

February 2024

Latest News from Down Syndrome WA



CEO's Corner

This month the team have focussed on several large grant applications across a range of topics including Employment, Aging, Story Telling and the Advisory Network. These grants are all based in areas of significant interest and importance to our community and we are hopeful of securing some of the grant options.

In early Feb I had the opportunity to work with our Board on the associations risk strategy. It was an excellent workshop identifying and considering our risks and mitigation strategies for the association.

As we move into March, we continue to look forward to some very exciting things in the coming weeks and months including fabulous World Down Syndrome Day celebrations, and this year, the very exciting illumination of key infrastructure in Western Australia in the global World Down Syndrome Day colours of blue and yellow. Well done to Rachel from our team who has made this happen.

We will soon be releasing details of the Siblings camp, another exciting initiative for this year. Following WDSD and Siblings Camp, we will hold the Annual Gala dinner. This has been so popular this year and we can't wait to see you there.

My sincere thanks to Nikki and Rachel for presenting and providing tech support for the Educating Students with Down syndrome workshop. The team had great attendance at the event with over 45 teachers attending.

After a long recruitment process, we are delighted to announce Michelle Lyndon as the new DSWA Admin Coordinator. Michelle has a passion for working with our association and brings a wealth of knowledge and experience. We are delighted she has joined our team and I am looking forward to working closely with her.

It has been wonderful to see the improvement in attendance at both Aim High and Friends for Life, and I acknowledge the diligent work of our new coordinator Laura, in her approach and enthusiasm for our teen and adult members and what interests them. The Jurien Getaway is also attracting a lot of interest and we hope more will take up the opportunity for this fantastic weekend to build friendships and new skills.

Finally, I want to express my sincere and heartfelt thank you to our staff and community for their support over this last week. As many will know Aimee Lee Clarke, mum to Wren and Hunter who lives with Down syndrome passed away last Wednesday. Aimee was a passionate advocate for people with Down syndrome and was a previous member of the DSWA board. Aimee was a very popular and respected member of our community and the kindness and support of the community has been greatly appreciated by Aimee's family.

Tania and Ian, Aimee's mum and dad, and husband, Cameron wanted to honour Aimee's dedication to DSWA and have set up a <u>MyCause account</u> in her honour to help DSWA continue our work to support members.

Personally, as Aimee's aunt, I am deeply grateful to those who have reached out personally, I am humbled by your kindness. *Cassandra*

Cassandra Hughes CEO Down Syndrome WA 0432 407 527 ceo@downsyndromewa.org.au

DSWA Gala 2024 - Early Bird Ending!

Tickets are ON SALE for the 5th Annual DSWA Gala Dinner.

The Early Bird special of \$90 per ticket closes on the 6th March.

The Gala has been so popular that all tables have been reserved at this point. **If you have registered a table all tickets on your table must be paid for by the 6th March. After that date they will be released to the public.** There are single tickets available on some table and more tickets may be released on the 7th March.

If you have any questions please get in touch - admin@downsyndromewa.org.au or 08 6182 3690

Booking Link https://www.trybooking.com/CORTA

We will again be entertained by the amazing The Drycleaners Band, playing all of our favorite tunes, and supported by Dylan J King providing the sound engineering. We are so grateful.

We would love your support in seeking donations and prizes again this year for our raffles, silent auction and live auction. We do also have a number of opportunities for sponsorship this year.

Please reach out if you have any questions - admin@downsyndromewa.org.au



Meetings and Association Events

24 March - Board Meeting
20 March - World Down Syndrome Day Stakeholder function
21 March - World Down Syndrome Day morning tea
23 March - World Down Syndrome Day family picnic
22 April - Board Meeting
20 May - Board Meeting
18 May - DSWA Gala
24 June - Board Meeting

World Down Syndrome Day

The countdown begins! We're just one month away from World Down Syndrome Day 2024, and this year's global theme is "End the Stereotypes."

