
Latest News from Down Syndrome WA



CEO's Corner

Can you believe it is already July.....

There are a number of opportunities to participate in research in the next few weeks. Participating in surveys and research is so important to the development of new and valuable information and resources for our community. Please see the detailed information further in the eNews. We hope you can participate.

Special Olympics – a very important message

As some of you may be aware, the Western Australian Premier recently announced that the WA Government will not be providing financial support for the 2027 Special Olympics World Games to be held in Perth. Our community is obviously very disappointed with this decision. An event the size of the World Games cannot proceed without significant financial support from both the State and Commonwealth Governments. The Special Olympics World Games Perth bid team has worked tirelessly and with great passion over the past three years and we commend them for their efforts. It is our understanding that if held in Perth the Games do not need infrastructure to be constructed but the funding requests have been declined. Please support the Special Olympics team to have this decision reversed. In WA we have a number of athletes looking forward to competing, including a wonderful group of WA ballroom dancers. I hope our collective efforts will help to have this decision reversed. There is a lot of funding allocated to support bringing major events and sports to WA, where we have an abundance of sports like AFL, Basketball and Soccer. These Special Olympics offer an amazing opportunity for our athletes to showcase their skills. From the Special Olympics website "Special Olympics Australia is part of a global inclusion movement using sport, health, education and leadership programs every day around the world to end discrimination against and empower people with intellectual disabilities".

World Congress is now less than 12 months away. Being held on 9-12 July 2024 at the Brisbane Convention & Exhibition Centre. The conference brings together people with Down syndrome, family members, researchers and service providers to showcase the latest research and best practice as well as the lived experience of Down syndrome from around the world. Register your interest later in the eNews.

Being a small organisation with limited resources which we dedicate back to our membership we have had to find an innovative way to provide leadership development to our team. Together we are working through the Brene Brown leadership book Dare to Lead and thanks to her generosity the free online workbook. Doing this as a team gives us powerful consistent language, a deeper understanding of one another and increases our leadership skill. In addition to working through the Dare to Lead program we have invited business leaders to share their leadership journeys with the team. Our first speaker was Jemma Norton Manager of Procurement and Partnerships at SMEC. Jemma was amazing with the team, and we are very

grateful to her and her organisation for Jemma's time. Next month we will be joined by the fabulous Caroline Robinson, a powerful and energetic leader in regional WA.



Following the same theme, we don't always have the resources we need to grow the organisation, but thanks to our new relationship with the McCusker centre, DSWA has just hosted 2 interns for the Winter break. Arista and Mansi joined us 3 days per week for five weeks, working on a Social Media plan and a fundraising and grant research project. Both have added considerable value to DSWA and saved many hours of staff time, we appreciate them both for the interest they showed in the association. In Semester 2, we will be welcoming three interns 1 day per month for three months. They will individually focus on; supporting some IT and Data updates including our upcoming Member Details update, the Event intern will be supporting the 2023 Step UP event team to deliver the event on 8 October and finally a research intern who will be doing a global literature review project on information on Down Syndrome Regression Disorder which will significantly add to our resource library.

We have two support groups now, the Down Syndrome Regression Disorder support group and also the new Dementia support group. Meetings times:

- The new Dementia Support group will meet on Friday 18th August at 10am (Register at <https://www.trybooking.com/CJXY>)
- and the next DSRD Support Group meeting will be on Saturday 19 August at 10am. We now have a survey created from the generous sharing of the DSRD parent group, this survey can be sent to any family who have seen a change in their child and are unsure of the cause. The survey adds to the data we are currently collecting. Please email me directly at ceo@downsyndromewa.org.au for a link to the survey.

For Families and Carers of Adults members with Down syndrome we have a specific socials page the Adult Family and Carer Network, a group specifically designed for families of Adults (over 18) with Down syndrome to ask questions, share information and have discussions freely and openly in a safe space. Only members of DSWA will be accepted to this group, your

loved one with Down syndrome must be on our data base and be over 18. Acceptance to the group is limited to ensure that you are able to use this group in privacy and safety. This is a link to the group <https://www.facebook.com/groups/3236214346598901> where you will be asked membership questions. Apologies for any delays in accepting, as we check each person who asks to join. This page has been created in response to requests from families to have a safe space to discuss and celebrate the adults in our community.

