



Down Syndrome  
New South Wales

# Annual Report 2019-2020



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Down Syndrome NSW works alongside people with Down syndrome and their families so that they may reach their full potential and live the lives they choose.

This Annual Report celebrates connectedness, diversity and community.

## VISION

To support all people with Down syndrome in NSW to achieve their full potential in all life stages.

## MISSION

Down Syndrome NSW provides social and educational opportunities for people with Down syndrome; provides information and support to families, carers and supporters; and helps advocate for changes to break down barriers and systems that stand in the way.

## VALUES

### MEMBER CENTRED

We are champions and advocates for the rights of people with Down syndrome to be valued and engaged in the community.

### INCLUSIVE

Our services extend from people with Down syndrome to families, carers and associates. Our whole-of-life approach enables a broader impact on the wider community.

### INTEGRITY

We are respectful and transparent in our actions. We work together to achieve our mission and share knowledge and strengths for best outcomes.

### RESPECT

We respect and value personal and professional diversity. We treat the community, colleagues and stakeholders with respect and courtesy, having regard for their dignity.

## WHAT WE DO

We work to provide the best opportunity for people with Down syndrome and their families to achieve their full potential.

We do this by providing high quality, evidence based information via phone, email, through social media, face-to-face, in the home or place of work.

### Our work includes:

- Prenatal support
- New parent support
- Ongoing support and information for families through all life stages
- Peer to peer connection through social and community groups like UP!Club for adults and Up Up & Away for children and young teens
- Workshops and community events
- Professional development, education and training for health, education and employment professionals
- Promoting public awareness and advocacy at local, state and federal levels
- Helping with self-advocacy opportunities for people with Down syndrome



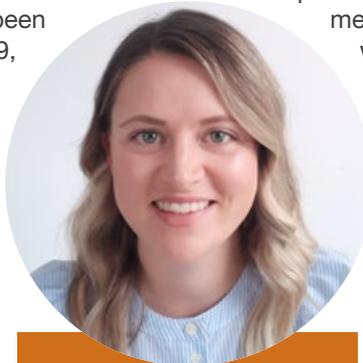
# JOINT MESSAGE FROM PRESIDENT & CEO

2019-20 marked another solid year for Down Syndrome NSW. Progressing the Association and ensuring financial security were the main objectives for 2020 and it is with pleasure we advise that both have been achieved. Despite the challenges of COVID-19, we continued to deliver professional services to our members and were able to deliver a surplus.

One of the highlights of the year was the 2019 Health Conference in September, focusing on the challenges of ageing for people with Down syndrome. The conference was a resounding success bringing together expert information and lived experience with a practical focus. We aim to continue to deliver high quality services across the lifespan from prenatal through to older age and to continue to support our members through life's transitions.

In February 2020, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability convened hearings on health issues in Sydney. We had strong representation from people with Down syndrome and their families throughout the two weeks of hearings. Members of Down Syndrome NSW were among those who shared their personal experiences and shone a light on the importance of people with Down syndrome being treated with dignity and respect by those in the health profession. Further we led the Down Syndrome Federation's submission to the Commission on Health issues.

Across the country we all faced the sudden impact of the COVID-19 pandemic, and the uncertainty and social isolation that surrounded it. Our members were worried about the loss of their routine social avenues and its impact on their health and wellbeing. We worked with our members to provide new opportunities for social connection, information and support. We would like to take this opportunity to acknowledge the hard work of our exceptional staff in adapting to a new way of working to ensure continuity of services to our members. Our members with Down syndrome showed great resilience adapting to the online programs with many of them thriving in the new environment, developing new relationships and strengthening their communication, literacy and IT skills. Their families and carers, as usual, rose to the challenges enabling on line participation and we have heard many stories of the joy they felt in observing their sons and daughters engagement with the online activities.



Hayley Warren, President

*"We aim to continue to deliver high quality services...and to support our members through life's transitions."*



Jennifer Evans, CEO

A number of initiatives supported increased reach to our regional members this year. Travel scholarships were sponsored for the health conference for regional members and planned regional seminars were transitioned to online forums further increasing the reach across NSW. The Staying Connected and online peer support sessions opened new windows of opportunities for participation from anywhere in NSW. Board meetings are now convened online enabling wider representation of our membership.

This year was also a time of change in the staff and board of Down Syndrome NSW. We welcomed Nicholas Gotsis and Gemma Namey to the board and farewelled President Jason Lloyd, Vice President Greg Simmons, Treasurer Michael Hogan, Mark Bezzina and Megan Smith who resigned from their positions throughout the year. A special thanks to Jason and Greg who generously gave their time for years to lead the Association. We also farewelled CEO Kathy Chapman and a number of dedicated staff - Carolyn Frichot (Communications Manager) and Information and Support Officers, Gillian Lipitz, Jo See, Megan Smith, Lakshmi Ramjas, Marissa Rafati and UP!Club Coordinator Flavio Fernandez-Maldonado.

