Down Syndrome Western Australia

Latest News from Down Syndrome WA

November 2022



Cassandra's Corner

And here we are, the end of November 2022, the year has gone so quickly!

This last month has been full of activity with another Aim High camp for our adult members. Full programs for both Playgroups, FrienDS for Life and the KiDSClub.

The Employment program continues to grow, and gain more interest. We are so proud of our two members, Brayden Wake and Jack McKevitt who have both been made permanent in their roles in their first month of work. More on them both later in the eNews! Our employment mentors are doing great work with our members in employment and Sue Summers, now working as a Mentor is also offering Discovery and Get Ready For Work Programs one to one for a couple of members as well. Thank you to all families that have supported the Employment Program, we hope you are all as delighted as us int the progress of the program.

Employment Coordination is currently unfunded, so I have taken on the coordination role, so we can keep this critical service running. We will receive some grant funding in January, we are waiting on information in regard to what must be delivered under the funding agreement.

The team have almost completed their planning for 2023. We will have draft calendars of events and activities for all social groups, and also Getaways in the December eNews.

In other funding news, we are very pleased to be in year two of our three year funding cycle with the Stan Perron Charitable Foundation to support the KiDS Club and are waiting on announcements regarding 2023 Telethon funding to support Family Support, Regional outreach and Playgroups. Last week we were notified that DSWA will receive rollover funding through Down Syndrome Australia and the Federal Government DSS, ILC grant. This is continuation of three programs, Employment, Pathways and Information for Life. These have only been funded for a further 1.5years through to Jun 2024, at slightly less than current funding. When we receive the requirements for the funding, we will complete

our planning and staffing arrangements for 2023.

Last weekend I met with a group of parents who's adult children with Down syndrome are experiencing a range of complex and challenging issues, read more about this in the article about their story on Down syndrome regression disorder.

I also had a Dad reach out to me this week to let me know that his son had had some very worrying pre Covid symptons including fainting and dizziness, which led to a large range of tests, however it was determined to be a pre-Covid issue, it was very worrying for the family and he asked that i share this, in case you have similar incidents.

Finally this month we have had some wonderful community support and fundraising. Firstly a huge thank you to the Maylands Peninsula Golf Club, who ran their annual PenPairs event and nominated Down Syndrome WA as their beneficiary. Thanks to Stuart Brown and the committee. It was a beautiful day for the golfers and our thanks for the chance to tell you a little about DSWA over dinner. The club are donating \$2000 to DSWA. A corporate sponsor, Herron Todd White, made a donation of \$1000 and raised over \$2000 in the StepUP for Down Syndrome #21Your way campaign. Thank you so much for you support.

Another huge shout out goes to WA's Disc Golf community who have been so supportive of the assocation, weve put a little article below about their support.

Wishing you all a great start to December.



Warmest regards, **Cassandra**

0432 407 527 ceo@downsyndromewa.org.au

Upcoming Meetings and Events

SPECIAL GENERAL MEETING

7pm, Monday 12 December 2022

The board welcomes all members to the meeting and would love to see you in person.

Zoom is available for those that are unable to attend in person

For those that are not able to attend, please remember you can vote as you choose, by allocating a Proxy to hold a vote on your behalf.

Please see the webpage for all links, forms and information.

To register go to https://www.trybooking.com/CEMSO



To register go to https://www.trybooking.com/CEMSO

Constitution Update

As you are aware I wrote to you by email after the September Special General Meeting to advise you that the special meeting would have to be re-called. To provide some clarification, at the time of writing that email, DSWA had received verbal notification that a member had made a complaint to Consumer Protection, Associations and Charities section, that DSWA had not posted by mail, the notice of meeting (and proposed resolution) as is required by DSWA's constitution. As a result, we were instructed that the meeting, and resolution to adopt the new constitution were invalid and that a new notice of meeting and proposed resolution to adopt a new constitution would need to be posted.

Subsequent to the verbal notification, DSWA received 2 letters from Consumer Protection notifying us of complaints received by the department from two members.

In summary these complaints were:

- 1. that the notice of meeting was not sent by regular, prepaid post as required by the constitution;
- 2. that there was an improper practice in regard to securing proxy votes;
- 3. concerns regarding the inclusion of the Board Advisor role into the constitution, particularly that it infringed human rights; and
- 4. That the member register was not properly maintained.

