
Latest News from Down Syndrome WA



CEO's Corner

It doesn't seem possible that the first quarter of 2024 is already complete. The days and weeks pass so quickly!

March is such a wonderful month with the lead in to and celebration of World Down Syndrome Day. This year we had a lot of events to celebrate our members and raise awareness. On 20 March we held an outstanding stakeholder event attended by over 40 people from a range of organisations. We were delighted to be joined by so many wonderful existing and new supporters. It was a wonderful night showcasing the artistic talents of a range of members in our community. Our thanks to our artists Adam Crisp, Annisha Manokoran, Angelina Kell, Callum Spickett, David Guhl, James Hooper, Julia Hales, Rachel Parker, Daniel Bydder, Naomi Lake, Patrick Ricciardo. The evening was MC'd by our own very successful actress Julia Hales and our members displayed artwork, handicrafts, dance and music. Thank you everyone, you and your artforms were fantastic and really showed that we should all Assume I can.

On World Down Syndrome Day, the 21st March, we celebrated with an open invitation to morning tea to which more than 45 people attended. It was a beautiful morning with members catching up with old friends, lovely music from Patrick Ricciardo and our amazing art display.



For both events we were very privileged to hold our events at the Forrest Centre here in Crawley, it is such a beautiful centre providing 60 PhD research students from across the world the opportunity to study here in WA. We were honoured to have Tyrone one of the centres researchers' welcome guests to the Centre.

WA were also very fortunate to be represented by an outstanding ambassador, Mr Andrew Denton, who flew to Canberra to join other self-advocates from across the company at Government House and Parliament House in Canberra.

On Saturday we had a beautiful family picnic, the day was warm, sunny and perfect for the event under the trees at Perry Lakes. More than 90 members enjoyed the day with the playground, our giants' games and parachute from Telethon 7, and the wonderful support and activities provided by Nature Play WA.

The World Down Syndrome Congress, being held on July 9-12 is approaching fast. Early Bird registrations have been extended to 7 April, so you can still get your discounted registration. It is wonderful to see WA so warmly represented with several speakers successfully submitting abstracts and the association participating in at least 4 abstract discussions.

The Down Syndrome community in South Australia have been supported by Down Syndrome Australia with a representative on the ground in SA. In December 2023, the on-ground representative resigned and DSWA has agreed to provide some support to the SA community remotely, and by hiring a casual staff member on the ground. We are delighted to be assisting the DS community in SA and hope that we can provide opportunities in the community. Nikki visited SA last week to support their Teacher PL and Education – for Parents days and to meet members of the SA community.

We would like to congratulate Joseph Salt on successfully being granted Sherry Hogan Foundation Scholarship to attend World Down Syndrome Congress.

The Pathways team successfully delivered an excellent Behaviour Management Course, supported by the professional skills of Kelly Oldfield from Child Development and Behaviour specialist. We have received outstanding feedback about this course, and hope to run it again in the future, depending on funding.

As we move forward, we have more exciting activities and events coming up with a Busselton Getaway in May, the Gala Dinner in May which is now sold out, Relationships for Adults, and Siblings Camp which we are forecasting to be held in early June, as well as all of our regular programs.

We have applied for an interesting array of funding opportunities from the Federal Government including Aging, Story Telling and DSRD, as well as a National employment grant. We also hope to benefit from grants submitted by Down Syndrome Australia. Our association, as you know is poorly funded, with no funding for Adult programs outside of those NDIS programs we run. We are committed to developing our services and work for our adult members, supporting all things related to adulthood and aging.

If members, family, friends and supporters would like to donate to our World Down Syndrome Day efforts, this is the my cause link. We would love you to share the link with others who may wish to financially support the association through donations. World Down Syndrome Day <https://www.mycause.com.au/page/341760>. It is very important that we continue to attract donations, fundraising, grants and philanthropic support to continue to provide crucial services and advocacy to our members.

