Good afternoon - I found an error in the newsletter which needed to be corrected. Please find the replacement newsletter. As CEO I apologize for any inconvenience. Regards Cassandra



Latest News from Down Syndrome WA

Newsletter May 2022



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Cassandra's Corner

Another month closes and we have certainly had a wet end to the month, but that hasn't slowed down the work or progress. May has seen us close out our NDIS -Quality and Safeguard- Stage 2 Audit. The organisation performed very well through the audit. The process of audit preparation has left us with more robust systems and processes and ensures that we are meeting the standards required in our industry. It was also an opportunity to look strategically at our structure, and how we conduct our business.

Member Survey

I am very grateful to the community members that took time to complete the Member Survey. 40 Members completed the survey from across a broad spectrum of the membership. On average, there was a satisfaction rate across the respondents of 3.8. Which means we are meeting our goals in some areas and for some members, and not for others. Some areas of



concern which were raised were 1. Lack of regional activities, 2. Website content, 3. Aging, Dementia, Housing, need to be focussed on, 4. Specialist knowledge loss, and 5. services in areas such as Education. As we have now come through six months of stabilisation and governance improvement, we are already focussing on a number of the areas raised.

The Regional Outreach program has been being developed since January and is due to commence in June and July. We now have volunteer coordinators in the Midwest (Geraldton), South West (Bunbury) and Great Southern (Albany). We will be visiting these regions to conduct training and induction, and to hold an initial event in those communities. We are delighted to be providing some services in each of these locations and hope to build on that with the input of the community. Each region now has a Facebook page to connect members in their area. There is a fourth Regional Page, to connect those in Rural and Remote WA.

The Website review and update is underway, and we are mindful of the request for more information, research and links to be included. As we build the quality of content on the website, I would be very grateful for any suggestions or links you believe should be included on the site. The collective knowledge in our community far exceeds any I could hope to have, and as such, your input is extremely valuable to me.

Education is absolutely an area of focus, and we ran a Teacher Professional Learning Day earlier this year. This was run online to support regional teachers and to address COVID concerns. A second day will be run in the second half of the year. We do not currently have any funding to run Education programs, but we are investigating what is available and how we can fund an increase in our service levels.

The demand for information and services around Aging, Dementia, Housing, Independent Living, and from our own on the ground experience, Psychology services are pressing. I am committed to increasing our service in these areas and am commencing discussions on how to progress, and to find funding. To begin, we do have some workshops coming up to address these topics coming up so please watch for the Pathways to Independence workshop series.

From the survey, 9 members expressed an interested in being part of the strategic planning process. I will be in touch with each of those members personally, to discuss how they would like to participate. There was much more value in the survey, and we are addressing all feedback given.

Workshops

We have a strong workshop series this year, however participant numbers have varied. Recently we advertised a Relationships Workshop for our adult members. This program has been developed by the Down Syndrome Associations across Australia through DSA and was also going to be attended by Relationships Australia. The program, where attended has been very successful and informative. Relationships form and having knowledge and information to help transition to a relationship, understanding relationships between friends and people we are just meeting are key life skills. Often relationships form from DSWA events and social groups, and this has been identified as an area in which more information would be valuable. Unfortunately, the DSWA workshop was cancelled due to lack of registrations. I have asked the staff to reschedule this workshop and to provide more information on the content of the workshop by email. We hope to be able to run this vitally important life skills workshop very soon.

Research Opportunities

Researchers from Perth Children's Hospital and the Telethon Kids Institute will be holding a Members meeting, hosted by DSWA in the coming months to talk about what the main Gaps are in Down Syndrome Research. They would like to understand the communities research priorities and have your input. We will provide more information very soon on the meeting date and how you can be involved. We are starting to see a lot of interest from researchers, and we will pass on these opportunities to relevant groups and families.

Employment

With the recent announcement that Activ would be closing its employment centres, I put out an email to all families with children over 15 to provide what support we can to those who are affected. The DSWA employment program is going from strength to strength, and we would like to support as many people as we can, in what I am sure will be a very challenging time. Please see the piece on our employment program further in the newsletter. We are also keen to increase social groups, and possibly form a social group for older members, beyond our 30+ group.