We were later notified by Consumer Protection that a further letter of complaint had been received from other members. DSWA has not been provided with that letter but has been notified that the only additional complaint was that; at the 2021 AGM the auditor was not appointed correctly.

Since receiving the complaints, DSWA has worked closely with Consumer Protection to address any areas of non compliance.

Preliminary findings have been sent to DSWA and the three complainants. Whilst the final determination has not yet been delivered by Consumer Protection, we felt it appropriate to provide this update to our membership in the interim.

1. Notice of Motion - On behalf of the board and myself, I extend my apologies to the membership for not sending notices of motion by post. In previous years, the notices were sent via email which is a quicker and more cost effective option and I did not question the practice upon my commencement as CEO. This issue has been remedied with the notice of Special General Meeting on December 12, being posted to all members.

2. Proxy votes – We await a final determination in relation to this complaint. Lobbying for votes for or against any motion is the right of any member. This occurred from those both in favour and against the constitutional changes. DSWA's process, and notification for proxy voting was followed strictly and carefully. Every vote was received on the appropriate forms, in the appropriate time frame, recorded and read at the AGM. In regard to the specific complaint, DSWA will await the final outcomes before providing further comment.

3. Board Advisors - DSWA was told that a member would consider making a Human Rights Violation claim, if we were to proceed with the inclusion of board advisors in the constitution. The intent of the clause for board advisors was to give legitimacy to the role our fantastic board advisors play in providing the board with a voice of people with Down syndrome. To ensure the smooth passage of the new constitution this clause has now been removed.

4. The member register - The member register did require an update which had been scheduled for October 2022. This was immediately actioned, and notification was sent to all members by email to update their residential addresses, to ensure we could post you the notice of motion. Members who had not updated within a week, received a reminder email. The Associations Incorporation Act 2015 allows for the register to contain either a postal, residential or email address, however DSWA's constitution requires a residential or postal address in order for members to be notified by post. The register has been updated by members that chose to update their details. If a member has not notified DSWA of a change of address mail will have been sent to the address in the register or if they have not provided a complete address, they were not sent the notice of motion.

5. Auditors - DSWA <u>did not</u> breach its constitution in relation to the removal of its auditor. The constitution is silent on the notice period required for resolutions in relation to the removal of an auditor, however, we overlooked the requirement in the Associations Incorporation Act 2015 to provide the members two months' notice of the intention to move such a motion, or alternatively to secure a letter of resignation from the outgoing auditors. DSWA has now received the letter of resignation and completed the necessary notification form and submitted that to Consumer protection within 72 hours of notification of the complaint.

The new Draft 2022 DSWA Constitution provided to you by link in the Notice of Motion posted to members in late November 2022, has used the Model Rules, provided by Consumer Protection as a base to ensure that all key elements have been included.

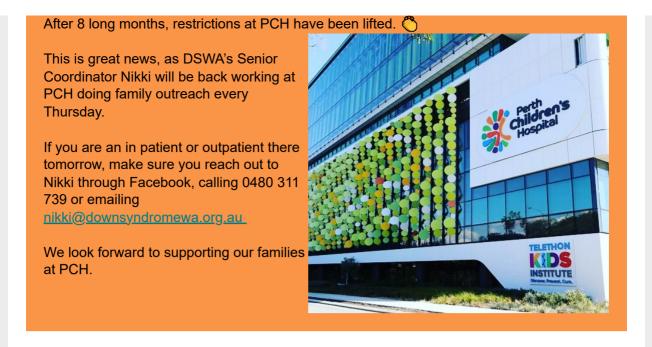
The proposed new constitution does not include the Board Advisors, but has included the important disputes resolution clause, and addresses all critical schedule 1 items required for a robust constitution. Wherever possible the Board has taken into consideration previous feedback received from its members.

The 2015 DSWA Constitution is no longer fit for purpose and requires significant amendment to ensure compliance with laws, including the Associations Incorporation Act 2015. This amendment should have happened earlier and has been a priority of myself and the Board since my commencement.