Finally, this month we say farewell to Sue Summers. Sue began her journey with DSWA as the Employment and Pathways coordinator. When funding for the Employment project ceased Sue took on employment mentoring and 1:1 SLES program delivery.



We are so grateful to Sue for her outstanding contributions to DSWA and specifically to Jack McKevitt, Sian King and Marco Smuts. We will miss Sue being part of the DSWA team, but wish her well in her journey to follow her music dreams.

Cassandra

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

Meetings and Association Events

21st August - Board Meeting
18th September - Board Meeting
October - Step UP! for Down syndrome



DSWA PRESENTS

STEPUP!

**SAVE THE DATE
8TH OCTOBER**



IT'S TIME TO STEP UP FOR DOWN SYNDROME AND MAKE A DIFFERENCE



Member Details Update

In August, DSWA will be sending a request to all members to update to your member and family details. We will use this information to update our database which we use to communicate with our members. The request will be sent from a downsyndromewa email address and will include questions about your contact details, date of birth (for members with Down syndrome only) and family members.

In particular, if you have been a member for some time, some details such as date of birth might not be in our member database. These are important details for ensuring we send relevant information to specific age groups.

If you have any queries about the email please contact us - admin@downsyndromewa.org.au

A message from Special Olympics Australia



WE NEED YOUR SUPPORT!

I am reaching out to you today to highlight an incredible opportunity that requires your support and urgent action. As you would be aware, we have been actively lobbying for over 3.5 years to host the Special Olympics World Games 2027 in Perth, a significant event that will promote inclusivity on a global scale.

Funding commitments from the City of Perth, WA State, and Federal Governments of Australia are crucial to secure the hosting rights. Without these commitments by the upcoming deadline of July 31, 2023, we will lose this unprecedented opportunity to showcase Australia's commitment to inclusivity.

Unlike many major events, Perth's bid does not require significant infrastructure investment. The bid is financially sound and has garnered the support of over 40 businesses through MOUs, ensuring a robust commercial pipeline.

The time for Australia to make a decision has arrived and we need your support! We kindly ask for just two minutes of your time this week to reach out to the relevant authorities and advocate for the necessary funding required.

Please send this statement "I support the green and gold decade of sport for all Australians including the Special Olympics World Games Perth 2027" to:

City of Perth: Basil.Zempilas@cityofperth.wa.gov.au

WA State Government: wa-government@dpc.wa.gov.au

Australian Federal Government: A.Albanese.MP@aph.gov.au

Please follow <https://www.facebook.com/SpecialOWA/> to support the social media campaign or feel free to post this media tile below to your socials:

Special Olympics
Australia



**WE SUPPORT THE
GREEN AND GOLD
DECADE OF SPORT
FOR ALL AUSTRALIANS
INCLUDING
THE SPECIAL OLYMPICS
WORLD GAMES PERTH 2027**



Thank you for your continued support. Together, let us unite and embrace this extraordinary opportunity.

Tanya Brown
Director
Special Olympics Australia

A graphic of a spotlight shining from the top right corner, with several small yellow stars scattered around it.

RESOURCE SPOTLIGHT

Down Syndrome Regression Disorder

DSWA has compiled papers and webinars on our website at: <https://www.downsyndrome.org.au/wa/resources/resource-downloads/down-syndrome-regression-disorder/>

Anaesthesia Consumer Workshop

If you're a parent of a child living with Down Syndrome/Trisomy 21 or a person living with Down Syndrome/ Trisomy 21, please register your interest to join the Perth Children's Hospital Anaesthesia Research team, for a consumer workshop to help identify the most important research priorities needed to improve the clinical care of children living with Down Syndrome/ Trisomy 21.

All participants will receive \$100 for participating.

