

DOWN SYNDROME NSW 2018/2019 ANNUAL REPORT



Down Syndrome
New South Wales

Annual Report 2018/2019

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Our Vision

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

Our Mission

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

Our 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 our community to achieve their full potential. We are available on the phone, by email, through social media, face-to-face or in your 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
- A comprehensive library resource centre
- Public awareness and advocacy at local, state and federal levels
- Self-advocacy opportunities for people with Down syndrome.

Board members

Jason Lloyd - President

Greg Simmons - Vice President

Hayley Warren - Secretary

Michael Hogan - Treasurer

Margot Elliffe

Evelyn Scott

Mark Bezzina

Chris Elenor

Our supporters

Sherry Hogan Foundation

Eusiebus Trust

Novotel

Broadspectrum

Perry Gilsenen and the team from Scrapheap Adventure Ride

Paula Flynn

Patricia Gharsa

Denise Emmett

Daniel Lodge

Melissa Cotterill

Step Up! Coordinators: Anne Herne, Hannah Edwards, Claire Martin

Down Syndrome NSW volunteers and UP!Club volunteers

Letter from the President – Jason Lloyd



It has been a great privilege and honour to be the President of Down Syndrome NSW for the last two years. As the father of an adult son with Down syndrome, I know how important it is to have an Association focused on people with Down syndrome, offering high quality information and support to families like mine, building social connections, and advocating for better outcomes for people with Down syndrome.

Over the last year, we've seen some great achievements. We are working to professionalise the organisation by looking at an update to the Constitution, while still ensuring we remain a strong community-based service to our members who have wide ranging needs.

We've been working more closely with Down Syndrome Australia and the federation, as it is important to be looking for national funding grants, finding national efficiencies, and reducing duplication.

On a personal level, I've enjoyed being part of Scrapheap, and seeing this event grow and reach its 10 year anniversary. Scrapheap's founder Perry Gilsenan is an inspiration, growing this event from just a few mates to 100 riders. Scrapheap remains our largest community fundraising event.

I'd like to thank my fellow Board Directors for their support, guidance and dedication in helping to govern Down Syndrome NSW. They have all given enormously of their time and expertise. I'd like to acknowledge previous Board members Jackie Little and Luke Warner, who stepped down from the Board in March. Both made an enormous and long-lasting contribution to the Association over many years. Jackie's time on the Board spanned more than 10 years, and she was a passionate volunteer of the UP!Club, as well as undertaking a 6-month period as the Interim CEO in 2016/17. Similarly, Luke's time and energy spent in support of the Association is much appreciated. He too was a volunteer at UP!Club. This year, Hayley Warren took on the role of Secretary and Michael Hogan took on the role of Treasurer. Sadly, we say goodbye to Greg Simmons who has served the Association with great dedication over 6 years as President and most recently as Vice President. Mark Bezzina, who has been our expert on risk and governance, and Michael Hogan will also be stepping down from the Board. These changes mean we will have a strong combination of long serving (Hayley Warren, Margot Elliffe, Chris Elenor and Evelyn Scott) and new Board members to lead us into 2020.

Thanks to the staff team and Kathy Chapman, our new CEO. The dedication of our team has grown membership and strengthened engagement with our members.

Letter from the CEO – Dr Kathy Chapman



It has been a big and busy year since I started at Down Syndrome NSW last December. I want to thank everyone for the warm welcome I've received, especially the staff and Board members.

Down Syndrome NSW plays a vital role in championing the rights of people with Down syndrome to have the same access to society as everyone else. Together with the team and the Board, my focus has been to identify and grow partnerships with government, other non-government organisations, service providers, and community members; and ensure we strengthen our communications with you, our members.

We have been focused on improving our services understanding that our membership crosses the lifespan from prenatal, new babies to older age. It is very important our services focus on the important life transitions.

This area of focus has recently resulted in a staffing structure adjustment to ensure we are best serving the membership and their identified areas of needs. We are restructuring to present a whole of team approach to Information and Support and will be introducing a Community Events Projects Officer and a dedicated Family Support Manager.

I know it is important we strengthen our engagement with our members, build up our advocacy work, and ensure we have more services with impact. We are excited about the upcoming Health Conference on the challenges of ageing, and creating more employment opportunities that can make such an impact in an individual's life.

An exciting partnership for employment opportunities for people with Down syndrome is Project Etico, a social enterprise that aims to train people with intellectual disabilities into independent and skilled professionals of the hospitality sector. Down Syndrome NSW has entered into a Memorandum of Understanding with Project Etico to help identify and recruit from our membership those interested in training and working in the Hospitality sector.

