



**JUNE 2024** 

# Message from the CEO

Welcome to Down Syndrome Queensland's June update!

Last month I spoke about the new NDIS Bill. On 5th June, it successfully passed the House of Representatives. It is important to note, however, that the Bill is not yet law. It now heads to the Senate, where it will be debated and possibly amended.

#### Reforms in the Bill include:

- · taking a whole of person approach to participant support needs;
- improving service quality and safeguards; and
- reforming participant pathways onto the NDIS and working towards a unified system of support for people with disability.

Down Syndrome Regression Disorder (DSRD) is a condition that affects some young people with Down syndrome. It is characterised by an unexpected and severe regression in speech and functional ability. As a result of working with a group of families affected by regressive symptoms for over 12 months, Down Syndrome WA has developed a survey to gather relevant data. If you have a loved one that has experienced regressive symptoms, and wish to contribute to the data being collected, we encourage you to complete the survey.

The survey is intended to provide pilot data to help lobby for diagnosis and treatment for people suffering regressive symptoms and possibly Down Syndrome Regression Disorder. (All data will be deidentified in accordance with privacy requirements).

### **COMPLETE THE SURVEY**

DSQ's substantive funding is linked to several government grants which we deliver on their behalf to the intellectual disability community in Queensland. Recent advice unfortunately has confirmed that some of our previous federal government grants will not be forthcoming. This noticeable tightening of government grant funding has a widespread impact across the sector.

To this end, DSQ has lobbied at a state and federal level seeking some funding relief with the aim that our community/family supports and services are maintained.

DSQ's mid-year fundraising appeal is also an important opportunity to raise funds. All funds raised through this appeal will be used to maintain our range of Support Services.

Your contribution will make a difference!

## **DONATE NOW**

Written by Chris McMillan, Chief Executive Officer

# A nights of glitz and glamour

# **FUNDRAISING & EVENTS**

Can you believe it's almost July? It feels like just yesterday we were writing newsletter articles about an optimistic year ahead. Yet here we are, at the halfway point of the year, with our gala dinner on October 25th at Victoria Park on the horizon.

In what promises to be an amazing night of glitz and glamour, celebrating people with Down syndrome living their best lives during Down Syndrome Awareness Month, this is one event you don't want to miss. Whether you come along with a friend, gather a group of friends to book a table of 10, or showcase your business to the community by sponsoring a table, this will be a night we can all be proud of.

Click below to find out more and book your tickets!

#### **BOOK YOUR TICKETS**

Written by Michael Harrison, Community Engagement & Fundraising Manager

# **SUPPORT SERVICES**

### Be Your Own Boss Program at Carers Queensland

Microbusinesses provide a great opportunity for people with disability to earn an income, increase self-confidence and achieve greater independence.

If you are interested in self-employment, our Be Your Own Boss Microbusiness Program will empower, educate and support you to create or grow your own microbusiness. Each program runs over a six-month period with fortnightly workshops facilitated by Carers Queensland, building towards an opportunity to sell and/or promote your products or services at the end of the program.

The Be Your Own Boss Program will commence in the Brisbane South (Redlands/Logan) and Toowoomba regions in June/July 2024. They are also seeking interest in a Rockhampton program in 2024-25 (to be confirmed).

For more information about the Be Your Own Boss program or to find out more about other Driving Inclusive Change programs, please click the link here: https://carersqld.com.au/ndis/inclusion-projects/

#### **Down Syndrome Health Record App**

The Down Syndrome Health Record App helps parents and support people of children with Down syndrome to record and monitor their child's health, growth and development. It can track active symptoms, record information about your health history share information with healthcare providers and help you prepare for upcoming appointments.

The Down Syndrome Health Record App is available on the App Store here: https://apple.com/3TC3AtV

Written by Laura Mugaba, Support Services Manager

**EDUCATION** 

Educators, don't miss this opportunity to attend the World Down syndrome Congress!

This year, Brisbane is fortunate to be hosting the World Down Syndrome Congress (WDSC). With only a month to go, the DSQ Education Team is preparing to present two sessions at the WDSC. The WDSC is an unmatched opportunity for people with Down syndrome, families, advocates, educators, allied health professionals, and researchers to meet and share knowledge, insight and experience with others from different countries and settings.

Why is the WDSC beneficial for educators?

- Extensive knowledge and skills to be gained about understanding Down syndrome and how to teach and support students with Down syndrome
- Great opportunity to meet leaders and members of Down syndrome organisations from around the world
- Face-to-face interactions with world-renowned speakers
- Opportunity to meet people with Down syndrome and hear what they have achieved in school and beyond

#### Save the Dates for Our Exciting Upcoming Events!

It's time to block out your calendar for two of our most anticipated events of the year! Mark your dates and get ready to join us:

- October 5-6, 2024: Teens Challenge Weekend
- November 22-24, 2024: Challenge Weekend
- Dec 31 Jan 1: New Years Eve Ball

Registrations will open soon so make sure you keep an eye on your emails!

## Can't Join Us In Person? Enjoy Our Online Activities!

Join our online karaoke/talent shows, trivia nights, Dance Parties and connecting with Down Syndrome Victoria a couple of times a month all from the comfort of home—it's a fantastic way to stay connected with our wonderful community and entertained.

Offering such diverse activities ensures there's something for everyone to enjoy! Click below to register. We look forward to seeing you!

Written by Georgie Greaves, Office Manager

SEE OUR UPCOMING EVENTS

# **BECOME A MEMBER**

www.downsyndrome.org.au/qld

