



Latest News from Down Syndrome WA



CEO's Corner

It has been a fabulous month culminating in the DSWA Gala Dinner on 18 May. This years Gala sold out very quickly and we are looking for a larger venue for next year to welcome everyone. 270 guests were entertained by the Drycleaners Band again this year, and by MC Adrian Barich. It was a fun night full of banter, laughter, dancing, fun and connection. On behalf of members, staff and Board we are deeply grateful to all sponsors and donors who are recognised later in the eNews. The Gala raised just over \$20,000.

The Gala was held on the same night as the Disability Service Awards at Crown. DSWA were nominated in three categories, and I congratulate Nikki Schwagermann and the Employment team for their outstanding nominations. The

Employment team were recognised in the top three nominees which was a wonderful achievement, along with the organisation's nomination for Innovation in Service Delivery. The work we do is only possible with the support and skills of our amazing staff. Nikki's nomination is testament to her outstanding contribution and leadership of the Family Support team. Thank you to Sue Summers for attending the awards on behalf of DSWA.

We had a wonderful evening at the Energy Producers conference with the support of <u>Baker Hughes</u> who introduced Brooke and Brendon to the incredible scope of work within the energy sector. It is heart warming to see such engagement from organisations in our employment program.

We are now preparing for Siblings camp in June, which whilst it has had a slow uptake in bookings has attracted some regional families which is outstanding. We look forward to a wonderful day and a half with siblings, to have fun and understand more about their sibling journey. Our thanks to the Siblings Research team at TKI for supporting the camp. (Please note, at the time of writing, the Siblings Camp in at risk of cancellation due to low numbers - we will stay in touch with families who have booked. We are doing everything we can to keep the camp running, which does need a minimum numbers of 20 to proceed)

A great deal is changing here at DSWA as of June 30 where the ILC (Information, Linkages and Capacity Building) grants are ending and we have not been successful in the following rounds, in fact only one Western Australian organisation was granted funds over three grants. As the Government move to the creation of foundational supports as a result of the NDIS review, we are likely to see significant interruption to the funding cycles for organisations. Together with the other states and territories we are sending advocacy letters to both Federal and State ministers, expressing the importance of funding between now and when foundational supports begin. The loss of ILC will mean that DSWA programs such as Pathways (workshops), Employment and Health Ambassadors. We are continuing to seek alternative funding for these programs, and also for new programs that may offer new types of support and activities for members with Down syndrome and their families. In light of the funding reductions, we are reviewing the employment program and hope to have an alternative program structure to allow us to continue the very successful employment program. However the loss of employment coordination will take its toll on the excellent work of the last three years.

Later today, you will also receive an email from myself and Board Chair Nia Parker, explaining further the impact of the funding cuts, and how you can support DSWA by contacting your local member/s. In that email, there will be a link to a letter template, that you can use, and I ask you to please customise that letter and tell the Minister the impact of this loss of funding on your family.

This month I had the wonderful opportunity to spend some face-to-face time with my colleagues from around Australia with a very quick trip to Melbourne. It was a very productive 2 days with us working on issues around ongoing funding, outcomes of the NDIS review and the World Down Syndrome Congress.

The World Down Syndrome Congress is almost here and we are so looking forward to the event and to supporting members who will be attending. For those DSWA

members that are attending the Self Advocates day, I will be attending the day, and will be in the room to provide any support you may need, which will allow your parents and supports a chance to enjoy all that Brisbane has to offer, whilst you contribute openly to discussion about issues that are important to you. For members giving presentations at Congress, if you would like any support prior to or at the congress, please let us know. We would love to know who is attending congress and catch up with you whilst we are all there. Please reach out and let us know that you are speaking, or attending as a congress delegate. Please remember to also visit us at the Down Syndrome Federation stand.

At Congress, DSWA will be well represented with presentations from members with Down Syndrome, DJ Incredible pumping out the tunes, I will be speaking about Regression Disorder and Nikki Schwagermann and Emily McCain will give a presentation on their connection through their children and the value that connection bought them. The program is jammed packed and it is not too late to book. If you want to check out the <u>full program here</u>. I am really looking forward to hearing each of our members speak at congress.

