

Newsletter April 2022

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What is happening at the Association?

Cassandra's Corner

I trust everyone had a lovely Easter break and celebrated in a way that honours your family's traditions. This year I missed attending Dawn Service for the first time in 17 years, with the last two commemorated at the top of my driveway with my neighbours. This year, I sat on my back veranda and listened to the service in the darkness. Anzac day is always a time of reflection and introspection for me, and I was left feeling grateful for the world we live in, with all of its challenges, opportunities and beauty. April, shortened by the public and school holidays was still a productive month for



the Team. The Work Readiness trial has commenced, and is going well with participants enjoying the course, both face-to-face and remotely and we are grateful for the federal ILC grant through DSA which funds this program. We have continued with systems development and introduced Support Coordination into our service offerings. Our social programs continue to grow and develop, and we value your input to the coordinators on how we can continue to deliver the best service possible to each participant group. We have recently sent out a survey on behalf of the board as they work toward formulating a new 2022-2025 strategic plan. We hope you will all participate in the survey to give us the widest range of feedback possible. You can click this link to access the survey - <https://forms.office.com/r/ESBN7ZzrC6>

May is looking full and vibrant. On 9th and 10th May we will undertake our NDIS audit and preparations for that will take up most of our time for the next two weeks. We will also be attending the Disability Expo at the Perth Convention and Exhibition Centre on 20th and 21st of May and the Quiz Night on the evening of the 21st... that will be a busy day.

Fundraising has been challenging this year with COVID, but some very exciting things are coming. The quiz night is still going ahead and tickets can be purchased on TryBooking - <https://www.trybooking.com/BZDTB>. We need your help - can you support the quiz night? Our staff team are donating their time to come on the night and run the event BUT a great quiz night – needs great prizes. If every family could donate a prize of some sort small or large, we can put together some amazing auctions and raffles on the night. If you can help, please contact admin@downsyndromewa.org.au. It would be great to see a full house on 21 May - see the advertisement later in the newsletter.

After some changes and a mistake from me, the Gala is confirmed to be held on August 13th. We are so excited to see the Gala unfold and to assist in any way we can. Personally I apologise for the mix up with the date change, which was inadvertently the night before fathers day, and we don't want our dads to miss out on their special day.

As the End of Financial Year approaches and people consider preparation of their tax returns, we have set up a MyCause page for anyone who might wish to make a EOFY tax deductible Donation to DSWA. You can find the page <https://www.mycase.com.au/page/282600>

As with all of our events, activities and donation campaigns, I ask for your support, we use every communication channel we have available, newsletters, social media, direct emails, but we need to share our messages and campaigns widely. Could you please share the links for events and campaigns and encourage members of the wider community to participate in and support our organisation.

Earlier in the year we received letters of concern regarding health treatment in hospital, should a member of our community become ill with COVID. We wrote to the Minister for Health, her reply follows this article.

In June, there will be a Special General Meeting to Update the Constitution in line with legislative changes introduced in 2017, and to appoint the 2022 auditor. The meeting will commence at 6pm and be held in the Zenith training room at 32 Burton St, Cannington.

Finally from me, like all jobs, ours have their ups and downs and our team work very hard to deliver the best possible service we can. My commitment is that as a team we genuinely Support a Life of Possibilities and your feedback and contribution to us is so important. We get a lot of helpful suggestions and input, and from time to time, we receive an email that touches our hearts and reminds us why we do what we do. Below is an example of a beautiful email, sent to our new KiDS Club Coordinator, Siobhan. Thank you Fiona for taking time to put pen to paper, your communication, compassion and support makes a difference to not only Siobhan but the whole team.

Hi Siobhan,

Thank you for all your hard work - I'm sorry you had to start right at the start/middle of Covid for Perth! I can't imagine how tricky that's making it, but just wanted to assure you that we're normally the most outgoing bunch of families who absolutely delight in getting together and our kids relish the opportunity that KiDSClub provides. Thank you.

