
Latest News from Down Syndrome WA



CEO's Corner

Here we are, at the end of yet another financial year! These annual milestones provide us the opportunity for review and reflection. Currently we are reviewing data collection, CRM system and the financial year end and we are planning all of our activities in line with the 2024-2025 year budget.

On reflection, we have delivered an outstanding body of work over the last 12 months achieving all the milestones we set and then a few more including; StepUP

2024, the whole of Association Christmas Party, three World Down Syndrome Day events and our first ever Siblings camp, Employment for 3 more people with Down syndrome, a fabulous Relationships workshop, Keyword signs and all of our social group activities. We have also continued to learn, discuss and support those affected with regression symptoms. Finally, we participated in providing feedback on a range of Policies and reviews, the NDIS review and the Disability Royal Commission findings, providing feedback through our Federation partner DSA. We have had a lot of laughs and fun with members, and some deep sadness too which have impacted us all. We are looking forward to this next financial year and continuing to work on delivering the best service we can.

As you are aware, maintaining a financially sustainable Association is an ongoing challenge with funding from Government, Philanthropists and our own community being critical for our success. Following this ENews will be an email for me, which will hopefully provide you with more understanding of how the Association is funded and how / where we need additional support to ensure the future of the Association. All of our income needs can't be provided by Government, and as such we need to find ways we can all contribute to financial success.

For the coming 12 months, we have some exciting projects and activities planned, however many will be dependent on our capacity to cover their costs. We are all looking forward to the World Down Syndrome Congress and are extremely proud to see so many WA members speaking on the program. Congress will also see Nikki Schwagermann (Mum and Staff Member) and Emily McCain (Mum and DSWA Board member) talking about their journey as parents of two teens with Down syndrome and I am delighted to be speaking and presenting the pilot data from WA's Regression Symptoms survey that has now gone national. The survey now has over 35 responses giving us invaluable data to move forward with. If you have an interest in completing the survey, you can follow this link <https://forms.office.com/r/L07pN7Z9ts>.

On August 16th and 17th we will be attending the Disability Expo at the PCEC, the 2025 Playgroup Calendar shoot will go ahead with 24 committed families already signed up for their Calendar spot and September will see production of the Annual Report ready for the AGM on 23 October.

October is a full month. October is AGM Month, and it would be lovely to have the AGM be a time to catch up with old friends, learn what is to come with the Board strategy and reflect on this year which is about to close, I hope we will see more of you at the AGM as an opportunity to celebrate all we are as a community.

StepUP has continued to evolve and change over the years, with last year having wonderful activities, rides, market stalls, fabulous adventure walk and entertainment, however it was our lowest attendance to date and hence our lowest fundraising in StepUP history, deeply impacting DSWA's finances. So, this year we are trying something new StepUP and Dance for Down Syndrome. **Save the date!**

Sunday 6 October. There is much more news to come on this fun event. We will attend the Telethon Family Fun day again in late October and in November we will be heading to the Darlington Arts Festival with our DSWA Artists to display and sell their work. The following weekend, we are holding our first ever Teen Getaway proudly sponsored by Telethon 7. See further in the eNews for more information. This will then lead us into our second All of Association Christmas Party, on December 6 and we hope as many of you with all of your children, and family will come and join us.

As you are aware, in May, we sent a number of advocacy letters of to various State and Federal Ministers, asking for reconsideration of the ILC funding for the next 2 years. As a result Employment Coordination grant has been rolled over for another 12 months, however there has been no movement on ILC, which means that unfortunately our Pathways project, and all of its associated workshops over the last 3 years will no longer be available through grant funding. We are looking at ways to continue to deliver these to the community with a cost recovery model which does mean having to charge for workshops and courses. As with other services, we may now have to implement some fee for service work for that work, which is unfunded. Thank you to those that sent letters to Ministers, we greatly appreciate your support.

