



### **Latest News from Down Syndrome WA**



### **CEO's Corner**

In our driest April on record in WA, it has been raining opportunities and activity for the DSWA team.

We are still waiting on notification of three grants, which focus on Aging, Story Telling and the Advisory Network, they are federal grants, and highly competitive eagerly sought out by agencies across Australia. We are also looking at a range of other funding opportunities in grants, philanthropy and fundraising. Funding continues to be the most challenging element of the association, finding funds for key services and programs to continue. The very successful Employment program funding expires on June 30 and recent National funding rounds have been unsuccessful. I am working on a fee for service model, to allow us to continue the program. We are continuing our search for funding for the coordination of the Employment program at both National and State levels. Those involved in this

program will receive more information from Stephanie shortly. We are continuing fundraising efforts and looking at novel ways to engage the WA community in our association.

In April, we again celebrated with the Telethon community at the 2024 Giving Breakfast, where the power and strength of Telethon continues to be demonstrated. Telethon provide DSWA will all family services up to 17years old. We are extremely fortunate to be a Telethon Beneficiary.

Staffing programs particularly with casual supports is an ongoing requirement with many that come to us, being students and holding other positions. We have a great pool of casuals and recently interviewed two more staff that will join Friends for Life, Aim High, Getaways, Teens Holiday program and the Employment mentoring role. We welcome Andrea and Joel to the casual team and trust that they will enjoy their journey with us.

The Board recently finalised the 2024-2026 Strategic Plan which is on the website. The new operational plan will be written in line with the strategy and the 2024-2025 budget. Budgeting is well underway, and we will continue to have extremely tight financial management again this coming financial year to support us to build some reserve funds, critical for emergency funding should grants and other funding not be available. DSWA prepare an extremely detailed financial budget, which assists us to ensure key services continue. We do budget for major fund raising activities such as the Gala, and StepUp as well as numerous campaigns throughout the year. Should you wish to be engaged in any DSWA fundraising, please reach out to me directly, I would love to hear from you.

We have been attracting very positive attention from researchers in recent months and are engaged in conversations with Curtin University, UWA and the Telethon Kids Institute. Each project supports further research and information which will be of extreme value to our community. We are currently engaged in siblings research (TKI) and a small project on regression with some masters students from UWA and in discussion on topics such as play, exercise and education for the future.

I have recently had the DSWA Regression survey reviewed by a research team. We have made some minor updates and will be sending that survey out across Australia in coming days. This will help us to collect needed pilot data to support the need for further research, diagnosis and treatment. This perplexing and deeply impactful condition continues to often be undiagnosed, leaving families with limited options for effective treatment. We are very fortunate to now be in discussion with Dr Jonathon Santoro, who is one of the worlds leading researchers in this area. We will be having Dr Santoro join us to deliver an online workshop very soon.

The Relationships workshop is now well subscribed and I recently met with parents to discuss the course, its content and focus, providing information for families and getting feedback from parents on the content before the course begins. We are looking forward to the six-week course, with 9 members registered for the course.

It is heartwarming to see the increased attendances at Kids Club, Friends for Life and Aim High in April. During March and April we connected with Kids Club parents asking for and implementing feedback on that program with great success.

I am absolutely delighted to announce that the Board has recently announced the successful members of the inaugural DSWA Advisory Network. Congratulations to Andrew Denton (Chair), Matilda Geoghegan, Jessica Toster, Patrick Ricciardo, Rachel Parker, Adam Crisp, Naomi Lake, Brooke Canham and Anna Collis. We are delighted that this group nominated, your videos about why you wanted to be self advocates and to join the Advisory network were inspiring. The advisory network will provide the board with feedback and input on a range of topics. They will undertake a leadership development program, and meet regularly to discuss key topics of relevance to people living with Down syndrome. We also hope to engage the members in presentations and committee representation.

In a month of exciting announcements, on behalf of the board, I am delighted to announce that Samala Ghosh a regional member, and Andrew Denton have been the successful applicants for the 2024 World Down Syndrome Congress Scholarship. Congratulations to you both.

Coming up we have some key events, the 2024 Down Syndrome WA Gala Dinner is almost here. The gala sold out in record time almost entirely to our members and their families. We are thrilled to have 270 guests attending. The gala is again supported by the amazing Dry Cleaners band, who are supported by sound engineering by DylanJKing. Both donate their time to the gala for free which is an incredible donation, for which we are extremely grateful.