Register at <https://forms.office.com/r/RZyRab7nf8>



Government of **Western Australia**
Child and Adolescent Health Service



You're invited!

To share your opinions

If you're a parent of a child living with Down Syndrome/Trisomy 21 or a person living with Down Syndrome/ Trisomy 21, please register your interest to join the Perth Children's Hospital Anaesthesia Research team, for a consumer workshop to help identify the most important research priorities needed to improve the clinical care of children living with Down Syndrome/ Trisomy 21.

All participants will receive \$100 for participating.

When: Saturday, 26th August 2023 @ 9:30am

Where: Perth Children's Hospital

Registration form link/ QR code:

<https://forms.office.com/r/RZyRab7nf8>



We'll be discussing what is important for you and others living with Down Syndrome. We'd love for you to help us shape the course of research and clinical care!



Down Syndrome
Western Australia

ANAESTHESIA
RESEARCH
PERIOPERATIVE MEDICINE TEAM

How can health care services best support the needs of families of children and young people with chronic conditions?

You are invited to take part in a health literacy project for children and young people with chronic (long-term) health conditions and/or special health care needs. This project requires you to complete an online survey that will take approximately 20 minutes.

Complete the survey

at <https://redcap.telethonkids.org.au/redcap/surveys/?s=3PKRMMJELHPYFW8P>

How can health care services best support the needs of families of children and young people with chronic conditions?

We want to hear from parents of Australian children who have special health care needs, chronic health conditions and/or disabilities. These children may see many specialists and services, both in hospital and in the community.

This study involves completing an online survey to understand how care is coordinated. It should only take about 20 minutes to complete.

Your views and experiences will help us understand how the health care system can meet your needs and provide the best care for your child.



If you would like to find out more, please contact:

Dr Rachel Skoss:
E | Rachel.Skoss@nd.edu.au

OR

Associate Professor Jenny Downs:
E | Jenny.Downs@telethonkids.org.au

To take part in this survey, scan the QR code below or visit: <https://redcap.telethonkids.org.au/redcap/surveys/?s=3PKRMMJELHPYFW8P>



Managing health conditions in children and young people with disability - Focus Groups

Are you the parent/carer of a person with disability aged 12 - 25 years? Have you been responsible in managing their health and helping them access health services?

We want to hear from parents about their experiences in supporting your child's health so we can help other families. Complete the survey at <https://redcap.telethonkids.org.au/redcap/surveys/?s=JL7XWY3CFEC4RRCN>

Managing health conditions in children and young people with disability

We want to hear from parents about their experiences in supporting your child's health so we can help other families.

Are you the parent/carer of a person with disability aged 12 - 25 years?

Have you been responsible in managing their health and helping them access health services?

We are running focus groups on the following topics:

- Managing health of a person who uses a wheelchair to get around in the community
- Managing eating, swallowing or gastrointestinal issues for people who take food by mouth
- Managing health related to communication, behaviour, mental health, and sleep
- Managing epilepsy
- Managing respiratory health or infections
- Managing dental care



If you are interested in participating in one or more of these focus groups, please follow the link below or scan the QR code to register your interest.



➤ <https://redcap.telethonkids.org.au/redcap/surveys/?s=JL7XWY3CFEC4RRCN>



The focus groups will be online and will take around an hour.

For more information, please contact
A/Prof Jenny Downs:
E - Jenny.Downs@telethonkids.org.au

Dress for Success Workshop

ONE FOR THE LADIES.....

DSWA is partnering with Dress for Success Perth to provide a wonderful workshop for our ladies with Down syndrome to have a personal styling and attend a workshop on style and presentation.

The cost is \$60 and you get to take home the outfit you are styled in. The workshop component is sponsored by the Pathways to Independence project funded by the Department of Social Services and DSWA. There is a 1:3 support staff charge for the 3 hours which will be billed separately.

There are two dates available with a maximum of 6 people at each session. If we only get six people there will be just the one workshop, but we think this will be popular so we have scheduled 2 sessions. Bookings for both dates close at the end of July.

