



Latest News from Down Syndrome WA



CEO's Corner

Happy 2024! I hope that this year brings you and your family a great deal of joy, good health and success.

We are very excited about what's to come in 2024. We have some fantastic things happening and are looking forward to engaging with more and more of you, getting your feedback and celebrating with you.

So, here we go, some of our fantastic plans for 2024.

The DSWA Aging Project, will be looking to create at least 4 member based social activities for our over 40's members. We will be seeking you out, asking for your input, and hoping to meet with more of you this year. It is our focus to build a robust, valuable and essential service around aging for people with Down Syndrome. We don't have all the expertise yet, but it is building, and we hope you will be a part of helping us to grow the services essential to you.

Our 18-30's group, has a wonderful new coordinator. Laura who is just a natural with our members, and is so organised and enthusiastic. Laura will be leading our groups social activities and will be reaching out to all of you to work out how to make Aim High and Getaways exactly what you want. We will also be looking for your input on how to make these events relevant and exciting to you. This is an important phase of life and having fun, learning new skills all whilst developing your communication skills which supports your best future. Our numbers have been down with a lot of changes over the last 2 years, but we ask you to give us another chance, it would be amazing to see our group numbers at 20 or 30 so you can truly engage with others, form new friendships and work together to learn new skills. Aim High is an important program, and to make it effective for members, each activity ideally has a minimum of six people attending.

We are also very keen to know what else is important to you other than the social program.

Relationships Course and Speed Dating Event; we have been planning this course for a long time! Recently our counterparts in Queensland ran a very successful Relationships course, and followed it with a speed dating event. Now, following their success we will be running a very similar event here in WA. It is currently scheduled for late April/May 2024. There is a lot more to come on this, and there will be an information session for parents before the beginning of the course. We know there is a lot of interest in this from our members.

For the Teens group, there is a lot happening this year, with some very exciting news!! We have successfully secured funding to hold a one-night Teens camp. The camp will be held locally here in the Perth area at one of the adventure camps. It will be funded, making it affordable for all families. We will announce a date and location very soon and we hope you can join us. We will also be looking for a group of volunteers to assist at the camp, preferably young adults 18-30 who can support the staff at the camp. The camp is supported by funding from Telethon, and we are so grateful for their partnership. Friends for Life is also run by Laura who has led a very successful January School Holiday program as her first activity. We are looking to get feedback from our teens on what activities you want to do this year. Please provide your feedback so Laura can develop the best program possible.

Kids Club run by Siobhan had some fantastic activities last year. This wonderful social program, funded generously by the Stan Perron Charitable Foundation is critical to maintaining links and friendships made at playgroup that will benefit our little people as they grow into their teens and adulthood. Kids Club is also so important for parents to continue / develop the networks of friends and families on the same journey.

Kids Club will continue to provide monthly activities and I know Siobhan has asked for your feedback. I am looking forward to joining you at an event this year to catch up with you all.

Our two wonderful **Playgroups** run by Renee and Tracy and supported by Nicole and Danica go from strength to strength and this year will again be offering dance, music, arts and crafts, presentations for parents and all the love and connection that is formed during the playgroup years. Please remember to book in for playgroup and this year for those that wish to, we will be offering term payments to make it easier.

Social groups can only be maintained if they are supported, and as we are learning from our adult cohort, they wish those networks had been available to them as their children grew. Please support the programs our team work so hard to put together for you.

Family Support, had a very busy year with a 18 new babies welcomed to the membership and 15 new older or returning families joining us as well as supporting all programs, workshops activities and events. We are delighted to announce that through the generosity of Telethon funding, we have been able to appoint a second family support officer and we welcome Danica Bowes to the family support team. Danica will be known to many of you as the Playgroup assistant at the Metro playgroup and of mum of the gorgeous Amelia. We are so pleased that Danica will be joining us two days per week.

Admin Support is now desperately needed for the association. For the past 14 months we have been without admin support, and now with the growth in our programs, must return to having a part time admin. We have now finalised our initial recruitment and are moving on to shortlisting and interviews.

With more exciting news, I have also been able to secure funding for a **Siblings Camp**. I am so excited about this. We see the love and support our siblings give to our members and we want to say thank you, to understand more about your siblings' journey. I can't wait to share more about this camp, but it is going to be an amazing, one night camp, again at one of our adventure camps in Perth.