Join Down Syndrome WA as we mark this special day with a series of events aimed at promoting inclusivity and ending stereotypes. Save the date for:

- March 21st: "End the Stereotypes in the Arts" Morning Tea Let's showcase and celebrate the artistic talents of our community members! Book at <u>https://www.trybooking.com/CPNBC</u>
- WA Lights Up watch landmarks around WA light up in support of WDSD 2024
- Lots of Socks Campaign Stay tuned for how you can participate in spreading awareness within your local community!
- March 23rd: DSWA Family Picnic A day filled with love, laughter, and cherished moments with our loved ones. We will be joined by our office neighbours Nature Play WA who will be running some nature crafts. Book at <u>https://www.trybooking.com/CPLWL</u>

Keep an eye out for updates on how you can get involved and show your support in ending stereotypes this World Down Syndrome Day. Together, let's create a more inclusive and accepting world for everyone!



Fundraising Thank You!

Rebecca, with lots of help from friends and family, organised a Women's and Teens clothing sale with all proceeds going to Down Syndrome WA!

Rebecca's niece is DSWA member Avery, pictured below with her Mum, Felicity.



Rebecca said many of the people who visited the sale were happy to round up their sale to make an extra donation. In total they raised \$1200! Thank you for supporting DSWA.

Family Support Team

The proactive educators from NIDO Early Years Banskia Grove, contacted Down Syndrome WA to request in person support to ensure a smooth transition for one of our young members Ryder. Ryder recently started attending NIDO Early Years Banksia Grove, and the educators recognised the importance of providing the right support and wanted to be properly informed.

Down Syndrome WA was able to provide support through our Senior Coordinator Nikki. Nikki visited the childcare centre to assess the environment and meet with staff. During this visit, Nikki shared insights on specific developmental stages and milestones specific to Ryder. Nikki was also able to educate the staff on Down syndrome by providing informative materials from Down Syndrome Australia, including fact sheets, and addressed any questions or concerns raised by the educators.

This collaborative effort between NIDO Early Years Banskia Grove and Down Syndrome WA exemplifies a proactive approach and partnership to inclusion and support for children with Down Syndrome. By working together and customising the care approach, we have been able to ensure that Ryder's transition to daycare is not only smooth but also empowering and enriching for all involved.



Siblings Snapshot Project!

You're invited! Researchers from the Telethon Kids Institute are conducting research which explores the unique bond between siblings using photography. They are looking for research advisors AND research participants to be involved in their study.

This project will be supporting the Siblings Camp.



Research advisors give advice and feedback on study materials (information sheets, consent forms, interview questions), and can be:

- Siblings with or without Down syndrome aged 16-25 years, or
- Parents of siblings aged 16-25 years where one has Down syndrome

Research participants who are sibling pairs aged 16-25 years (where one sibling has Down syndrome) are also needed. Participation involves using your phone to take photos of things which capture your relationship with your sibling. You will then participate in an interview with your sibling to discuss the photos you have taken.

Participation as a research advisor or research participant will take approximately 3 hours of total commitment, and you will be paid for your time.

To register your interest as a research advisor, research participant or both, visit The Sibling Snapshot Project (<u>telethonkids.org.au</u>), or email siblings@telethonkids.org.au to find out more. This research has ethical approval from UWA (2023/ET000565).

Facebook Audit Update

Cyber Security is an ongoing challenge. To ensure that you and your loved ones are not exposed to anyone other than members of DSWA we are making our closed Facebook pages safer, and only DSWA members will be allowed to access a closed Facebook page.

We have notified Facebook group members in our Dec 23 and Jan 24 newsletters and,Facebook posts on the 23 Jan and 5 Feb 24. If we couldn't find your details in the DSWA member database you will have received notification via Facebook messenger from Rachel Slevec (DSWA IT and Communications Coordinator).

We have started deletions of members of this page that are not a person with Down syndrome or a family member/ carer on the DSWA membership.

It may be that you think you are registered on the DSWA database, or the name you have on our database is different than your Facebook profile name. If you believe you have been deleted in error, please contact us at admin@downsyndromewa.org.au.

You can of course reapply, and ensure you are a registered member. Membership application can be made at <u>https://forms.office.com/r/4Q3YMcRKW4</u>.



Health and Disability Complaints Office

Did you know that you have a right to safe and ethical health care?

Health and Disability Services Complaints Office (HaDSCO) is an independent service that can assist the community to resolve complaints.

Your health care provider has a responsibility to give you care that is free from financial, physical, and sexual harm. They should be clear about their services and should not make false claims about what they can do for you.