We also have our first ever siblings gathering. This event is aimed at all siblings, young and adult. Members can attend just for the day on Saturday and dinner or stay overnight. There will be challenges and activities galore, an opportunity to network with others and for adult siblings to share and mentor some younger siblings, who's journey may benefit from your thoughts and experience.

As I continue in this role, there is still so much to do and focus on. In particular in coming eNews I will be providing updates on legislation, NDIS review and other topics as they arise. We do provide significant input through Down Syndrome Australia, who provide federal lobbying and advocacy on behalf of all people with Down syndrome, and I know there is much more to do here in WA.

Without funding for adult support team, I am very privileged to offer support to families over 18, particularly in the areas of Aging and regression and also at other key times. It is something special and remarkable to be trusted by families, to sit alongside them when the most need help. It continually reminds me why each of us do this work.

Coming up I am taking a fews days off, and then heading to Melbourne for a once a year meeting of the CEO's of the Ds organisations around Australia. As always a huge thank you to our Board, my Team and the community for your commitment and support of DSWA.

Cassandra

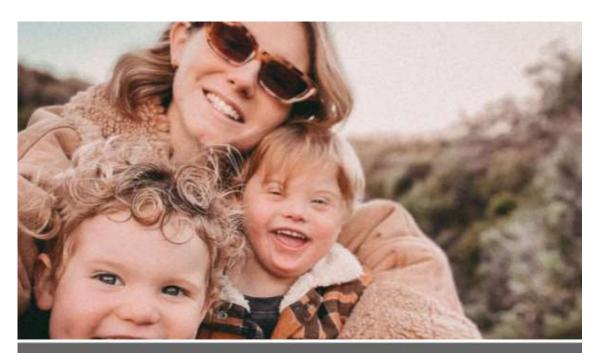
Cassandra Hughes CEO Down Syndrome WA 0432 407 527

### **In Memory of Aimee Clarke**

Aimee lost her life on 21 February 2024, she was mum to Hunter and Wren and passionate supporter of DSWA. Aimee's fund is hoping to raise enough money for counselling support services for parents and carers of loved ones with Down Syndrome.

Aimee's parents Tania and Ian set up a MyCause account in Aimee's memory in the hope of raising money to support Counselling services at DSWA in the future to support parents and carers.

You can donate to Aimee's Memorial Fund at <a href="https://www.mycause.com.au/page/339646/">https://www.mycause.com.au/page/339646/</a>



### In Memory of Aimee Clarke

### **Meetings and Association Events**

20 May - Board Meeting

18 May - DSWA Gala

8 June - Siblings Camp

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

### **Telethon Giving Breakfast**

Cassandra and Danica enjoyed another incredible Telethon Giving Breakfast, celebrating the amazing work and generosity that Telethon supports. We missed Nikki at the event who has such a positive relationship with the Telethon team.

Telethon supports DSWA to provide our Playgroups, Regional Outreach and the Family Support Team.

Congratulations to the 136 beneficiaries and the incredible work you do. We are honoured to be part of the Telethon Family.





### **DSWA Gala!**

■ Get ready to dazzle in black and white! ♥○

As we gear up for Down Syndrome WA's Annual Gala, we're thrilled to announce our theme for the night: "Connecting the Dots"! And what better way to embody this domino theme than through the classic elegance of black and white attire?

We invite all our fabulous guests to dress in their finest black and white ensembles, as we come together to celebrate connection, unity, and the beautiful mosaic of our community. Let's paint the night in the timeless contrast of monochrome magic.

We can't wait to see all the fabulous black and white outfits lighting up the night!

We're on the lookout for prizes and donations to help us create amazing experiences for our attendees and raise funds for our wonderful cause. Whether it's a gift voucher, a product, a service, or anything else you think could add a sparkle to our event, your contribution will make a real difference in the lives of individuals with Down syndrome and their families.

If you or your business would like to donate a prize or contribute in any way, please contact admin@downsyndromewa.org.au as soon as possible.





### **Thank you East Hamilton Hill Primary School**

Students and staff at East Hamilton Hill Primary School had a crazy sock day to celebrate World Down Syndrome Day and raised a total of \$204.70!

Thank you so much to all the students and staff. Every donation helps DSWA continue our vital work in supporting people with Down syndrome and their families.