Today, in 2022, we are committed to resolving all issues in relation to our governance, including those above and ensuring that we have a robust, compliant and sustainable organisation into the future.

When the final determination is received, if there are major outcomes that have not already been addressed, the membership will be updated.

Perth Children's Hospital Family Outreach



Disc golf dosh for DSWA!

Four months ago we came across a video of US pro disc golfer Scott Stokely chatting with the Down Syndrome Disc Buddies, a group of young people from Geneva, New York who enjoy social disc golf. We reached out to Scott to see if he could help us run a disc golf activity at our StepUP for Down syndrome event, held annually at Taylor Street Reserve in Victoria Park, which has a permanent disc golf course. Despite being a busy sporting celebrity, Scott took the time to chat with us over video in the lead-up to the event, and then also offered to donate half of any winnings at the 2022 Australian Disc Golf Championships, which were held in Queensland last week. Well, Scott came good, and went one better, donating his entire winnings of \$515 for fourth place, to Down Syndrome WA.

When upcoming WA pro disc golfer Blake Houston heard about Scott's donation at the event's closing presentations, he was moved enough to do the same. Blake is only 15 and yet came equal 7th in a field of 31, mostly adults, in the Mixed Pro division at the event. The donation was suggested by the tournament directors Adam and Patrick of Sunshine Coast Disc Golf Club when Blake explained he would not take cash in order to retain his amateur status. Instead of taking prizes in kind or passing the \$165 on to other Pro division winners, all agreed to bring the cash over to our DSWA staffer and disc golfer Sue Summers to donate to our organisation.

Also, earlier in the year Mundaring Sporting Club Disc Golf donated \$5 per player at their PDGA Women's Global Event disc golf tournament, at \$90 for DSWA.

That makes a tidy \$770 from disc golfers this year. Thank you for your generosity!

If you want to know more about disc golf and are interested in learning how to play, get in touch with us and we'll help you with information.





We are very excited and proud to have been contacted by Telethon Community Cinemas who reached out on behalf of the Mongolian Consulate. A beautiful film called Trio has been produced in Mongolia, the film has already received awards in USA, Thailand and Mongolia. The film was produced by the founding Chairperson of the Down Syndrome Association of Mongolia. Trio features a young boy with Down syndrome, which is the first time in the Mongolian film industry. The TRIO film aims to defend human rights, to promote inclusive society, to raise public awareness of Down Syndrome globally, to fight discrimination, to support racial equity, and to terminate historic misuse of the term "Mongol", "Mongolism", and "Mongoloid".

Down Syndrome WA have been invited to be a co-beneficiary with the Down Syndrome Association of Mongolia, of funds raised at the screening of the film in January.

We hope that you will support the film and both of our Down Syndrome Associations and come along on the night.

Sunday 22 January 2023 Burswood Community Cinemas.

Down syndrome disintegrative disorder (DSDD) or Down syndrome early regression disorder

This is not a medical article, and has been put together at the request a group of DSWA parents to share their experiences and raise awareness.

This disorder has recently come to light here at DSWA with a number of families reaching out to the association for support and assistance with very similar stories. In response to these requests, the association recently held a meeting for those parents who had reached out, to allow them to meet and discuss what is occurring for their children/adults.

DSDD or Early Regression currently leaves more questions than answers. Its effects on the person and families who attended the meeting was described as devastating. Each of these parents has felt alone in their quest to understand the changes they have witnessed, each embarking on a harrowing medical journey, to little end.

Having brought the group together, they described similar symptoms and experiences, which they asked us to share, to see if there are more parents experiencing similar situations. They described their witnessed symptoms as variable, but with several consistencies such as,

Aggression or frustration
Existing OCD exacerbation
Slowness in walking, getting ready and eating
Dramatic weight loss
Speech loss
Slowed activity rate or participation, lower levels of independence
Insistence on wearing the same clothes
Catatonia
No ability to reason
Issues with continence

These changes have mostly seemed to occur over a relatively short period of time. Parents have visited many doctors and practitioners seeking help and a positive outcome, attending significant testing with common diagnoses of Psychological/ Neurological but nothing definitive. Often parents have had to fight hard to have their stories heard and believed.

Testing has included, MRI's, Blood Tests, Autoimmune markers, and many others.

