
Latest News from Down Syndrome WA



CEO's Corner

What a great March we have had!

This month we were fortunate to be able to join a webinar hosted by Down Syndrome QLD with Dr Cathy Franklin who talked about Down Syndrome Regression Disorder. Dr Franklin has experience and research with patients

diagnosed with DSRD, and she provided clear and helpful information for the families who attended. Please follow this link to watch the presentation - <https://www.youtube.com/watch?v=Tj2p1dOAP1k&feature=youtu.be> If you have an interest in DSRD please contact myself or our Chair Nia Parker. The DSRD family group meet about every 8 weeks, with another meeting at the end of April.

The Annual Teacher Professional Learning day attracted 48 teachers and assistants to the full day workshop. The event was available both in person and online and was a fantastic day with great speakers. It was very inspiring to meet a group of education professionals committed to providing the best learning and social environment possible for our members. Congratulations to Nikki and Rachel from our team for putting the event on and managing the technology. This was a great event and we have already been requested to run it again later in the year.

March provided us with the opportunity to celebrate our community and raise awareness of Down syndrome with World Down Syndrome Day, 58 people had a wonderful morning overlooking the Swan River on the balcony of our new office. We had fabulous speeches from Sian King about the SLES program she has been undertaking, and from Brayden Wake (working at WireAid) and Gabriel Coles who works at DSWA. We also had a quick impromptu speech from the inimitable Joshua Ford about his love of his role at the Perth Mint. A huge shout out to those that raised funds for DSWA and especially to the team at the Perth Mint that raised over \$1800 for DSWA.

In the evening of the 21st, I was honoured to be asked to chair a researchers panel with the Telethon Kids

Institute (TKI) It was a great presentation and will soon be available on our website. The Panel consisted of DSWA Chair Nia Parker (online), Dr Colin Derrick Consultant Paediatrician at Perth Childrens Hospital, Dr Sebastien Malinge, Head of Translational Genomics in Leukaemia at the and Profession Jenny Downs, Program Head of the Development and Disability, both at TKI. It was a great insight into the value of research to our community and how research is able to influence and improve how we deliver our services and design our programs.



On Friday 24th Nikki and myself attended the annual Telethon beneficiaries breakfast, it was a beautiful, heartwarming event, recognising the incredible work of 107 beneficiaries in 2023. DSWA is enormously grateful for the incredible support we receive from Telethon each year to provide Family Support by phone and in person, and for funding for regional outreach and both developmental playgroups. Thank you to all of our team that deliver

the work funded by Telethon, the work you do matters.

Whats coming up for the Community (and our team)

The 2023 Gala is approaching fast. We hope that members will join us for this beautiful event, themed "Colour and Connection", representing Diversity, Equity, Inclusion and Belonging. I will shortly be inviting a group of our young adults to come and make table decorations with me in late April and I am really looking forward to that. The Gala this year is to be held at the WA Italian Club, early bird tickets are \$80 per person for a three course meal, drinks are available for purchase at the venue. A number tables have already sold or been reserved. This year you can book online, choose your table from the seating plan, and each of your guests can login in and join your table and pay for their own tickets. We hope that this system will really help our members and keep it simple. Please join us for this event, we are looking forward to our 4th Annual Gala Dinner.

World Congress

It is time for us all to start planning for the World Down Syndrome Congress being held in Brisbane from 9-12 July 2024. A little over a year away, DSWA will be seeking sponsorship opportunities to sponsor members with Down syndrome to attend the conference. If you have any contacts that could support the costs of sending some of our members to the Congress, I would love to hear from you.

Changes

We have had two of our fantastic staff have to make some life changes this month, our fabulous Adult Social Group Coordinator Dannie, has recently had to step down from her role as Aim High coordinator due to family commitments however we are so fortunate to have Dannie staying with us to do some casual work and continue with Support Coordination. The lovely Claire, our Friends for Life Coordinator for the past 2 years has also recently resigned to pursue other commitments. I am grateful to both Claire and Dannie for their work with DSWA. I have taken the opportunity to review both programs we are keen to secure one coordinator to run both programs – if you know anyone who may be interested in working with our adults and teens, in this critically important role, please email a cover letter, and CV to ceo@downsyndromewa.org.au.

Aim High and High Flyers Adult Social Groups

Over the past 12 months, we have trialled a great number of suggestions that were put forward by families, such as mid week events and getaways, more regular getaways and more events each month. Unfortunately these changes have not been successful and have not been appealed to the broader Aim High community, unfortunately we have had to cancel 9 events so far this year, which incurred planning and coordination costs to DSWA.