Fun and Fundraising

Thank you to the 150+ people that attended the sold-out Quiz Night on Saturday. It was a stellar event, and the feedback has been fantastic. We had a lot of fun with some crazy questions, lots of games and activities, and support from our members and community. Thank you to Julia Hales for welcoming our guests and to Jessica Toster for drawing the raffle prizes and announcing the winners. Thank you to the Volunteers who came along and were so positive and supportive. I wish to pay a special tribute to our small staff team who arranged the quiz night in just a few (3.5) weeks and volunteered their time at the event. It really was a great night and on top of having a lot of fun, we raised just over \$6000 for DSWA. Thank you to my team, your teamwork, commitment, and passion for this organisation whether you have been here a long time, or just starting, is inspiring. I want to pay special tribute to the many sponsors who donated wonderful prizes to the

Quiz night. There was something for everyone. (See our sponsor list further in the newsletter – please support those that support us)

Upcoming Important Dates

June 13 – Special General meeting to Appoint the 2022 Auditor and to update the DSWA Constitution which needed to meet legislative changes that were made in 2016 and required to be implemented by 2019.

August 13 – 2022 Gala Dinner – what a beautiful evening this promises to be. Well done to Jessica Davies and Emily Cutting for volunteering to organise this years event.

September 21 – 2022 AGM

As your CEO, a personal note from me... I know that we have a long way to go to providing services across all ages and to engaging in a positive and meaningful way with our members, and I want to assure you that this is my commitment. I know that many of you aren't able to contact us during our opening hours or find it difficult to engage with some of our communication channels, so I invite you to reach out to me by email or phone. I am happy to make appointments to come and meet with you, and to speak to you after hours. This is a wonderful organisation, and we can be even better, but will only be able to do that if we have two way dialogue and interaction. I need your input because we can't improve without it. Recently I saw a post from a member on a Facebook group, linking to a very interesting paper on Employment, these are valuable resources and ones we read! Your collective knowledge is important, and I hope you will engage with me and the team to continue to grow this wonderful organisation.

Warmest regards Cassandra

0432 407 527

ceo@downsyndromewa.org.au

Quiz Night





Board Meetings

The Board will next meet on Monday 13th June 2022, includes a Special General Meeting for Constitutional updates and Appointment of Auditor.

Dates for the remainder of the year are as follows:

- 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.

Member Story

from Kerri-Anne, Archer's Mum

We were surprised with Archers diagnosis of Down syndrome at birth despite testing. Feeling lost about the unknown, I was put in touch with Nikki at Down syndrome WA. She was so warm and welcoming, which is what I needed in this time of the unknown. Nikki delivered a welcome pack from DSWA and Celebrate T21 to myself and Archer while in hospital and it was like Christmas. It was so exciting to unpack and made me feel like I wasn't lost anymore and had somewhere we belonged.

Having someone from DSWA at Perth Children's Hospital (PCH), able to come and visit was so important to me. I had someone there to relate to and who I felt comfortable voicing my concerns. She celebrated the small milestones with me that are so important to our babies, and was someone who could give me a glimpse into the future of what our lives may look like.

Soon after leaving hospital, we joined DSWA's South Metro Playgroup. As a mum of 4 I have been to many playgroups and mothers groups, but this one is different. It is like a support family. A safe place, full of knowledge, where I can ask all of my questions and voice my concerns. A place where all my children are welcomed with open arms. I have met so many new friends and families that I know will be there for me during the good and bad. I am so thankful to have playgroup available to us









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

Follow our socials to receive the latest news and events:







Gala Dinner

2022 Gala Dinner planning is underway. The fantastic team of Jessica Davies and Emily Cutting are again the Organisers of the 2022 DSWA Gala Dinner.

In the preparation for the Gala we are putting the call out for Members who might like to perform at this years Gala Dinner. You will remember the beautiful group performance by the Ballroom Dancers last year who charmed us with their style and grace.

So, to our Members -

- Would you like to perform at this year's event?
- Do you have a particular talent that you would like to share with us?

Please send an email to Jessica Davies via the <u>fundraising@downsyndromewa.org.au</u> email address. Please tell us;

- · What performance you would like to give,
- · How long you have been doing this,
- How long you would need for your performance.

We will look at all Expressions of Interest and choose the performances that will best suit the gala dinner. We know there is a lot of talent out there – Apply now!

The Gala is a key social event and an opportunity to celebrate and enjoy. It is also an opportunity to raise some funds for DSWA. If you know someone that could make a donation for Silent Auction prizes or might be interested in making a financial donation to cover the cost of the event, please let us know on the fundraising@downsyndromewa.org.au email.

Financial Donations can be made via this link https://www.mycause.com.au/page/284605

Tickets to the event will be available from Friday 27 May via TryBooking. Links to the event will be available through all Social Media pages.

