Down Syndrome Victoria

Supporting Victorian families since 1978

Annual Report 2021-2022

Down syndrome

Down syndrome is a genetic condition that occurs at conception. People from all different backgrounds and ages have children with Down syndrome.

Our bodies are made up of trillions of cells. In each cell there are tiny structures called chromosomes. The DNA in our chromosomes determines how we develop. Most people have 23 pairs of chromosomes in each of their cells (46 in total). People with Down syndrome have 47 chromosomes in their cells. They have an extra chromosome 21, which is why Down syndrome is also known as Trisomy 21.

We want to create a society where people with Down syndrome are valued, and enjoy social and economic inclusion.

Together, we can and will create this inclusive community.

Thank you to artists Katherine Mansour, Connor McGurk and Ned Middleton for contributing the original artwork elements included throughout this document.

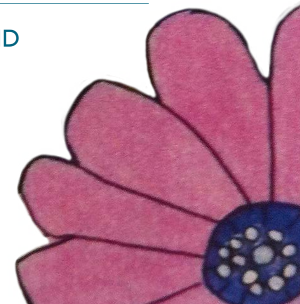
Down Syndrome Victoria is a not-for-profit membership association.

We work alongside people with Down syndrome and their families to reach their potential and live the life they choose.

This Annual Report celebrates Down Syndrome Victoria's achievements towards this mission.

Contents

04 ABOUT US
05 HIGHLIGHTS OF OUR YEAR
06 BOARD AND STAFF
07 PRESIDENT'S REPORT
08 A MESSAGE FROM OUR CEO
09 A MESSAGE FROM OUR ADVISORY NETWORK CHAIRPERSON
10 DOWN SYNDROME VICTORIA ADVISORY NETWORK
11 FAMILY SUPPORT
12 MYTIME
13 ADULT SUPPORT
13 REGIONAL FAMILY NETWORKS
14 CLUB21
16 TRAINING
17 MAJOR PROJECTS
18 PROJECT SPOTLIGHT: PATHWAYS TO INDEPENDENCE
19 EDUCATION SUPPORT SERVICE
20 EVENTS
21 COMMUNICATIONS
22 VOLUNTEERS
23 FINANCIAL SNAPSHOT
23 DONORS, SPONSORS AND SUPPORTERS



Our values shape our actions.

About Us

Down Syndrome Victoria (DSV) is Victoria's statewide peak association representing people with Down syndrome and their families. We are a community-based, not-for-profit membership association with a proud history of supporting individuals, families and the community since 1978.

DSV provides information, training, general support, education support and services with and for people with Down syndrome, their families, professionals, and the wider community. This includes prenatal support and information to expectant parents and health professionals.

DSV advocates with and for people with Down syndrome to have access to the same opportunities, supports and community activities as other Victorians. We work within a human rights framework, consistent with the United Nations Convention on the Rights of People with Disability.

Our Vision

A society where people with Down syndrome are valued, reach their potential and are equal in every aspect of life.

Our Mission

We work alongside people with Down syndrome and their families to reach their full potential and live the life they choose.

Our Values

'Do the right thing' We are honest, ethical and trustworthy. We take accountability for our actions to deliver in the best interest of people with Down syndrome and their families.

'Passion for members, families and communities' We exist for our members and community. We listen, lead, create opportunities and take action to ensure an inclusive future.

'Respect for people' We develop lifelong relationships, based on value, trust, compassion and respect.

In early 2021 we launched our 2021-2023 Strategic Plan which outlines three key pillars:

People with Down syndrome live the life they choose
Support families and carers
Shifting community attitudes

You can view our Strategic Plan on our website: downsyndrome.org.au/vic

We are continually working towards our goals to foster inclusion, empower families and carers and play a lead role in shifting attitudes.

Highlights of our Year

45

Successful tender for MyTime seeing DSV expand our program to more than 45 groups across Victoria

Launch of Regional Family Network position

DSV office relocation to Our Community House in North Melbourne

Successful Federation grant to provide the national Employment Connections project

Successful grant to translate FitSkills research into an ongoing service opportunity for our community

Advisory Network presentation at the virtual World Down Syndrome Congress Dubai

Authentic Inclusion in Schools Education Conference

Family Fun Day at Werribee Zoo

Commenced Club21 regional expansion project

6,721

6,721 community engagements (excluding MyTime) up 8.4% from previous year

84

84 students supported

680

680 participants attended 44 information, training and support sessions across all life stages

459

459 Club21 activities

10% increase in core membership (people with Down syndrome)

29

29 new babies welcomed to the DSV family, 40% identified as coming from a culturally and linguistically diverse background

Board & Staff

as at June 30 2022

Our team is comprised of five dedicated and passionate board members, alongside 39 hard-working and highly skilled staff.