We will be reverting to one Aim High event a month and one Getaway every 2 months. We will also be offering "We Design" events, where you tell us what you want to do with a group of friends and we will arrange it for you. Until we can rebuild our numbers at these events and garner more support we will only have one event per month which will be a combined event for all adults over 18 years.

I want to thank the community for the amount of engagement we have had with you so far in 2023. Personally, I have been able to connect with a large number of families of adults with Down syndrome that either have not been members for a long time, or had not previously reached out to the association. It is fantastic to see the increased engagement across the life span of our members, and I am excited about what we can create for our adult families to follow on from our very successful junior programs. As always if you have any suggestions or feedback I welcome your calls. Our housing workshop in partnership with Nesti should be very informative around steps toward independent living and some of the options and we hope you can join us.

Cassandra

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

Webinar – Down Syndrome Regression Disorder

Dr Cathy Franklin discusses regression disorder in young people with Down syndrome. This webinar was hosted by Down Syndrome Queensland and attended by a number of WA members, CEO and Board Chair.

Find the webinar
at <https://www.youtube.com/watch?v=Tj2p1dOAP1k&feature=youtu.be>

Upcoming Meetings and Association Events

24th April Board Meeting
22nd May Board Meeting
27 May DSWA Gala Dinner
19th June Board Meeting

DSWA Gala Dinner

We are so excited that we already have a number of tables for this years gala already booked.

Remember to get in early to get your Early Bird tickets and reserve the table you want.

HOW TO BOOK

This year Trybooking has made it even easier. You can book to sit on the table you want.

If you want to reserve a table so different guests can book to sit on your table, please call us to reserve your preferred table number. All reserved tables must be fully paid by 28 April.

Then... your guests can go on and book the table you have chosen.

If you are booking for a whole table or others you are sitting with, you will need Names and Dietary Requirements for all guests.

If you dont have a group to sit with, choose your preferred table and it will be filled with others in the same situation.

We can't wait to share this fabulous night with you all.

Book here: <https://www.trybooking.com/CGXUF>

The seating plan is below and indicates those tables that are already reserved or sold.



Aim High - We Design

Do you have an idea for an event with a group of friends?

Contact us and we can arrange your custom Aim High event -
aimhigh@downsyndromewa.org.au or 6182 3690.



+ WE DESIGN

- Families work together with their young person to develop and design their own activities and holidays away.
- DSWA will help support families with ideas, staff supports, venues and activities that their young person might like to experience.
- Aims to increase the range of available choices, provide supports that enable new opportunities and improve ability
- To make decisions independently.

Member Story

Earlier this year Naomi Lake was nominated for citizen of the year.

Naomi has just returned from a trip to Canberra where she was advocating for better educational outcomes for people with Down syndrome.

She met the Prime Minister at Parliament House and had the honour of having afternoon tea with the Governor General at Government House.

Naomi also had a two hour meeting, spoke to the education people and the Minister for Social Services, attended a advocacy forum discussing the Disability Strategy and put a strong case forward for inclusion.

She had a very busy time.





Book for the Housing Workshop at <https://trybooking.com/CHGAN>

Housing Workshop

PRESENTED BY NESTI

Topics covered

- SDA funding
- SDA Housing
- Support in the home
- SDA Provider

Tuesday the 18th of April

Time: 7:00 pm

Link:

<https://www.trybooking.com/CHGAN>



CONTACT - DANNIE

Phone: 0422 795 160

Email: dannie@downsyndromewa.org.au



Book for the Housing Workshop at <https://trybooking.com/CHGAN>

HBF Run for a Reason

HBF Run for a Reason happens on Sunday 21 May 2023. This amazing event allows runners to and teams to designate a charity to benefit from their efforts. Follow the link below to:

- enter and run to raise funds for DSWA or
- donate to a team.

<https://runforareason23.grassrootz.com/dswa>

WE CAN BE YOUR REASON

FUNDRAISE FOR DSWA DURING THE 2023 HBF RUN FOR A REASON

<https://runforareason23.grassrootz.com/dswa>

Down Syndrome
Western Australia

Enter or make a donation at <https://runforareason23.grassrootz.com/dswa>

SOCIALS!

DSWA's Social pages have up to date information between newsletters.

We have a range of pages, including our public facing page, and specialty groups for DSWA Family Network, Social Groups; Aim High, Friends for Life, Kids Club, Playgroup, DSWA Employment, Education Support and four rural pages for Rural and Remote, South West, Mid West and Great Southern regions.



New DSA Resource – Becoming a Teenager

Becoming a teenager is an exciting time in a young person's life. This age can also bring administrative challenges for parents and supporters. The latest DSA resource covers key administrative tasks that families and supporters can assist with during the teenage years.