Tribute

<https://www.mycause.com.au/page/339646/>

We pay tribute to Aimee Lee Clarke, mum, advocate and previous board member of Down Syndrome WA.



Aimee lost her life on 21 February 2024, she was mum to Hunter and Wren and passionate supporter of DSWA. We are grateful to the community for their outstanding compassion and support during this time, and to those who reached out and attended the funeral.

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

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

Cassandra

Cassandra Hughes

CEO Down Syndrome WA

0432 407 527

ceo@downsyndromewa.org.au

Meetings and Association Events

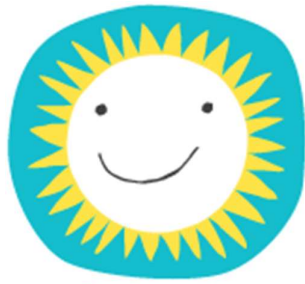
15 April - Board Meeting
20 May - Board Meeting
18 May - DSWA Gala
17 June - Board Meeting

World Down Syndrome Day 2024

The DSWA community had a wonderful WDS. We celebrated with an evening stakeholder event, member morning tea, family picnic and WA landmark lighting.

Watch our social over the next few days to see all the photos!





Registration
now open

WDSO 2024

BRISBANE, AUSTRALIA

Brisbane Convention & Exhibition Centre

www.wdsc2024.org.au

World Down Syndrome Congress!

Hear from one of the exciting Plenary Speakers Brian Skotko at the World Down Syndrome Congress, and see what his thoughts are on attending.

Hear from Dr Brian Skotko

Why is Congress important?

For real change to be made for and with people with Down syndrome, we need collective advocacy and action. The World Down Syndrome Congress is our global gathering of self-advocate, family members, clinicians, researchers, and other leaders—and event where we declare to the world (and remind ourselves) that people with Down syndrome are important members of our society who deserve our continued advocacy.

Dr Brian's advice

Come with an open mind, and you will be certain to leave with a ton of great information. The Congress is also a unique opportunity to meet a community of researchers and professionals, who are uniquely dedicated to maximizing the potential of people with Down syndrome.

What can delegates expect to hear from you?

I look forward to talking about a brand new online resources that makes up-to-date healthcare information available to every family around the globe. I will be reviewing the demographic changes of people with Down syndrome around the globe—and how these numbers might be changing as the availability of prenatal testing expands around the globe. The goal is to highlight best practices while shining a light on geographic areas most in need of our collective advocacy.

Dr Brian's hobbies

When I am not in the hospital, you can find me either on the squash court playing with friends or cooking in the kitchen with my wife.

What are you looking forward to?

We are a global community—but nothing beats seeing everyone in person! When self-advocates, families, and professionals from around the world gather, the forward-thinking energy will be contagious, I am certain.



Register at <https://www.wdsc2024.org.au/registration.html>

WDSO Scholarships

The DSWA Board is delighted to be able to offer two scholarships to support two members with Down Syndrome attending the World Down Syndrome Congress in Brisbane from 9-12 July 2024.

There are two scholarships available to a maximum of \$1500 each .

- Members must be aged 18 and above
- Be a person living with Down syndrome

Application will be by video and the winners will be determined by a DSWA Board committee.

Video's must be submitted by 7 April 2024

Scholarship Questions to be addressed by Video submission.

- What is your name?
- What do you think the Congress is about?
- Why do you want to go to congress?
- What do you think you will learn at the congress?
- How will you share your experience of the congress with others when you get back?
- How would you like to help out DSWA whilst you are at congress?

Participants are encouraged to subtitle their video or use flash cards to support sharing their message if required.

Send your videos by email to admin@downsyndromewa.org.au or for large videos send by Whatsapp to 0432 407 637 (include your name and email address in the message)

**Scholarships
Apply Now**

**Attend the
World
Down Syndrome
Congress 2024
in Brisbane**

Apply now for one of 2 scholarships of \$1500 now available for members with Down syndrome, over 18 years. Provided to support you to attend Congress

Apply by Video - see details in the post above

Gala Dinner

Gala tickets have SOLD OUT in record time. We're looking forward to a wonderful night of dinner, music and dancing!