We have developed a new Code of Conduct that has defined the important values of Down Syndrome NSW, such as being a stronger member-centred organisation and inclusiveness.

Transitioning into an NDIS service, while also being mindful of the importance of offering free community-based services, has led to us improving our policy and quality management systems.

Finally it is important that we work towards financial sustainability of the organisation. Fundraising and applying for grants remain an important focus to develop and grow our services to the community it is our privilege to serve.

Down Syndrome NSW Organisational Functions



Building Social Connections

UP!Club

UP!Club is a social group for adults with Down syndrome that encourage connections with local communities and skills development to exercise greater choice and control in their own lives, in a fun and social environment. Over the last year, there were 71 UP!Club events held with 660 participants.

Throughout this reporting period UP!Club transitioned to an NDIS service model to ensure the program remains sustainable well into the future. This transition was an excellent opportunity to review all aspects of the operation and ensure that policies, procedures and operating systems meet the standards expected of a registered provider.

The review identified three main areas of focus for future development:

- 1) Increase the number of UP!Club coordinators to support the expanding program of activities and provide a higher level of skilled support across the multitude of UP!Club activities in many various locations.
- 2) Consolidate group locations where necessary to ensure sustainability of the groups and encourage more peer-to-peer connections in bigger groups. Consequently, Penrith, South-

West Sydney and Blue Mountains have become Greater Western Sydney, with its own Group Coordinator.

- 3) A demand for expanding groups into the Hunter, Central Coast and Illawarra regions, which will be the focus of our future strategic development.

UP!Club also launched its own stand-alone website, that hosts everything participants need to know about UP!Club online. Activities can be booked online, resources are available and the site even contains a gallery, capturing some of the many UP!Club highlights.

In March 2019 Down Syndrome NSW hosted a camp for adults with Down syndrome at Berry Sport and Recreation Centre. With 45 participants this was our biggest camp to date. Fifteen people attended camp for the very first time. In the future, we will hold two camps a year, in March and November, in regional areas to maximise access for our members right across NSW.

Up, Up & Away

Last year we recorded our intention to create more opportunities for children with Down syndrome and their families. Throughout this reporting period we have established Up, Up & Away” groups in the South West, Parramatta and more recently Inner West.

These groups meet regularly and are targeted at children aged between 4-16 years. Siblings, parents and carers are encouraged to attend. Some of the most popular activities have been a disco dance workshop, a group event at the cinema and a visit from a Petting Zoo.

We intend to roll this program out more broadly across NSW, by working closely with volunteer members and community supporters to help establish Up, Up & Away groups. If you would like to see this happen in your area, we encourage you to contact us to discuss how we can work together to make it happen.

Service Provision

Supporting our members with credible and relevant information

The Down Syndrome NSW team has continued to support new families via telephone, email, personal visits, either at home or hospital as well as delivering resources via email or mail to those living in regional NSW.

Many of our members prefer to use social media as a means of peer-to-peer contact and support. Earlier this year, we established the Down Syndrome NSW Family Support Group (closed face book group), for families primarily with a younger person with Down syndrome. The group is encouraged to share experiences and support each other. To date we have 190+ members.

Information resources through all life stages, from prenatal to ageing, made available by Down Syndrome Australia, have greatly improved our ability to provide professional resources. They have been very well received by members, health professionals and service providers.

Better Start Early Days Workshops

Five Better Start workshops were delivered between February and May 2019, with a total of 54 participants. The purpose of these workshops was to provide support to parents of 0-7 year old children with Down syndrome with relevant information for the “early years”.

At each Better Start workshop a representative from the local Early Childhood Early Intervention (ECEI) Access Partner and NSW Department of Education co-presented with Down Syndrome NSW staff. Two workshops were held in Sydney metro locations (Parramatta and Penrith), and three in regional areas (Byron Bay, Newcastle and Wollongong).

Family Weekend Gerringong

A Family Weekend was held in Gerringong from 29th – 31st March 2019. Eleven families enjoyed a relaxed and informal environment to build social peer to peer connections. Everyone enjoyed the social day at Jamberoo Action Park on the Saturday. On Saturday night there was a community dinner at the Mercure that included a lucky door prize, gifts for the children and Bingo after the meal. Most families agreed that, cost permitting, they would keep on coming back for future opportunities to build social connections with other families.