Find the resource at https://www.downsyndrome.org.au/wp-content/uploads/2023/03/DSA_Becoming-a-teenager_WEB.pdf

SUPPORT COORDINATION

My name is Dannie and I am part of the Support Coordination team at DSWA. My role is to support people to make the best use of their NDIS plan.

I can assist to build capacity which will help you:

- understand and use your NDIS plan to pursue your goals,
- connect you with NDIS providers, community, mainstream and other government services,
- build your confidence and skills to use and coordinate your supports,
- help people to make the best use of their supports in plan.

I can also provide quotes for DSWA programs, to be used as supporting evidence at NDIS reviews.

For further information or to discuss please contact me on 0422 795 160 or support_coordination@downsyndromewa.org.au



World Down Syndrome Congress 2024

The World Down Syndrome Congress will be happening in Brisbane from 9 - 12 July 2024. Over the coming months we will be releasing information on the program, registrations and how you can get involved.

We look forward to seeing you in Brisbane!

Register your expression of interest on the WDSC website to stay up to date:
<https://www.wdsc2024.org.au/>

Telethon7 Beneficiaries Breakfast

Thank you telethon7 for an amazing morning at the Gift Giving beneficiaries breakfast.

Such a magical morning listening to speeches from people who have benefited from support from Telethon Beneficiaries.

DSWA is one of the 107 beneficiaries to receive funding for 2023.



WORLD DOWN SYNDROME DAY

MORNING TEA

DSWA celebrated the day with a morning tea at our new office. It was so great to see so many of our community attend. From young to old, new families and families that have been members for a long time.

We heard speeches from 3 of our members and enjoyed some lovely morning tea over looking the river. Thank you to everyone who came to the event and to our community for sharing and increasing awareness of Down Syndrome across the world.



FAMILY PICNIC

The DSWA community ended our WSDS celebrations with a family picnic.

It was a beautiful afternoon of catching up with old friends and meeting new ones. We were so excited to welcome 3 new families to the community.



Regional Outreach

DSWA Great Southern

DSWA Great Southern support group enjoyed a Saturday afternoon catch up full of smiles and laughter.

The next catch up is on 22nd April, Eyer Park. Contact DSWA for further information - admin@downsyndromewa.org.au



DSWA Mid West Support Group

DSWA MID WEST SUPPORT GROUP



Join us for an afternoon BYO picnic, at Stow Gardens on the Geraldton Foreshore, while we enjoy the sounds of Sundays by The Sea.

A chance to get together and catch up before Easter.

Please bring your own food and drinks and a picnic blanket or some chairs to sit on.

When: Sunday 2nd April 2023

4.00pm - 6.00pm

Contact: Emily 0438 537 278



PCH Outreach
DSWA's Senior Coordinator
Nikki Schwagermann is at PCH every Thursday.



Contact Nikki for a visit
and support on
0480311739
or
nikki@downsyndromewa.org.au

PROUDLY SUPPORTED BY
telethon 7

Educating students with Down Syndrome

DSWA held our annual 'Educating students with Down Syndrome' professional learning day today.

48 Teachers, Education assistants and school administrators joined us both face to face and online.

Cassandra and Nikki from DSWA were joined by presenters, Kirsty, Kelsey and Yvette. Rachel Parker, one of DSWAs ambassadors, did a presentation on her journey of schooling and what inclusion means to her.

Thank you to all of the Teachers, EAs and administrators for giving up a day of your valuable time. Not only are you making a huge positive impact on your student with Down syndrome, but all of their classmates, school and community.



Make your booking at - <https://www.trybooking.com/CGXUF>

4th Annual

DSWA GALA DINNER

Come and join us for a colourful
night of dancing and fun

Saturday 27 May 2023

WA Italian Club - Fitzgerald St West Perth

6.30pm - late

\$90 per person - Three course meal
(Early bird tickets \$80 pp CLOSING 28 APRIL)

Live Band - The Drycleaners

Bar available at venue



Down Syndrome
Western Australia



Make your booking at - <https://www.trybooking.com/CGXUF>

PLAYGROUPS

NORTH METRO PLAYGROUP

Wow what a fun and bright term we have had at North Metro Playgroup. Danica have been over the moon to see some many families each Friday. Our kids have really enjoyed the themed playgroup sessions this term. We explored different textures with our sensory Autumn day and brought out all our clovers and green craft for St Patrick's Day.

We joined together to celebrate our kids, families and our Down Syndrome Community for World Down Syndrome Day. Our kids enjoyed decorating yellow and blue cookies that they could take home.

As we wrap up this term with our Easter celebrations we look forward to more fun in term two. It will be filled with a messy mat session from Messy Mat Perth and an informative session from a guest Speech Therapist. We hope you can join us for all the upcoming fun.

