

# DOWN SYNDROME NSW 2018 ANNUAL REPORT



# Annual Report 2018

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## Mission statement

*We work with and represent people with Down syndrome to help them achieve their full potential in all life stages. We deliver value to the people we represent, and their families and carers, through information, peer support, advocacy, education and service, from a dedicated professional team with lived experience.*

Down Syndrome NSW encourages people with Down syndrome to fulfil their potential for successful and happy lives, in a society which knows their abilities and is supportive of their needs. We represent the interests and respond to the needs of people with Down syndrome in the major aspects of their lives; as members of the family, in their individual pursuits and as members of the community. We want all people with Down syndrome to reach their full potential as individuals and citizens within the wider community in NSW and Australia.

We provide

- A dedicated information and referral service for families and professionals
- Peer to peer support to families at all life stages
- A library resource centre of information and resources about Down syndrome in Australia
- Workshops and community events for members
- Professional development and training for education and health professionals
- Representation for the interests and needs of people with Down syndrome - state and federal
- A voice for people with Down syndrome and their families in public discourse and policy development
- Social networking and self-advocacy opportunities for adults with Down syndrome.

DSA NSW is a member of Down Syndrome Australia, a federation of eight State and Territory associations which represents the interests of our constituency at a national level.

## Board members

President: Jason Lloyd

Vice-President: Greg Simmons

Secretary: Jacqueline Little

Members:

Margot Elliffe, Luke Warner, Mark Bezzina, Hayley Warren

## President's letter



I am honoured to be the president for our association that is moving towards supporting all of our Down syndrome community in NSW. Thanks to Greg Simmons for the past two years, preparing us to move ever more forward. A huge thank you also to Chris our CEO, and the office team, that facilitate our growth as we negotiate further into the NDIS world, and coming ILC requirements. Without our passionate staff this could not be possible.

We have had many significant milestones achieved during the past year. There is not enough room to list them in their entirety. Some that come to mind are:

**Membership.** A growth in excess of 300% since June 2017, reconnecting with many families and excited new members.

**Negotiating the NDIS.** The association is now registered as a provider and can now maintain, expand and provide long-term sustainability to programs.

**Federal Government grant for the association under ILC.** The news was delivered just prior to the end of financial year. From my recollection, this is the largest grant in the association's history.

**Scrapheap.** For the last eight years, and now heading into a ninth year, Scrapheap has supported the association, consistently raising in recent times, in excess of 70K each year for Down Syndrome NSW.

Before expanding on these exciting items, I would like to thank the tireless work by Chris our CEO and the entire team in preparing applications, audits and submissions for the NDIS and ILC applications (working with Down Syndrome Australia on ILC). There are new opportunities that have been presented to us for long-term stability with financial security.

The NDIS has opened the opportunity to expand the services of UP!Club throughout the state, especially into some regional areas. This will be a huge task that the CEO and staff take on. The board unanimously feels that this is a very important task as we build community engagement via a service in local and regional areas of NSW. We also acknowledge and thank the continued support of the Sherry-Hogan Foundation to assist in the transition toward a sustainable service with NDIS.

The ILC Grant will allow us to expand the very important Information and Support Team. This allows us to improve and develop our services and support of the 4000+ members of the NSW Down syndrome community, including parents, siblings, relatives and carers. There will be some new faces joining our team, allowing us to continue the outbound contacts to reach people who may need our assistance or even just a chat. It also expands our overall capability with Information, Support and Advocacy. We believe the full team will have the expertise, networks, knowledge/background and lived experience to fully assist our community.

