning and pulling together some great UP!Club and Up Up and Away sessions for 2022 after getting feedback from our UP!Club members and look forward to delivering on them.

In 2022 we are focusing on listening to members and acting on the feedback we receive. On that note, please take the time to respond to the member's survey ([link below](#)), and our information support team are only a phone call away if you need information and support.

Grab a cupper, and enjoy reading this month's newsletter.

Sherie Avalos
CEO

Office Update

Our team are all back on board for 2022.

Service hours, being Monday to Friday from 9am to 5pm.

At the end of 2021 we packed up the Parramatta office and are on the lookout for office space that will meet the needs of our members, support us in flexible delivery of services and house the amazing library.

Staff are working from home while we relocate and re-establish our office. We hope to be back into an office by the second half of 2022.

We are still contactable by

Phone: (02) 98414444

Post: PO Box 3173 North Parramatta NSW 1750

Email: admin@dsansw.org.au

Staff Update

New UP!Club Coordinator

Mark has 20 years of experience working in human services with people with a disability, where he has provided advocacy support for people with an intellectual disability. Mark also ran personal development programs, where a significant part of his role was supporting people with a learning or intellectual disability to feel welcome, included and comfortable.

For the last two years, Mark has worked closely with NDIA Plan Managers and Case Managers to ensure that people received the best possible support they required to match their needs. Mark has also worked as a Residential Care Worker in a group home for adults with an intellectual disability.

Mark commenced on the 15th December 2021.

You Talk, We Listen: Member Survey

As we plan for 2022 and World Down Syndrome Day with the NSW Minister for Disability Services, we are seeking your valuable input and honest views as part of our bi-annual member surveys.

You talk, we listen!

We would greatly appreciate you taking time to share your views with us.

Everyone in your family can fill in their own survey - the more the merrier, as we want to hear all views, especially the views of people with Down syndrome. If you are a family member, feel free to fill a survey in for yourself, then support your loved ones to also contribute their views in another survey.

[You can access our survey here.](#)

We are kindly seeking responses by Friday 4 February.

For the first time, we will be producing a report card to our members on high level survey results, along with actions we will take to meet your needs.

Advocacy, Policy and Strategy Update

Working with our members to create an inclusive, diverse and vibrant NSW for all people with Down syndrome, their families and carers

Funding Update

As announced in our last newsletter editions, we have recently been successful for a number of tenders and grants, allowing us to further our vision and mission. In doing so, we are busy working with the Board to plan how we best use these funds to amplify our current strengths and introduce new initiatives in response to demand from our members. Our member survey out now is a critical part of this process.

We are currently working through the implementation plans for a range of initiatives, including:

- Introducing a Down Syndrome Advisory Network, comprised of members with Down syndrome to inform our Board and strategic direction as well as lead key projects;
- Updating our pre-natal and new parent resources, including our existing DVD's, parent information packs and newborn register;
- Working with NSW Health to ensure all children with Down syndrome have the very best start from birth throughout their early years;

- Developing an annual report card to members on our progress against [our Strategic Plan](#);
- Introducing our “Life Matters” series of workshops focused on different stages of the lifespan, to be delivered online and around metro, regional and rural NSW;
- Creating a clearer framework to provide support to students with disability and their schools through specialist inclusion and behaviour support services;
- Developing a resource library for parents and carers, including reinvigorating our library and translating it to digital formats;
- Focusing on our programs for youth and teens, mixing some with our adult activities and offering a revamped Up, Up and Away program;
- Catering to the needs of our older members with Down syndrome, through an UP! Club 35+ dedicated program;
- Supporting our members better in relation to key issues such as future planning, wills/estates, ageing, dementia, health and more,
- Establishing parent support networks across NSW in all NDIS regions, lead by parents and supported by DS NSW, to meet, connect, share and grow on this journey together, locally.

In terms of new funding opportunities, we have submitted applications for the following, awaiting result:

- Australian Government Strong and Resilient Communities Grant

We are applying for a range of upcoming funding opportunities also, and will include updates to our members in these newsletters.

Government Relations Update

A reminder of our World Down Syndrome Day celebration at NSW Parliament House, to be hosted by Minister Henskens on Tuesday 22 March 2022 for morning tea. With Covid restrictions still in flux, we will send out full details to our members closer to the event. This will be our second consecutive event, for which we are grateful to have the Minister’s support.