If you receive health care that does not meet your expectations you can let us know, and we can independently assess your case.

You can find out more information at <u>www.hadsco.wa.gov.au</u> or call us on 6551 7600.



Member Story

Vik Strizek wins community award

Downs Syndrome WA member Viktor Strizek was named the Young Community Citizen of the Year for the City of Nedlands, at their recent annual awards.

Vik runs a very success microbusiness called Recycle Man which he started in December 2021.

Recycleman operates in the Western Suburbs (City Beach, Mosman Park, Wembley, Subiaco, West Perth and all suburbs in between). People simply register with Viktor to have a recycle bin at their home and he and his team will collect and empty the bins. Vik enjoys working for himself, as it helps him achieve his goals.



Congratulations Vik, what an awesome achievement.

School Leavers Employment Services

Money Management

Our Down Syndrome WA, seven-week Money Management course started on Wednesday 21st February.

The participants had an introduction into recognizing money, where money comes from and discussed the difference between needs and wants.

Facilitator Laura is excited about delving deeper into understanding needs versus wants, spending versus saving, budgeting and safety (spending money online).

NDIA Workshop

A great morning of fun in the spirit of research

Down Syndrome Australia (DSA) partnered with National Disability Insurance Agency (NDIA) to delivery outcome workshops around Australia.

It was a pilot project being performed as part of the NDIA's Investment Effectiveness Program to better understand how funding links to outcomes.

The outcome of the workshops is to gain a better understanding of two key questions:

- What outcomes matter to participants?
- What value do different cohorts of participants apply to different outcomes?

The Perth workshop was on Saturday, February 17th and hosted by Kylie Preston from DSA. Kylie ran through a range of fun activities and worksheets to better understand what is important to participants as well as their likes, wants and desires.

The activities were about choice and control, relationships, life-long learning, social community and civic participation, home, work health and wellbeing and daily living.

Each participant got to share their favourite song, and the morning finished with a little bit of dancing and singing along.



World Down Syndrome Congress 2024



Only 1 month to go before Early bird closes on 21 March! Register now to secure your spot and enjoy a fantastic 10% off the standard registration fee with our Early Bird offer! The Congress is an amazing opportunity to form connections across Australia and around the world.

To register go to https://wdsc2024.org.au/registration.html

PCH Outreach



DSWA's Senior Coordinator Nikki Schwagermann is at PCH every Thursday for our PCH Outreach program thanks to Telethon.

Nikki can visit you if your child is admitted on the ward or can catch up with you before or after an outpatient appointment.

Please reach out by phone or email. 0480311739 nikki@downsyndromewa.org.au



DSA Education Resources

(DSWA is a member of the DSA Federation)

Are you a parent or teacher looking for resources to help with the start of the school year?

The DSA Shop has free downloadable resources including:

- Emotional Regulation Cards
- Communication Desk Strip
- Subject Timetable Cards

• School Readiness Checklist

See the all resources at <u>https://www.downsyndrome.org.au/shop/product-</u> <u>category/education-resources/</u>

Regional Outreach

Look who our CEO, Cassandra, bumped into in Albany. The Down Syndrome WA Great Southern team had a sausage sizzle at Bunnings. They were raising funds to support their group.



No Limits Netball

Free Come and Try Day on the 20th of March at 5pm. Come down to the courts and try some fun activities, beginner netball drills and team games.

The netball program runs for 9 weeks with weekly training on a Wednesday at the Joondalup Netball Association. (For ages 12+).

You can register on the day or at <u>https://www.playhq.com/netball-australia/register/acda49</u>





Educating Children with Down syndrome Professional Learning

DSWA staff were joined by 48 Teachers, Education Assistants and school administration staff at our Educating children with Down syndrome Professional Learning day, last Friday the 23rd February.

The day was held as both face to face and online, making it widely available to all Schools across Western Australia.



There were presentations from DSWA Senior Coordinator Nikki Schwagermann, Brianna Wimbridge from Joondalup Education Support Centre spoke about communication, classroom adaptations and pre literacy and numeracy skill. Kelsey Collins from SSEN Disability presented on Functional Behaviour Assessments and Behaviour Support, and Yvette Mistry presented on Developing Individual Education Plans. The day was a positive example of the collaboration between Down syndrome WA and multiple education professionals, coming together to create a more supportive and inclusive education environment for students with Down syndrome.