We are now seeking donations and prizes to make the night e amazing. See the sponsorship opportunities below. We're also seeking prizes for the raffle and silent auction.

Please get in touch if you can contribute to the night -
admin@downsyndromewa.org.au or 08 6182 3690



DSWA
2024 GALA

Sponsorship Opportunities for 2024

- Photo Booth - \$950 - Sponsored
- Sound Equipment Hire - \$2000
- Decorations - \$1000 - Sponsored
- 1 Drink on arrival - \$2500
- Venue Hire - \$1200
- Sponsor tickets - \$110 per ticket
- Security Staff - \$800

An evening of fun, dancing and celebration.
Black and White colour scheme based on our
domino connection theme



**The power of
connecting the dots**
Maximum Capacity 270



Whats on!

4 April

PCH Outreach

4 April

Dementia Group
Meets

7 April

WDSC Scholarships
Apps Close

11 April

PCH Outreach

11 April

DSRD Group
Meets

15 April

South Metro
Playgroup

17 April

Relationships
Course Starts

19 April

North Metro
Playgroup

19 April

Ghostbusters Movie
Aim High

20 April

Circus Workshop
Kids Club

20 April

Jurassic World
Friends for Life

30 April

Parent and Bubs
Morning Tea

18 May

DSWA Gala!

24 - 26 May

Busselton
Getaway

9 - 12 Jul

World Down
Syndrome
Congress

Member Story

DSWA member Joe Salt has been awarded a Together We Can Scholarship to attend the World Down Syndrome Congress. He'll be taking on a leadership role which will include public speaking and lots of other tasks to make the congress all come together!

Congratulations Joe. You are involved in so many fantastic activities in the community. We hope you have an amazing time at the Congress.



WSDS Fundraiser

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

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

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

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

A graphic for a fundraiser. On the left, the text "World Down Syndrome Day Fundraiser" is written in a dark purple font, enclosed within a large, thick, orange curved shape. To the right of this text is a purple speech bubble containing the words "Donate Today" in white. Below the speech bubble is a QR code with a small teal icon in the center. The entire graphic is set against a white background.

Supporting DSWA to support our
community



Regional Outreach

Did you know that we have 5 private Facebook groups for different Regions in WA. If you are a DSWA member, you can join the group in your area to keep up with any community events happening and make connections closer to home.

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>

With thanks to funding from Telethon, we are excited to be starting a new regional outreach region in the Peel area. DSWA Peel Support Group. If you live in the peel area, please join the new group

here <https://www.facebook.com/groups/399481359497440>

To join our Facebook groups we require that you are a member of DSWA (membership is free). Not a member? Complete our online form at <https://forms.office.com/r/nDxiDRDuDw>

PCH Outreach

Don't forget to reach out to Senior Coordinator Nikki Schwagermann if you are at PCH on a Thursday. She can visit you as an inpatient or meet with you if you are there for an appointment - nikki@downsyndromewa.org.au or 0480 311 739.

DSRD and Dementia Support Groups

Based on the feedback received we have made the support group dates on alternate days to meet the needs of everyone in the group.

At this stage meetings will be held at the DSWA office unless another suitable venue is found.

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

Please contact Cassandra on 61823690 or ceo@downsyndromewa.org.au

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 Regression Support
Dates:
Thurs -11 April - 10am
Sat - 8 June - 10am
Thurs - 8 August - 10am
Sat 19 - October -10am
Thu 28 November - 9am

Dementia Support
Dates:
Thu - 4 April - 10am
Wed - 5 June - 10am
Tue - 6 August -10am
Wed - 2 October - 10am
Thu - 28 November -11am

Down Syndrome Western Australia

Workshops

Relationships

Down Syndrome WA will be hosting a FREE Relationships course for people with intellectual disability.