Your activities are spot on and I'm sure it's just Covid affecting numbers and participation. So sorry!

We also wanted to let you know that we as a family, are going around Australia for 7 months leaving May 21st. So we won't be able to attend, but we'll be there next year with bells on!!

We were in Bunbury when you had the first meet and greet, so we didn't get to meet you then, but here's a photo of James (8yo) and us all. Thank you for taking on this important and so appreciated role - I'm sure it will all get back to normal attendance soon once the wave past and we're all accustomed to having Covid here.



All best, Fiona and James

In closing, I wish all the mums a very happy and special Mothers Day which we will all celebrate before the next newsletter.

Warmest regards
Cassandra

0432 407 527

ceo@downsyndromewa.org.au



**Hon Amber-Jade Sanderson MLA
Minister for Health; Mental Health**

Our Ref: 76-10722

Ms Cassandra Hughes
Chief Executive Officer
Down Syndrome Western Australia
ceo@downsyndromewa.org.au

Dear Ms Hughes

Thank you for your and Ms Salt's letter of 17 January 2022 to the Minister for Health regarding COVID-19 and people with a diagnosis of Down Syndrome. The Minister has asked me to respond to you on her behalf.

I acknowledge that the issues raised in the *Guardian* article are concerning for the Down Syndrome Western Australian community.

I wish to reassure you that the WA health system is committed to accountable and ethical decision-making for all consumers. Health professionals working across WA Health need to abide by Mandatory Policies for Clinical Governance, Safety and Quality, including WA Health Consent to Treatment Policy as well as their professional codes of ethics and relevant legislation.

It is important that, where possible, people are vaccinated against COVID-19 to minimise risks of serious illness.

Thank you for bringing this matter to the Minister's attention.

Kind regards

Stacey Hearn
CHIEF OF STAFF

22 MAR 2022

Level 5, Dumas House, 2 Havelock Street WEST PERTH WA 6005 Telephone: +61 8 6552 5900
Email: Minister.Sanderson@dpc.wa.gov.au

Board Meetings

The Board will next meet on Monday 9th May 2022.
Dates for the remainder of the year are as follows:

- Monday 13th June - (Includes a Special General Meeting for Constitutional updates and Appointment of Auditor)
- Monday 11th July

- Monday 8th August
- Wednesday 21st September from 6.30pm (AGM)

Board Meeting minutes are available upon request to the CEO (ceo@downsyndromewa.org.au) 21 days after the meeting.

Key Word Sign Workshops

Register now: <https://www.trybooking.com/BYOHK>

Key Word Sign Workshop

KWS Presenter Charlotte Wigham

\$150 per person



**Saturday
28th May 2022**

9am-4pm

What does the workshop cover?

- Principles of Key word Sign and gesture
- How sign helps communication development.
- How to choose which signs to teach
- Learn a basic vocabulary of signs to use in everyday settings.

Who is the workshop suitable for?

Parents, carers, family, teachers, educators, support workers.

If you have an interest in supporting someone with hearing challenges, this course will be beneficial to support verbal communication.

**Venue: Down Syndrome WA
32 Burton St, Cannington**

What is included?

- Morning tea and Afternoon tea (BYO Lunch)
- Getting Started with Key Word Sign booklet
- Certificate of completion.

Can I use my Childs NDIS funds to attend?

If you are self managed or plan managed, Yes, Parents can use their child NDIS funding. Parents can build their capacity and skills to help their child achieve their goals.

Can I attend if I don't have a child on NDIS?

Yes, you can choose the 'Public' ticket option.

Cost: \$150 per person- Go to the Trybookings website for ticketing options.

Register Now: <https://www.trybooking.com/BYOHK>

Registrations close on the 21st April.

For more details contact

admin@downsyndromewa.org.au or

62534752



**Down Syndrome
Western Australia**

The Key Word Sign workshop covers:

- An interactive teaching environment
- Learning a basic vocabulary of signs to use in everyday settings
- How to choose which signs to teach
- Principles of Key Word Sign and Gesture
- How sign helps communication development.