We would like to thank Kathy for her contribution to the Association, particularly for her work in advocacy and the Health Conference and her leadership during the initial response to the critical impact of COVID-19 pandemic. Throughout the year we welcomed several new staff - Kathryn Hammond (Community Events Coordinator), Bernadette van Wijnen (Information and Support Manager), Jessica Viera (Up Up & Away Coordinator) and in May our new CEO Jennifer Evans.

We would like to thank our board members for their support and hard work and all the staff of Down Syndrome NSW and the many volunteers, donors and supporters for their contributions in 2020. As we enter our 40th year as an Association we look forward to continuing to support our members through all life stages, whilst being particularly mindful of the impacts of the COVID-19 pandemic.

Hayley Warren  
President

Jennifer Evans  
CEO

# ORGANISATIONAL DEVELOPMENTS

## ● COVID-19 Pandemic response

On 23 March, like most of NSW, we closed the Down Syndrome NSW office in Parramatta and transitioned our staff to work from home arrangements and commenced providing services through virtual platforms. We acknowledge the ingenuity and responsiveness of our staff in ensuring that our services not only continued to support our members at this time of crisis but actively increased the reach to our regional membership through this new medium.

In April we conducted a survey of our members to understand the impact of the pandemic on their daily lives and wellbeing, and how we could assist. The survey showed that 73 per cent of respondents felt very or extremely concerned about the coronavirus situation and 47 per cent were not confident that their family

*73 per cent of respondents felt very or extremely concerned about the coronavirus situation.*

member with Down syndrome would be able to get access to the health services they needed. Another 44 per cent were concerned that they would not have access to the NDIS services they required. They asked for information on social distancing and in looking after their mental health.

To support our members during the intense period of isolation, new online information and social sessions were developed for members. These included Staying Connected social sessions for adults with Down syndrome, an online version of Up Up & Away sessions and online Check In & Chat sessions for parents. We also reshaped existing services to an online format including new parent support and training for professionals supporting people with Down syndrome. Considerable reference to the response to the pandemic will be found throughout this report.

## ● Planning for the Future

Down Syndrome NSW's board is committed to ensuring the effective running of the organisation to best meet the needs of its members. Given the considerable changes in the external policy and funding environment the board commenced a review of its operations and directions in late 2019 with the assistance of Avril Henry, Change Management Consultant. This resulted in an organisational restructure in response to funding changes and opportunities.

Further work is continuing on a new strategic plan. The board also commenced work on revising the constitution.

## ● Board development

The board initiated a series of workshops on key issues including governance, risk management and planned for later this year on financial management.

## ● Strengthening the voice of our members with Down syndrome

In November, we held an advocacy workshop for a group of adult members with Down syndrome to learn about the different types of advocacy - individual and as a collective. We invited guest presenter Yvette Proud from the NSW Council of Intellectual Disability and were very fortunate to have two members from the Down Syndrome Australia advisory network in the group.

NSW representative Kylie Scott gave a short speech on the highlights of her role and chairperson Michael Sullivan encouraged us

all to "learn together, support each other and get excited" about advocacy and community leadership. The main takeaway was a very strong commitment from our members to work together and support each other in overcoming barriers and being community leaders and advocates.



## ● Improving access to information for our members

Using our strength as a Federation we have been able to deliver a number of new initiatives this year. A national unified website has been implemented to enable better access to information and resources on Down syndrome and to support increased collaboration and sharing of expertise across the network.

We also implemented a common national information management system on our membership and services. This will enable development of a national common data collection to support advocacy and funding applications.

The successful application by Down Syndrome Australia for funding for the Federation, through the Information, Linkages and Capacity Building (ILC) NDIA grant program for 2020-23 will support our work in providing information and support, skill development programs for our members and in educating the health sector on the needs of people with Down syndrome.

## ● NDIS Registration

Down Syndrome NSW continues to progress the implementation of NDIS to support its members' access to programs. Late in 2019 we underwent an independent audit as part of the re-registration process with the NDIS Quality and Safeguards Commission.

This was a very resource intensive process, and we were pleased to receive a 'highly recommended' rating by the auditors. We are registered for the provision in three categories of services: Development Life Skills, Group/centre activity, Participate community.

# ADVOCACY - Improving access to services

**The last 12 months has witnessed significant efforts by governments to better understand the needs of people with a disability, including those with Down syndrome within the wider service system.**

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability commenced in April 2019 and quickly initiated a series of public and private hearings, issues papers, and calls for submissions and the provision of community engagement opportunities. Its focus has been wide reaching examining accommodation, education, health, and the impact of the COVID-19 pandemic. Down Syndrome NSW had two meetings with representatives of the Royal Commission, one to assist with preparations for the health hearing and one on behaviour support.