As we sign off for another month, it is truly heartwarming to see the external fundraising that has been happening for the association, check out the fundraising article, but my huge thanks to the Kailee for her amazing Run for a Reason, Great Southern Police Team, and St Brigid's Primary School.

Wishing you all a lovely June, hopefully with some rain filled winter days to bring back some greenery to our beautiful state.

Cassandra

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

Meetings and Association Events

17 June - Board Meeting

22 July- Board Meeting

19 August- Board Meeting

30 September- Board Meeting

19 November- Board Meeting

7 December - Association Christmas Party



Disability Services Awards 2024

Down Syndrome WA was honored to be amongst an outstanding group of nominees at the Disability Services Awards 2024. The award presentation event was held on the same night as the DSWA Gala, and Sue Summers, our previous Employment Coordinator attended on our behalf.

We received nominations in three categories.

Excellence in Home and Family Support - Nikki Schwagermann

Nikki was honoured in the nomination for her outstanding contribution to DSWA community over the past 12 years, with a focus on the specific impacts she has had on families in her role as Family Support Officer and now as Senior Coordinator. Nikki's contribution to the community was recognised as outstanding, and we also acknowledge her incredible passion, willingness to go above and beyond to help families, and her dedication to the association. Nikki's heart and focus have always been on delivering person-centered, individualised support, and we are incredibly grateful to have her leading our Family Support Team, she is an incredible asset to the DSWA community. Her dedication has made a profound impact on the lives of our Down Syndrome WA families, and we are honoured to celebrate her and proud of her incredible achievements over the past 12 years.

Excellence in Supporting Employment Outcomes – The Employment Team - Finalist

Nominated for the creative delivery and commitment to supporting people with Down syndrome to find meaningful, paid roles in open employment. The success of the program comes down the the amazing staff who run and deliver the program. Congratulations to Sue, Stephanie, Mariana, Zali and all of the mentors who have also worked in the program.

Innovation in Service Delivery - Cassandra Hughes - Finalist

Recognised for the work in bringing awareness of Down Syndrome Regression disorder and supporting families with DSRD and also the Dementia support group.





Gala Sponsors

Thank you to all our amazing sponsors. We couldn't do it without you!

A special thanks to the Dry Cleaners, Dylan J King Music, Oil and Energy, Buddiup and Sisterup, SVN, Seashells and Harvey Norman.



DSWA Gala

What an amazing night! Thank you so much to everyone who celebrated with us, we can't wait for next year.



Thank you Great Southern Police Team!

This fabulous team of police officers were undertaking training in the Great Southern. Aimee (Clarke) was due to join them on this camp. Together, they

decided that all the silly things that happened on camp would attract a fine, and those fines would be donated to DSWA in Aimee's memory.

Thank you to Matt and the whole team and to the A/Supt who chipped in to bring the total raised to \$850.

The team shared some of the fines they received for a giggle:

- "Not liking Horses by Daryl Braithwaite"
- "Thinking squid comes from the ocean in the form of squid rings"
- "Arranging ex MMA fighters to act as the instructors/subjects for training"
- "Turning a plastic picnic wine glass into a piece of modern art"
- "Promising brownies and not being able to deliver on it"
- "Being born in a tent"
- "Getting the frisbee down from the roof, only to immediately throw it on the opposite roof"

We are forever grateful for your support and your connection to and memory of Aimee.

These funds will be added to the total of Aimee's Fund, which brings the current total to over \$5700.

As we go forward these funds will be used support parents in some way in the future.



St. Brigid's Primary School hosted a Silly Sock Day for DSWA, raising an awesome \$347!

It looks like they had so much fun! Thank you so much to St. Brigid's for their generosity.



Thank you Janette and Kailee!

On May 19th Kailee Cook, a vibrant member of DSWA, and her Mum Janette, participated in the HBF Run for a Reason.

They joined a record-breaking 37,000 participants, to traverse the course with determination. Their efforts were not just about crossing the finish line; they were a testament to the strength of community and the power of giving back.