DSWA was asked to lead a **National Grant application** for Employment on behalf of the Federation members and we are delighted that the grant has now been submitted. We wont know the outcome later in the first half of the year, but we will keep you updated. We are hopeful of securing funds for 2 years from Jul 2024 to continue to grow and development the employment program.

Something that has been in the planning for some time has been the creation of a formal **Down Syndrome WA Advisory Network**. I am thrilled that this will pilot program has been funded by Synergy. See my article later in the eNews for details on what the advisory network is, who it applies to and how to apply. Personally, I am very excited to lead this project and work with our adult members to more deeply include them in the association, working alongside them as they become strong self-advocates for people with Down syndrome in WA.

Celebrating and Socialising the DSWA Gala dinner has been booked – Saturday 18 May 2024 at Mineral Resources Park, Lathlain there is a maximum of 270 people at the venue and tickets will be on sale now. The nights theme is Connection and this year demonstrated by Dominos and their impact as each of them connect. So black and white is the theme and it is going to be an amazing night again supported by the fantastic Dry Cleaners band. Tables for the Gala are being reserved early, so jump in soon and book your tickets. We are again supported by the amazing DryCleaners Band and Dylan J King music to have us filling the dance floor.

And finally – **World Down Syndrome Day 2024** is going to be a fabulous event this year and will highlight "In the Arts". We have a lot of members that are

engaged in the Arts in some way through dance, drawing and painting, writing, song, acting, public speaking and so much more. We have an advertisement later in the Enews calling for expression of interest from members who are involved in the arts in some way. We will be holding an awareness and fundraising event for key stakeholders on the evening of the 20th March showcasing the artforms of our members, with an opportunity for members to participate, perform and show their work. This exhibition will be continued through to Morning tea on World Down Syndrome Day – 21 March 2024 to which members are invited and will be followed by a wonderful Family Picnic on Saturday 23 March.

I am excited for our team to deliver this action packed schedule of activities, events, workshops, social programs, employment programs for you this year. With a very small team it is quite a feat to deliver such a full program for you.

Please remember to send in your member stories for the eNews. We really want to share your stories in the eNews. Your stories inspire and support others.

As always, I am delighted to be your CEO and look forward to working with more of you again this year. to Cassandra

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

Some Sad News

It is with deep sadness that we pay tribute to two young members of our community who recently lost their lives.

Roisin was just 20 years old when she suddenly lost her life in her sleep. Roisin was a beautiful active member in Geraldton in the midwest region, where the community has been deeply impacted by her passing. Our thoughts, support and love to Jo, Roisin's mum who is also a very active member in the Mid West.

The second tragic loss, was of little Jeorge, just 9 months old. Mum Jazman, Dad Jacob and little Jeorge, fought so bravely and did everything possible for him. Our love and support will always be with you.

Losing our loved ones is so painful. Our DSWA community will always hold Roisin and Jeorge's families close to our heart and you will always be part of our community.

DSWA Gala 2024 - Save the Date!

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

Tickets are \$110 per person, Get in quick for the Early Bird special at just \$90 per ticket which closes 6 March.

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

You can again choose your table - check out the floor plan! We will keep updating the floor plan on our social pages and on Trybooking.

We will again be supported by the amazing The Drycleaners Band playing all of our favorite tunes 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



Board News

The past few years have seen a number of changes at Board level and I thank all those who have served on the Board, in whatever capacity.

Following our AGM in October only one member was Nominated and appointed-Jemma Henderson as Treasurer. Jemma was coopted earlier in the year and has been an excellent addition to the board.

2 Directors stepped down at the AGM and no further nominations were received. In accordance with our Constitution, the board decided to coopt 3 new Directors to enhance the collective skills of the Board.

Jason King is the father of Sian, a young lady who featured in our last newsletter, following her success in our Employment Programme. Jason has a wide range of business experience to offer as well as lived experience.

Aaron Crowther is an experienced company director, having worked extensively in public relations and organisational design.

James Shaddick works in the area of organisational governance and risk, with a strong focus on strategic planning.

The new Directors have been co-opted until our next AGM, at which point they will stand for election.

We undertook a review of our Strategic Plan in December and will be doing an Organisational Risk Assessment in February.

2024 augers as an exciting year for DSWA and I look forward to working with my fellow Board members and staff to deliver some wonderful outcomes for our Down Syndrome community.