With the leadership of Down Syndrome Australia (DSA), the federation of Down Syndrome Associations (Federation) made two major submissions to the Commission, one on Education and Learning issues in December 2019 and one on Health issues in March 2020. NSW contributed substantial leadership to the submission on the Health issues paper. This paper highlighted that people with Down syndrome face health inequities across the health system and are confronted

with barriers when accessing and receiving health care including inadequate communication, attitudes, values and assumptions of health professionals. There is a need for training and education of the health workforce with respect to patients with cognitive disability.

The third public hearing focused on health issues. It was held over two weeks in Sydney in February 2020. Many members of the Federation gave evidence at the hearings including several members of Down Syndrome NSW. We appreciated the strong representation and contribution made by our members, Kylie Scott, Tara Elliffe, Christine Regan, Lorraine Clarke, Margot Elliffe and Evelyn Scott. They shared their personal experiences and highlighted the importance of people with Down syndrome being treated with dignity and respect by health professionals.

The Royal Commission into Aged Care Quality and Safety held a public hearing in Melbourne in September 2019. It considered the younger people in residential aged care. It focused on people who enter aged care before the age of 65, the impact this has on them and their families and why they move into aged care. The access to suitable accommodation for our members with Down syndrome remains of significant concern. This is especially so for those with more complex health and cognitive challenges and those that experience early onset of dementia. This area is an important issue for our members.



*A DSANSW Advocacy Workshop in action*

*The 2019 Health Conference was held in September and focused on the challenges of ageing.*

We welcomed the NSW Ageing and Disability Commission Review led by Commissioner Robert Fitzgerald into how advocacy organisations are funded in NSW. We actively contributed to this important review. We met with the Commissioner in August and tendered a submission on the importance of advocacy funding to support the work of organisations like ours in assisting people with a disability to access services. To support this submission, we were pleased in January 2020 to welcome Gareth Ward, the Minister for Disability Services NSW, to meet with representatives of Down Syndrome NSW. Our members shared their insights into the challenges they have faced in accessing services and the beneficial support they have received from Down Syndrome NSW. Tara Elliffe spoke about how Down Syndrome NSW has given her a voice and leadership opportunities and helped her make friends through UP!Club and camps.

Melissa Cotterill described how being visited by a staff member when Alyssa was born helped her immensely

and described how the Up Up & Away program has built social connection for families.

Paula Rix and her son Tom discussed the vital advocacy role of Down Syndrome NSW in helping families navigate through the NDIS and the wide range of information needs such as with ageing and health care. Paulina Bezzina shared her struggles with ensuring inclusive education during her son Michael's primary school years.

The Commission recommended a new funding program to deliver a more sustainable, equitable and high quality advocacy service for people with disability, called the NSW Disability Advocacy Futures Program. The onset of the COVID-19 pandemic has disrupted the progress of the recommendations.

We were also pleased in March to welcome Penny Sharpe, NSW Shadow Minister for Family and Community Services, and Shadow Minister for Disability Inclusion.



*Minister Ward & Association representatives and staff*



*L-R: Kathy Chapman, Kylie Scott and NSW Shadow Minister Penny Sharpe*

## 40 years of Early Ed

The commencement of the Early Ed organisation 40 years ago signalled a new era for people with Down syndrome. This was the first private provider of early intervention in NSW that was closely followed by the specialised pilot program for children with Down syndrome led through Macquarie University in 1975.

What progress has been made since then in the provision and access to early intervention and inclusive education that helps our children to flourish. Miriam Philomena, social worker and a parent of a daughter with Down syndrome attended the celebrations.

# Member and Community Education Forums

## HEALTH CONFERENCE

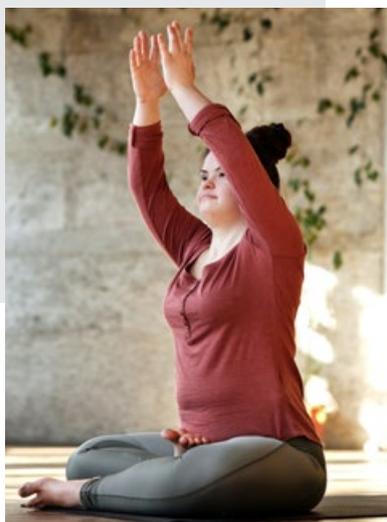
In September 2019 Down Syndrome NSW hosted its first Health Conference on the challenges of ageing. More than 100 people made up of parents and siblings of adults with Down syndrome, support workers and professionals, attended the stimulating and informative conference in Sydney.

The aim of the conference was to increase awareness of, and provide practical strategies around, the challenges of ageing faced by people with Down syndrome and the consequent health implications. These implications can include higher rates and earlier onset of dementia, mental health issues including depression and anxiety, and oral health problems. Experts in the field of intellectual disability were on hand to discuss these issues.