### **Siblings Camp**

Siblings Camp is here and ready for you to book. We are so excited about this camp and being able to celebrate the amazing contribution, love and support our siblings give. The camp will be full of fun activities, socialising, games, connection and little bit of (fun) research.

Now you might think that a siblings camp is just for the kids – but as an adult sibling you've seen it all. The one day and one night event has been specifically designed to have fun, take on a new challenges, meet or catch up with families you may not have seen for a long time.

Your contribution to your sibling with Down syndrome is important to them, and to your family, and you might be able to share something simple or something amazing to help our younger siblings along their journey.

We would love to have you join us, for the day and dinner, or overnight if you are game. It will be a great weekend of fun, challenges and activities for you and our younger siblings. We hope you will continue to support us, and other families and come along for an adventure.

Supported by the Siblings Research Project at Telethon Kids Institute.

You can book now on Trybooking: https://www.trybooking.com/CQZCN

For the details please see the <u>Fact and Info Sheet</u> and read the <u>Terms and</u> Conditions on Trybooking.



### **WDSD** Fundraiser

World Down Syndrome Day has been an outstanding success this year here in WA.

As many would know a lot of services we provide are unfunded as are our operational costs.

We don't charge membership fees to ensure everyone is able to be a member and receive services.

Please consider making a donation today and sharing the mycause link - https://www.mycause.com.au/page/341760







### Supporting DSWA to support our community



### **Regional Outreach**



Thanks to funding from Telethon7 we have grown our regional outreach program to include the Peel region.

Join the new DSWA Peel Support Group now <a href="https://www.facebook.com/groups/399481359497440">https://www.facebook.com/groups/399481359497440</a>

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 <a href="https://forms.office.com/r/nDxiDRDuDw">https://forms.office.com/r/nDxiDRDuDw</a>



### **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 - <a href="https://www.trybooking.com/CQNGK">https://www.trybooking.com/CQNGK</a> If you need assistance booking please email your details to admin@downsyndromewa.org.au



### **Relationships Course**

### FREE 6-week Relationships course - DATE CHANGE, GREAT RESPONSE

Further to our promotion of the upcoming Relationships workshop, due to initial low numbers, we have changed the dates. The course will run for a period of six weeks on Wednesday evenings commencing on Wednesday 8th May.

Since the change of dates we have had a wonderful response.

### About the Course:

The relationships course is not all about intimacy, it is about communication, what relationships are, what is a healthy friendship / relationship, how to navigate

friendships and the course does cover romantic relationships – what is appropriate, rights to say no, how to approach someone you like.

The course will run 5 weeks with a Speed Dating event at week 6, where participants can practice social engagement, conversation/connection skills, honouring boundaries, and enjoy the opportunity to engage in a safe environment with peers, with the possibility of meeting new friends or potentially someone they might go on a date with.

Please click here to register <a href="https://www.trybooking.com/CQDJJ">https://www.trybooking.com/CQDJJ</a>



### 2024 School Leavers - Life After Graduation

If you, or a loved one is currently in year 12 at school, it is time to start planning for life after graduation.

Register your interest to participate in a 6-week Ready for Work course in November - employment@downsyndromewa.org.au

Prepare yourself for the world of work, with some practical skills and training. The course will include:

- Goal setting
- Identifying the ideal workplace
- Preparing your resume
- Preparing for and looking for work
- Interviews



### **Employment**

The world of Open Employment continues to provide great opportunities for our members who are looking for work.

As mentioned in our last newsletter, we continually reach out to potential employers, offering the chance to learn about our open employment program, in the hope of prospective roles. We currently have many members keen to get into the workforce and our our endeavors are not satisfying our requirements.

### Can you help?

Some examples of the types of roles we are looking for include;

- Garden/outside or warehouse work in the Wembley/Claremont/Nedlands area
- General office work and general hospitality/café work in Roleystone,
   Bateman, Kardinya, Duncraig, Ravenswood and Chidlow or areas nearby
- Warehouse work in Rockingham area

If you have a business or know of a business that you can introduce us to, please reach out to Stephanie at employment@downsyndromewa.org.au

### **Family Support Team**

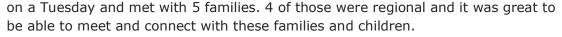


It's been an exciting month as we have welcomed new babies and families into our wonderful community. Our dedicated Family Support Team has been busy extending a warm welcome to these new members through phone calls, in-home visits, and hospital visits. We understand that the journey of welcoming a new member into the family can be both exciting and overwhelming, and we're here to offer our unwavering support every step of the way.