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

The 5 weeks are broken down into - different topics ie types of relationships (how to connect/interact with friends, colleagues), Healthy and Unhealthy relationships, as

well as the 5 stages of relationships. The concept of safety and consent is woven throughout.

The course takes the approach as outlined in the United Nations Convention on the Rights of Disabilities, which states that all people with disabilities have a right to relationships on an equal basis with others.

Please click here to register <https://www.trybooking.com/CQDJJ>

Relationships for parents

There will be a parent/support online workshop on Wednesday 10th April 2024 at 7pm, which will provide an overview of the above 6-week course.

It will offer a week-by-week course outline, with a guide to how the information will be presented. There will be an opportunity to share any concerns, and ask any questions. Please click to register <https://www.trybooking.com/CQDLG>

Behaviour Management workshop

Our recent online Behaviour Management workshop was a huge success.

More than 25 people registered to participate in the two-session workshop which was facilitated by Behavioural Specialist Kelly Oldfield

The topics covered included;

- Identifying Function of Behaviour and 5 Step Behaviour Modification
- Understanding the Reason Behind Your Child's Behaviour
- Supporting Escalation and De-Escalation
- Introduction to Positive Behaviour support

The participants were encouraged to join in, contribute, ask questions and share specific incidents and behaviours and Kelly was able to provide very well received suggestions and insights.

If you wish to reach out to Kelly, please visit her website

- <https://learning.cdbspecialists.com.au/>. Kelly shares lots of free resources on her website, Facebook page etc so feel free to connect with her.

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

School Leavers Employment Supports (SLES)

In an effort to boost her skills and eventually move into open employment, DSWA member Sophie has started work experience at DSWA.

Sophie is working with a mentor and is doing all manner of office tasks. Sophie will practice her computer skills, learn data entry, assemble education packs amongst other things.

All the best Sophie.



Family Support



Parent and Bub Morning Tea

Embarking on the journey of parenthood is a remarkable adventure, and when navigating the path with a child with Down syndrome, having a supportive community by your side can make all the difference. Come and Join our Family Support Team Nikki and Danica, for a relaxed gathering centred around fostering connections and enjoying coffee together.

Parent and Bub Morning Teas are a positive opportunity to connect with other parents and families who have a baby with Down Syndrome aged 0-2. We aim to provide a warm and welcoming environment for attendees to engage in meaningful conversations, share experiences, and potentially seek or offer support within a supportive community. Our Parent and Bub Morning tea is open to new and existing parents and families with children aged 0-2 years old, siblings are welcome to come also.

Save the Dates for our upcoming Parent and Bub Morning Teas.

Date: Tuesday 30 April 2024

Date: Tuesday 12 August 2024

Date: Tuesday 10 September

Nikki and Danica

familysupport@downsyndromewa.org.au



Sibling Snapshot Project!

You're invited! Researchers from the Telethon Kids Institute are conducting research which explores the unique bond between siblings using photography. They are looking for research advisors AND research participants to be involved in their study.

Research advisors give advice and feedback on study materials (information sheets, consent forms, interview questions), and can be:

- Siblings with or without Down syndrome aged 6-29 years, or
- Parents of siblings aged 6-29 years where one has Down syndrome

Research participants who are sibling pairs aged 6-29 years (where one sibling has Down syndrome) are also needed. Participation involves using your phone to take photos of things which capture your relationship with your sibling. You will then participate in an interview with your sibling to discuss the photos you have taken.

Participation as a research advisor or research participant will take approximately 3 hours of total commitment, and you will be paid for your time.

To register your interest as a research advisor, research participant or both, visit [The Sibling Snapshot Project](https://telethonkids.org.au/projects/siblings/sibling-snapshot-project/) (telethonkids.org.au/projects/siblings/sibling-snapshot-project/), or email siblings@telethonkids.org.au to find out more.

This research has ethical approval from UWA (2023/ET000565).



The Sibling Snapshot Project!

You're invited!

Researchers from the Telethon Kids Institute are looking for...