With the generous donations from supporters, Kailee and Janette raised over \$750 for DSWA. This contribution speaks volumes about the impact of DSWA's support network, which has been instrumental in their lives for over a decade.

Reflecting on their journey, Janette and Jason, Kailee's parents, expressed profound gratitude for the invaluable assistance provided by DSWA throughout Kailee's life. From the early stages of infancy to the upcoming transition to high school, DSWA has been a constant source of guidance and support.

The family fondly recalled attending DSWA's new parent morning teas and playgroups, where they not only gained crucial information but also formed enduring bonds with other families on similar journeys. Moreover, DSWA's KiDS Club and teacher professional development days have been instrumental in maintaining family connections and facilitating Kailee's growth and development.

As Kailee prepares to embark on the next chapter of her life in high school, Janette and Jason look to DSWA for continued support. They eagerly anticipate leveraging resources like the FrienDS for Life group to nurture Kailee's independence and foster new experiences and friendships.

In Kailee and Janette's inspiring journey, we witness the transformative power of community and the profound impact of organizations like DSWA. Their story serves as a beacon of hope and a reminder that with support, determination, and gratitude, every milestone is within reach.

Kailee's fundraising continues to the 30th May. Please support her cause by visiting her page at:

https://runforareason24.grassrootz.com/dswa/kailees-kruisers

Every donation, no matter the size, will make a meaningful difference in supporting DSWA's vital programs and initiatives.

Thank you so much to Kailee and her family!



Regional Outreach



Did you know that we have 5 private Facebook groups for different Regions in WA. If you are a DSWA member, you can join the group in your area to keep up with any community events happening and make connections closer to home.

DSWA Great Southern Support

Group- https://www.facebook.com/groups/562813961781133

DSWA South West Support

Group- https://www.facebook.com/groups/677923213272854

DSWA Midwest Support

group- https://www.facebook.com/groups/2502984533353870

DSWA Regional Rural and Remote support

group- https://www.facebook.com/qroups/357663433068076

With thanks to funding from Telethon, we are excited to be starting a new regional outreach region in the Peel area. DSWA Peel Support Group. If you live in the peel

area, please join the new group here https://www.facebook.com/groups/399481359497440

To join our Facebook groups we require that you are a member of DSWA (membership is free). Not a member? Complete our online form at https://forms.office.com/r/nDxiDRDuDw

Down Syndrome Regression Disorder Survey

DSWA has been meeting with a group of families affected by regressive symptoms for over 12 months. This survey was constructed with their help and feedback. The survey is intended to provided pilot data to help us lobby for diagnosis and treatment for people suffering regressive symptoms and possibly Down Syndrome Regression Disorder. This data also helps us to advocate for funding, research, treatment and support.

If you have a loved one that has experienced regressive symptoms we encourage you to complete the survey.

We are currently creating resources that may provide support for you when visiting your GP.

https://forms.office.com/r/L07pN7Z9ts

Contact CEO@downsyndromewa.org.au

DSRD and **Dementia Support Groups**

Meetings run for a maximum of 2 hours. Tea and coffee is provided.

Please book on trybooking so we know who is attending each session:

Dementia Support trybooking Link - https://www.trybooking.com/CQNGK
DSRD Support trybooking Link - https://www.trybooking.com/CQNHI

If you need assistance booking please email your details to admin@downsyndromewa.org.au

Support
Group
Meetings
at the
DSWA Office



Down Syndrome Regression Support

Dates:

Dementia Support

Dates:

Wed - 5 June - 10am

Tue - 6 August -10am

Wed - 2 October - 10am

Thu - 28 November -11am

Sat - 8 June - 10am

Thurs - 8 August - 10am

Sat 19 - October -10am

Thu 28 November - 9am

Employment

It was fantastic to attend the Australian Energy Producers conference this week with ambassadors Brendon and Brooke.



Brooke spoke to a number of delegates about her experience in the Down Syndrome WA Open Employment project and also her advocacy and policy work with Inclusion Australia. As a school leaver, it was a great opportunity for Brendon to experience the breadth of an industry sector and all that makes it work. It was also fabulous to see Brendon jump straight in and help of the cafe.