The workshop is suitable for:

- Parents/carers/family members
- Teachers, educators and support workers
- Anyone interested in KWS

Workshops Dates

Saturday 28th May
Saturday 25th June
Saturday 17th September
Thursday 17th November

Venues are to be confirmed but one will be South, one North and one Central. See the next e-news, our socials or contact DSWA for further information - admin@downsyndromewa.org.au

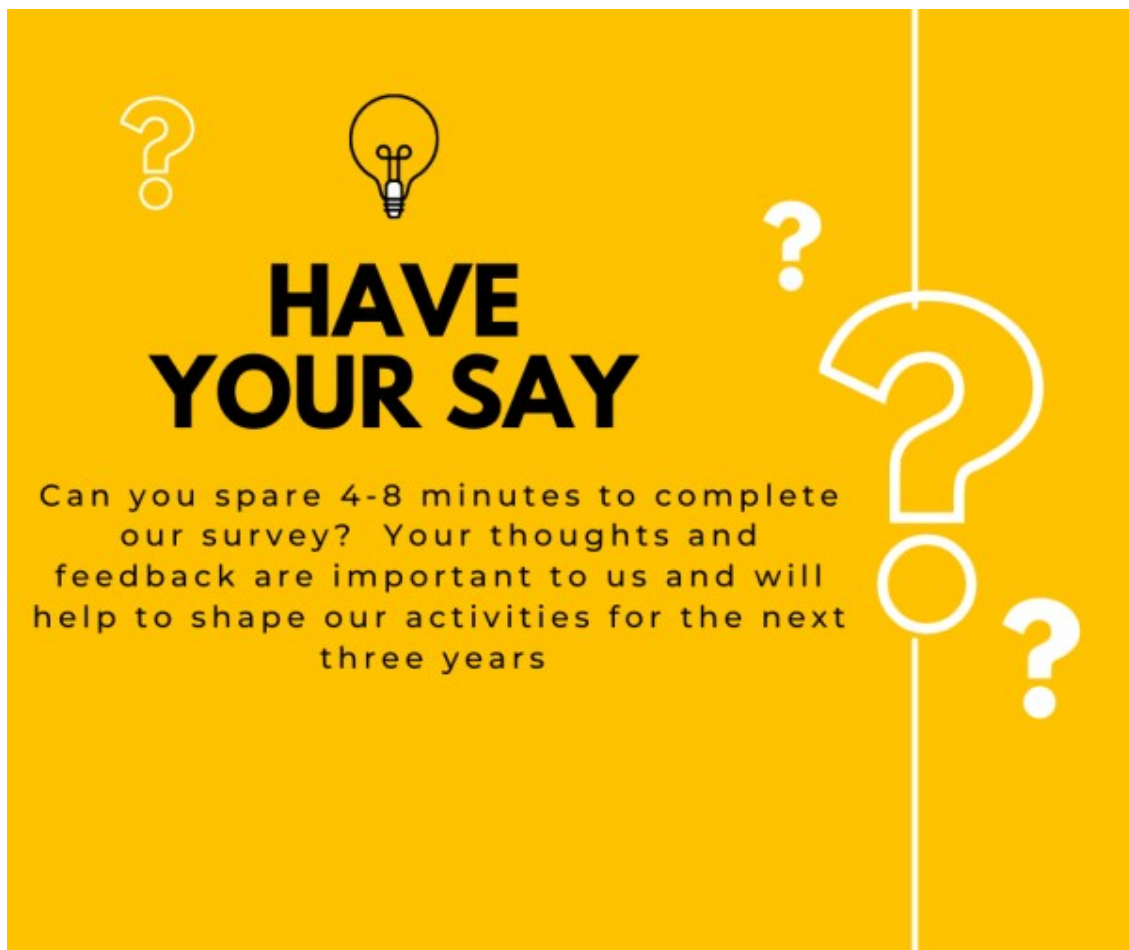
Perth Children's Hospital Family Outreach

Due to current restrictions, our Family Support Officer, Nikki Schwagermann, is unable to work at PCH at the moment. Nikki has started running fortnightly catchups via Zoom for anyone who would like to connect.