It's truly heartwarming to see our community expanding with each new bundle of joy and we look forward to welcoming them into our playgroups when they are ready.

We understand that families can often find themselves in challenging and confronting situations when it comes to advocating for their children's needs, particularly in educational and medical settings. Nikki has been working closely with some families to navigate complex systems and ensure that their children receive the support they deserve.

In addition to the regular Thursdays at PCH, Nikki and Danica did an extra day, at request of the community,



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

### **Resource Spotlight**

The Adult Down Syndrome Center is a health care centre in Illinois, USA. They have an extensive Resource library for people with Down syndrome, Families & Caregivers and Health Care Professionals.

The resources cover everything from Healthy Lifestyle, Social Skills, Sleep and videos such as How to Put Your Hair Into a Ponytail.

https://adscresources.advocatehealth.com/

### **Hand In Hand - Crossing for Inclusion**

Last year, we witnessed the first-ever Crossing for Inclusion initiative – where more than 1000 people joined hands and hearts in solidarity by crossing the Matagarup Bridge for an inclusive future.

We invite you to be part of this year's event to shine a light on the importance of disability inclusion. We're not just crossing a bridge; we're symbolising the bridges we can build, through the great game of football.

Join us on Friday night before the roar of the crowd rises for the round 9 Purple Hands Foundation game, where the Fremantle Dockers will clash with the Sydney Swans in a spectacle at Optus Stadium.

Date: Friday, 10th May 2024 Time: 4pm for a 4.30 pm start

Location: Matagarup Bridge, Perth, Western Australia (gather on the East Perth end

of Sailani Dve).

This is more than an event; it's a movement. A celebration of the diversity that defines us and the common goals that unite us. Together, we'll demonstrate that our community thrives when everyone is given the chance to shine.

Feel the warmth of shared stories and the joy of communal achievements as showcased by 7News. This initiative brings together WA All Abilities, Purple Hands Foundation, Starkick, the WAFC, the AFL, and the Fremantle Dockers.

Register at <a href="https://www.allabilitiesfooty.com.au/hand-in-hand">https://www.allabilitiesfooty.com.au/hand-in-hand</a>



# **CROSSING FOR INCLU**

MATAGARUP BRIDGE













For more information head to www.allabilitiesfooty.com.au



The preliminary program has been released. See all the details here <a href="https://www.wdsc2024.org.au/preliminary-program.html">https://www.wdsc2024.org.au/preliminary-program.html</a>

Time	Monday 8 July 2024 Pre-congress	Tuesday 9 July 2024 Pre-congress		Wednesday 10 July 2024 Day 1	Thursday 11 July 2024 Day 2	Friday:12 July 2024 Day 3
09:00-09:30		Health Professionals & Resogrehers Day Meeting	File Congress Self. Advocates Facum	Welcome ceremony	Day 2 starter	Day 3 starter
09:30-10:30					Keynote Session Sir Robert Martin Ms Chariotte Woodward	Reynote/Panel Session - hearin from adults with Down syndrome Mr Alesteir McEvrin AM Chair: Prof Roy McConkey
10:30-11:00				Morning tea		
11:00-11:55				Keynote Session Dr. Brian Skotko MD, MPP	Choice of Concurrent Sessions	Chaice of Concurrent Sessions
12:05-13:00				Choice of Concurrent Sessions	Choice of Concurrent Sessions	Choice of Concurrent Sessions
13:00-14:00				Lunch		
14:00-14:30	Pse-Congress Self Advocates - Meet & Greet			Posters	Posters	Posters
14:30-15:30				Choice of Concurrent Sessions	Choice of Concurrent Sessions	Keynote Session Prof Nora Shields
15:30-16:00				Afternoon tea		
16:00-17:30				Plenary Session Dr. Catherine Franklin Prof. Ernst Wolvetang Dr. Kathy Cologon Prof. Iva Stroedeya	Plenary Session A/Prof Jauneak Chowla MIT Alana Down Syndrome Or Katle Novak Prof Cameron Passell	Closing ceremony
Evening				Welcome Reception	Poster Reception	Congress Diriner



### **Playgroup South**

We've had a great couple of weeks getting back into our second term we've had fun with playdough and now we are getting stuck into our Mothers day crafts. Our mums made some clay earrings to go into our pamper gift bags xx

See you soon! Renee and Nicole



### **Playgroup North**

Term two is back for Playgroup north. We hit our term off with a paint and sip session for our kids. Our group enjoyed creating their art with watercolours and sipping on their juice and water in the sunshine.