Book Now for Session 1: August 15th at 10am <https://www.trybooking.com/CJXXN>

Book Now for Session 2: August 22nd at 10am <https://www.trybooking.com/CJXXY>

One for the ladies

50% sold- book now to secure your place

DSWA is partnering with

 **DRESS FOR SUCCESS**[®]
PERTH

TO BRING YOU A FANTASTIC STYLING AND PRESENTATION WORKSHOP

Open Employment success for Jack McKevitt

Jack McKevitt started his journey in open employment at The Boxman in November last year.

Working in his permanent role as a Storeperson/General Hand, in the beginning, Jack's role includes strapping bundles of cartons, stocking the showroom, and supporting the factory team, as he progressed, Jack now runs one of the Boxman CNC machines, making products that the Boxman sells.

Until now Jack has been supported by Sue Summers, his Employment Mentor. However, now Jack is self-sufficient at work and as of this week Jack will be working fully independently.

Jack has made a great contribution at The Boxman and has fitted in well and is a significant member of the team.

Dylan King, Operations Manager at The Boxman said "Jack is an important member of our team, he has a wonderful attitude towards his work. He is enthusiastic, and plays a fundamental role within our business". "We look forward to continuing to work with Jack to help him develop new skills and expand opportunities for him as we move forward" he said.



Congratulations to Jack on this great achievement and milestone. A big thank you to Sue for outstanding mentor work, and to Troy, Dylan and the team at The Boxman, for their continuing support and contribution to Jack's employment goals.

If you know a business that would be open to working with us, or if you are a person with Down syndrome looking for Open Employment, please contact Stephanie on 61823690, or email her at employment@downsyndromewa.org.au.

Also, if you are interested in working with us as an Employment Mentor, we would love to hear from you.

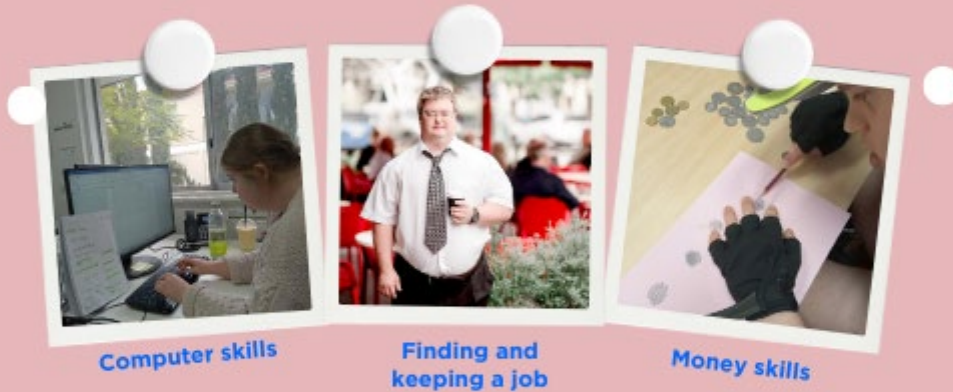
Watch out for our Employer Networking event coming in September.

Expression of Interest SLES 2023

DSWA will be formulating and delivering a formalized SLES program commencing in September 2023. We will be in a position to offer a range of SLES related services, and Finding and Keeping a Job activities later this year. To help us design the service for the first group of participants please complete the survey at <https://forms.office.com/r/zwAiaUbYk2>

SCHOOL LEAVERS EMPLOYMENT SUPPORTS (SLES)

REGISTRATION OF INTEREST



DSWA will be developing and delivering a formalised SLES program commencing in October. It will offer a range of related services for transitioning from school to workplace. To help us formulate the content, please complete the survey at <https://forms.office.com/r/zwAiaUbYk2>



Fundraiser!

One of our wonderful member families fundraises for the Association through the Entertainment Book "App".