The conference received substantial support. We were pleased to welcome the Parliamentary Secretary for Health to open the conference and to receive the Minister for Health's support with \$20,000 in funding. We also received support from Scott Hirst of Pure Traveller providing a \$1,500 sponsorship to support travel scholarships for six regional members to attend the conference. Hire Up provided \$1,000 sponsorship.

We received very positive feedback with the high quality of presenters and information and networking opportunities viewed as conference highlights.

Building on the interest and success of this first conference, planning begun on the second Health Conference with the topic "Challenges of Obesity and Metabolic Diseases" to be held in June 2020. Due to the COVID-19 pandemic this was postponed and in April work commenced on the best way to present this in an online environment in the next financial year.



## ESTATE PLANNING & WILLS SEMINAR

Navigating the complexities of estate planning and wills in making provisions for children with Down syndrome is a challenge faced by many. We were pleased to have the expertise of Jonathan Harris from Harris Freidman Lawyers to lead two sessions, one in August 2019 (in Sydney CBD) and one in February 2020 (in Parramatta) with 50 people attending each seminar.

“

*A very helpful and clear explanation provided, was good to have interactive Q&A. Covered a range of issues that are common to parents.*

”

## KEY WORD SIGN SEMINARS

Key Word Sign uses manual signs and natural gesture to support communication. It is a great way to encourage and support language development for those experiencing difficulties with communication development. These key workshops are designed specifically to suit parents of young children with Down syndrome through to early teenage years. We appreciate the support from Dr Leigha Dark, speech pathologist and a parent of a child with Down syndrome in providing these seminars. The focus was on practical skills as well as group activities to practice sign skills. Two sessions were held, one in Sydney and one in Parramatta.

“

*It was multi-faceted for me. It is always great to meet the team at DSNSW but also meeting new parents is great. Also learning more things and gaining confidence in being a mum of a child with Down syndrome. I thought the presentation by Leigha was exceptional and would highly recommend it to others.*

”

# Information & Support Programs

Our information and support services support families at key times across the life span from the time of diagnosis to issues arising in education, health, employment and housing. During the year we responded to just under 300 enquiries for information and support. We also receive many calls requesting support with the development of behaviour to support successful participation across many settings. The outcome of many of these requests is the provision of information and training sessions for families and key personnel in the various settings to support their understanding of communication, learning and developmental needs. This year we provided 22 group training sessions for support workers and professionals across schools, aged care and accommodation settings.

Check-In & Chat Zoom sessions were provided from March to support families during the pandemic lockdown.

Our work in supporting families with new babies is very important to us. We were pleased to welcome 30 new babies and families this year. We are finding that with developments in antenatal testing, changes to postnatal care and development of ECEI providers, needs and timing of support are slowly changing and we are reviewing how best to support families during this early period.

We gratefully acknowledge the funding provided by NDIA's Information, Linkages & Capacity Building Grant in support of this work.

A series of 6 Better Start Information Sessions for parents of children 0-12 were held throughout the year, funded through the Department of Social Services.

These sessions help parents understand the service system and to build connections with each other. For the last five sessions we transitioned to online service delivery format in response to the impact of the pandemic. More than 30 people attended these sessions with some 60 per cent of the participants coming from a culturally and linguistically diverse background. NDIS representatives (ECEI and LAC) provided relevant information. Many sessions were co-facilitated with parents with lived experience.

“  
*The information was very relevant and it opened my eyes to all the services available.*  
*(Mother of a 6 month old baby with Down syndrome)*”

We are increasingly utilising social media to assist in connecting our members and providing information. We keep our members updated via our Facebook

page, with not only Down Syndrome NSW specific information, but wider information that supports people with Down syndrome and their families.

The new Family Support Facebook Group created in April is for parents and

carers to share information and recommendations and members continue to join this group.

*"I found the online session very helpful and insightful. The process of getting children into school is daunting and even more so for our children... There are so many available resources out there but it isn't quite consolidated, and it is ever changing, to be able to speak to people who can give you clear, direct answers is just so refreshing!"*



Amelia and Charlie Burfit and family

# BUILDING SOCIAL CONNECTIONS

## Camps

Our camps continue to be a wonderful way to connect and the feedback tells us they are having a very positive impact on those who attend. Two highly successful camps were held during the past 12 months for adults with Down syndrome, both at Milson Island Sport and Recreation Centre just north of Sydney. We had been looking forward to holding our first camp for teenagers but unfortunately this was cancelled due to COVID-19.

Arriving at Brooklyn, north of Sydney, in November a private ferry took campers to our very own secluded island. The days were action-packed with water sports, bushwalking, canoeing, archery and reflection time. At the Saturday night disco there were some very creative costumes on display and even more creative dancing!

Over 40 adults with Down syndrome attended camp and many new friendships were forged. It was exciting to see people from all over NSW from places like Dubbo, Orange, Jervis Bay and the Blue Mountains and Hunter regions.