This small group of parents wants to ensure that if there are other families in this situation that you know that you are not alone and you are welcome to join them at their next catch up. They hope that their stories, and what they are experiencing helps you.

There are some medical papers and research available which DSWA will share on their new closed Group Parents and Carers for Adults with Down Syndrome page. If you don't have Facebook and would like copies or links to these articles, please reach out to our CEO.

If you are in a similar situation and would like to reach out to the group please contact our CEO Cassandra Hughes or A/Chair Nia Parker.

As an association, it is our plan, that together we can get the support of a researcher to include those in WA into a research project, to find more answers and provide more support. It will also enable us to notify the NDIA that this is a condition that necessitates our members to need additional funding to meet their changing circumstances



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



NEW SOCIALS PAGE for PARENTS AND CARERS OF ADULTS with Down Syndrome Now, we have a new page specifically for Parents and Carers of Adults with Down Syndrome. We have recently set this page up in response to feedback from parents that once children leave school and become adults, it can be quite isolating for parents, sometimes losing contact with other families. Life as a parent of an adult with Down Syndrome brings new joys and challenges, and we hope that on this page we can share resources, and helpful information specifically tailored for you. Only members caring for Adults (18years plus) will be able to join this page

- https://www.facebook.com/groups/3236214346598901

Supporting a life of Possibilities

SUPPORT FOR FAMILIES AND CARERS OF ADULTS WITH DOWN SYNDROME



DSWA ADULT FAMILY AND CARER NETWORK

www.downsyndrome.org.au/wa

ceo@downsyndromewa.org.au

DSWA Resources

New Website Page - Dementia and Down Syndrome Includes information about risks, getting a diagnosis, further information and resources <u>https://www.downsyndrome.org.au/dementia-and-down-syndrome/</u>

Healthy Relationships

Our Healthy Relationships brochure is now available in Chinese, Arabic, Vietnamese, Japanese, Mongolian, Korean, Spanish, Greek and Somali. See the translations page on our website - <u>https://www.downsyndrome.org.au/translations/</u>



We're delighted that Dannie from our team will be joining the Support Coordination team in January 2023. Throughout December, Nikki and Dannie, will be working together support our members to reach their NDIS goal.

Please contact Nikki and Dannie at: <u>supportcoordination@downsyndromewa.org.au</u> 0480 311 739



▲ ▲ 2023 Playgroup Calendar ▲ ▲

A beautiful way to keep track of your busy lives. Order now whilst stocks last.

Available now

on <u>https://dsawa.bigcartel.com/produ</u> <u>ct/2023-playgroup-calendar-posted</u>.

Or give us a call Ph: 62534752 or Email:

admin@downsyndromewa.org.au

OpenEmployment

DSWA's Employment Program providing more new opportunities.

We have two new superstars to add to our growing list of members who are now working in Open Employment. Our recent two appointments are Brayden Wake, working at WireAid and Jack McKevitt working at The Boxman. Both men are making a great contribution to their new teams and loving their new jobs and both have been offered permanent positions in their first month of work. A great achievement!

Jack McKevitt is working as a Storeperson/General Hand. Jacks' role includes strapping bundles of cartons, stocking the showroom, supporting the factory team and welcoming customers. Jack has fitted in so well with the team and is loving his new job.

Dylan King, Operations Manager at The Boxman said "DSWA approached us with an opportunity to employ Jack to assist us in some key areas of the business a couple of months ago. From Day one of

Jacks employment he has been a great benefit to us, he is enthusiastic, pays attention to detail and has a great attitude. We look forward to providing Jack with more opportunities as we move forward, his assistance has been a great help"

From Jack's family, "we are really pleased that Jack is now working in open employment. Many thanks to Cassandra, Sue and The Boxman for providing Jack this opportunity. Thanks again for your hard work and persistence" Rosanna and Mike McKevitt.



Brayden Wake is working in the role of Wire Processin g Officer. Brayden' s role is involved in cutting, rolling and processin g of wire products for the



mining industry, he contributes to the finished WireAid products and is working alongside his factory team Sam Hosier, General Manager at WireAid, said mates. "Although only at the start of our partnership journey with DSWA, we have been pleasantly surprised by the immediate impact our candidate Brayden has had on our business and his fellow staff. We are proud as a business to be able to extend employment opportunities in this way and we remain positive about the ongoing benefits of this moving forward for all involved". DSWA CEO, Cassandra Hughes said "Brayden is so enthusiastic, and energetic. He is such a good fit for this

role and WireAid.