Siblings with and without Down syndrome aged 6-29 years
AND
Parents of siblings aged 6-29 years, where one has Down syndrome

To be paid research advisors on a project exploring the sibling relationship using photography.

Participation involves attending two meetings and giving feedback and advice on our study materials (approximately 3 hours of total commitment).



Email us at siblings@telethonkids.org.au for more information or to register your interest!



TELETHON
KIDS
INSTITUTE
Discover. Prevent. Care.



THE UNIVERSITY OF
WESTERN
AUSTRALIA



UWA HREC Approved
(2023/ET000505)

The Sibling Snapshot Project!

You're invited!

Researchers from the Telethon Kids Institute are looking for **sibling pairs aged 6-29 years (where one sibling has Down syndrome)** to participate in research which explores the unique bond between siblings using photography.



What's involved?

Participation involves **using your phone to take photos** of things which capture your relationship with your sibling. You will then participate in an **interview** with your sibling to discuss the photos you have taken.

Participation will take approximately 3 hours of total commitment, and you will be paid for your time.



Email us at siblings@telethonkids.org.au for more information or to register your interest!



TELETHON
KIDS
INSTITUTE
Discover. Prevent. Care.



THE UNIVERSITY OF
WESTERN
AUSTRALIA



UWA HREC Approved
(2023/ET000505)



Playgroup South

What a fantastic last couple of weeks of our term. We had new families join us. We painted Easter eggs. Celebrated World Down Syndrome day with everything blue and yellow ♥♥♥♥ and most importantly we shared our stories over a coffee. Looking forward to seeing everyone next term for more crafting and kiddy fun xx take care over the school holidays xx

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



Playgroup North

What a big Term North Metro has enjoyed! Our families were treated to three sensory filled sessions from Sensorium Theatre. This gave our kids the chance to play with instruments and feel different textures in a fun and interactive experience.

Our last session of playgroup for the term included a celebration of World Down Syndrome Day and Easter crafts. Our kids took great delight in making their own blue and yellow DSWA Easter hats.

We have more fun programs returning to playgroup next term with sessions from Messy Mat Perth and specialised therapy sessions to help give advice or answer questions you may have.

Danica and I would like to thank all our families for showing their support for playgroup and enjoying all the wonderful activities. We wish everyone a happy and safe Easter holiday and we can't wait to see everyone next term.

Tracy and Danica
playgroup@downsyndromewa.org.au



Kids Club

Supported by



STAN PERRON
CHARITABLE
FOUNDATION

Roll up, roll up for an afternoon of fun!

Get ready to run away with the circus at our upcoming Circus Skills Workshop, hosted by Down Syndrome WA Kids Club!