To Scrapheap, the extended family of Down Syndrome NSW, a huge thanks again to Perry Gilson and his "scrapers". Supported by the office, these events have in excess of 100 riders from all across the state (mostly regional), even interstate, who ride en masse to a known destination, usually a small town somewhere, on a "scrap" motorbike purchased or modelled on a limited budget of \$1000. The "scrapers" spend the lead-up and the event raising awareness of people with Down syndrome, and funds, to support our organisation. Many of these riders/teams and support people have no other connection to us other than via a friend or with other riders. And as we head towards this year's event, we believe we will have over 100 riders and raise an estimated \$75k plus for the association. I have been to these and encourage anyone who wishes to join in this adventure to give it a go. You'll have heaps of fun!

All of these major items are included in the strategy and unanimously supported by the full board. As we continue to grow and expand, we look forward to another exciting year ahead for Down Syndrome NSW.

And of course, to the full community of people with Down syndrome, you motivate and inspire us all. Keep on making us smile and striving to reach your full potential. We are proud of you all.

*Jason Lloyd*

## Information and Support

The Information and Support team has supported many new families via telephone, email, personal visits, either at home or hospital in metropolitan Sydney, as well as delivering resources via email or mail to those living in regional NSW.

At our hospital and home visits, we have continued to provide new families with the book, "Now I See", an inspiring collection of Australian essays and photos by parents of children with Down syndrome and the "Down Syndrome today" DVD.

Support has been provided throughout the varying ages and stages of life - from prenatal, through to new born, babies, toddlers, preschool, school age, adolescents, young adults and adults. Prenatal information kits and New Parent information folders have been distributed by hospitals to new families. In addition to the general information contained within the New Parent folders, the booklets "A Guide for New Parents", "Breastfeeding Your Baby with Down syndrome" and the "Routine Health Checklist" have been well received by families. New information on Early Childhood Early Intervention explaining how NDIS can help children between the ages of 0-6 years was also added to the folder.

### **Better Start Early Days Workshops**

Four Better Start Early Days workshops were delivered: two in December 2017 in our office at DSNSW and two in March 2018 in Bankstown and Liverpool LGA. These workshops supported parents of babies and toddlers with Down syndrome and discussed among other things, Early Childhood Early Intervention and the National Disability Insurance Scheme (ECEI NDIS). Parents and carers were very appreciative and believed that the workshops were a very positive and informative experience.

### **Mothers Day Weekend**

Mother's Day Weekend was held from the 20<sup>th</sup> October to 22<sup>nd</sup> October 2017 and was targeted to mothers of children with Down syndrome who are members. It provided an opportunity to come together in a safe environment to discuss topics and issues around raising a child with Down syndrome, relationship-building activities and an opportunity to learn the latest information on raising a child or supporting an adult with Down syndrome.

### **Family Weekend**

Family Weekend was held in Dubbo, to create a closer connection with families in regional NSW. An information session, community dinner and trivia night was organised and this helped to bring everyone together in a relaxed and informal environment. The highlight of the weekend was the 2 day entry pass to the Dubbo Zoo.

## Training and Education

In 2017/18 Training and Education has delivered a wide range of services for our members and for those professionals who are working with people with Down syndrome.

In March 2018, the annual EdCon provided over 60 teachers and learning support staff with two days of specialist training. This was our first NESA accredited workshop – ten hours. We were again fortunate to secure Dr Rhonda Faragher who shared her extensive research and experience in delivering numeracy and literacy programs to children with Down syndrome. Joining her this year was Rachel Wallace from DS Qld, to discuss Reading Our Way – an innovative reading program that has been designed to teach early reading and word recognition to children and Julie Wakelin, Early Education, who demonstrated Visual Supports and why we need them. We also welcomed back Suzanne Lawrence from NSW Public Schools, who talked about curriculum differentiation, Hannah Edwards, Occupational Therapist, who shared Sensory Processing Strategies In The Classroom/Mod's, and Judy Davidson who presented DSA NSW's flagship sessions on Understanding Down syndrome, Behaviour & Communication, and Social Development.

The training arm has delivered a wide range of services for our members and for those professionals who are working with people with Down syndrome. During 2017-18 we have increased the number of workshops delivered to professionals in both metropolitan and regional areas.