Both, Jack and Brayden are currently being supported by Employment Mentors, who will over time drop hours, working toward complete independence in the workplace.

Congratulations to both Jack and Brayden, keep up the great work!

Our heartfelt thanks go to the teams at WireAid and The Boxman, for their fantastic support and contribution to both men.

If you know a business, or are a person with Down syndrome looking for Open Employment please give our CEO, Cassandra a call or send an email to employment@downsyndromewa.org.au. Cassandra is currently coordinating the employment program and is supported by a fabulous group of mentors. We are still looking for more employment mentors!







Inclusion Australia

Tell us what you think about employment for people with an intellectual disability We are writing a report to the Disability Royal Commission and the Australian Government about employment for people with an intellectual disability. We want to tell them what needs to change so more people can get jobs they like and be paid properly.

The voices and expertise of people with an intellectual disability and their families are really important to this work.

We have made a survey so you can tell us what you think.

*If you'd prefer to talk instead of doing the survey, contact Jackie Softly who is doing interviews with family members.

jackie_softly@yahoo.com.au . Inclusion Australia staff with intellectual disability are doing interviews with people with intellectual disability.

We want you to tell us about your experiences of work. We want you to tell us what has been good and bad about your work.

Here is an online survey for people with an intellectual disability: <u>https://www.rixeasysurvey.org/kiosk/alq3</u> Here is an Easy Read download version: <u>https://www.inclusionaustralia.org.au/.../ADE-experiences...</u> Here is a survey for families of people with an intellectual disability: <u>https://forms.gle/uJsmjGk1f7XxawK69</u>

What is a WA Photo Card? For 16 years and older

The WA Photo Card is a voluntary card to assist people who do not hold a driver's licence or passport in conveniently proving their identity. It is available to people 16 years and older who normally reside in WA.

WA Photo Cards are valid for five years and cardholders have the option of including their address on the card and can choose to have two cards one showing their address and one without it.

WA Photo Cards have the same level of security as a driver's licence and display the following information:

- Name
- Date of birth
- Signature
- Photograph
- Address (optional)

Application for a WA Photo Card fee is \$46.80



There are three steps to getting a WA Photo Card

Step 1: Complete the Photo Card application (Form PC1)

Step 2: Attend a Driver and Vehicle Services centre or regional DoT office/agent Step 3: Application will be processed and the card is manufactured.

For more information and the link to all forms needed to apply, please go to <u>https://www.transport.wa.gov.au/licensing/wa-photo-card.asp#28973</u>

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

Housing Workshop PRESENTED BY NESTI **Topics covered** SDA funding SDA Housing Support in the home SDA Provider When: Wednesday 14th December Where: Online event Time: 7:00 pm Book https://www.trybooking.com/CEQEZ Now **CONTACT - DANNIE** Phone: 0435 831 085 Email: dannie@downsyndromewa.org.au Ш

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

Workshop Updates!

Social Emotional Learning

We had a great afternoon Saturday for the Social and Emotional Learning Workshop at DSWA with Dannie and Sharon.

We learnt a lot, and shared about our emotions and how our brain affects emotions. Bridget Scott a Positive Behaviour Therapist from Microboards Australia joined our group to provide information on Microboards Australia and the services they offer, including behaviour support and a parent and support worker training called 'Is There a Better Way'. Sharon Ross (OT/ DSWA Staff) has completed this

training and highly recommend it. <u>https://itabw.org.au/</u>

If you were unable to attend the workshop, DSWA can create a tailored resource pack for you to use with your family member and supports. If interested, please contact Dannie <u>dannie@downsyndromewa.or.au</u>

Toilet Training

We had a great afternoon Saturday for the Toilet Training workshop presented by Therapy Focus – with Tabitha Poole.



We received great information and shared our challenges and experiences around toilet training children.

Tabitha Poole provides information on <u>Therapy</u> <u>Focus</u> and the services they offer to support families.