Since our last eNews, I have attended the Siblings Camp, which was a huge success. It was wonderful to see the group bond and watch friendships begin. We hope our siblings will come along to other events like StepUP and Christmas party where they can catch up again. Our biggest thanks to the Siblings Project team, Emma and Kate for your wonderful research and for supporting the Siblings Camp. I had the privilege this month to also attend a presentation by a group of Masters Students from UWA who worked on a project called Enhancing Awareness and Understanding of Dementia and Regression Disorder in Down Syndrome. From this venture, two students are coming on board to volunteer for DSWA and support me in the DSRD project.

This week, I am busily finalising the 2024-2025 budget for the board to consider, and preparing for the World Down Syndrome Congress being held in Brisbane. And finally, the BIG news - you can put the 2025 Gala in your diary. We have booked a new, bigger venue and the Gala will be held on Saturday 3 May 2025. Save the date, this is going to be a fantastic event celebrating Family and Friends.

We have just 3 days left until the end of financial year. We ask you to consider everything that membership brings you, Advocacy when you need it, Connection, Friendship, Resources, Events and Activities, Community Awareness and most importantly your Connection to others. We ask to to consider making a donation this year, perhaps in lieu of not having to pay membership fees. You can make a Taxable Donation at; <https://www.mycause.com.au/page/347004>. So far our end of year campaign has only raised \$1100. Our Goal was \$50,000

My thanks as always to you all for your support and engagement.
Warmest regards
Cassandra

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

Meetings and Association Events

22 July- Board Meeting
19 August- Board Meeting
30 September- Board Meeting
23 October - Annual General Meeting
19 November- Board Meeting
7 December - Association Christmas Party

Please note, due to reduced funding, the DSWA office will be closed on Fridays from the 1st July.

Whats on!

28 June

North Metro
Playgroup

30 June

Drum Workshop
Kids Club

1-11 July

Teens School
Holiday Program

4 July

PCH Outreach

9-12 July

World Down
Syndrome
Congress

6 August

Dementia Support
Group

8 August

DSRD Support
Group

13 August

Parents and Bubs
Morning Tea

16-17 August

Perth Disability
Expo

13 September

Key Word Sign
Intermediate

6 October

Step UP & Dance
for Down
Syndrome

23 October

Annual General
Meeting

2-3 November

Darlington Arts
Festival

22 Nov

Key Word Sign
Beginner

7 Dec

DSWA
Christmas Party



Teens Camp

We are so excited to be holding our first Down Syndrome WA Teens Camp thanks to the generous funding of Telethon7 Perth.



Please fill out this form to express your interest for your teenager aged 12-17 years living with Down syndrome, to attend.

**Please note this is not a registration form, it is to gauge interest for numbers. .

Details of the camp:

Who: DSWA members aged 12-17 years living with Down syndrome (please note parents and teen must be DSWA members) in the link you will find more information
Date: Saturday 9th November 10am to Sunday 10th November 10am
Venue: At an Adventure Camp in the Perth region TO BE CONFIRMED
Cost: \$100 per person.

The balance of the costs for the Teens camp is funded by Telethon.

Express your interest now: <https://forms.office.com/r/GiaUJ45qHV>



Calling All Artists!

Our CEO has booked an Art Stall at the Darlington Arts festival for DSWA artists with Down syndrome to display and sell their works. Register your interest at <https://forms.office.com/r/Bt163sNk8f>

CALLING ALL ARTISTS

Darlington Arts Festival

2 & 3 November 2024

After the success of the
World Down Syndrome Day
Art Exhibition
Our CEO has booked an Art stall
at the Darlington Arts Festival
in November for DSWA artists
with Down syndrome to display
and sell their works at the
Festival

**Register your
interest now!
Complete the
Expression of
Interest Form**

Regional Outreach



Community Highlight: Great Southern Catch Up

Our families located in the Great Southern area, enjoyed a heartwarming catch up last Sunday! Braving the chilly weather everyone gathered for some great conversation, company and some tasty food, the kids enjoyed some play and fun. It was wonderful to see some of our farming families travelling far to attend, we appreciate every single person's presence at these events and catch ups!