Look at this fantastic offer. Great for you and wonderful for the association.
<https://subscribe.entertainment.com.au/fundraiser/83m541>

Get a bonus eGift card
valued at

Up to **\$40**

when you buy a Membership*
to The Entertainment App

[Support now](#)

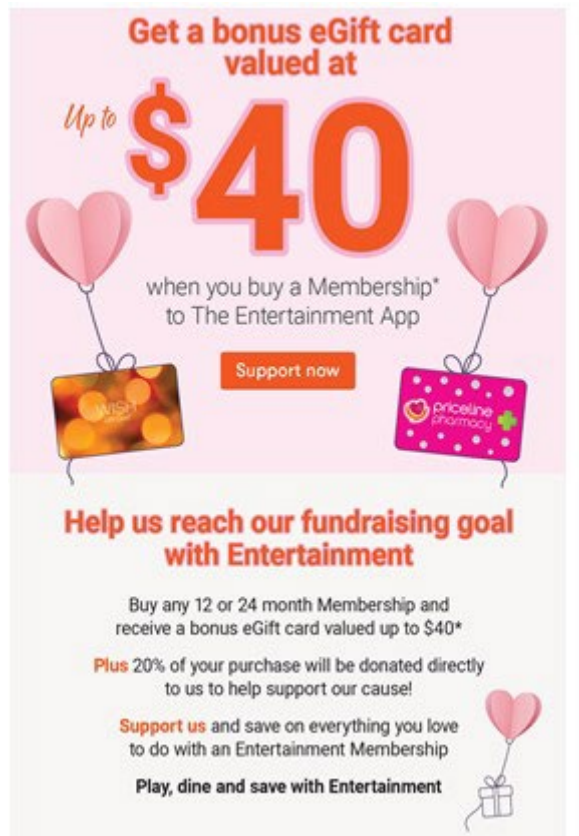
**Help us reach our fundraising goal
with Entertainment**

Buy any 12 or 24 month Membership and
receive a bonus eGift card valued up to \$40*

Plus 20% of your purchase will be donated directly
to us to help support our cause!

Support us and save on everything you love
to do with an Entertainment Membership

Play, dine and save with Entertainment



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.



World Down Syndrome Congress 2024



Save the date! The World Down Syndrome Congress is being held in Australia next year. For information and to register for updates go to <https://www.wdsc2024.org.au>

Regional Outreach



Visit Dates

Mid West

Thursday 7th - Saturday 9th September

South West

Thursday 21st - Saturday 23rd September

Great Southern

Thursday 5th - Saturday 7th October (School Holidays)

Nikki is currently planning the regional outreach trips for 2023. The plan for each area is to have a community dinner, workshop and family catch-up.

Currently Nikki is looking into service providers in the area to attend. If you live in the regions, and have any suggestions on who you would like to hear from please contact Nikki on nikki@downsyndromewa.org.au

Staying Healthy Workshop

Learn the importance of healthy eating, exercise, mindfulness and speaking to health professionals.

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

Staying Healthy Workshop

Learn the importance of

- Healthy eating
- Exercise
- Mindfulness
- Speaking to health professionals

10am - 2pm
Saturday 19th August 2023
Down Syndrome WA
Cygnet Hall
17 Hackett Drive
Crawley

Book here to attend this free event at
<https://www.trybooking.com/CKEST>



Dementia Support Group

We welcome any families experiencing dementia to come along and form connections with others, and share and learn from the group.

The next meeting is on Friday 18 August at 10am at Zamia Cafe. The reservation is booked and is in the name of DSWA.

Please can you register for this via Trybooking
- <https://www.trybooking.com/CJXY>. If you aren't comfortable with Trybooking, please email our CEO Cassandra at ceo@downsyndromewa.org.au to RSVP.

**Down Syndrome
Western Australia**

**Please join us
at our new
Dementia
Support Group**

Friday 18 August
10am
**Zamia Cafe
Kings Park**

**TYPES OF
DEMENTIA**

Dementia is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

- Alzheimer's
- Vascular
- Lewy body
- Frontotemporal
- Other, including Huntington's
- * **Mixed dementia:** Dementia from more than one cause

Please book via the try bookings link, to let us know you are coming

Do you have a story to tell? Are you a writer or do you draw pictures?