Playgroup South

What a busy start back to the year for Playgroup South. We welcomed new members. Had a visit from our lovely Nikki Schwagermann.

Celebrated Valentines day and made some cute gift bags. Had some sensory play and we created some beautiful rainbow and sun paper plate creations to remember our dear Aimee xxxx

See you soon! Renee and Nicole playgroup@downsyndromewa.org.au



Playgroup North

Playgroup North have recently enjoyed the delights of Sensorium theatre. Our kids have been treated to an under the sea performance where they were able to touch and play with different sensory materials.

We are so grateful for Sensorium theatre that has been kindly sponsored by Telethon. It brings our kids a new opportunity to be immersed in the sights and

sounds of the theatre. We are looking forward to our last session this week that brings rocking horses and country singing to our group.

Tracy and Danica playgroup@downsyndromewa.org.au







The KiDS club had a wonderful relaxing morning with Sacred Yoga for our February event.

The yoga class consisted of breathing, yoga shapes, games, and relaxation. Our instructor Priesh was amazing and the kids all had a great time.



The March KiDS Club October event is a Park and Play at Bibra Lake Regional Play space. Book at <u>https://www.trybooking.com/CPDNH</u>

Check out the KiDS Club calendar for our upcoming events - <u>https://docs.google.com/document/d/1PpYTShwvBiBxHsUvHNGm_EHm8G5E5uwsqlB9rUXEu6Q/edit?usp=sharing</u>

If you have a child aged 5 to 11 with Down syndrome and would love to connect with other families to encourage peer relationships, social skills and networking for parents, please get in touch to register.

Siobhan kidsclub@downsyndromewa.org.au



Friends for Life

Our Friends for life February event was a great one! We started off with some team cricket in the park before heading to our class. I believe most, if not everyone, has attended a Capoeira class before, and again, they all loved every minute.



A huge thanks to all at Capoeira for their amazing workshop, they put on for us and the kindness of their staff.

We had a good range of exercise, skills and music during our session, some drum playing, some singing, learning some new kicks and generally having a great time!

Our next event is a a picnic in the park. Book at https://www.trybooking.com/COAIW

If you have any questions contact Laura at friendsforlife@downsyndromewa.org.au or 0422 795 160.



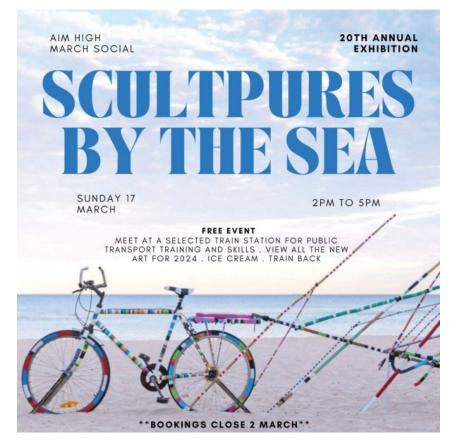
AIM HIGH

Our Aim High February event was a hot one! We ventured into the city on the train, and went to watch "Our Country". We only had a few for this event but the girls loved the show.



Our next event is Sculptures by the Sea. We'll meet at the train station for public transport training and skills. Then view all the art for 2024, have an ice-cream and catch the train back. Book at https://www.trybooking.com/COAJK

Take care and see you soon Laura - aimhigh@downsyndromewa.org.au or 0422 795 160



Getaways!

For information or to book contact Laura - aimhigh@downsyndromewa.org.au or 0422 795 160

Book at https://www.trybooking.com/CPIPZ



Compliments and Complaints

We always welcome your feedback and suggestions. Send your feedback to admin@downsyndromewa.org.au or use our <u>online form</u>.



Copyright @Down Syndrome Western Australia, All rights reserved {{msdyncrm_contentsettings(9345d3f5-4a4a-eb11-a812-0022480fea01).msdyncrm_addressmain}} (08) 6253 4752 admin@downsyndromewa.org.au You are receiving this email because you have previously indicated that you would like to receive updates from Down Syndrome Western Australia.

Unsubscribe or contact us to opt out