A huge thank you to the team <u>Baker Hughes</u> for inviting us to the event, and being such strong advocates for diversity, equity and inclusion. We look forward to working with you again in the near future.

Congratulation to Brooke and Brendon, and our thanks to everyone involved in this brilliant opportunity.

DSWA provides workplace presentations to organisations to discuss customising

roles for people with Down syndrome/intellectual disability and the amazing contribution they make to your workplaces.

Please reach out to employment@downsyndromewa.org.au for more information.



Relationships Course

Wow! What a huge response

Our 6-week Relationships course commenced on Wednesday 8th May, with 11 members participating.

Week one covered the "Different types of relationship" professional, family, friends, acquaintances and romantic. Participants discussed the differences with these relationships and learned some great tips on suitable conversation starter topics for each.

Week two covered "Healthy versus unhealthy relationships". What behaviours you might see in a healthy relationship compared to that of an unhealthy relationship. Our facilitator also talked about appropriate behaviours for relationships, the importance of communication, having a voice, speaking up and your rights.

To date the course has been very well received, with the well-balanced audience of 5 men and 6 women in attendance, participating and engaging in the conversation.

Week three will cover "Friendships to Romance". What is attraction, and what are the signs.

Family Support Team



As we move through the year, our dedication to fostering a supportive and connected community continues to shine brightly. We're excited to share some important updates and heartwarming news with you all.

Save the Date: Next Parent and Bub Morning Tea

We're delighted to invite you to our upcoming Parent and Bub Morning Tea, a wonderful opportunity to connect with other new parents and families who have a baby with Down syndrome. Join our Family Support Team, Nikki and Danica, for a relaxed gathering centered around fostering connections and enjoying coffee together.

Date: Tuesday, August 13th Time: 10:00 AM - 12:00 PM

Location: Capoeira Australis, 1/301 Selby St N, Osborne Park WA 6017

Book: https://www.trybooking.com/CQCSA

Our New Parent Morning Teas are designed to provide a warm and welcoming environment where attendees can engage in meaningful conversations, share experiences, and offer or seek support within a nurturing community setting. We look forward to seeing you and your beautiful bubs there!

Navigating Winter: Support During Hospital Stays

As the winter season brings new bugs and viruses, we are seeing a rise in admitted children to Perth Children's Hospital (PCH). We know that unplanned hospital stays and medical appointments can make this a challenging time for families. Our Family Support Team is here to offer support during these times. Whether you need a listening ear, assistance with navigating hospital procedures, or just a friendly face, we are here for you.

We look forward to seeing you at our next Parent and Bub Morning Tea and sharing many more moments of connection and support.

Don't forget if you are an inpatient or outpatient at PCH on a Thursday, Contact Nikki for a visit - familysupport@downsyndromewa.org.au or 0480311739

Key Word Sign Workshops

We're excited to announce our upcoming Key Word Sign Workshops, sponsored by Telethon, designed to enhance your communication skills and provide valuable tools for interacting with individuals with communication challenges. Led by Alison, a dedicated speech pathologist with over 20 years of experience in the disability sector, these workshops are a fantastic opportunity to learn and grow in a supportive environment.

Beginner Key Word Sign Workshops

In this introductory workshop, you will learn the principles of key word sign and gesture, discover how it can be used alongside other communication methods, and understand the differences between key word sign and Auslan. You'll gain up to 80 new signs and practice them in interactive activities.

Friday 21 June 2024

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

Friday 22 November 2024

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

Cost: \$250 (includes morning and afternoon tea; please bring your own lunch) NDIS Payment Options Available

Intermediate Key Word Sign Workshop

For those who have completed the beginner workshop or have prior experience, this intermediate course will build on your foundational knowledge. You'll explore advanced signs and gestures, practice in complex scenarios, and develop strategies to support and engage individuals with communication challenges.

Friday, 20 September 2024

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

Cost: \$250 (includes morning and afternoon tea; please bring your own lunch) NDIS Payment Options Available

Don't miss these opportunities to enhance your communication skills in a fun and supportive setting. Secure your spot today by booking for your preferred date and location!