We had 19 participants attending for the first time and six participants of these were from regional areas. The camp was supported by 18 staff, a mixture of Down Syndrome NSW staff, new volunteers and two parents who provided 1:1 care.

We were welcomed back to the Milson Island Sport and Recreational Centre for the Aloha Summer Camp in March which was our biggest and arguably, our best ever with 46 people with Down syndrome taking part along with 16 staff/volunteers.



“

*“Thank you so much for organising the camp last weekend. Greg had the time of his life and was so happy and talkative when he got home.*

*He “LOVED arrows, swimming, swing, dancing, steak, hamburger”.... limited speech could not halt the string of words and excitement.*

*Thank you from the bottom of my heart. Please do more camps if possible as Greg will always come.*

*It was so good for his socialisation (as he tends to be isolated with limited language).*

*Please thank everyone who helped at the camp to make it such a memorable experience.”*

”

This Hawaiian themed camp provided a tropical paradise with activities including swimming, water games, basketball, tennis, arts and crafts and more. Archery proved the most popular activity followed by canoeing.

We were pleased to welcome 12 new people to their first camp. These included several from regional NSW. It was wonderful to again see the new friendships forged amid a wonderful experience.

Our camps continue to be a wonderful way for our members to connect and the feedback we received was very positive for both these camps. A huge thank you is due to all the volunteers that contribute their own time to attending our camps. We cannot run these camps without their generosity.



## UP!Club & Staying Connected – for adults with Down syndrome

UP!Club is our long running and very successful flagship program for adults with Down syndrome to support the development of social connections. Prior to the onset of the COVID-19 pandemic, successful events were held including an archery championship, a Harbour Bridge climb and a visit to Cockatoo Island.

The onset of COVID-19 restrictions called a halt to the face to face aspect of UP!Club. It was quickly noted that the changed circumstances for our members would likely have a negative impact on their health and wellbeing.

“

*Truly, Up!Club online activities have been a key plank in Ro feeling positive and finding a path towards the 'new normal'. Hugs to you all.*

”

Accordingly, UP!Club transitioned to an online format and overnight the **Staying Connected** program commenced to help reduce the impact of the isolation and loss of everyday routines. It helped us all discover another way of communicating and leaning.

Staying Connected began with two pilot sessions on Zoom in late March with a view to showing people how to use the new technology and stay connected when physically distant.

This took off very quickly and early April had 28 participants for a total of 96 engagements. By the end of June we had held:

- 144 zoom sessions, an average of 10 per week.
- at the height of demand 14 sessions a week, 2 sessions 7 days a week.
- a total of 1,956 participants, an average of 13 per session attending.

Activities have been diverse and have included show and tell, trivia, tai chi, boot camp, and a fancy dress. The COVID 19 safe sessions, Street Wise were also popular.

Staying Connected has been a great opportunity for new members to be able to connect and make new friendships with fellow members of our UP!Club group. These Staying Connected sessions allow Down Syndrome NSW to play its role in reducing feelings such as anxiety and isolation, as we all adjust to a different way of living. Participants joined our sessions from across NSW, from Jervis Bay to all the way to Wee Wah. It is an accessible and increasingly popular way to connect.



*"Thank you to everyone at DSNSW! You really are doing a marvellous job!*

*People often ask us, usually tentatively "so how is Sam coping?" and we can honestly reply "he's having the best time! With DSNSW sessions and especially seeing Ellen, he's on cloud 9!!" .....please, keep doing what you're doing.*

*It's been so good to be involved with Up Club. We're kinda hoping you might occasionally stick with the online model and have a few sessions this way so us regional lot can keep in touch! What a lovely group!"*

*(Mother of a participant in Staying Connected)*

## Up Up & Away

The Up, UP & Away club meets the needs and interests of children with Down syndrome aged between 4 and 17 and their siblings and families for increased social connection opportunities

Activities were run in Liverpool and then expanded to Parramatta and Inner West areas by our casual coordinators Melissa Cotterill and Jessica Viera.

We were in the process of recruiting new coordinators to expand the activities to other areas within the state, but with the onset of the pandemic this physical expansion was put on hold. We conducted a needs analysis with parents to ascertain what support would be helpful during the pandemic.

The families told us they were finding the adjustment to demands of home schooling and therapies during the shut down somewhat overwhelming and were not interested to begin online programs until May.