Make sure you are part of our private Facebook group 'Down Syndrome Western Australia Family Support Network' for the events and zoom links. If you are not on Facebook, please email Nikki and she can keep you informed of when the next one will be: nikki@downsyndromewa.org.au

Member Survey

Please visit <https://forms.office.com/r/ESBN7ZzrC6> and complete our members survey.



Socials!

Follow our socials to receive the latest news and events:



Feedback, Compliments and Complaints

We are committed to providing high-quality services and meeting your needs. We value your feedback – including complaints. To let us know what we do well and where we can improve our services, [please visit our web page](#)

PCH Survey

Calling all parents/carers of a loved one with Down Syndrome/T21 of all ages. Medical researchers working at Perth Children's Hospital are doing research to come up with the top 10 priorities of clinical care, from a Parent/Carers perspective. Please complete the short survey - <https://bit.ly/3tZXnCh>. *All data will be stored confidentially and without any identifiable information by the study team.*



Perth
Children's
Hospital

T21 Clinical Care Priority Survey **for Parents and Carers**

Medical research is needed to ensure the best possible medical care can be given to our children.

But what should be researched?

We are researchers based at Perth Children's Hospital and we are working with consumers to come up with a list of the top 10 research priorities for the clinical care of children with Trisomy 21 / Down Syndrome.

We would like to identify the particular needs of the families with children with Trisomy 21 / Down Syndrome.

In order to improve the lives of children with Trisomy 21 / Down Syndrome we would like to see what is most important in the eyes of the families and carers of children with Trisomy 21 / Down Syndrome with regards to their clinical care.

This is a voluntary survey which should take you less than 5 minutes to complete. We are asking you to state your top 3 research priorities in the clinical care of children with Trisomy 21 / Down syndrome. Your data, without any identifiable information, will be stored confidentially by the study team.

[HTTPS://BIT.LY/3TZXNCK](https://bit.ly/3TZXNCK)



We will be exhibiting at the

PERTH DISABILITY CONNECTION EXPO 2022

SPONSORED BY ST JUDE'S

We hope to see you there!

Register today

20th - 21st MAY, 2022 / Perth Convention & Exhibition Centre



Support Coordination

Support Coordination

Building capacity to increase independence

We can;

Link you in with suitable providers

Help you to reach your plan goals

Monitor service bookings and budget

Make connections to mainstream
and community supports

As you will be aware, DSWA have recently commenced offering Support Coordination for our members. I have capacity to assist additional participants and families to support you with regard to meeting the Goals in your plan.

Whilst Support Coordination is a new service for DSWA, I have 13 years of lived experience and have been working at Down syndrome WA for over 10 years. In this time, I have developed knowledge and experience supporting our members and our community and understand many of the services that you may require.

Please let me know if you have Support Coordination in your plan and would like to have a chat about this service. If you are unsure if you have Support Coordination in your plan, I would be happy to have a look and let you know.

If you don't have Support Coordination in your plan, but this is a service you would like to access for your next plan, I can help with a report to support your request.

I look forward to hearing back from you.

Please do not hesitate to give me a call on 0480311739 during my work hours/days (Tuesday-Friday 8am-4pm) or email - nikki@downsyndromewa.org.au

Quiz Night!



For bookings go to - <https://www.trybooking.com/BZDTB>

Employment Update

Work Readiness program pilot has started with seven people beginning an exciting journey learning about how to prepare for and get a job. The workshop continues for another 7 weeks.

Our Business Connector Sue has been hard at work seeking out new employers for our previous and current work readiness workshop participants. Stay tuned for news in future newsletters about more job opportunities! Do get in touch if you would like to employ someone with Down Syndrome, or can refer an interested employer. Email employment@downsyndromewa.org.au.