Resource Spotlight

Free Course: Down Syndrome: The Essentials

Health professionals, boost your skills with our RACGP accredited 6-hour e-learn. Learn how to provide the best care for people with Down syndrome and challenge bias in healthcare.

Did you know? People with intellectual disabilities face twice the rate of avoidable deaths compared to the general population. Let's change that.

Course highlights:

- Key insights and practical tools
- Real experiences from people with Down syndrome
- Improved communication and care strategies

Perfect for health professionals, support workers and anyone supporting people with Down syndrome. Make a difference in healthcare today.

Enrol at https://buff.ly/3yBfGna

World Down Syndrome Congress 2024

Together we Can: Celebrating Diversity and Inclusion

Congress is where the global Down syndrome community gathers – families, advocates and professionals. Let's come together, learn, celebrate and make positive change!



The Full Program is now available on the <u>WDSC 2024</u> website or see it here.

My Perspective Competition

My perspective is an international photography competition for people who have Down's syndrome.

Since 2010, outstanding images by photographers from around the globe have been celebrated in this unique competition that enables people who have Down's syndrome to show us how they see the world.

There are 5 photographic categories and a short film category.

https://www.downs-syndrome.org.uk/our-work/our-voice/my-perspective/

Closes 23 June.

Stella Young Award 2024

Arts Access Victoria cherishes the memory of our collaborator Stella Young and honours her by awarding a young Australian artist with a disability with \$3,000.

This is a great opportunity for young artists with a disability aged between 16 and 30 years old to be recognised for their impact on disability activism and culture through their artistic practice (in comedy, performing arts or screen culture).

Applicants must:

- identify as a Deaf and/or Disabled person;
- have created work (paid or voluntary) in either comedy, performing arts or screen culture;
- be between the ages of 16 and 30
- be a permanent resident of Australia; and
- have made a powerful impact through their practice.

https://www.artsaccess.com.au/stella-young-award-2024/



Playgroup South

We've had a beautiful month at Playgroup South . We have celebrated mothers Day by making coffee mug planters, clay earrings and crafts.

The lovely Chantal from Messy mats paid us a visit, the kids loved getting and getting messy. we also made some rain cloud /rainbow pictures to celebrate winter. Most importantly we had connecting supportive talks over warm coffee whilst the kids played and crafted xx

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



Playgroup North

Playgroup North has experienced and explosion of colours and creations this term! We started our term with some Anzac poppy craft and a special morning tea. The

team from Messy Mat Perth came to visit our centre and treated our kids to a Mother's Day theme sensory play.

We have welcomed many new families to our playgroup this term which always creates a buzz of excitement within our group. Mother's Day was celebrated in style with handprint flowerpots and take-home message jars.

We are only halfway through this term and still have so much more on our calendar with a dance session from Ambience Dance Studio and an OT therapy talk hosted by the wonderful team at Bright Bunch Therapy.

Danica and I are always so excited to meet all our new families and see all our familiar faces each week at playgroup. The connections our families make are so heartwarming and it creates a strong and loving community together.

Tracy and Danica playgroup@downsyndromewa.org.au







What a fantastic time we had at the Slime Time Workshop hosted by Messy Mat! The event was a huge success, filled with creativity, laughter, and plenty of gooey fun!

Our young scientists dove right into the world of slime, exploring different textures, colors, and glittery additions to make their perfect creations. The excitement was palpable as kids mixed, stretched, and squished their way to slime masterpieces!

The workshop was expertly led by the amazing team at Messy Mat, who ensured that every child had a hands-on experience and learned the art of slime-making in a fun and engaging way. Their enthusiasm and expertise made the workshop not only educational but incredibly entertaining.

Highlights of the day included:

- Glitter Galore: Kids loved adding sparkles to their slime, making it shimmer and shine!
- Color Explosion: From vibrant blues to neon greens, the colorful slimes were a feast for the eyes.
- Bubble Stretch: We had learning how to blow bubbles with our slimy creations

Parents and siblings joined in the fun, making it a true family event. It was heartwarming to see everyone getting involved, creating together, and sharing in the messy joy.