To complement our celebration and expand our profile, we are going to hold an art and photography exhibition at NSW Parliament House in March. We will soon be releasing information about how to be involved. We are thrilled to be

invited to showcase the stories of our members and their families.

Advocacy

As noted later in this newsletter, we are currently advocating to NSW Health to prioritise children with Down syndrome for vaccinations, as identified by our members as a key issue. We are also advocating for adults with Down syndrome to be prioritised for boosters.

We are developing an issues paper to submit to the Minister for Disability Services prior to World Down Syndrome Day, taken from feedback to our members survey. This will cover all key issues identified by our members, and then inform our annual policy and advocacy agenda for 2022 which we will share with our members.

As always, we will continue to monitor and respond to all relevant government inquiries and consultations. We share information daily on our Facebook page. [To stay up to date, connect with us on Facebook.](#)

COVID Update

Keeping our members safe, protected and active across the lifespan.

In response to feedback from our members as well as our ongoing advocacy on this important issue, we are currently advocating to NSW Health for children with Down syndrome to be prioritised for vaccinations, and adults with Down syndrome to be prioritised for boosters.

Our member, Ruth Cromer, was recently asked by NSW Health to feature in a video with Dr Jan on Covid. You can view the video here: [Vaccination - COVID-19 information for people with disability \(nsw.gov.au\)](#)

Ruth was also featured in a recent article in the Sydney Morning Herald on 14 January, detailing the issues faced by people with disability and their support workers during the pandemic. You can read the article here: [COVID furloughs hit disability services \(smh.com.au\)](#)

A reminder of accessible resources developed by the Council for Intellectual Disability to assist in navigating Covid:

[COVID Vaccination Stories - YouTube](#)

[Booster doses of the COVID vaccine fact sheet - Council for Intellectual Disability \(cid.org.au\)](#)

[The third dose of the COVID vaccine fact sheet | CID](#)

[COVID vaccine third dose vs booster dose fact sheet | CID](#)

The latest NSW Health rules in relation to Covid 19 are available here:

[COVID-19 rules | NSW Government](#)

The latest figures for NSW are here:

[COVID-19 \(Coronavirus\) \(nsw.gov.au\)](#)

Information and Support Update

In the last 6 months we have connected with and provided information and support to over 380 people. This has included information on pre-natal, becoming a new parent, education, social connection, training, NDIS/ECEI, mental health, aging and housing to name a few.

We are only a phone call away. If you require information or support please contact us on Phone: (02) 98414444 or send an email to admin@dsansw.org.au

UP! Club Update

UP!Club

Program for adults with Down syndrome aged 18+ years

February Program

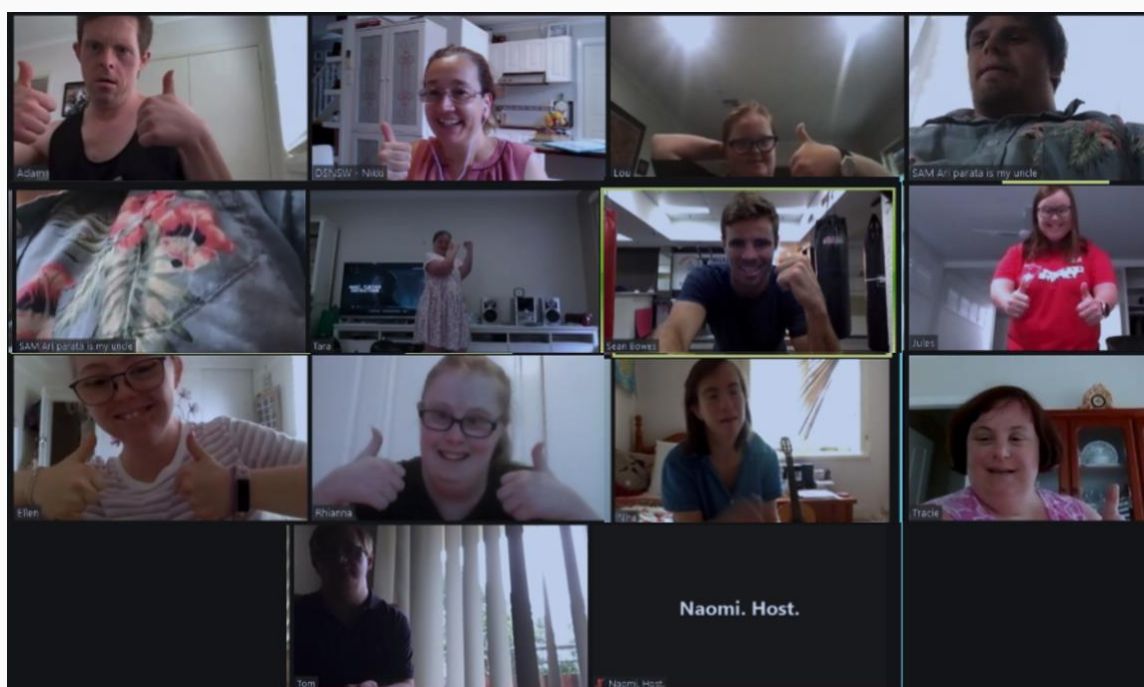
We are back! Join us through the rest of January and February.