For more details and to register go to https://www.trybooking.com/CDXCQ



For more details and to register go to https://www.trybooking.com/CDXCQ

Christmas Party Disco Friends for Life and Aim High

Come along and party the early evening away, enjoy great music with DJ Incredible Cara Baldwin and share some christmas dinner with your friends.

Date: Sunday 11th of December Time: 5.30pm-8.30pm Venue: Forster Park Community Centre, 130 Keane St, Cloverdale WA

Friends for Life Link to register: <u>https://www.trybooking.com/CEJLX</u> Aim High Link to register: https://www.trybooking.com/CDUNQ

AIM HIGH FRIENDS FOR LIFE CHRISTMAS DINNER AND DISCO

When: Sunday 11th December Time : 5:30 -8:30pm Where: Forster Park Community Centre

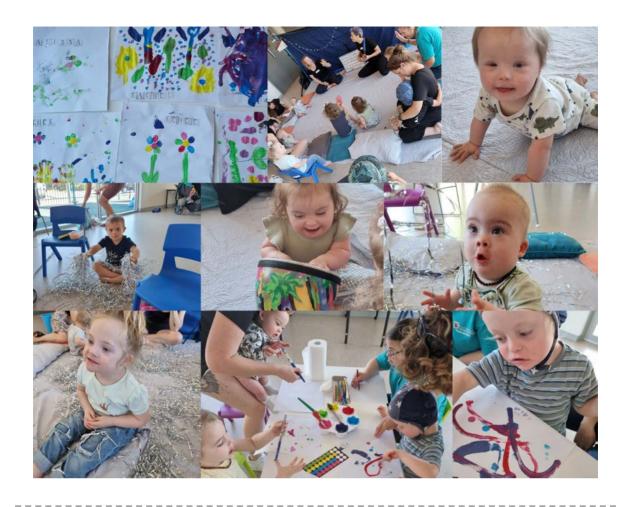


Please ensure you Book/RSVP by Wednesday the 7th of December

DSWA Playgroups

South Metro Playgroup

At Playgroup South this term we have been doing lots of finger painting and playing with our friends. We had a lovely visit from the Sensorium Theatre and everyone had some much fun signing twinkle twinkle little star and play with the drums and tinsel xx



North Metro Playgroup

North Metro Playgroup enjoyed all the fun dress ups from Telethon weekend to Halloween week at our centre. Our kids loved the costumes and our mess free sensory play.

We have spent the last three weeks of playgroup creating and exploring all things under the sea. As we are coming to the end of our fun packed year, we will begin our Christmas craft and celebrations in the final weeks.



Danica, Tom and I have just loved seeing our families each week, we would like to thank all our parents and kids for coming along to our sessions and joining our wonderful community.

Tracy tracy@downsyndromewa.org.au

KiDS Club

The KiDS Club had a wonderful time at our November event, a Disco Night!

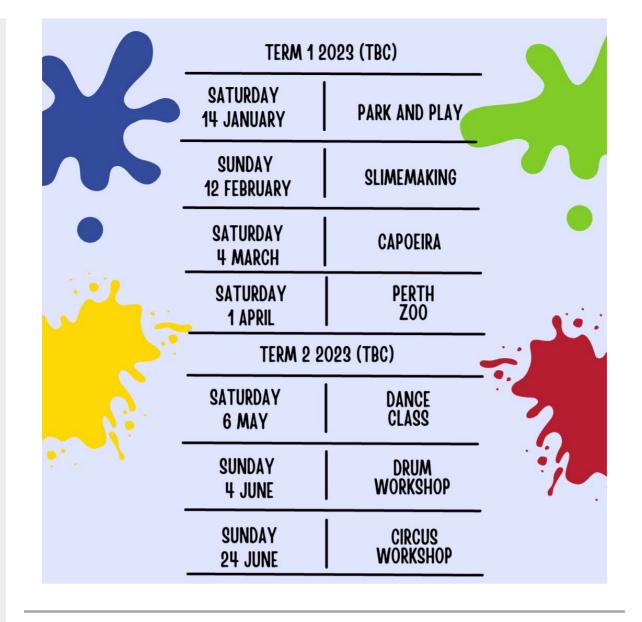
Singing and dancing filled the night with lots of fun (and noise). Children got to have a go singing on the microphones, and the evening finished with pizza and juice.