Annual Baby Day

Our Baby Day workshop held in Burwood in August 2019 was a full house! There were 44 adults and 33 children. While the children played with colouring-in and other activities, we presented our information sessions that included:

- Getting to Know Down Syndrome NSW
- Early Intervention

- Introduction to Keyword Signing
- It Takes Two to Talk

Parents and carers were very appreciative and believed that the workshop was a very positive and informative experience.

Behaviour Management and Training

Down Syndrome NSW is a registered NDIS provider for specialist behaviour management and positive behaviour support plans. Our Social Worker, Miriam Philomena, supported 94 clients requiring behaviour support over the last year, with an average of six interactions per client. Our Social Worker also conducted 13 tailored training sessions in schools on the learning profiles of children with Down syndrome.

We have continued to support people with disability and their families throughout the year by developing individualised support plans in preparation for their NDIS individual packages.

We are fully committed to working with people with Down syndrome and their families to help them plan a good life. We continue to provide specialist advice and guidance every step of the way, including:

- Free assistance in developing your pre-plan
- Preparation for your NDIS planning meeting
- Understanding and advising on the types of supports you may need
- Goal setting and goal reaching
- Advice, guidance and advocacy on plan reviews

Employment Opportunities

People with Down syndrome want to work for the same reasons as everyone else – to be independent, contribute to society, earn their own money, connect with peers and feel valued. We remain focused on providing opportunities for employment for our membership.

In February this year we celebrated the one year work anniversary of Ellen Hester, our Office Administration Assistant. Ellen's skills have developed from general office duties to detailed data entry and communications assistant for UP!Club. We have also introduced a new volunteer role in the office, ably held by Sophie Grivas, who assists with UP!Club administration and member communication.

ERA

Employer Recruitment Assistance (ERA) is a professional employment program, developed by Down Syndrome NSW, specifically to assist the employer with the individual support needs of employing a person with Down syndrome in open employment. The program's objectives are to:

- provide professional expertise in the additional support a person with Down syndrome might need while working
- provide lived-experience knowledge to create the best possible profile match of employer and employee
- improve the lives of our community members with meaningful and sustainable employment opportunities
- support independent employers in providing employment opportunities for our community members.

This program helps employers throughout the entire recruitment process to reach the best possible outcome for both employer and employee. It integrates with traditional job support agencies for ongoing support and training in the workplace, for as long as it is needed.

As the program has developed over the past year, ERA has been responsible for the placement of seven members with Down syndrome into open employment. The program has also delivered support training to around fifty 50 employers and disability service providers to date. Recruitment campaigns for new positions are always underway.

Project Etico

Down Syndrome NSW is partnering with Project Etico Australia to explore opportunities for collaboration to promote employment opportunities for people with Down syndrome, as well as support development of independence and social connection.

Etico is a social enterprise that aims to train people with intellectual disabilities into independent and skilled professionals of the hospitality sector. The project provides an integrated approach to training, employment and independent living. Trainees work towards a TAFE Certificate II or III in Hospitality, training in a “working” hotel supported by hospitality professionals. Trainees may also be given the opportunity to live at the hotel during training, to learn how to live and work independently.

The first Project Etico Australia will be based at a hotel in the Blue Mountains, west of Sydney. Down Syndrome NSW is partnering with Project Etico to provide assistance in identifying and recruiting interested members to work at the Blue Mountains hotel, due to open later this year.

Community Engagement

Member's Afternoon Tea

We welcomed 61 members to our Afternoon Tea on Sunday 24th March at Novotel Sydney Central, to celebrate World Down Syndrome Day. Members came together to socialise, meet new friends and enhance their connection with Down Syndrome NSW. Dr Ellen Skladzien, CEO of Down Syndrome Australia was guest speaker with a strong message on advocacy. Ellen Hester, our office admin assistant, also presented a welcome speech on "what makes me proud". One of the highlights of the day was a touching moment when our oldest member with Down syndrome was cradling in her arms our newest and youngest baby member.

Lots of Socks

Lots of Socks is an international event that celebrates World Down Syndrome Day every year throughout March. This year, all the way from Parliament House to the Blue Mountains, Dubbo, northern NSW and beyond, people of all walks of life participated wholeheartedly with their crazy socks apparel. Over 22 schools, preschools and businesses engaged on behalf of Down Syndrome NSW, raising funds for the Association and celebrating our community.

Thank you to everyone who participated. Together, we got more of the world thinking and talking about World Down Syndrome Day.

Step UP! for Down syndrome

Step UP! for Down syndrome is an annual community participation event. In NSW, events were held throughout September and October to raise awareness about Down syndrome.