[View the full January program online.](#)

[View the full February program online.](#)

Staying Connected this Month

Our UP!Clubbers kick started our January program with our monthly Fit & Fun session with personal trainer volunteer Sean Zooming to us from his gym. We hope to visit Bowes Fitness in person later in 2022 to really hit our fitness goals.





Caption: Adam, DSA staff Nikki, Lou, Sam, Tara, Trainer Sean, Julia, Ellen, Rhianna, Nina, Tracey, Tom

In our 'Crafternoon' sessions, we held began thinking about our goals with the use of Vision Boards



Vision Board Material List

- *Cardboard or canvas to use as your base
- *Paints, markers, stickers, etc.
- *Glue
- *Magazines, travel brochures, print outs of things that inspire you
- *Your imagination, creativity & dreams!

9: UP! Skill Academy – Thursday 20 January



**All things
are difficult
before they
are easy.**

When

Starts: 3:30pm

Ends: 5:00pm

Topic

Interactive skills building workshop designed to help you be your best and achieve your goals!

- With a certificate issued to you at the end.

Face to Face Events

We did have to cancel our Movie time face to face outing planned for 15 January because of low booking numbers, but we are still running our Taronga Zoo event at the end of the month, Saturday 29 January.

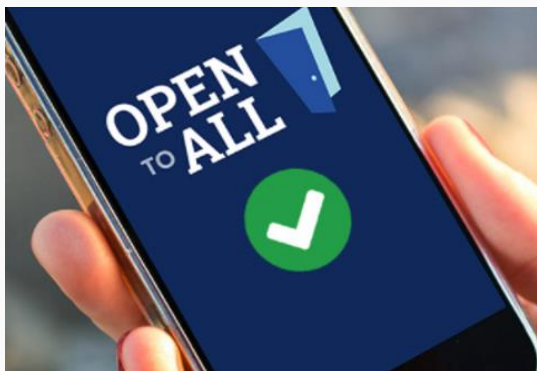
So, for a New Year animal experience in the outdoors, please book in, we have 4 spots left for our Down syndrome members who are double vaccinated with no COVID symptoms.

The zoo has its own COVID-19 safety measures in place - all guests are required to wear a mask in indoor areas such as cafes, shops and indoor exhibits and Taronga Zoo strongly encourages guests to wear a mask when they can't physically distance outdoors. All guests will be required to pre-register their visit online.

Open Events to continue

We want to ensure that our events and activities meet the needs of our members with Down syndrome as well as be inclusive and open. With this in mind, we have created some events with community engagement in mind and

you will continue to notice that some events in your monthly program are listed as “open” events.



Look out for the “Open events” which are shown with the “Open to all” image.

Some of our events are going to be open to our Up, Up & Away younger participants, family, friends and those outside of UP!Club, with or without Down syndrome.

As with all things UP!Club, talk to Nikki if you need any more information on our events or individual help on booking in: Nicola.Hayhurst@dsansw.org.au

Up, Up & Away Update

Up, Up & Away
Program for children with Down syndrome aged 4-17 years

Up Up & Away is a program for children with Down syndrome who are aged between 4 and 17 and their siblings. This program allows for not only the child with Down syndrome, but their brothers and sisters and family to interact and build connections and support. We have two sessions of the project, one for kids 4 -11 and one for those 12-17 and also joint sessions.

Up Up and Away is on its way Up again. There will be 1 to 2 events each month including 12 to 17 years old combining with some UP!Club events.

SAVE the DATE: First event for 2022

Saturday 19th February, Basketball in South Western Sydney.