Thank you to Jean and Wendy for organising and hosting such a great catch up.

If you are in any of our regional areas and are interested in hosting a catch up with other DSWA families in your area please email familysupport@downsyndromewa.org.au to find out how!



Did you know that we have five private Facebook groups for different regions in WA? These groups are a fantastic way for DSWA members to stay updated on community events and make connections closer to home. Here are the groups you can join:

- DSWA Great Southern Support
Group- <https://www.facebook.com/groups/562813961781133>
- DSWA South West Support
Group- <https://www.facebook.com/groups/677923213272854>
- DSWA Midwest Support
group- <https://www.facebook.com/groups/2502984533353870>
- DSWA Regional Rural and Remote support
group- <https://www.facebook.com/groups/357663433068076>
- DSWA Peel Support Group

We are thrilled to announce a new addition to our regional outreach program! Thanks to funding from Telethon, we are launching a new support group in

the Peel area. If you live in the Peel area, please join the new DSWA Peel Support Group here - <https://www.facebook.com/groups/399481359497440>

To join our Facebook groups, you need to be a DSWA member (membership is free). Not a member yet? Complete our online form to get started - <https://forms.office.com/r/nDxiDRDuDw>

Stay tuned for more events and join your regional group to not miss out on these fantastic opportunities.

Stay connected and engaged with your local DSWA community!

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 provide pilot data to help us lobby for diagnosis and treatment for people suffering regressive symptoms and possibly Down Syndrome Regression Disorder. This data also helps us to advocate for funding, research, treatment and support.

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

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

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

Contact CEO@downsyndromewa.org.au

DSRD and Dementia Support Groups

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

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

Dementia Support trybooking Link - <https://www.trybooking.com/CQNGK>

DSRD Support trybooking Link - <https://www.trybooking.com/CQNHI>

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

**Support
Group
Meetings
at the
DSWA Office**



Down Syndrome
Western Australia

Dementia Support

Dates:

Tue 6 August -10am
Wed 2 October 10am
Thu 28 November -11am

**Down Syndrome
Regression Support**

Dates:

Thurs 8 August - 10am
Sat 19 October -10am
Thu 28 November - 9am

Save the Date

2025
GALA DINNER
3 MAY 2025

Relationships Course

The sounds of excitement and chatter fill the room at the Relationships Course. Learning, conversing and sharing tips on going on a date. Appropriate people to ask, understand who is not appropriate and how to ask someone out. Getting ready, looking your best, what to wear, thinking about subjects to chat about. And of course, how to stay safe on a date.

The extremely important topic of consent and what that means was covered in detail and reiterated weekly. Understanding your right to say NO, asking questions if you don't understand and the right to change your mind.

And the delicate but necessary topic of intimacy and sex. Including the seriousness of it, understanding if you are ready for it, trust and safety.

The course has been extremely well received, participants had the time to get to know each other which gave them the courage and confidence to speak up and join in the very important conversation.

The participants are excited and ready for next week's final session of the course – Speed dating. Where they 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.

Entertainment Book Fundraiser

Jenny and DSWA. We receive 20% from every membership sold and there is currently a great deal on when you purchase an Entertainment Membership from them.

For a limited time, grab any [Single City Entertainment Membership](#) and get a FREE upgrade to a Multi City Membership! Plus, receive a \$20 Everyday WISH Bonus eGift Card!

Imagine up to 50% off kid-friendly restaurants, thrilling activities, exciting outings, travel adventures, and so much more. All with a 12-month Entertainment Membership starting at just \$70.

Don't let boredom strike. Jump on this incredible offer now and keep the kids entertained all holiday long while saving big and supporting DSWA.

Get your membership here -

<https://subscribe.entertainment.com.au/fundraiser/83m541#membership>

WE ARE FUNDRAISING WITH


School Holidays Sorted More value, more fun!