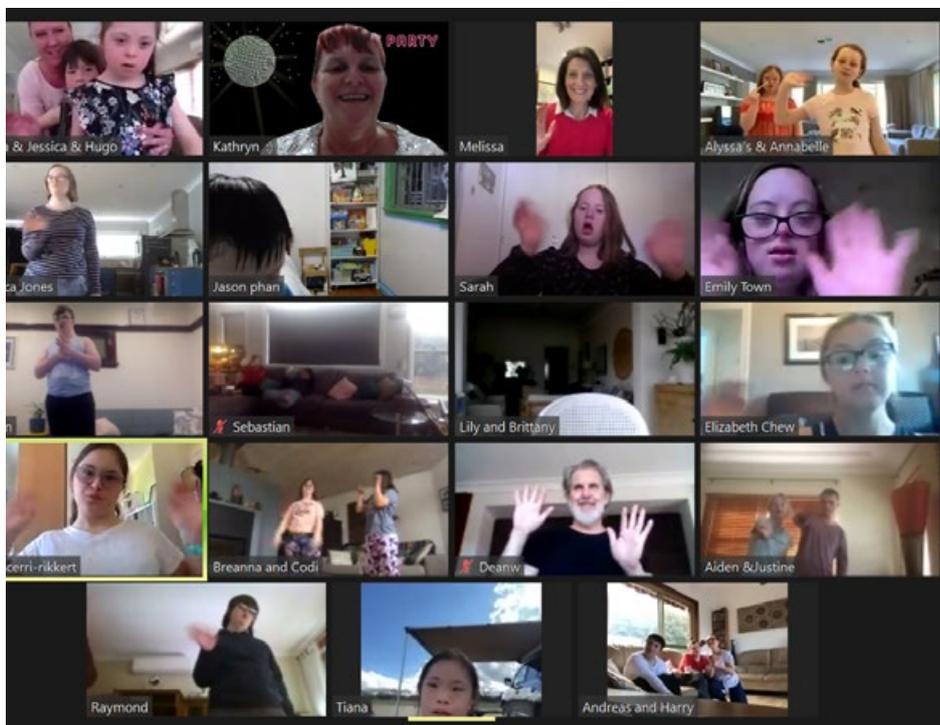
These sessions have continued monthly since then with our teenagers really enjoying the social opportunities.

We greatly appreciated the grant of \$10,000 from Mounties Group via Club Grants to support this program and to Parramatta Council for the grant of \$10,000 to support enhancements to our IT infrastructure.

*"Rebecca has attended all of the sessions of the Zoom teen disco through Down Syndrome NSW. It has been a real joy to watch how much she has loved the experience. She talks about it when it's coming up, and really gets into the dancing.*

*Living in rural NSW, attending events in the city is a major undertaking for our family and the creation of Zoom based activities is something we hope will continue way past restrictions.*

*There's nothing like seeing people in person, but Rebecca will be able to attend many more events through Zoom than we would be able to organise with a trip to Sydney, accommodation and the time it takes versus switching on the computer. Kathryn and her helpers did a great job of running the event."*



## Dream Night at the Zoo

Dream Night at the Zoo is an annual event with Taronga Zoo providing free tickets for families to attend the Zoo for a special evening.

This event is specifically for children with special needs and their families. This year, we had 45 families attend the event.



# AWARENESS & FUNDRAISING EVENTS

## International Women's Day

A partnership was developed with Western Sydney Community Forum, which saw one of our members, Tara Elliffe, speak at their International Women's Day

"Voices of the West" event. Tara shared the stage with 8 other women from different cultural and professional backgrounds as part of a living library, including the United Nations, elite sport and Aboriginal organisations.

Tara gave her speech 3 times and made a great impression on the audience with her confidence and articulate speech. An additional positive outcome was that Tara's presentation elicited enquiries about employment for people with Down syndrome.



*Tara Elliffe, second from right, at the International Women's Day "Voices of the West" event in March*

## World Down Syndrome Day events 31 March

Several events were planned to recognise World Down Syndrome Day which promotes the rights of people with Down syndrome. Many of these events were cancelled due to COVID-19 restrictions including the morning tea at Parliament House.

The annual 'Lots of Socks' awareness campaign invited schools and community businesses across NSW to join us in wearing colourful socks to engage in conversations about Down syndrome. Some of the registered 25 schools and 18 businesses were able to hold virtual 'Lots of Socks' gatherings contributing more than \$2,000 to our work.



*"Lots of Socks" event in Liverpool*

# StepUP! for Down syndrome

Throughout September and October, StepUP! events bring people together to walk, socialise and enjoy activities and entertainment. As Australia's largest annual Down syndrome community event, StepUP! is dedicated to improving the lives of people with Down syndrome. It is a great way to get to know your local community while celebrating Down syndrome awareness month.

This year events were held in Picton, Sydney, Coffs Harbour and Penrith. Through speaking with participants at each event, it was clear that StepUP! plays an important role in bringing community members together. The event participants contributed \$17,000.

A big thank you to Anne Herne, Hannah Edwards, Claire Martin and all the other staff, volunteers and families who assisted. A big shout out to top fundraisers Petra Bonamy, 21 Smiles for Riley, Tui's Bravehearts and Isla Lila's team.



# Fundraising

We had several member led initiatives this year that helped raise awareness of Down syndrome and raise funds to support our work. Their ingenuity and hard work is very much appreciated.