Dulcie Stone was a disability advocate from Victoria. She was a big supporter of people with intellectual disability and writing. VALID created the Dulcie Stone Writers Competition to remember Dulcie and to encourage people with an intellectual disability to be creative.

Together with Writers Victoria and Inclusion Australia the competition has been expanded so anyone with an intellectual disability in Australia can take part.

You can choose what you want to write about. The closing date is 30 September 2023.

Visit the VALID website for more information and to download the Easy Read application form - <https://valid.org.au/dulcie-stone-writers-competition>

Updates from Down Syndrome Australia

The Down Syndrome Australia Federation is made up of state and territory associations (including DSWA) providing support, information and resources to people with Down syndrome and their families across the country.

NDIS Review Panel

The NDIS Review Panel has released an interim report "What we have heard". Part A of this report draws out five important issues which the Review has identified and Part B provides more detail on 10 priority areas for improvement.

For each area, the Review Panel have included questions which they are inviting responses on. You do not have to answer all of the questions, and you can make a submission in any format you choose.

Down Syndrome Australia, as the national voice for people with Down syndrome in Australia, will be making a submission responding to these questions on behalf of all Australians with Down syndrome.

You can tell us your thoughts so that we can include them in our submission by emailing them to info@downsyndrome.org.au. We are also, upon request of the Review Panel, conducting specific consultation sessions on some of the areas identified in this report.

Read the full NDIS report here: What we have heard report <https://www.ndisreview.gov.au/resources/reports/what-we-have-heard-report>

You can give your feedback here: Have your say | NDIS Review <https://www.ndisreview.gov.au/have-your-say>

The National Roadmap for Improving the Health of People with Intellectual Disability

The National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap) was released in August 2021.

This 10-year program was developed through numerous roundtable discussions with stakeholders. Down Syndrome Australia played a significant part in these discussions in our role as the national voice of people with Down syndrome.

The Roadmap outlines how we can create a health system where people with intellectual disability are valued, respected and have access to high quality, timely and comprehensive health care. It seeks to put people with intellectual disability at the centre of the reform process.

The first Annual Progress Report has been published and is available on the Department of Health and Aged Care website.

<https://www.health.gov.au/resources/publications/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability-annual-progress-report-2022>

There is also an Easy Read version of the report. <https://www.health.gov.au/resources/publications/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability-annual-progress-report-2022-easy-read>

Down Syndrome Australia continues to play an important role in the delivery of the Roadmap as a member of the Roadmap Implementation Group.



NORTH METRO PLAYGROUP

North Metro playgroup is going to be kept very busy in Term three. We are excited to welcome some new families to our group and show them all the fun things we get up to on a Friday morning.

Term three is a buzz of excitement as we start our calendar shoot days for our annual DSWA playgroup calendar. Our amazing models will be issued some more details soon to confirm our shoot days and locations.

Sensorium theatre are also set to shine for three magical playgroup sessions this term. Our very own Julia Hales will be performing with the Sensorium cast. These sessions are always such a hit for our kids as they captivate them through music, signed songs and interactive play.

Danica and I are so excited to see all our families again for term three and welcome our newest members to our community.

Tracy and Danica

playgroup@downsyndromewa.org.au



SOUTH METRO PLAYGROUP

We've had such a fun start to the term at playgroup! We had a relaxed session when Amanda Berry visited us for some yoga therapy. We've also enjoyed some finger painting, craft and lots of play.

Renee and Nicole

playgroup@downsyndromewa.org.au



Kids Club

Supported by



STAN PERRON
*CHARITABLE
FOUNDATION*

In August Kids Club is visiting the DFES museum!

DFES EDUCATION AND HERITAGE CENTRE

Join us for an early access session at the DEFS Education and Heritage Centre!

Date: Saturday 5th August, 9am-10am

Location: 25 Murray St, Perth

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

After the session join us at Wellington Square Park for a parent catch-up and play.