BONUS

Multi City
Membership Upgrade

&

\$20 eGift Card*



When you buy any
Single City Membership.

*T&Cs apply.



Give back and unlock thousands of exclusive offers

Save up to 50% off dining, travel,
shopping and fun things to do!

Buy today and 20% of the purchase
price goes directly to our fundraising
cause.

[Support us now](#)



Family Support Team



Family Support Update

There will be limited family support from the 8th-12th July due to staff attending the World Down Syndrome Congress. For urgent support please contact the DSWA office - 08 6182 3690 or admin@downsyndromewa.org.au.

Upcoming Parent and Bub Morning Tea

We are delighted to announce that we already have 5 families registered for our next Parent and Bub Morning Tea! Nikki and Danica are thrilled to welcome you all and provide a warm, supportive space for you to connect with others navigating the early stages of this parenting journey. If you have a child with Down Syndrome aged 0-2 years register and come join us! Siblings are also welcome.

Event Details:

Date: Tuesday, August 13th

Time: 10:00 AM - 12:00 PM

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

Register: <https://www.trybooking.com/CQCSA>

Our Parent and Bub Morning Teas offer a fantastic opportunity to build meaningful relationships with other parents who share similar experiences. It's a time to exchange insights, tips, and advice in a relaxed and welcoming atmosphere, over a cup of coffee.

We believe that these gatherings are essential for fostering a supportive community where you can find comfort, understanding, and connection. Whether you're facing new challenges or celebrating milestones, sharing these moments with others can make all the difference.

Parents and Bubs



Meet up and Morning Tea



Tuesday 13 August 2024



10:00AM - 12:00PM



Capoeira Australis Studio

1/301 Selby St North, Osborne Park



Family Support and Community Connection

Our Family Support Team is here to offer guidance and support at any stage of your family's journey. This month, we've seen a rise in families seeking connections with others who understand the similarities of the parenting journey. We understand the challenges you may face when trying to connect with others and want to highlight how valuable attending the programs and events offered by Down Syndrome WA can be. These opportunities help create new friendships and allow you to stand in rooms filled with people who accept and understand you and your children.

In addition to our in-person events, we have a wonderful online community at your fingertips! Our private Facebook Family Network group is a fantastic place to reach out, share experiences, and find support from others who truly understand your journey. Don't hesitate to join and become part of this vibrant and caring community.

We are eager to see you and your beautiful bubs at the Parent and Bub Morning Tea! Your presence will help make our community even stronger.

If you have any questions or need further information, please feel free to contact Nikki and Danica at familysupport@downsyndromewa.org.au

Key Word Sign Workshops

We are thrilled to share the success of our Key Word Sign Workshop held last week! The event was a fantastic opportunity for participants to enhance their communication skills, and we couldn't be more pleased with the outcome.

Highlights of the Workshop:

- **Engaging Sessions:** Participants delved into the principles of key word sign and gesture, learning up to 80 new signs. The interactive activities allowed everyone to practice using speech and signs together, making the learning process both fun and effective.
- **Expert Guidance:** Alison, our dedicated speech pathologist with over 15 years of experience, led the workshop. Her expertise and passion for helping individuals with communication challenges shone through, providing invaluable insights and support.
- **Positive Feedback:** We received wonderful feedback from attendees, who appreciated the hands-on approach and the practical skills they gained. Many expressed how confident they now feel in using key word sign in their daily interactions.

Participant Testimonials:

- "It felt positive to know that I am already incorporating Key Word Sign in my everyday already I now feel much more confident to support my clients."
- "The interactive activities were incredibly helpful. It was great to practice in a supportive environment."

What's Next? Given the success of this workshop, we're excited to announce our upcoming Key Word Sign Workshops:

Beginner Key Word Sign Workshops

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

Friday 22 November 2024

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

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

Intermediate Key Word Sign Workshop – Please note the New Workshop Date!