We have created a new Open Employment Facebook group - join us over there for news and stories on open employment in WA for people with Down Syndrome: <https://www.facebook.com/groups/1162904941186365/>.

DSWA job opportunity – we've extended the application due date another couple of weeks. If you have Down Syndrome and you're interested in a job at DSWA, apply! See Job Opportunity below for the details.

Sue Summers
Employment Connections Coordinator



Job Opportunity

We are very excited to have an opportunity for a person with Down Syndrome to work in the DSWA office in Burton St, Cannington.

Initially this position would be working in Administration for 4 hours per week. The initial period will be for three months paid at L1.1 SCHADS Award.

To register your interest and see if we are a good match for you, please send an email to Sue Summers, Employment Connections Project Co-ordinator by 11 May 2022.

This position would have an employment mentor assigned which can be paid through NDIS if employment is in your plan. This is a great opportunity for someone who is new to the workforce or looking to try their skills working in Admin.

There is a bus stop nearby, and we can offer support and training required as part of Finding and Keeping a Job.

Contact Sue: Employment@downsyndromewa.org.au

If you need any assistance to check your plan, please talk to Nikki at supportcoordination@downsyndromewa.org.au

End of Financial Year Donations

Down Syndrome Western Australia

IT'S TIME TO MAKE YOUR END OF FINANCIAL YEAR DONATIONS

Are you preparing for your EOFY tax return and noticed you haven't made your annual community donation yet?

You can make an end of financial year donation to Down Syndrome WA and help us continue to support people with Down syndrome and their families. Donations from \$2 are tax deductible. DSWA is a not for profit organization which provides programs, events, activities, support and information to people with Down syndrome, their families, carers and the wider community.

Many services we offer, are not funded programs. Everyday, we provide support and information to the community, new members, parents, participants and many other groups, which requires the support and generosity of the WA community. Make a donation today and help us support a Life of Possibilities.

Please visit <https://www.mycase.com.au/page/282600>

Pathways to Independence

Next workshop – Relationships (for people with Down Syndrome).

Sign up for our next workshop, which will help you learn about the different types of relationships, healthy and unhealthy relationships and how to stay safe.

Date: Saturday 28 May 2022

Time: 11am-1pm

Location: 32 Burton Street, Cannington WA

Book on Trybooking: <https://www.trybooking.com/BZBTF> or email Sue for more information.

Pathways to Independence

Capacity building workshops

Workshop for people with
Down Syndrome:

Relationships

11am Saturday
28 May 2022

Down Syndrome WA
32 Burton St, Cannington

A workshop for people with Down Syndrome.

We will explore different types of relationships, healthy and unhealthy relationships, and how to stay safe.

Book at www.trybooking.com/BZBTF
For more details contact Sue Summers at
sue.summers@downsyndromewa.org.au
or 0480 394 544.



Down Syndrome
Australia

Upcoming workshops

Save the date!

Tuesday 21/6 - Housing Options (for families)

Tuesday, 12/7 - Staying Healthy (for people with Down Syndrome)

Saturday 23/7 - Supporting Healthy Lives (for families)

Tuesday, 30/8 – Relationships (for people with Down Syndrome)

And keep an eye out for workshops being planned in...

- Toilet training
- Wills and Trusts
- Arts and crafts
- Energy techniques

Sue Summers
Pathways to Independence Project Coordinator
+61 0480 394 544
sue.summers@downsyndromewa.org.au

DSWA Playgroups

South Metro Playgroup

Term 2 starts back Monday 2nd May. It will be filled with Autumn, Winter and space activities and a visit from Messy Mat. We look forward to seeing everyone!

South Metro Playgroup
playgroup@downsyndromewa.org.au



North Metro Playgroup

North Metro playgroup rounded up a fun filled term one with a special Easter themed Messy Mat session. The team from Messy Mat Perth put on a magical Peter Rabbit sensory play which all our playgroup kids loved.

Danica and I loved seeing how much the kids have grown and developed by playing with all the different materials and textures.