Tracy and Danica

playgroup@downsyndromewa.org.au



SOUTH METRO PLAYGROUP

Happy World Down Syndrome Day everyone! At Playgroup South we celebrated all things T21.

We painted our pots yellow and blue and finally planted our sunflowers. We also made yellow and blue macaroni necklaces and dressed up in our tutus.

Hope everyone had a great day celebrating our beautiful babe's.

Renee and Nicole

playgroup@downsyndromewa.org.au



Kids Club

The KiDS club enjoyed a fun filled afternoon at Capoeira for our March event. The workshop was run by one of our own DS families!

Capoeira is an inclusive and holistic Brazilian martial art that integrates elements of dance, acrobatics, music and culture. The kids learnt some of the basic Capoeira movements and had a go at playing the traditional musical instruments through engaging games and exercises.

After the class families enjoyed a catch-up over afternoon tea. Thank you again to Lee and Mariana for such an amazing event!

In the coming months we have a picnic at the zoo, a dance class, and a drumming workshop. For more information and to sign up to the events head to the KiDS Club calendar https://docs.google.com/document/d/1SEfA4cro7BU3kN5dVOpDM_NpcLssK5iUuwsEyEtBaX8/edit?usp=sharing

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

Fun Time - ✨



Friends For Life

Book at <https://www.trybooking.com/CHCIB>

Friends for Life



Date: April 16th - Sunday
Venue: Royal Perth Yacht Club
6 Australia II Dr, Crawley
Time: 9.15am-12.30pm

Register here

<https://www.trybooking.com/CHCIB>
(RSVP by 9/4/23)

Friends for Life is a NDIS service. If you do not have a current Service agreement with DSWA, please email friendsforlife@downsyndromewa.org.au before registering for the event.

Book at <https://www.trybooking.com/CHCIB>



DISCO AND KARAOKE

FRIENDS FOR LIFE

SAVE THE DATE

MAY 6TH

5-8 P M

Venue TBA

If your child is not a
Friends for Life member yet, please email
friendsforlife@downsyndromewa.org.au to register
them so they don't miss out.

AIM HIGH

See our upcoming events below!

Fremantle Getaway - book at <https://www.trybooking.com/CFWNE>

JOINING FORCES – EXPLORE FREMANTE GETAWAY



Friday 28 April 2023 10:00 AM -
Sunday 30 April 2023 4:00 PM



East Perth Train Station or advise if
you want to meet at the venue

CONTACT EVENT ORGANISER



AIM HIGH AND 30+
**YOU MUST HAVE PHOTO ID AS
PROOF OF AGE.**

BOOK NOW

<https://www.trybooking.com/CFWNE>

**Booking will close on the 31th march 2023
If we do not receive enough interest the
activity will be cancelled
(min 8 members)**

**For more information please contact
Dannie on 0422 795 160
or
email:
aimhigh@downsyndromewa.org.au**



Fremantle Getaway - book at <https://www.trybooking.com/CFWNE>

High Tea - book at <https://trybooking.com/CFWLK>



Bite by D - High Tea

Sunday the 29th of April 11:00 – 5:00

Savoury

House-made cheese and chives scone with butter
Beetroot and cream cheese tart with spiced dukkha
Gourmet salad cup with our house-made dressing
Petit croissant with pesto, cheddar, and rocket



Dessert

Summer burst – Coconut dacquoise with mango and raspberry mousse and passionfruit jelly (GF)
Berry financier with toasted meringue and freeze-dried raspberries (GF)
Dulce de leche brownie with chocolate crumb (GF)
Lemon meringue tart
Gluten-free, Nut-free, Dairy-free and Vegan options available at request

TryBooking: <https://www.trybooking.com/CFWLK>

<p>Goals</p> <p>Social interaction with peers - Building friendships and relationship in the community. Having fun with peers and communicating with each other on the days events;</p>
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High Tea - book at <https://trybooking.com/CFWLK>

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Superhero Disco - book at <https://trybooking.com/CFWLY>



Superhero Disco
Friday 14th of April

Where: Perron Place
61 Kitchener Ave, Victoria Park WA 6100

Time: 5:00 pm- 10:00 pm Dinner included
Or
7:00 pm - 10:00 pm Attend Disco only

[Try booking link](https://www.trybooking.com/CFWLY)
<https://www.trybooking.com/CFWLY>
(booking essentials)

Superhero Disco - book at <https://trybooking.com/CFWLY>

As always please get in touch if you have any questions or ideas for our Aim High Program.

Dannie
0422 795 160
aimhigh@downsyndromewa.org.au

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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