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

Friday, 13 September 2024

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

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

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

KEY WORD SIGN

BEGINNER WORKSHOP



Perth Disability Connection Expo

DSWA will be at the 2024 Perth Disability Connection Expo.

When: 16 - 17 August

Where: Perth Convention and Exhibition Centre

See all the expo details at <https://developingauscommunities.com.au/perth-expo-2024/>

Resource Spotlight

New Down Syndrome Australia Resource - Coeliac Disease

The Down Syndrome Australia Health Ambassadors made this resource to help explain what Coeliac Disease is.

Find the resource here - <https://www.downsyndrome.org.au/blog/resource/coeliac-disease-easy-read/>

World Down Syndrome Congress 2024

Together we Can: Celebrating Diversity and Inclusion

Congress isn't just for adults - it's for the whole family! There are exciting programs to ensure that kids of all ages, including those with Down syndrome, have a fantastic time while you enjoy every moment of the event.



The experts from Corporate Kidz Australia will provide safe, engaging and age-appropriate activities for children at the Congress venue.

Learn more about the [Childcare & School-Age Program at Congress and make a booking](#).

The Full WDSC Program is now available on the [WDSC 2024 website](#) or [see it here](#).

Join the Learn and Lead Group

Down Syndrome Australia need 10 people to form the Learn and Lead Group they're organising for the National Centre of Excellence in Intellectual Disability Health.

To apply, you must:

- live in Australia
- be an adult with an intellectual disability
- attend online meetings every two weeks.

Applications close at 5 pm on Friday 26 July 2024.

Learn more about the Learn and Lead Group [at https://www.downsyndrome.org.au/national/learn-and-lead](https://www.downsyndrome.org.au/national/learn-and-lead)

For more information, contact Alison Richardson:
alison.richardson@downsyndrome.org.au.

Participate Playground App

The Participate App is designed to support families who have children with disabilities to access playgrounds in their community with less barriers. The application includes reviews of over 100 playgrounds located around the Perth metro region, with new playgrounds being added and updated monthly.

The app enables the user to view each playground's level of accessibility, by providing information on parking, toilets, accessible play, floor surfaces, facilities and more. By viewing the playground's features and photos ahead of time, parents and carers can plan ahead and decide on an appropriate playground that suits their family's needs prior to arrival.

For further information and to download please visit the Healthy Strides Foundation <https://healthystridesfoundation.com/participate-app>

Focus on Ability

2024 Focus on Ability Short Film Festival Australian Screenings

Join the 2024 Focus on Ability Screening Event. Experience the power of perseverance, creativity, and resilience. Your presence will make these events truly unforgettable! The event in Fremantle is on the 5th September.

The event is free but places are limited, so reserve your spot today at <https://www.focusonability.com.au/FOA/screeningEvents.html>



Playgroup South

What a lovely month at Playgroup South, we've enjoyed free play, celebrated our lovely volunteer and DSWA member, Anna's birthday, made our rain sticks and had a blast with our friends from Sensorium Theatre.

Most importantly we have kept warm with our hot beverages and snuggly baby cuddles.

Looking forward to repeating it all next term. Please be safe over the holidays and enjoy your family and friends xx

All our love Renee and Nicole
playgroup@downsyndromewa.org.au



Playgroup North

Winter is here and Playgroup North has been keeping warm by moving and grooving with dancing and sensory play for our Fridays!

Our families were treated to an OT and Speech session that was hosted by the wonderful team at Bright Bunch. This was a great opportunity for our new parents and caregivers to ask therapy related questions during the early years of their child's life. Our kids delighted in playing and touching the Australian themed OT activity that was put together by the Bright Bunch team.

We have two weeks left of playgroup for term two and we are looking forward to jumping into story time sessions that will include some fun interactive play and sensory discovery.

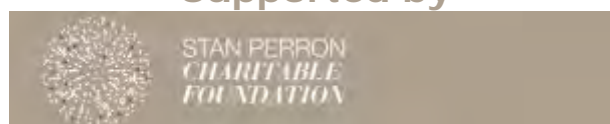
We hope to see all our families then before we break for the Winter school holidays.