Further information will be sent to UP UP and Away members and posted on Facebook and Down Syndrome NSW Website.

Employment Connections Program Update

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

Our Employment Connections Project will address the barriers to employment experienced by people with Down syndrome and will be delivered nationally in collaboration with the Down Syndrome Australia and State and Territory Associations. The project is being funded by the Department of Social Services (DSS).

As we proudly announced in last month's newsletter, our first Employment Connection Ambassador is UP!Club regular participant, **Ellen Maher!** Ellen has been doing some leadership training so she can do a great job as our ambassador in 2022 to share her experiences of working in a paid job in open employment.

Calling those in our Down Syndrome community who are interested in paid employment – we are gearing up to provide a work readiness program so that we can start to connect you into the right jobs where you will thrive with customised support for your needs. If this interests you, contact Nikki to register your interest: Nicola.Hayhurst@dsansw.org.au

Employment Opportunities: Access Easy English

Access Easy English interpret documents into simple, everyday language, supported with images so that people can read, understand and use the written information.

The goal is for important messaging to be presented in the simplest and most effective way. Sometimes they ask us to help them out which is called consumer testing.

Do you have lived experience of speech and language problems?

A new one-off paid work opportunity has arisen for one of our members who experiences difficulties with their speech, especially someone who uses augmentative and alternative communication (AAC).

Speech Pathology Australia have asked us to link them up with someone with this lived experience of communication difficulties to help review some documents about the words that people use to talk about their difficulties when communicating.

Whether you use high tech (IPad or speech generating device) or no tech options (gestures, writing, drawing, photos, pictures), your consumer review will really help.

Please let Nikki know if you would like to register your interest for this paid work opportunity: Nicola.Hayhurst@dsansw.org.au

Be involved in our World Down Syndrome Day stories

For World Down Syndrome Day each year the Down Syndrome Australia Federation share 21 stories from across the country of people with Down syndrome who are achieving their life goals.

In 2022 our organisations are collaborating and want to feature members from DSNSW who are currently working in open employment.

Do you have a job and want to share your employment story for World Down Syndrome Day in 2022?

Availability

We are doing photo shoots on Monday January 31 between 10am – 3pm at the Redfern Community Centre (200 metres from Redfern train station).

Contact Nikki on 0415 312 714 or nicola.hayhurst@dsansw.org.au if you would like to be involved.

Your Stories

Our new newsletter section, dedicated to sharing your wonderful stories with our DS NSW community.



The incredible Marissa Matthews who achieved a life goal in competing in a dance eisteddfod. Not only did she compete, she placed 2nd! Marissa

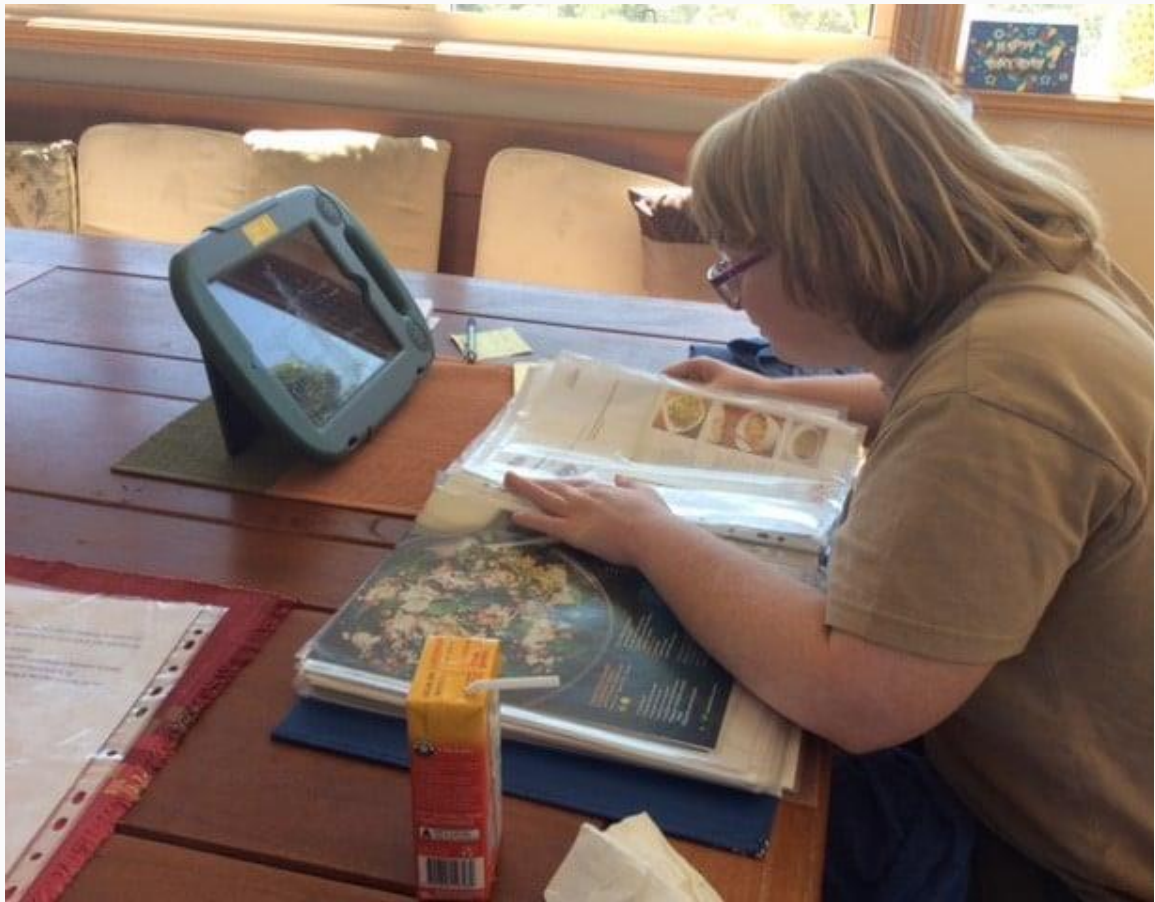
demonstrated exceptional technical skill during her performance and placed second in her category. An amazing achievement in her first eisteddfod!