Date: Saturday, 20 April 2024

Time: 1:00pm – 2:30pm

Location: The Freo Big Top, 90 Adelaide St, Fremantle

Price: \$10

Get your tickets here: <https://www.trybooking.com/CQFYK>

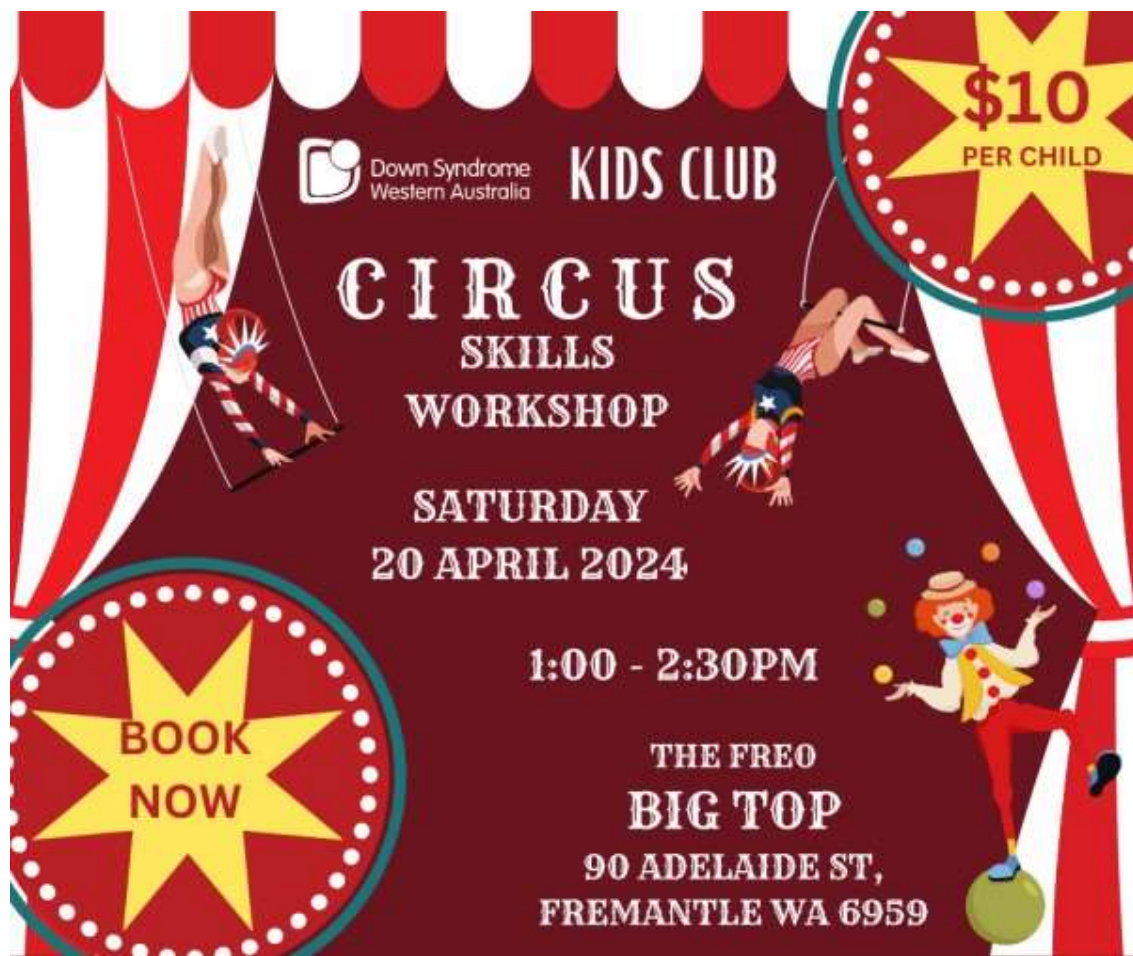
Join Siobhan Painter and the team for an unforgettable day of laughter, learning, and jaw-dropping fun! From juggling and acrobatics to clowning around, this workshop promises thrills for everyone!

Let's create magical memories together! Trust us, this is one event you won't want to miss!

RSVP now to secure your spot under the big top!

Can't wait to see you there!

Siobhan
kidsclub@downsyndromewa.org.au



Friends For Life

Friends 4 Life are going to Jurassic World at Burswood Park! Book now at <https://www.trybooking.com/CQNRW>.

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

BOOK NOW!

FRIENDS 4 LIFE APRIL EVENT

20 APRIL

1PM - 4PM

BURSWOOD PARK

BOOKINGS MUST CLOSE
3RD APRIL



Our Friends for Life social this month was a picnic and play in the park. We had board games, uno, cricket, footy plus all the playground use!

Everyone managed to go off in their groups and be able to play whatever interests them. This was the first event where we had more girls than boys! The day was beautiful, perfect weather and all participants had a ball.



AIM HIGH

For our next event we're going to see the new Ghostbusters movie - Frozen Empire!
Book at <https://www.trybooking.com/CQNRH>

Take care and see you soon

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



**BOOK
NOW!**

AIM HIGH APRIL EVENT

19 APRIL

7PM - 10PM

TELETHON COMMUNITY
CINEMAS

BURSWOOD

BOOKINGS MUST CLOSE
3RD APRIL

This month we took a trip to Sculptures by the Sea on the coast. Starting in Subiaco we got the train and bus as a group and made our way to the beach. It was windier than the city and it was quite busy being the last weekend.