Tracy and Danica
playgroup@downsyndromewa.org.au



Kids Club

Supported by



Our recent Kids Club Cooking Class was a delicious success! Under the organised guidance of Siobhan our young chefs cooked up a storm and had an absolute blast

creating their tasty pizza, from rolling the dough to sprinkling the cheese, every creation was a hit!

Parents and siblings joined in the fun, making it a wonderful family affair. A big shout out to Lee one of our wonderful KiDS club Dads who brought the fun and games while the pizza's bubbled away in the oven! The joy and laughter shared was truly heartwarming.

Thank you to everyone who attended and made this event unforgettable. Your enthusiasm and support are what make our Kids Club events so special. We can't wait for our next adventure!

Upcoming Event: Drumming Workshop!

Get ready to march to the beat of your own drum at our Drumming Workshop with Down Syndrome WA Kids Club! This is an event you won't want to miss!

Date: Sunday, 30th of June

Time: 10:00 – 12:00pm

Location: Menzie's Park Pavilion, 95-117 Egina Street, Mt Hawthorn WA 6016

Price: Free for Member with DS, \$5 per sibling

Book your Ticket here: <https://www.trybooking.com/CQFYX>

Join us for an exhilarating drum circle led by Martin from Rhythm Fix! Children will have a blast rotating between different instruments, exploring rhythm, and unleashing their inner rockstars!

After the drumming session, get ready for some seriously fun games and dancing! From congo lines to dance-offs and epic solos, this workshop promises excitement from start to finish!

Secure your spot now and let's make some noise and create unforgettable memories together!

Thank you for being part of our amazing community. We look forward to seeing you at our upcoming events!



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

For May, our Friends for life team headed to Laser Tag and Bowling. We had a lovely big group, some regulars, some who we haven't seen for a while but all the same it was lovely to see everyone having so much fun with their friends. This group had a blast running around at laser tag, followed by a game of bowling which is some of our participants favourite activity. We all had dinner whilst bowling and the group had a great night.

Our Friends4life group went to the movies for June's social event. We saw Inside out 2! We had a small group this time, but the movie was enjoyed by all. It was a perfect way to spend a Sunday, with friends at the movies with popcorn and treats!

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
0422 795 160.



FRIENDS FOR LIFE

Save the

DATES

-  August  Bingo & Disco
-  September  Mini Golf
-  October  DSWA STEP UP!
-  November  Christmas Light adventure
-  December  DSWA Christmas Party

Calendar of Events

Getaway's - Aim High

September
20, 21, 22
Perth Hills

November
15, 16, 17
Pemberton

January
31, 01, 02
Margaret River

2024/25

Save the Dates!



Friends for life June





AIM HIGH

May's social event for Aim High Club was a Mandurah Dolphin Cruise. The weather was trying to go against us all the way up until the morning of, but when it was time, the sun shone for us. We saw pods of dolphins within the first five minutes, so everyone was happy. We were very lucky; we saw multiple pods along the tour and had a lovely cruise along the Mandurah canals. We had many participants from Perth, so we all got the train together which was all part of the experience! We finished off with a lunch at Cicerello's before heading back up to Perth. The participants had a very enjoyable experience.

June's social event for Aim High Club went for a pub dinner and bowling for their social event. Perth city was bustling on Saturday night, so it was quite busy. We walked through the city to Forrest chase strike bowling. Some of our participants go bowling regularly so they showed us their bowling skills! I was very impressed!

Be sure to join us on our next month's adventure, go check out what we have on, and I hope to see you there!

Take Care

Laura

aimhigh@downsyndromewa.org.au

0422 795 160



AIM HIGH

Save the

DATES

-  10 August  Bingo & Disco
-  29 September  Mini Golf
-  6 October  DSWA STEP UP!
-  23 November  Christmas Light adventure
-  7 December  DSWA Christmas Party





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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(08) 6253 4752

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