A huge thank you to Messy Mat for hosting such a memorable event and to all the families who attended and made it a day to remember. We can't wait to see you at our next exciting workshop!



Exciting Announcement: Upcoming Cooking Class!

We are thrilled to announce our next event: a fantastic Cooking Class making pizzas! (The class and all ingredients will be gluten free)

This is a wonderful opportunity for kids to learn how to create simple, delicious dishes in a fun and supportive environment.

Date: Sunday 9 June 2024 Time: 11am - 1pm

Location: Reabold Hill Tennis Club

Price: Free for Member with DS \$5 per sibling **Ticket link:** https://www.trybooking.com/CQYMU

Join us for:

- Hands-On Cooking: Kids will get to cook and bake a variety of tasty treats.
- Expert Guidance: Learn from Debbie's expertise and infectious enthusiasm.
- Family Fun: An event that brings everyone together to create and enjoy food.

Don't miss out on this delicious adventure! Secure your spot now and get ready to cook up a storm with Down Syndrome WA Kids Club!



Check out the KiDS Club calendar for more information, and for our other upcoming events: <u>KiDS Club timetable 2024</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 contact Siobhan Pat kidsclub@downsyndromewa.org.au for registration details.

Friends for Life

Our popular school holiday program will be running the July school holidays. More details to follow very soon.

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



AIM HIGH

For this month's getaway our Aim High Club headed to Busselton. We left town Friday and headed south to begin this getaway adventure. We stopped off at a bakery for lunch before heading to the Busselton jetty for our train and underwater observatory tour. Everyone enjoyed looking at the fish and all the coral underwater. We then headed back to accommodation and had nachos for dinner which everyone

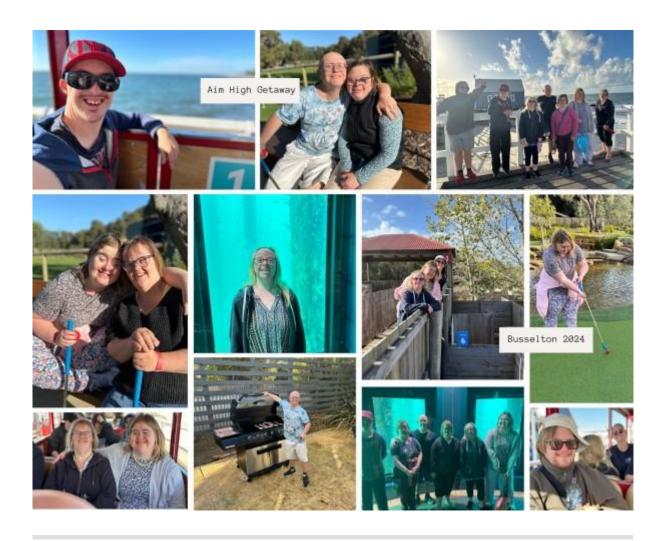
was a great help cooking as a team! Freo Dockers was playing so we watched the Friday night footy as a group which was thoroughly enjoyed!

The weather wasn't in our favor for our Saturday morning, so we had a slow morning cooking a fry up and getting ready slowly before the clouds cleared. As soon as the sun was out, we hit the road to Yallingup maze and mini golf! We did a three-team challenge, of who can get to the tower first, and the girls came in first! It was quite tricky, big, and challenging but everyone made it to the top. We had lunch at the cafe, whilst playing the puzzles and brain teasers , then we headed over to the mini golf where we spent the rest of the afternoon. Sunday, we started to make our way back to Perth stopping off at Bunbury Dolphin Discovery Centre on the way. We saw many fish, starfish, turtles, we even got to see some stuff through the VR googles!

All participants said they had a great time on the getaway. Be sure to join us on our next month's adventure, go check out what we have on, and I hope to see you there!

Take Care Laura aimhigh@downsyndromewa.org.au 0422 795 160





Compliments and Complaints

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











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admin@downsyndromewa.org.au
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