In 2018, over 1000 people with Down syndrome, their families and friends, walked and lunched together at events in The Domain (CBD), Picton, Penrith and for the first time, Coffs Harbour, making this more of a state-wide event.

Picton and Penrith were, as always, wonderful community events with amazing support from local communities. Coffs Harbour was a fabulous example of what our community can achieve, bringing people together from all over the North Coast of NSW. We are extremely grateful to the people that drove these events and their teams of family and friends that do so much heavy lifting to make these days possible for our community.

Our major event in the city, held in the grounds of the Domain, featured a lovely walk through the Botanic Gardens taking in the picturesque back drop of Sydney Harbour.

A huge thank you also to all of our generous sponsors, supporters, volunteers, and for their incredible support and hard work, which helped to make Step UP! NSW 2018 such a great success!

Scrapheap Adventure Ride 2018

In 2018 the destination for Scrapheap Adventure Ride was the remote town of Poongahie, population 40. With over 100 riders making their way from all over NSW and beyond, Scrapheap Adventure Riders aka “Scrappers” turned some heads along the way.

With some challenging weather conditions and some last minute revision of the route, the riders were happy to set up camp along the banks of the Darling River and enjoy a weekend of relaxation and celebration. The Saturday evening gala dinner, which includes an awards ceremony and charity auction, was again a wonderful evening.

Overall, the participants of Scrapheap 2018 raised over \$80,000. We sincerely thank all involved for a fabulous weekend and their contribution to Down Syndrome NSW.

In particular, we acknowledge Scrapheap Founder Perry Gilsenan and his dedicated network of helpers.

Perry is an inspirational father who is always up for an adventure. When Perry's daughter Grace was born with Down syndrome sixteen years ago, this began a close link between Perry and the Down syndrome community. He wanted to raise awareness and funds for the association that provides support to people with Down syndrome and their families. In the past nine years, this major fundraising event has raised nearly \$700,000 for Down Syndrome NSW.

Scrapheap 2019 will celebrate the 10th Anniversary in Evans Head, with over 100 riders and their supporters raising money and awareness for Down Syndrome NSW along the way.

Dream Night at the Zoo

In December 2018, Down Syndrome NSW members joined with other not-for-profit groups for Dream Night at the Zoo. This very special annual event gives children with special needs and their families the opportunity to meet with zoo keepers during a private zoo visit including seal and bird shows, and the opportunity to get up close and personal with a number of the Zoo's ‘personalities’. Other highlights included face-painting, Star Wars entertainers and other animal displays.

Down Syndrome NSW would like to thank Taronga Zoo for continuing to host such a fabulous event.

Advocacy

Down Syndrome NSW is a leading advocate voice for the Down syndrome community. In association with other states and territories, and our federal organisation, we actively participate in systemic advocacy to help bring about social change and improve opportunities for our community.







We participate in the Down Syndrome Australia Advisory Network, with our own NSW representative, Kylie Scott, sitting on a panel of people with Down syndrome from each state and territory. The network meets regularly to bring their voice to the strategic direction of Down Syndrome Australia.

Currently in development is the Down Syndrome NSW Advisory Network. This will closely replicate the national model. The group will consist of people with Down syndrome from all over the state, who will meet regularly to provide their input into our strategic planning to help Down Syndrome NSW better understand what is important to people with Down syndrome.

How we serve our community

	Result for 2018/19 FY to date (12 months)
Information & Support	
Total number of clients contacted	1302
Total number of interactions	3217
Number of new babies	69
Babies' interactions	137
Pre-natal	27
Prenatal interactions	54
Number of information and support events held	9
Number of participants at information and support events	209
Behaviour Support and Training	
Number of clients supported	94
Number of Interactions	626
No of training sessions in schools	13
UP!Club	
Number of events held	71
Number of participants	660
UP!Club Camp (Berry) Number of participants	45
UP, UP & Away	
Number of events held	11
Number of participants	265
Membership	
Overall number of members	1458 Ordinary Members including 241 PwDs 137 Affiliate Members
Number of new members	151
Number of renewed memberships	721

Financial Report for 2018 – 2019

	Revenue	How much money we got	\$952,143
	Expenses	How much money we spent	\$1,083,952
	Deficit	How much money we overspent	\$131,809
	Total Assets	How much money we have	\$1,110,469
	Total Liabilities	How much money we owe	\$513,237
	Equity (net assets)	How much money would be left if we sell everything we own and pay all the money we owe	\$597,232