Nia Parker Chair (DSWA board)

Meetings and Association Events

26 February - Board Meeting

18 March - Board Meeting

20 March - World Down Syndrome Day Stakeholder function

21 March - World Down Syndrome Day

23 March - World Down Syndrome Day family picnic

15 April - Board Meeting

20 May - Board Meeting

18 May - DSWA Gala

17 June - Board Meeting

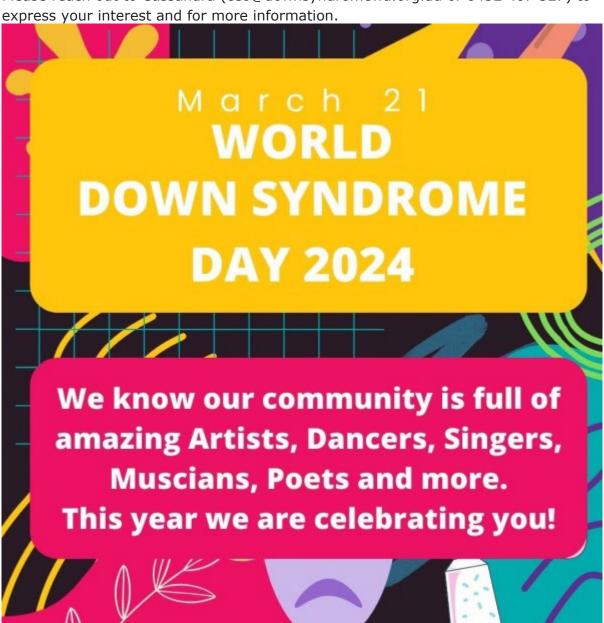
World Down Syndrome Day

This years World Down Syndrome Day theme is "Breaking the Stereotypes". So we have decided to celebrate our members living with Down syndrome working in and enjoying the Arts in all its forms.

If you are an actor, painter, you draw, dance, sing, maybe you write poetry, like to public speak, crochet amazing things we would love to hear from you. We will be having an exhibition for stakeholders on 20th March in the evening and a Member function on the 21st of March.

This will be an opportunity for you to showcase your work. We would also like to celebrate your work with 21 stories over the 21 days of March

Please reach out to Cassandra (ceo@downsyndromewa.org.au or 0432 407 527) to





Down Syndrome WA Advisory Network

We are very excited to announce the launch of the inaugural Down Syndrome WA Advisory Network. The Advisory Network will provide an opportunity for adults living with Down syndrome to undertake a leadership program, develop skills at working together on a committee, and becoming powerful self advocates for others in WA living with Down syndrome.

We are very grateful to SynergyWA for the grant received, to run this pilot project. Applications for the Advisory Network are open to Adults (18+) with Down Syndrome who would like to advocate on behalf of others. The group will support the board and the CEO, giving their opinion, thoughts and feedback on issues that relate to them.

To apply please send in a Video where you give your answers to these three questions.

- 1. Why do you want to join the advisory network?
- 2. Name something you would like to discuss with your community.
- 3. What is something you are passionate about?

email your video to; ceo@downsyndromewa.org.au

The below links tell you more about the role.

Easy Read about the Advisory Network https://www.downsyndrome.org.au/wa/wpcontent/uploads/sites/11/2024/01/DSWA-AN-Governance-Easy-Read.pdf

Full Governance Document for Advisory Network https://www.downsyndrome.org.au/wa/wpcontent/uploads/sites/11/2024/01/DSWA-AN-Governance-Web.pdf





Would you like a seat at this table?

Apply now to become a member of the first Down Syndrome WA Advisory Network



Educating Children with Down Syndrome - Professional Learning Day

DSWA will host our annual professional learning day for teachers, educational assistants, and school administrators on Friday 23 February 2024. The event is being held both in person and online to allow regional education staff to attend.

It will include presentations from DSWA staff and guest presenters who are specialists in the areas of classroom adaptations, pre-reading and numeracy, boundary setting and protective behaviours and understanding behaviour and classroom management.

This is an outstanding day, providing expert speakers on Educating Children with Down Syndrome in the classroom.