We have a huge term two planned filled with Autumn, Winter and space activities. We can't wait to return to playgroup to start the fun!

Tracy
tracy@downsyndromewa.org.au



KiDS Club Events

Term Two

Saturday 7th May 9:00am-11:00am: Playground catchup!

Saturday 11th June 5:30pm-8:00pm: Movie night

Saturday 2nd July 9:15am-11am: Build a bear workshop

Term Three

Saturday 6th August 9:00am-11:00am: Music workshop

Saturday 3rd September 10.00am-12.00pm: Animal farm

For more information about events or any other KiDS Club questions contact Siobhan
- kidsclub@downsyndromewa.org.au

Aim High Club

Over the weekend, our members enjoyed two incredible events. As the new coordinator I thoroughly enjoyed meeting some of our wonderful members, their supports and our volunteers.

Our first event was held at UWA Octagon Theatre. We enjoyed some delicious dinner together at Broadway Fair Shopping Centre in Crawley, a popular choice was the fish burger!

We then wandered over to UWA Octagon Theatre for our event. What a wonderful delight it was, the stage was set with over 100 candles with the beauty of a string quartet playing all our favourite and memorable Abba songs. It was an unforgettable experience that our group really enjoyed.

Thank you to the wonderful supports and volunteer who attended.

Our second event was held at Perth City Farm. We had absolutely magnificent weather, while we enjoyed a tour of the amazing environmental initiatives that take place in the garden. One of our members learnt that coffee pods can be recycled and brought down to Perth City Farm. We then partook in a recycling craft workshop; where we coloured in and cut up plastic water bottles to create sun catchers. Our group was amazed about the different uses for common household rubbish. As one member said "it's amazing what you can make with what you have lying around at home"! We

then caught the Cat Bus to Elizabeth Quay where we enjoyed a delicious lunch and walk around the Quay.

Thank you to our remarkable volunteer Alice for your support!



Our next event will be Friday the 6th May at event cinemas in Innaloo, where we will be watching the newly released Fantastic Beasts- The Secrets of Dumbledore.


Thank you to all those who have replied to our Getaway emails. Our next Getaway will be in Margaret River 10th-12th June 2022. Stay tuned for the program which is coming out soon.

Amandine

0422 795 160




aimhigh@downsyndromewa.org.au

Date	Activity	Meet	Bring	Out-of-Pocket Activity Payment
Friday 3rd April 3:00pm – 6:00pm	BBQ Sundowner (Bring a friend) Join us for a relaxing BBQ Sundowner event. We will cook a BBQ together and enjoy some games together.	City Beach Challenger Parade, City Beach	Hat Water bottle Something to sit on Games	\$20.00
Saturday 9th April 6:00pm – 9:00pm	The Ellington Jazz Club: Sketches of Blue- Brenda Lee Jazz Quintet Join us for a night of jazz at this popular event.	Ellington Jazz Club 191 Beaufort Street, Perth Western Australia 6000	Companion card Valid ID	\$25.00
Friday 22nd April (30+) 6:30pm-9:30pm 	UWA Octagon Theatre: Candlelight- A Tribute to ABBA Meet for dinner at Broadway Fair shopping centre in Nedlands. Show will start at 8:30pm.	UWA Octagon Theatre 35 Stirling Highway, Crawley, Western Australia 6009	Bring money for dinner.	\$35.00

Saturday 23rd April (18-30) 10:00am-1:00pm 	Perth City Farm Tour and Lunch at Elizabeth Quay This tour will include animals and food production. We will go for lunch after the tour at Elizabeth Quay.	Perth City Farm 1 City Farm Place, East Perth Western Australia 6004	Comfortable walking shoes Water bottle Hat Bring money for lunch Smart rider	\$35.00
Friday 6th May (18-30) 6:00pm-9:00pm 	Event Cinemas: Fantastic Beasts- The Secrets of Dumbledore Come and watch this exciting and <u>newly-released</u> movie.	Event Cinemas Innaloo 57 Liege Street, Innaloo Western Australia 6018	Companion card	\$15.00