Check out the KiDS Club calendar for our upcoming events.

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.

Friends For Life

In July the Friends for Life Program went to Zone Bowling Cannington. We had two goals for our event, building strength through moving our bodies and introducing conversation cards. It was fantastic to see some new faces and meet their lovely families. We had so much fun bowling and eating a yummy lunch. The introduction to conversation cards was great and is a way for participants to get to know one another and explore different conversation starters. These cards will be used at most events moving forward, where we can build on the conversations each month.

Thank you to all our wonderful participants who made it to this month's event and to our volunteers/supports for their encouragement and help throughout the day. Next month we are doing Capoeira, this is a form of martial art dance! You can book into the August event now through Try Bookings at <https://www.trybooking.com/CJMUF>

Daisy
daisy@downsyndromewa.org.au
0422 795 160



Next Event - Capoeira!

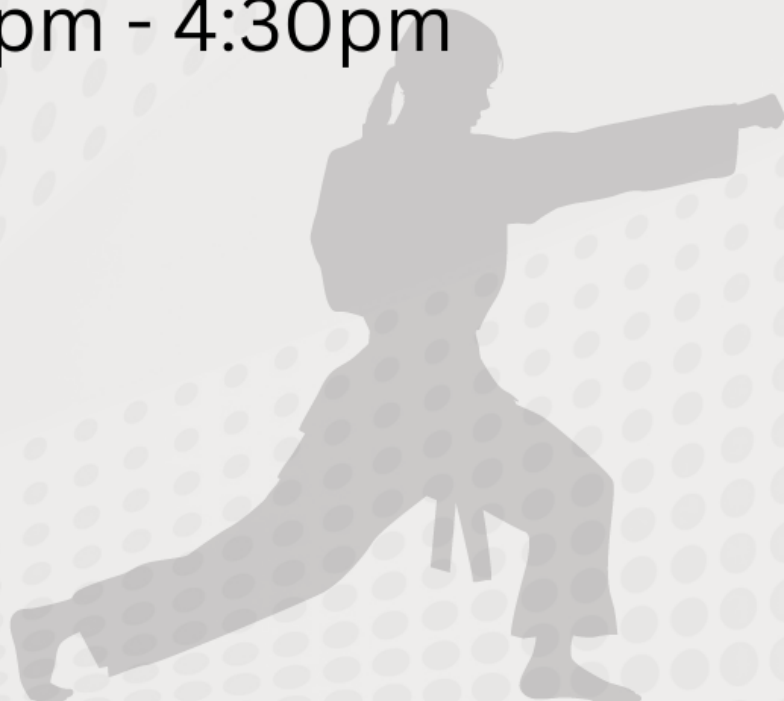
Book at <https://www.trybooking.com/CJMUF>

CAPOERIA AUSTRALIS

Where: Meeting location to be announced!

When: Saturday the 26th of August

Time: 1:30pm - 4:30pm



AIM HIGH

July was the month for the footy, the Aim High Program participants rugged up in our jumpers and purple to support the Fremantle Dockers. It was an awesome game with some great seats, there was cheering, music played when goals were kicked and a little bit of disappointment when Freo didn't win but we had such a good time together that it didn't matter.

Thank you to the participants that made it to this month's event, it is always great to see you! And a big thank you to Kellie Black and the Fremantle Doctors for their generosity in providing the tickets.

Next month we will be exploring Ancient Egypt at the WA Museum Boola Bardip, you can book in now through Try Bookings - <https://www.trybooking.com/CJMSF> I would love to meet some new participants, so if you haven't come to Aim High in a while the August event may be a great way to reconnect with the group.

Daisy
daisy@downsyndromewa.org.au
0422 795 160



Next Aim High Event - Discovering Ancient Egypt!

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

DISCOVERING ANCIENT EGYPT

When: Sunday the 27th of July

Where: WA Museum Boola Bardip

Time: 10:00am - 1:00pm



Compliments and Complaints

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



Down Syndrome
Western Australia



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admin@downsyndromewa.org.au

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