Book at TryBooking https://www.trybooking.com/CNQZQ

If you have a child with Down syndrome and would like us to contact your school with the information please send us an email at admin@downsyndromewa.org.au



Down Syndrome Professional Learning Day

EDUCATING CHILDREN WITH DOWN SYNDROME



Open to Teachers, Educational Assistants and Administrators

Book Now: Trybooking



DSWA Gala Sponsorship Opportunities

Events come with a lot of expenses and last year we had amazing sponsors that really assisted cover some of the event costs.

This year we thought we would get in early and give everyone a chance to share this message so we can attract some event sponsors which helps us raise funds for our unfunded activities.

We can't wait to see you all at the 2024 Gala.

Booking link: https://www.trybooking.com/CORTA for those early birds.

A big thank you to Oil and Energy Pty Ltd who are sponsoring our photo booth again! Last minute update: Thank you to Buddiup and Sisterup who have sponsored the decorations.



Ready for Work

Our first nine week Ready for Work program is complete and was a great success.

The topics covered over the past few weeks included;

- How to be a valued employee;
- When I need help in the workplace;
- Knowing my job and things to help me in the workplace
- Job Interviews

The team of four the team has gained some valuable information and a new found confidence to take with them on the next step of their journey towards open employment.



Register now for the next Ready for Work program

The course was such a success, we will be running the next one commencing in February.

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



Employment

The new year has started off with a bang with our Open Employment program.

Two of our members who have been in the market for work, will next week be attending an interview for a role with a new employer based in West Leederville. Watch this space for further information.

We are working with a record number of members who are looking for work thorough our open employment program which is very exciting. Please, if you have a business, work for a business or know of anyone that has a business and open to a conversation about the possible provision of a role, we would love the opportunity for a meeting.

We are specifically looking for an employer in the Rockingham area in the cabinet making or similar industries.

Stephanie - employment@downsyndromewa.org.au

Workshops

\$\$\$ Money Management Workshop \$\$\$

We will facilitating a seven-week money management course commencing in February. The course will cover;

- Recognising money
- Where would you get money?
- Spending versus saving
- Needs versus wants
- Budgeting
- Safety spending money online

Please reach out to employment@downsyndromewa.org.au if you are interested in registering or have any questions.

Behaviour Management Workshop

A two-session behaviour management ONLINE workshop will be hosted by DSWA in late January or early February (dates to be confirmed).

The course will be presented by Behaviour Specialist, Kelly Oldfield from CDB Specialists.

Kelly will present on:

Session 1
 Identifying Function of Behaviour and 5 Step Behaviour Modification &
 Understanding the Reason Behind Your Child's Behaviour

Session 2
 Supporting Escalation and De-Escalation & Introduction to Positive Behaviour support

Keep your eyes open for further details in our e-news, socials and website. Or email stephanie@downsyndromewa.org.au to register your interest.

Part of a National Capacity Building Program run by DSA and funded by the Australian Government through the Information Linkages and Capacity Building (ILC) Grant program

World Down Syndrome Congress 2024



Call for Presentations

The Call for Presentations (Abstracts) is due to close on Friday 2 February 2024.

See further information at https://wdsc2024.org.au/presentation-congress.html

Early Bird Registrations

Take Advantage of the Early Bird registration rates and register yourself to WDSC 2024. Early Bird registrations close 21 March 2024.

Register at https://wdsc2024.org.au/registration.html

Speakers

Introducing the Third Plenary Speaker, Dr Jasneek Chawla. Dr Chawla is a Paediatric Respiratory and Sleep Medicine Specialist at Queensland Children's Hospital, Brisbane and leads the Kids Sleep Research Group at the Child Health Research Centre, University of Queensland.

See the latest list of speakers at https://wdsc2024.org.au/speakers.html

Family Support



The Family Support service for DSWA have received a huge boost with additional support from Telethon to provide an additional 3 days per week of Family Support. We are so fortunate to have the support of Telethon to provide services to families 0-17.

We are delighted to welcome Danica Bowes to the Family Support team. Danica will join Nikki in providing support across the 0-17 age group. The services of our team range from pre and post natal visits, support to families and children whilst inpatients or visiting outpatients at PCH and home visits. We provide support on the transition years such as going to school, primary to high school and what happens at the end of high school as well as workshops to provide information and events to keep our community connection. Our team can provide advocacy and support you to find information you need.





The team also manage the Facebook and Instagram pages for the Family Support Network and social groups, and the run the new parent morning teas. We will be increasing our connection activities for all families this year holding events to bring you together.

