

Dear SA Community

It was lovely to meet a group of parents from SA at the World Down Syndrome Congress. It was a wonderful event, and inspiring to see so many young adults presenting their lived experience.

I will be visiting South Australia from Monday 5 to Friday 9 August and would like to catch up with as many families as I can. I am attending a forum on Monday morning in Southern Adelaide, and have a couple of other meetings arranged, Wednesday afternoon and Thursday morning.

Being from regional WA I am no stranger to regional travel and would like to travel to meet as many people as I can and hear from you what you feel you need in SA to support your child with Down syndrome and your family and how we can help.

If you are interested in catching up with me whilst I am there or have recommendations of services or others you would suggest I touch base with, I would love to hear from you directly [ceo@downsyndromewa.org.au](mailto:ceo@downsyndromewa.org.au).

I am very keen that we begin producing an SA Newsletter to share stories, events and activities that are happening across SA. It would be great to start this in August, and I would love for you to send through any stories you may have to share, or events/activities relevant to our community. Please send information, photos, and stories through to [infos@downsyndrome.org.au](mailto:infos@downsyndrome.org.au)

**A quick summary of WA's support for SA families.**

- Please know that I fully intend to appoint someone on the ground in a casual role to assist with organising

events, activities and family visits. After the August visit we will be producing a Position Description for the role which we will put a link to in the first newsletter.

- As WA have an experienced Family Support team in place, who both have lived experience, we can offer a fast response to enquiries 4 days per week. We will also refer to or speak to those on the ground. WA have already responded to 17 support enquiries from families in SA. DSWA's family support team that can be contacted via email [InfoSA@downsyndrome.org.au](mailto:InfoSA@downsyndrome.org.au). We can also offer family support meetings by video link or phone.
- One benefit we hope is useful in WA's support is that when we run programs, courses or activities that are online, you are welcome to join.  
Our intent is to simply enhance the level of services and resources that are available, and help families in SA.

Shortly we have a Down Syndrome Regression Disorder seminar with Dr Jonathon Santoro from LA, via Zoom, please see the details below. All families and medical professionals are welcome to join this presentation. Register to join us at <https://www.trybooking.com/CTXFW>



Down Syndrome  
Western Australia

Invitation

## A presentation on Down Syndrome Regression

We invite you to join us via  
presentation by

Dr Jonathon Santo  
Saturday 10 August  
12 noon Perth Time

Open to Families and  
Medical professionals



Join us by Zoom - Get the  
Zoom link when you Book  
your free ticket via  
Trybooking.  
Scan this code, or follow the  
link

I sent an email to all of those on the database we were provided on 13 June 2024. Some people let us know that they didn't get that email. Those on the email list, are the ones we have from handover and we are looking to add as many additional families as possible. If you have friends that you think might not be on the list, please share this email with them. To be added to the data base, people can complete this short form - <https://forms.office.com/r/YvSKGtt8p9>

I look forward to meeting as many families as I can whilst in SA for the week.

Warm regards  
Cassandra



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Member of Down Syndrome Australia Federation  
Finalists WA Disability Support Awards 2024  
Finalist Belmont and WA Small Business Awards 2023  
Finalist Belmont and WA Small Business Awards 2022

*Please see below for the email sent on the 13 June*

Good afternoon SA Down Syndrome Community,

On behalf of DSA, we would like to recognise the contribution Sam Roach who provided information services to SA for just under 4 years. Sam provided great support for people with Down syndrome in SA and we want to recognise her contribution to the community.

With Sams resignation DSA approached Down Syndrome WA to provide service delivery to the SA community to leverage our on-ground experience and connections to support you. We will be appointing a person on the ground in SA to provide face to face services and contacts, however our team are available on phone and teams as well. I have just had confirmation that our contract to deliver services will continue for the next 12 months from 1 July 2024 – June 30, 2025 and I believe that together we can achieve a lot in this time.

#### **So far**

- In March this year the team from DS Victoria presented the Teacher Professional Development day and followed this with an education day for parents. Nikki Schwagermann, Senior Family Support Coordinator from DSWA also attended and met families and educators.
- We have recently updated the data base for SA and look forward to adding a lot of new people to the data base and building an active member group.

- Article in the Voice
- 12 Family engagements by phone or email
- 7 school connections and phone consultations

I hope to meet those of you who are attending the World Down Syndrome Congress in Brisbane in July and I will be visiting SA in August.

#### **A bit about our services. DSWA deliver**

- 2 playgroups, social groups for 6-11yrs, 12-17yrs and 18+ years.
- Family support, regional outreach, advocacy, education support and a range of other services.
- Workshops and programs from time to time (unfortunately this funding has now ceased, but we will be looking at new grants to continue to deliver workshops and education) and we will make any online courses available to you.
- School Leaver Employment Supports and an Open Employment program
- A Regression Support Group in WA, supporting families who have experienced regression symptoms and behaviours in their children with Down syndrome. We currently have a survey running on possible regression, and invite anyone in this position to complete the survey. <https://forms.office.com/r/L07pN7Z9ts> . We have had 33 responses to date, and I will be presenting at the World Down Syndrome Congress in July. We do offer a support group which can be joined online.

DSWA's family support team that can be contacted via email [InfoSA@downsyndrome.org.au](mailto:InfoSA@downsyndrome.org.au). We can also offer family support meetings by video link or phone.

#### **Future**

- We will soon be sending a short survey to those families on the database and would appreciate you sending on to others who we may not be in contact with. The survey is intended to gain a greater understanding of what services you have, what is missing and how might be able to support you.
- I have attached a membership form, which will allow us to check and update your information on the existing data base, or add you if you are not currently

on the list. It would be extremely helpful to get as many people as we can registered and updated so we can engage with more SA families.

- Staffing - If you have an interest in providing Casual Family Support on the ground in SA, I would love to hear from you.
- E News - I would like to put together an ENews letter to you all but to do this effectively and make it valuable, it would be great to have information about groups, activities, and personal member stories as possible. You can submit anything for the new SA ENews to [InfoSA@downsyndrome.org.au](mailto:InfoSA@downsyndrome.org.au)

Please feel free to share this widely among the Down Syndrome Community in SA so that we can reach as many as possible, I look forward to hearing from you and to meeting you at Congress or in August.



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<http://downsyndrome.org.au/sa/>

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