It was great to see everyone get involved and show off their dance moves to the group.

Our next event is a trip to Maylands Waterland on Sunday the 4th of December from 9:30am-12:00pm. Tickets are \$5 per child, and morning tea is provided.

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 Painter at <u>kidsclub@downsyndromewa.org.au</u> for registration details.





FrienDS for Life

7 Friends for Life members had a great afternoon doing some Yoga in Park. The ladies from 'Let's Yoga Perth' joined us under the shady trees and ran an hour class of yoga and mindfulness. Everyone was really well engaged and enjoyed the session. They then had some afternoon tea and a play on the flying fox and the tall tree walk.

It is so great to see all of the friendships forming and everyone's confidence and skills growing each month. Our last event for the year will be the Christmas Party on the 11th of December. Go here for more information and to get your ticket now. <u>https://www.trybooking.com/CEJLX</u>

Claire - Coordinator friendsforlife@downsyndromewa.org.au



Aim High Club

Our Aim High group started our month watching our very own member, Cara perform her DJ Gig at the Sewing Room in Perth CBD. Our group loved tearing up the dance floor to Cara's music as she got everyone dancing and smiling. Our group had so much fun!



Next for the Aim High Club was Laser Tag. We all headed to Laser Blaze in Willeton. Our group joined in with member on the community as we navigated around a Laser Tag course. There was strategies, focus and excellent team work by our members.



To finish off our events for November we enjoyed a fun Tennis session run by the wonderful tennis coach Ben. We enjoyed some fun team work games while learning volleying, forehand and backhand skills. There were lots of smiles, encouragement and laughter. Thank you Ben for a great session!



AHC What's On



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

Aim High Club is on the hunt for volunteers. If you or someone you know are interested in supporting our program either at events or Getaways, please get in touch with the coordinator at aimhigh@downsyndromewa.org.au or 0422 795 160.

Amandine 0422 795 160 <u>aimhigh@downsyndromewa.org.au</u>

AHC Getaways

Albany Getaway

The Aim High group just spent an amazing 4 days in Albany exploring the Great Southern! It was a weekend full of adventures, skill development, team work and fun. We all created memories that will last for a long time to come. Thank you to all the wonderful members that joined us and our incredible supports!

Maybe add our next adventure will be our Getaway to Fremantle/Rottnest and Penguin Island this weekend. Stay tuned for more information and pictures in next months newsletter.

Our planning for 2023 has well and truly started. Stay tuned for our calendar of events for 2023 that we will be releasing very soon!





















Fremantle/Rottnest/Penguin Island Getaway

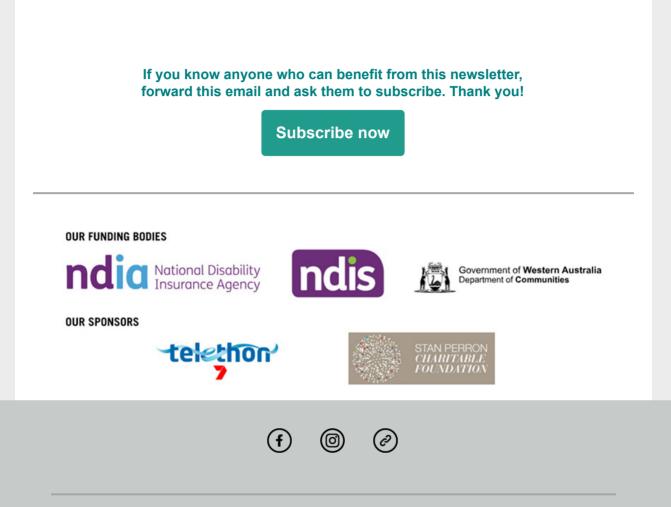
Friday 2nd-Sunday 4th December



If you would like to register for any of these Getaways or events please contact the Aim High Coordinator, Amandine on <u>aimhigh@downsyndromewa.org.au</u> or 0422 795 160.

Compliments and Complaints

We welcome all feedback and suggestions. Send your feedback to <u>admin@downsyndromewa.org.au</u> or use our <u>online form</u>.



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