For our 18+ members we also provide family and individual support and advocacy. As well as events, activities and are commencing our work in Aging, Housing, Dementia and continuing our work on Down syndrome Regression Disorder.

We don't have all specialist areas in house, but the team are here to support you to find the information and support you need.

Get in touch at familysupport@downsyndromewa.org.au

NDIS Meal Service - Our Ruby Girl

Our Ruby Girl is excited to let you know we can now service customers who have a Home Care Package or who are on the NDIS simply and efficiently.

We are using a platform called Cookaborough to help manage the split payments and invoicing to Care Managers for HCP recipients and Plan Mangers for people on the NDIS. It means you can order meals from our weekly menu as part of your allowance.

If you are interested in using this service please sign-up by clicking the link below.

<u>I'd like to order meals from Our Ruby</u> Girl

Once you've signed-up please send an email to events@ourrubygirl.com with the following information:

For Home Care Package customers please provide the following information in the email:

- Your name
- Your Care Provider company name
- Your Care Manager's name
- A contact phone number for your Care Manager
- An email address for your Care Provider

For NDIS Customers

- Your name
- Your Plan Manager company name
- Your Plan Manager's name
- A contact phone number for your Plan Manager
- An email address for your Plan Manager

If you have any questions please get in touch via our contact details below. Thanks,
Sarah

Sarah Yates - Owner 0477 014 197 sarah@ourrubygirl.com www.ourrubygirl.com



As many of you know, DSWA offers a range of closed Facebook groups to our membership.

We have commenced an audit of all DSWA closed Facebook groups. Everyone on a DSWA closed page must be a member of Down Syndrome WA and we are finding a large number of early members of pages that are not DSWA members. We will commence deleting people on our closed pages that are not members on 16 February. This is to ensure that members are protected on our pages from trolls, spammers and marketers.

Your privacy and the safety is of utmost importance to us, and membership of our Facebook groups is critical to support families to share and connect, and to tell stories and ask for help and suggestions.

If you're not already a member or are not sure, please urgently complete the form at https://forms.office.com/r/4Q3YMcRKW

Membership of Down Syndrome WA is free and membership of our supportive online community is one of the many benefits of membership.

13th World Down Syndrome Day Conference



21 March 2024 - You are invited!

Join the United Nations in New York as we call for Health Equity for People with Disabilities.

On World Down Syndrome Day, the Down Syndrome International network will be launching a campaign calling for Health Equity for People with Disabilities.

On 21 March 2024, they will take the campaign to the United Nations for the 13th World Down Syndrome Day Conference.

Self-advocates, supporters, government and UN officials and NGO representatives will share knowledge, experience, and good practice.

You can register to attend, apply to speak at the conference or join the conference online. Go to the website at https://events.ds-int.org/13thWorldDownSyndromeDayConference#/

DSA Resources

Have you used the Resource Hub on the website?

This covers a huge range of topics including housing, health care, navigating legal issues, relationships and education.

See the full range of resources

at https://www.downsyndrome.org.au/wa/resources/resource-hub/

NDIA Feedback Workshop

We want your feedback, and we are prepared to pay for it!

Down Syndrome Australia has partnered with NDIA, in an effort to understand from people with an intellectual disability, what they want from their NDIS plan.

Kylie Preston from Down Syndrome Australia is coming to Perth to run a workshop for up to 10 people, (aged 14 – 24 years), to learn about their personal experience and what they want and value.

Members will attend a 2-hour workshop on Saturday, 17th February 2024 from 10am to 12 noon

Each participant will be paid \$100 for their valuable input and attendance.

Please contact Stephanie at stephanie@downsyndromewa.org.au by 31st January, if you are interested in participating.

Football Futures Foundation

Football Futures Foundation is an independent charity organisation that champions the inclusivity and accessibility of the game of soccer.

Under the banner of Football for All, they aim to ensure that all people can play. They also encourage and enable community clubs to be more inclusive to afford young people with disability to play outside of school.