## Scrapheap Adventure Ride 2019 Evans Head 10th anniversary

Perry Gilsener and his hard-working team together with the Down Syndrome NSW contingent led by Ryan Blunden, delivered the 10th annual Scrapheap Adventure Ride. Scrapheap involves motorcycle enthusiasts from all over the country purchasing a bike for no more than \$1,000 and doing it up for an adventure ride through the Aussie outback, all while raising money for people with Down syndrome.



This year the scrappers and crew were warmly welcomed by Camp Koinonia, Evans Head with 113 riders converging on the town and many hundreds more in support, including eight ambassadors from UP!Club. The ride drew in enthusiasts from far and wide across NSW with a few riders travelling from South Australia, Victoria, Queensland, Western Australia and Tasmania. We even had two people travel from New Zealand and Canada to join the ride.

We were thrilled to see so many of our regional members and communities join in to support the riders and the fundraising efforts. An amazing \$115,131 was raised by the collective efforts with this record breaking tally lifting the 10 year contribution to over \$800,000.

Lots of hard work resulted in heaps of fun, many friendships and lasting memories for all.



Little Peyton's "thumbs up" says it all about Scrapheap.



Perry Gilsener and daughter Grace

### Graeme & Peyton Girdler

Graeme was the highest fundraiser with \$6,050. He had a lot of support from family and friends, including his mother running a Mouldy-Oldie softball tournament.

“

Where do I begin expressing my gratitude to all involved in our 10th Scrapheap Adventure Ride? I would like to send a big Thank You to all the Scrappers, their supporters and our sponsors, Adventure Moto, Hare & Forbes Machinery House.

Perry Gilsenan, Founder,  
Scrapheap Adventure Ride

”

## Market Day Wattle Grove

Melissa Cotteril threw her talents and energy into a market day at Wattle Grove in November. She canvassed far and wide and drew together a great variety of over 20 stalls, selling items ranging from arts and crafts to exercise classes to clothes and Christmas cakes. Entertainment was provided by the Danebank Life Skills Dance Group.

Melissa gathered great support from the local community members, business and organisations providing gifts for the raffles and chocolate wheel.

The jumping castle, BBQ and Devonshire tea organised by the Lions Club were favourites.

The day raised more than \$6,000.



**All money raised goes to Down Syndrome NSW**

**Sunday, 17 November 2019**  
**9am to 3pm**  
**Wattle Grove Community Centre**  
**Village Way, Wattle Grove**

**Market Day Fundraiser**

MARKET STALLS  
GREAT OPPORTUNITY FOR SOME CHRISTMAS SHOPPING  
PRIZES  
RAFFLE (drawn on the day at 2.30pm)  
JUMPING CASTLE  
FACE PAINTING  
FUN  
SAUSAGE SIZZLE / DRINKS  
COFFEE / SNACKS  
ENTERTAINMENT - Special performances by:  
Lara Dabbagh (from The Voice 2019)  
Local Dance Groups  
Local Singers

**Down Syndrome**  
New South Wales

**SOMETHING FOR EVERYONE**

DOWN SYNDROME NSW PROVIDES SOCIAL CONNECTIONS / EVENTS & PROGRAMS FOR CHILDREN AND ADULTS; INFORMATION & SUPPORT FOR FAMILIES & CAREERS; and ADVOCATES POLICY CHANGE AND EMPLOYMENT FOR PEOPLE WHO HAVE DOWN SYNDROME. YOUR SUPPORT WILL ASSIST THEM IN ACHIEVING ALL OF THIS.

LOOKING FORWARD TO YOUR SUPPORT FOR THIS WORTHY CAUSE.

Email: [mmcotteril@bigpond.com](mailto:mmcotteril@bigpond.com) (Melissa Cotteril - Market Day Fundraiser Organiser)



*The Danebank Life Skills Group*

## Golf Fundraising Day

Peter and Kerrie Lind called on their community of fellow golfers to join them in a Golf Day at the lovely Strathfield Golf Club.

With much chat and competition across the greens, a wonderful \$6,000 was raised.



## Tax & Christmas Appeals

Our loyal supporters contributed to our Christmas and tax time appeals. The latter focused on the resilience our members with Down syndrome had shown in the face of the disruptions wrought by the COVID-19 pandemic.

More than \$20,000 was raised across these appeals.

## Business Support

We were pleased to receive the support from two businesses during the year.

We were invited to provide an online presentation to executives at **Microsoft** on Down syndrome as part of their employee Giving Month program. We greatly appreciate the support of its employees who raised \$10,100.

We also appreciated receiving support from **Community Underwriters** who provide our insurance coverage, in obtaining a grant for \$5,000 to assist us in providing online services.

## Trusts and Foundations

Two family trusts have been long term supporters of our work. We are very grateful for this consistent contribution towards our programs.

The generous ongoing support from **The Sherry Hogan Trust** of \$55,000 continues to provide support to our social connections and skills development program.