We all saw some pretty cool stuff, large and small, all shapes and sizes. Everyone was keen for ice cream after despite the cold winds and then we made our way back to Subi. Everyone seemed to have a great time, some old friends meeting again, new friendships blossoming and another successful social complete.



Getaways!

Our next Getaway is to Busselton from the 24th to 26th May. Bookings are now open at <https://www.trybooking.com/CQNQJ>.


For further information contact Laura - aimhigh@downsyndromewa.org.au or 0422 795 160





BUSSELETON GETAWAY

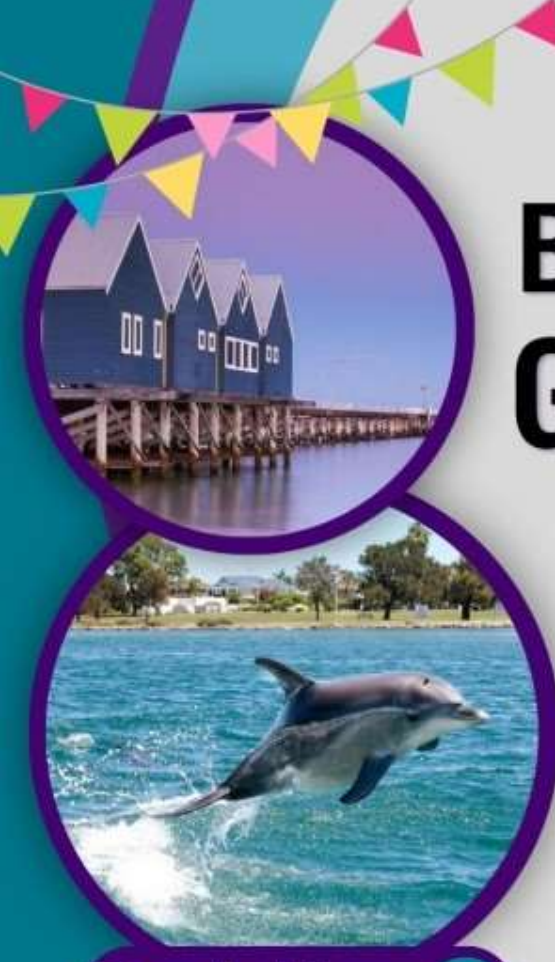
A weekend of activities to include; Visiting
bussleton jetty, exploring the Dolphin
Discovery Centre, Yallingup Maze and
Mini Golf, Pub dinner

Group cooking skills | Increasing skills in
Independent living | Conversation starting
with new friends | Team bonding and
building | Skill building for social and
recreational activities

Friday -Sunday 
24th - 26th May

Bookings Close 
Monday 22nd April

Book Now 



Our March Getaway was an amazing weekend with 9 of our members enjoying Jurien.

We went to Lobster Shack for lunch and a tour, 3 bay lookout and walk, Dynamite bay and beach in Greenhead (40 mins from Jurien) then beach in Jurien after a picnic lunch. On Sunday we visited the beautiful Pinnacles and had lunch at the pub.

Members worked on life skills, with them taking turns preparing and cooking BBQ and homemade pizzas for dinner and bacon and eggs and pancakes for breakfast. Everyone also helped with the cleaning up at the end of group meals. Everyone had an amazing time.



Compliments and Complaints

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



Copyright @Down Syndrome Western Australia, All rights reserved
{{msdyncrm_contentsettings(9345d3f5-4a4a-eb11-a812-0022480fea01).msdyncrm_addressmain}}
(08) 6253 4752
admin@downsyndromewa.org.au

You are receiving this email because you have previously indicated that you would like to receive updates from Down Syndrome Western Australia.

[Unsubscribe](#) or [contact us to opt out](#)