Their programs include:

- the i-league a Telethon funded football league for children aged 8-12 years old, with and without disabilities
 - https://footballforall.info/programs/i-league/. Players train with their team at their club once or twice a week and then meet other clubs on a game day (Sunday).
- Equal Footingball league which is for ages 12-18 and 18+, this league is club based, but purely for athletes with disability
 - https://footballforall.info/programs/equal-footingball/

For further information about their programs got to https://footballforall.info/our-programs/



Playgroup South

South Metro Playgroup starts on Monday the 5th February. We hope you've all had amazing summer holidays and we can't wait to see you then!

This term we're looking forward to a visit from Messy Mat and we'll be celebrating World Down Syndrome Day and Easter.

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

Playgroup North

North Metro Playgroup would like to say a big Happy New Year to all our wonderful playgroup families. We hope you have enjoyed a great summer holidays and Christmas. Danica and I have missed all of you and can't wait to jump into a super fun term one.

With so much to celebrate this term we have packed all our fun activities into an eight-week program. The wonderful Sensorium team will be joining us in week three for some music and sensory delights. We will also be celebrating World Down Syndrome Day, Valentines Day and Easter. We are so excited for this year and can't wait to return to our center to see you all again!

Tracy and Danica playgroup@downsyndromewa.org.au

Supported by
Our first event of 2024 is a morning at Maylands Waterland. Join us from 9:00am to 12:00pm on Sunday the 4th of February (32 Clarkson Rd, Maylands WA 6051). Book at https://www.trybooking.com/COCNN
Tickets are \$5 per child.
Come in bathers, and bring along something to sit on, a hat, and sunscreen.

Check out the KiDS Club calendar for our upcoming events

- https://docs.google.com/document/d/1PpYTShwvBiBxHsUvHNGm EHm8G5E5uwsqlB9rUXEu6Q/e dit?usp=sharing



Friends for Life

We had our first social event of 2024, and it was great!

Our Friends for Life group headed to 360 Allstars fringe show. The show was full of amazing tricks and a showcase of captivating entertainment. We all got to meet the stars after, and everyone was lucky enough to get photos and autographs!

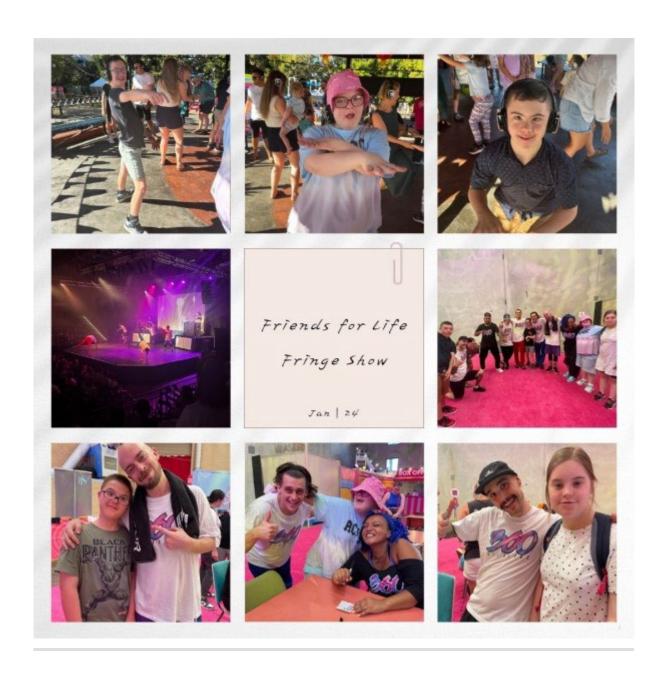
Then we headed over to the silent disco where some of us got to showcase our dance moves. The afternoon went quick, but everyone had a great time, all with a different favourite performer.

I met some new faces which was lovely, and the feedback was the fringe show was a hit so I will keep that in mind for future events.

See below for details of the show and our events for February and March. Book for Capoeira at https://www.trybooking.com/COAIS

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





AIM HIGH

We had our first social event of 2024, and it was great! Our Aim High club went down to Lake Monger Bowls Club for some barefoot bowls on Sunday.

It was a very warm day so we couldn't actually be barefoot but that didn't stop us from having a great time. We had many rounds all with different winners as skills and persistence increased throughout the arvo, we mixed up the teams a few times to get everyone bowling with new people, but the main point is that everyone had fun.

We had a great turnout and hoping to keep these numbers up, if not more!

See the details for our February and March events below. Book for the Our Country experience at https://www.trybooking.com/COAIM

Take care and see you soon





Getaways!

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



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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