**The Eusebius Trust** has also been a regular donor to our organisation for many years and this year we received special support of \$30,000 for our programs.

## Donors

We gratefully acknowledge the generous support of all our donors throughout the year.

### Down Syndrome NSW Christmas Appeal 2019



Please support us this Christmas. Help us deliver new services like the Inner West Up, Up & Away group, our newest social connections group for children and their parents.

[Donate Now](#)

# LIFE MEMBERSHIPS AWARDED 2019

## Two quite exceptional parents of children with Down syndrome were awarded life memberships at the 2019 AGM – Maie Barrow and Lorraine Clark (AM).

Maie, whose daughter Anni was the first child enrolled in the Macquarie University Early Intervention Program for children with Down syndrome, was recognised for many decades of service with Down Syndrome NSW.

A founding member of Down's Interest Group (DIG) and an early member of Down Syndrome NSW, Maie completed a Masters in Archives Management at the University of NSW which she put to use when she began work on the records of Down Syndrome NSW in 2014.

She undertook the mammoth task of cataloguing minutes of board meetings, records of fundraising events and seminars, early books and pamphlets, letters, photos, tapes, posters and ephemera.

This volunteer effort took four years to complete and provides a narrative of grass root parent involvement in improving the lives of their children with Down syndrome from the late 1970s. The work culminated with Maie compiling the Guide to the Records of Down Syndrome NSW 2017.



Lorraine Clark, mother of Gabrielle, was awarded the Member of the Order of Australia (AM) last year for her significant service to sport, especially the Special Olympics where she was chairperson NSW in the 1990s. She also served as a national board member and was on the national selection committee from 2011 to 2014.

Lorraine has done significant work for Down Syndrome NSW and its members and is a former board member and president. In 1994 she established the FAA (Future Adult Advisors) a peer support group for young people with Down syndrome which later became the UP!Club.

She was instrumental in Sydney being the host for the seventh World Congress on Down syndrome, in 2000, while she was president. More than 100 delegates with Down syndrome attended and through Lorraine's leadership and vision the Congress was a huge success with more than 750 delegates from around the world attending.



# BOARD, STAFF & ACKNOWLEDGEMENTS

## Board Members

Hayley Warren	President
Margot Elliffe	Vice President
Chris Elenor	Secretary
Nicholas Gotsis	Treasurer
Evelyn Scott	
Paula Rix	
Gemma Namey	
Sonja Volker	
Andrew Hinde	
Rene Pennock	
Janey Valencia Concepcion	

## Board Members that resigned during the year

Jason Lloyd	President
Greg Simmons	Vice President
Michael Hogan	Treasurer
Mark Bezzina	
Megan Smith	

## Chief Executive Officer

Kathy Chapman	CEO (August 2018 – May 2020)
Jennifer Evans	CEO (from May 2020)

## Down Syndrome Australia Advisory Network

Kylie Scott, NSW representative

## Pro Bono Support

Herbert Smith Freehills  
Avril Henry and Associates

## Support services provided by

Accounting for Good  
Varidan Managed IT Services  
Human Equation

## Staff

Ryan Blunden  
Melissa Cotterill  
Sophia Cuthbertson  
Flavio Fernandez-Maldonado  
Atlanta Finch  
Carolyn Frichot  
Alyssa Green  
Sophie Grivas (office volunteer)  
Kathryn Hammond  
Ellen Hester  
Gillian Lipitz  
Miriam Philomena  
Marissa Rafati  
Lakshmi Ramjas  
Emma Screaton  
Jo See  
Megan Smith  
Jessica Veira  
Bernadette van Wijnen  
Jennifer Weatherstone

## Volunteers

To all our volunteers,  
a special thank you.  
Your help lets us achieve  
so much more!



*Heather Crarer - Happy Birthday!*

# FINANCIAL SNAPSHOT

The 2019/20 financial report shows revenue and other income of \$1,224,078, an increase of \$271,934 FY2019. Once expenses are deducted, this results in a surplus \$227,734 compared to a deficit of \$131,809 in the previous financial year.

A copy of Down Syndrome NSW's complete Financial Statements is available on our website or on request.



Revenue	<i>How much money we got</i>	\$1,224,078
Expenses	<i>How much money we spent</i>	\$996,344
Surplus	<i>How much money we were in surplus</i>	\$227,734
Total Assets	<i>How much money we have</i>	\$1,121,126
Total Liabilities	<i>How much money we owe</i>	\$296,160
Equity (net assets)	<i>How much money would be left if we sell everything we own and pay all the money we owe</i>	\$824,966



**Down Syndrome**  
New South Wales

Tel: 02 9841 4444

Email: [admin@dsansw.org.au](mailto:admin@dsansw.org.au)

[www.downsyndrome.org.au/nsw/](http://www.downsyndrome.org.au/nsw/)