We welcome input from our members, so if there is a particular topic you would like to see a workshop on, please feel free to contact us at [admin@dsansw.org.au](mailto:admin@dsansw.org.au)

## Behaviour Management

DSA NSW is a registered provider for specialist behaviour management and positive behaviour support plans.

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

Our support planners offer a wealth of experience in the NDIS, through knowledge, understanding and their own lived experiences.

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 and guidance on plan reviews
- Advocacy and support

## Participation

Down Syndrome NSW continues to operate UP!Club groups across the Sydney metro region. UP!Club is a social group for adults with Down syndrome and other intellectual disability that provides group members with the opportunity to develop connections with their local communities and develop skills to exercise greater choice and control in their own lives, in a fun and social environment.

Nine groups were established over the past three years with funding received under the DSO Project. This funding ceased at June 30 2017 and Down Syndrome NSW had to face the potential outcome of closing down the UP!Club groups established under the project. Given the highly positive feedback received about UP!Club and a clear indication from members of the desire for the groups to continue operating, strategic planning was undertaken to achieve the goals of sustainability and expansion. In June 2017 Down Syndrome NSW registered as an NDIS Service Provider and will transition UP!Club to a service based model in the next reporting period. The new model will not only ensure sustainability of the current groups but is also scalable, allowing us to work with members in regional communities to establish UP!Club groups in their local areas. Community consultation in various regional areas is underway.

Along with the positive outlook for the future of UP!Club comes a realisation that there is much still to do in creating similar social networks for people of all ages. Down Syndrome NSW, with support from local members in the Nepean and South West Sydney areas, began a pilot program which allowed children with Down syndrome and their siblings to come together in a social setting, operating in a similar fashion to UP! Club, to create their own networks. Whilst the pilot is still only in the very early stages and there is still much to learn, it is hoped that a sustainable and scalable model for these groups will be established over the next reporting period.

## Events

### Step UP! for Down syndrome

Step UP! for Down syndrome is an annual event sponsored by Down Syndrome Australia and each state based organisation. In NSW, events are held throughout September and October to raise awareness about Down syndrome.

This year in NSW, people with Down syndrome, their families and friends, walked and lunched together at events in The Domain (CBD), Picton and Penrith.

Both Picton and Penrith were wonderful community events with amazing support from local communities. Our major event saw a move back to the CBD, held in the grounds of the Domain, with a lovely walk through the Botanic Gardens taking in the picturesque back drop of Sydney Harbour. The Royal Botanic Garden & Domain Trust were so impressed with the positive nature of the event that they offered a three year contract to host the event. We look forward to their support in growing this event in coming years.

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 2017 such a great success!

## Scrapheap Adventure Ride 2017

Green Valley Farm, just outside Inverell in the New England town of Tingha, was the setting for over 100 riders plus their support crews. The locals from Team Inverell were amazing hosts and put on an event that will be remembered for many years to come. Again we saw participants arrive from all over NSW and interstate.

Riders rolled in from the early afternoon until sundown, enjoying a hot dog and cold beverage on arrival, served by a group of our members with Down syndrome who travelled to Green Valley Farm to thank them for their efforts.

Saturday consisted of another ride which all reported to be a fantastic, whilst exhausting, experience. After stories were shared around the makeshift public bar came the Saturday evening gala dinner, awards ceremony and charity auction. Over \$80,000 was raised which is an outstanding result and we sincerely thank and congratulate all involved for a fabulous weekend and contribution to DSA NSW.

Once again we cannot offer enough thanks to Perry Gilsean, and his close network of helpers for another wonderful Scrapheap Adventure Ride.

Scrapheap 2018 will be riding to the far South Western NSW Wentworth Shire town of Pooncarie. This will be an adventure of epic proportions.



## Dream Night at the Zoo

In December 2017, Down Syndrome NSW members and their families 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 even