Saturday 14th May (30+) 10:00am-1:00pm 	Tai Chi and Picnic (bring a friend) We will relax and do an hour of Tai Chi together and then share a picnic together on the grass.	Hyde Park corner Vincent & William Streets, Perth Western Australia 6000	Comfortable walking shoes Loose clothing Water Bottle Hat	\$30.00
Sunday 22nd May (18-30) 1:00pm-4:00pm 	Tennis session and afternoon tea Join us for a <u>beginners</u> tennis session from 1pm-2:30 followed by afternoon tea until 4pm. Tea and coffee, fruit and muffins included.	<u>Reabold</u> Tennis Club Corner <u>Howtree</u> Pl and Oceanic Dr, Floreat Park Western Australia 6014	Comfortable walking shoes Loose clothing Water Bottle Hat Bring a plate to share	\$25.00
Saturday 28th May (30+) 11:00am-2:00pm 	Lunch and Group Walk Join as we have lunch together at the café and then a gentle walk.	Zamia Café Kings Park 50 May Drive, Kings Park Western Australia 6005	Bring money to buy your own lunch Comfortable walking shoes Water Bottle Hat	\$5.00

Friday 3rd June (18-30) 5:00pm-8:00pm 	Zumba and Cooking Session Join us as we have fun doing a Zumba session and then a cooking session. What will the recipe be!	Reabold Tennis Club Corner <u>Howtree</u> Pl and Oceanic Dr, Floreat Park Western Australia 6014	Comfortable walking shoes Loose clothing Water bottle Apron (optional) Hat	\$30.00 <u>approx</u>
Saturday 18th June (30+) TBC 	AFL Game: West Coast Eagles vs Geelong and Pub Meal Join us and barrack for your favourite team while we enjoy a pub meal together.	Wembley Hotel 344 Cambridge Street, Wembley Western Australia 6014	Bring money to buy your own dinner. Valid ID	\$5.00

Sunday 19th June (18-30) 10:00am-1:00pm 	Morning Tea at Heathcote Reserve (Applecross) Join us in Heathcote Reserve for morning tea. Bring a plate to share and we will have some games to enjoy together.	Heathcote Reserve Duncraig Rd, Perth Western Australia 6153	Bring a plate of food to share. Water Bottle Hat	\$5.00
Sunday 26th June (30+) 11:00am-2:00pm 	Art Gallery of Western Australia Tour and Lunch We will have a look at the stunning pieces in the Art Gallery followed by some delicious lunch.	Art Gallery of Western Australia Perth Cultural Centre, Perth Western Australia 6000	Companion card Bring money for lunch	\$5.00
Wednesday 29th June 6:00pm-9:00pm (18-30) 	Film "Poppy" Poppy: Kiwi movie about a girl with an extra chromosome in the works Kapiti film-maker Linda Niccol has recently received development funding from the NZ <u>Film</u> Commission for her movie Poppy. A story about a girl with "a little bit extra" – the Down syndrome chromosome – is being made into a film.	Palace Rain Square Level 2, Raine Square, 300 Murray Street, Perth	Companion card	\$25.00

FrienDS for Life



This month Friends For Life we played Mini Golf at Point Walter Golf Course which is nestled alongside Perth's Swan River with sweeping views and spectacular scenery. We had a booked out event which was great to see and we welcomed a new member Matthew Guppy to the group. It was great catching up with a few members who haven't been able to attend the last few events. Looking forward to catching up next month.

Our next catch up is on Saturday 21st May 2022 at AQUA, Hillary's; more details to follow, by email, very soon.

Claire - Coordinator

friendsforlife@downsyndromewa.org.au



*Stay well everyone and please contact us if you have any questions.
We are here to support, inform and connect our Down syndrome community.*

**If you know anyone who can benefit from this newsletter,
forward this email and ask them to subscribe. Thank you!**

Subscribe now

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