Three generations of love! Nicholas with his beloved Baba and mum Sonja after his vaccination.



Toby waving hello to his first day of his last year at daycare in Dubbo!



Miriam keeping very busy in lockdown looking up recipes, planning and making delicious delights.







Our UP! Club members sharing the Christmas cheer with their awesome tree photos!



Hannah looking incredibly festive and fantastic, getting right into the Christmas spirit! Love it!

[Stay tuned with all our news, photos, stories at our Facebook page](#) – we post every day!

Share Your Story

If you'd like to share your story with our community, we'd love to hear from you! [Please email Emily Caska with your story and any photos you'd like to share.](#)

We love hearing from you!

Christmas Appeal

Thank you to our supporters for an incredible result in our 2021 Christmas Appeal.

Connect with Us

In 2022, our monthly newsletter will be with you on the second Wednesday of every month. Watch that inbox as we share with you our latest news and announcements, as well as our activity programs and events for the next month to allow you to plan ahead.

In addition to our monthly newsletter, we are very active on social media. We share news articles, government reforms, consultations, member photos, good news stories, events, latest research and more.

Connect with us:

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

Community News

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 s to share with our members, [feel free to email us.](#)

Umbrella School of Music by Ingrid Bass

Jess has been enjoying singing and improving her musical, performance and communication skills with Principal Tutor, Ingrid Bass, at Umbrella School of Music since it opened in September.

Jess was in fact a keen student for several years of Ms Bass's previous school, Applause Musical Theatre Academy where she ran classes for people with disability and fell in love with these beautiful people whilst watching them grow in confidence, skills and happiness as they learned and performed musical theatre songs on stage.



Whilst originally Umbrella School of Music was intended to specialise solely in using music, singing and movement for people with disability and the elderly, several other students without disability have enrolled. So the school is rebranding and in 2022 aims to have performances, holiday workshops and events for all, with and without disability. Ms Bass's dream is to create a community and ultimately a society that is more inclusive and compassionate than what we currently have.



Inclusive music, singing and movement programs for
all ages, abilities and disabilities.

[Find out more on their Facebook Page.](#)

Front & Centre: Initiative Supporting Arts Leaders with Disability

Congratulations to the twelve skilled participants, including DSANSW member, Audrey O'Connor, selected for *Front & Centre* – a career coaching and professional development program for women and non-binary people with disability working in the arts, creative and cultural sectors across NSW, the ACT and Victoria.

Audrey is an actress, story writer, filmmaker and advocate for people with intellectual disability. She is an Ambassador with the Australian Human Rights Commission to promote more employment of people with disability.

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/>