This year there is a payment plan for our Members with Down Syndrome where you can pay a deposit of \$70 and then pay two payments of \$35 one in June and one in July, which you will receive an invoice. These invoice will have to be paid in full by 29 July for you to attend the event. Or you can just book the full price ticket if that is better for you.



Regional Outreach

VISITS

South West - June 9th, 10th, 11th Great Southern - June 23rd, 24th, 25th Mid West - July 21st, 22nd, 23rd Regional, Rural, remote Online training date to be announced.

Proposed Itinerary

Thursday midday - arrive and visit child health nurses, hospitals, etc Friday - Regional Representative training Friday evening - Dinner Saturday morning - Community catch-up



DSWA are looking for volunteer Regional Representatives for each region

For this program to work as effectively as possible, we need at least one or more Volunteer Regional Reps from the area.

What will the regional reps be doing you may ask??

- You will receive training from DSWA (Me) when I come down.
- You will be a point of contact for any new families in your region to support them and connect them to the community.
- You will be the voice for your community, relaying to DSWA what your community wants and needs from us.
- With help from DSWA, you will organize community catch-ups/events as frequently as your community decides.

We specifically don't have any volunteers for the Great Southern Region and only one for the Mid West region.

Please let me know if this is something you would be interested in and if you have any more questions contact Nikki Schwagermann - 0480 311 739 during my work hours/days (Tuesday-Friday 8am-4pm) or nikki@downsyndromewa.org.au

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, <u>please visit our web page</u>

Support Coordination



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

Nikki Schwagermann

Employment Update

Talk to Us!

With the recent news that Activ will be closing their employment services at the end of July 2022, we are conscious that this may be a difficult and uncertain time for some Participants and families. We are sure that there may be many uncertainties to navigate through in the coming weeks and months.

Down Syndrome WA is able to support people with Down Syndrome who are losing their employment as a result of the Activ closures. We do already offer a large range of employment services, including;

- The Discovery Process working one on one with participants to discover your work goals, dream job, strengths
- Work Readiness Program to assist in transition into the broader workforce, preparing resumes, how to prepare for work
- Employment connection job matching of our participants with prospective employers, and
- Employment Mentoring one to one employment support in the workplace

The **Employment Connections program** has been running at DSWA since 2020 and has been successful in a number of placements for participants in Open Employment roles, and providing participants that have existing roles in the workplace, further develop their skills and confidence. We can offer short and long-term support.

If there is any way that Down Syndrome WA can provide assistance to you, please do not hesitate to reach out. Our CEO Cassandra can be available for calls outside of business hours to provide support to members and families who work and/or do not have access to our service during traditional office hours. If there is a way we can support you to navigate this change, we are here to assist. You can email Cassandra at ceo@downsyndromewa.org.au or our Employment coordinator Sue at employment@downsyndromewa.org.au.

DSWA/DSA Employment resources:

DSWA Open Employment Facebook group - for news and updates on Open Employment Right to Work website - for information on employment for people with Down Syndrome, and potential employers Employment page at the Down Syndrome WA website

Email us: employment@downsyndromewa.org.au

Down Syndrome WA job opportunity

Applications closed last week. We are very excited to be at the applicant review stage. Stay tuned for news of our new staff member!

Employers

If you are, or know of an employer that is interested in employing a person with Down Syndrome, and would like to know where to start, we can help! Head to https://www.downsyndrome.org.au/right-to-work/employers/ for more information, and don't hesitate to contact us at employment@downsyndromewa.org.au for some tailored guidance.

Sue Summers
Employment Connections Coordinator
+61 0480 394 544
employment@downsyndromewa.org.au

End of Financial Year Donations



Please visit https://www.mycause.com.au/page/282600

Pathways to Independence Workshops

28 May Relationships workshop POSTPONED

Our upcoming Relationships workshop for people with Down Syndrome has been postponed. Stay tuned for a new booking date!

NEXT WORKSHOP: Toilet Training

Wednesday, June 1st at 7.30pm Zenith Room, 32 Burton St, Cannington WA Or online!

Our Toilet Training workshop will be presented by the amazing Tabitha Poole, Senior Continence Clinician at Therapy Focus. The workshop can be attended in person at DSWA, and also online!

Bookings filling fast. Head to Trybooking to secure your spot: https://www.trybooking.com/BZMUC

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...

- · Wills and Trusts
- Arts and crafts
- · Energy techniques

Get in touch with us if you have ideas for workshops you'd like to see us provide!

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

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DSWA Playgroups

Meet Renee!