Danica and I have a wonderful term two planned filled with fun sessions like dance workshops and Messy Mat Perth play. Thanks to Telethon we are able to provide these workshops to playgroup to help our kids development in a safe and fun environment.

We can't wait to see all our families and always look forward to welcoming new members to our group.

Tracy and Danica playgroup@downsyndromewa.org.au







If you loved the Circus Skills Workshop, get ready for our next exciting event: the Slime Workshop only two weeks away! Dive into a world of colourful, gooey fun as we explore the art of slime-making!

Date: Saturday 4 May Time: 12:00pm - 2:30pm

Location: Vincent Community Centre, 99 Loftus Street, Leederville

Price: FREE for KiDS club Member \$5 for siblings

Get your tickets here: <a href="https://www.trybooking.com/CQFYU">https://www.trybooking.com/CQFYU</a>

Join us for an unforgettable day of creativity and mess-making! From glittery galaxies to fluffy clouds, you'll craft your own unique slime creations to take home! Don't miss out—secure your spot now for another amazing event with Down Syndrome WA Kids Club!



What a fantastic afternoon we had at our Circus Skills Workshop! All the participants had an amazing time learning new skills and putting on a show that left everyone entertained and inspired.

A big shoutout to our brave volunteers who took centre stage and wowed us all with their resilience and newfound talents! Their performances were nothing short of extraordinary, and they had the crowd cheering all the way through!

It was heartwarming to see such a great turnout from our KiDS, siblings, and parents. Everyone was so excited to have a go at juggling balls and diablos, plate spinning, hula hooping and so much more. Thank you all for joining us and making this event truly special. Your support and enthusiasm added to the incredible atmosphere and levels of fun had for the afternoon.

A huge thank you to Joe from Suitcase Circus for his fun, energetic, exciting and inclusive approach. He brought so much care and support, and his high energy kept everyone engaged and entertained. His silliness, knowledge and sneaky little life lessons made the workshop an unforgettable experience for all!

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 Painter at kidsclub@downsyndromewa.org.au for registration details.





Friends 4 Life are going to bowling and laser tag! Book now at <a href="https://www.trybooking.com/CRFQC">www.trybooking.com/CRFQC</a>.

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



Our Friends4life crew went to Jurassic Kingdom for this month's social event.

I do believe this was the favourite activity to date. Before we had even left the park, I was being told how much fun was had, how some had the best day ever!

We saw so many dinosaurs, big, small, babies in eggs and the biggest T-rex! We checked out the fossil pit where you could dig up fossils, we walked through the dino lab, slushies were enjoyed, and we maxed out on all our rides!

Don't worry parents the kids made the most of their ticket! It was a very wholesome afternoon watching friends laugh together, see friends who they haven't seen for months and watching the group have so much fun.

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 friendsforlife@downsyndromewa.org.au or 0422 795 160.









The next Aim High Adventure is a Dolphin Cruise in Mandurah! Book at <a href="https://www.trybooking.com/CRFPP">www.trybooking.com/CRFPP</a>

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



This month the Aim High Club went to the Telethon Outdoor cinemas for their social event. We watched Ghostbusters under the stars, for one of the last movies of the season. It was great to see such a great turnout.

Everyone said they had a great time, ate some pizza then enjoyed the movie. It was a little chilly, but it was lovely to see the boys bonding and creating those new friendships.

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!

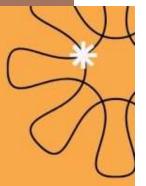
### Take Care

Laura - aimhigh@downsyndromewa.org.au or 0422 795 160



Aim High

## UPCOMING EVENTS





### Mandurah Dolphin Cruise

Sun 2nd June | 11am-2pm | Cruise, lunch, ice cream



### Kings Park Lightscape

Sat 15th | 5pm -8pm | Sunset, food trucks, trail



### Arts & Crafts Day

Sun 28th | 2pm -5pm | Location tbc but central

### \*Each event will be published once bookings are open

\*\*You must be registered with DSWA to attend the events, if you are interested in these events but not a registered member please get in touch with us

### **Compliments and Complaints**

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











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**