My name is Renee and I am the new coordinator for South Metro Playgroup. I am a mother of 5 and nanna to 15. I have my Diploma in Community Services Case Management and Cert III in aged care. I enjoy catching up with friends, reading when I get 5 mins, op shopping movies, cooking, talking to much and all things fun really. So much more I can write about myself, just happy to be a part of our beautiful network \bigcirc

South Metro Playgroup

We've had a busy term at playgroup South. We've welcomed new families and enjoyed doing a heap of fun activities. Lots of Sensory play. Easter craft, Mothers day, autumn fun, digging for treasures, painting and playing with our friends of course.

Renee renee@downsyndromewa.org.au



Playgroup North Metro has enjoyed an extended celebration of Mother's Day activities this month. Our kids enjoyed getting crafty with hand painted cards and even spoiling Mum's and Nanna's with a pamper Day.



As the weather continues to get cooler in the lead up to Winter, we have some lovely indoor activities planned for the rest of term two. Space discovery and Autumn sensory play are on the list to keep the fun rolling at playgroup.

We welcome all existing members and new families to pop in for a cuppa and cake, playgroup is a wonderful way to connect with other families and talked about shared experiences you make have with your children.

Tracy

tracy@downsyndromewa.org.au

KiDS Club

We had a wonderful time at Pia's Place Playground this month. It was wonderful to see some new faces! I am very excited for the next event, which will be a movie night taking place on Saturday the 11th of June 5:30pm-8:00pm. The movie starts at 6:00pm, and we will be running a poll on the KiDS Club facebook page next week to select the movie. The event will be at the Victoria Park Community Centre (248 Gloucester St, East Victoria Park WA 6101).

Tickets are \$5 per child. Popcorn & juice box per child provided. Please advise of any dietary requirements. Dress in pjs, bring blankets pillows and cushions to sit on.

RSVP by getting a ticket before June 3rd, https://www.trybooking.com/BZSZX.

I'm looking forward to seeing you there!

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 - kidsclub@downsyndromewa.org.au u for registration details.

KiDS Club Events

Term Two

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

FrienDS for Life

This month Friends For Life caught up at AQWA Aquarium at Hillarys. It was a perfect sunny day, perfect temperature and perfect company. We enjoyed learning about all the different sea life and going around the underwater tunnel, we went around guite a few times! We were able to sit outside and enjoy the beautiful scenery and play some fun games.

Our next catch up is on Saturday 18th June 2022 at Yanchep National Park; more details to follow, by email, very soon.

Claire - Coordinator friendsforlife@downsyndromewa.org.au

Aim High Club

The Month of May has been a great month for the Aim High Club.

We had a fun movie screening on Friday the 6th of May where we all watched Fantastic Beasts. It was lots of fun as we all had a laugh after the movie trying to pretend, we were one of the crabs- if you don't understand this reference, you'll have to watch the movie \bigcirc

Then we had an action-packed weekend, beginning with Karaoke on Friday the 20th. We all sung out hearts out and really enjoyed each other's company. Next was Perth Zoo on Saturday the 21st. The groups favourite things to visit were the penguins and the elephant. We finished our exciting weekend with Tennis on Sunday the 22nd. What a lot of fun that was, as we learnt how to hit the ball so it stays inside the court- well at least mostly \bigcirc

We have one more event this month on Saturday 28th May where we will have lunch and then a walk at Zamia Café in Kings Park from 11:00am-2:00pm.

It will be lots of fun!



Our June calendar has been published and it promises to be great fun with 6 Aim High events and our Margaret River Getaway! And see our full 3 month calendar here.

As always please get in touch if you have any questions or ideas for our Aim High Program. Thank you to our Aim High volunteers and staff for all your support!

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

JUNE EVENTS AIM HIGH CLUB

T: (08) 6534743 E: aimhigh@downsyndromewa.org.au



Zumba & Cooking 03 June 3 at 5pm (18-30)

Heathcote Reserve 19 June 19 at 10am (18-30)

Ballet Basics

Last Night of the Proms

Margaret River Getaway 10

Art Gallery of WA Tour 26

West Coast vs. Geelong 18 June 18 at 2pm (30+)

Film 'Poppy'













AIM HIGH CLUB GETAWAYS

T: (08) 6534743 E: aimhigh@downsyndromewa.org.au

Margaret River

June June 10 - 12, 2022



July

Perth CBD



Sept

Woodman Point

Oct

Mandurah

October 12-13, 2022

Albany

November 25-28, 2022



We welcome all feedback and suggestions about the e-news. Please send any feedback to admin@downsyndromewa.org.au or use or our online form.

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!

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