Board of Management

President
Katrina Enos

Secretary and Vice President
Brendan Edwards

Treasurer
Michael Pocock

Board Members
Aileen Ashford
Wendy McNabb

Our Staff

Administration and Database Officer
Anna Cook

Administration and Personal Assistant to the CEO
Stephanie Papaleo

Adult Support Manager
Debby Fraumano

Accounts & Administration Manager
Mara Wookey

Chief Executive Officer
Daniel Payne

Club21 Facilitators
Catalina Gonzalez
Cindy Huynh

Communications Manager
Lucinda Bain

Communications Officer
Pammy Meyers

Compliance Manager
Leonie White

Down Syndrome Advisory Network
Matthew O'Neil - Chair
Jenny Bowden
Keziah Glenane
Colby Hickey
Katherine Mansour
Emily Porter
Dominique Ressom

Education Managers
Paula Kilgallon
Ro O'Dwyer

Education Consultants
Megan Bramble
Amy Fitzgerald
Dianne Hickey
Carolyn Warren

Employment Connections Project Officer
Loan Findlay

Events Coordinator
Vanessa Ientile

Family Support Manager
Sonia Bonadio

Grants and Partnerships Manager
Jessica Jones

MyTime Facilitators & Play Helpers
Phillipa Bagus Putu
Sarah Chignell
Katie Eichelman
Loan Findlay
Jackie Getson
Dianne Hickey
Sue Lenzi
Donna Morris
Marie Symon

Program Director: Projects & Training
Janice Chan

Program Managers
Helen More

Project Manager: Health, Pathways & FitSkills
Zoe Shearer

Regional Family Network Coordinator
Linda Jungwirth

Senior MyTime Manager
Madison Robinson

President's Report

In last year's annual report I shared how excited I was that we had been able to establish our first Down Syndrome Advisory Network (DSANVic). Over the last 12 months, we have already seen the impact that this group is having. A couple of the stand outs for me have been Keziah Glenane sharing her perspectives on employment with some of our most senior politicians in the NDIS Jobs and Skills Forum and seeing Matt O'Neil, our DSANVic Chair, as one of the finalists for The Bridge 'Create Change' award at this year's 7News Young Achiever Awards. I am looking forward to seeing much more of the impact to DSV from this group.

Over the past year, we were more able to meet face to face again than the year before and we have seen the energy that those connections create. However, it has been great to see that Dan and the DSV team have continued to deliver online options as well for many services. This has allowed for a much more inclusive range of service offerings and has enabled us to continue to maintain, and increase, our connections with members in regional and rural areas.

But, as we get excited about what's new, and as we look to the future, it's always important to take the time to recognise where we've come from. I've been pleased to see Dan and the team continue to remain connected with our founders and life members; people without whom our organisation would not exist. And so an enormous thank you to you, our members, for your continued support.

Katrina Enos
President

A message from our CEO

2021-22 has been an important year for Down Syndrome Victoria (DSV) as we continue to work alongside, support and connect with more Victorians with Down syndrome and their families than ever before.

Eighty-nine days of COVID-19 lockdowns for many Victorians over the past year, and the genuine challenges transitioning from those periods, impacted every facet of our community and organisation. What remained consistent throughout was our absolute commitment to continue to support, inform, and create opportunities for people with Down syndrome and their families.

We made considerable progress on our strategic objectives throughout FY22. Highlights included:

- growth of community connections and opportunities with 6,721 engagements (excluding MyTime), up 8.4 per cent Year on Year (YoY)
- increased core membership (people with Down syndrome) by 10 per cent YoY
- implementation of a Regional Family Network coordinator role to increase regional and rural support, opportunities, and engagement
- significant impact from our Advisory Network across multiple strategic goals including advocacy, policy, co-facilitation and design, health, employment, and recreational participation
- increased social opportunities, delivering 467 Club21 activities, increasing unique participants by 20 per cent YoY
- delivered 44 information, training and support sessions across all life stages
- welcomed 29 new babies to the DSV family, 40 per cent who identified as coming from a culturally and linguistically diverse background
- relocated the DSV office from Abbotsford to OC House North Melbourne, increasing networking opportunities whilst further reducing operational costs
- increased the number of people with Down syndrome employed at DSV to nine.

The year ahead is incredibly exciting. Securing the Victorian MyTime contract is transformational for our organisation. DSV will be responsible for running over 45 family support groups throughout Victoria, significantly increasing access to quality, facilitator led peer support programs for our parents and community. With the commencement of projects to expand Club21 into multiple regional settings and a FitSkills trial, combined with inflight health and employment projects delivering significant community outcomes, there is a lot to be excited about.

The financial viability of various programs remains a significant challenge as we continue to meet the 300 per cent increased demand for DSV services and supports compared to pre-pandemic levels. The uncertainty of Information Linkages and Capacity Building (ILC) funding extensions for core services and projects, declining state government support (less than 10 per cent of DSV's total income), increased demand on corporate and philanthropic partners, and general economic tightening has resulted in an intentional shift to our financial and income diversification strategy. At the heart of this strategy is a desire to continue to increase strategic and impactful partnerships in the best interest of our community.

I want to acknowledge the support of new and existing partners and donors that allow DSV to work alongside so many people with Down syndrome and their families, and for this we are incredibly grateful. I would like to recognise the efforts and contribution of our volunteers, board of management and incredible staff who work tirelessly to deliver outcomes in the best interest of people with Down syndrome, as well as the Down Syndrome Federation for their ongoing collaboration and support.

In closing, I'd like to thank our DSV members and community. Thank you for your continued support of each other, and contribution to our organisation. We exist for you, and it remains a privilege to lead an organisation and community that displays strength, resilience, and an unwavering commitment for people with Down syndrome to reach their potential and live the life they choose and deserve.

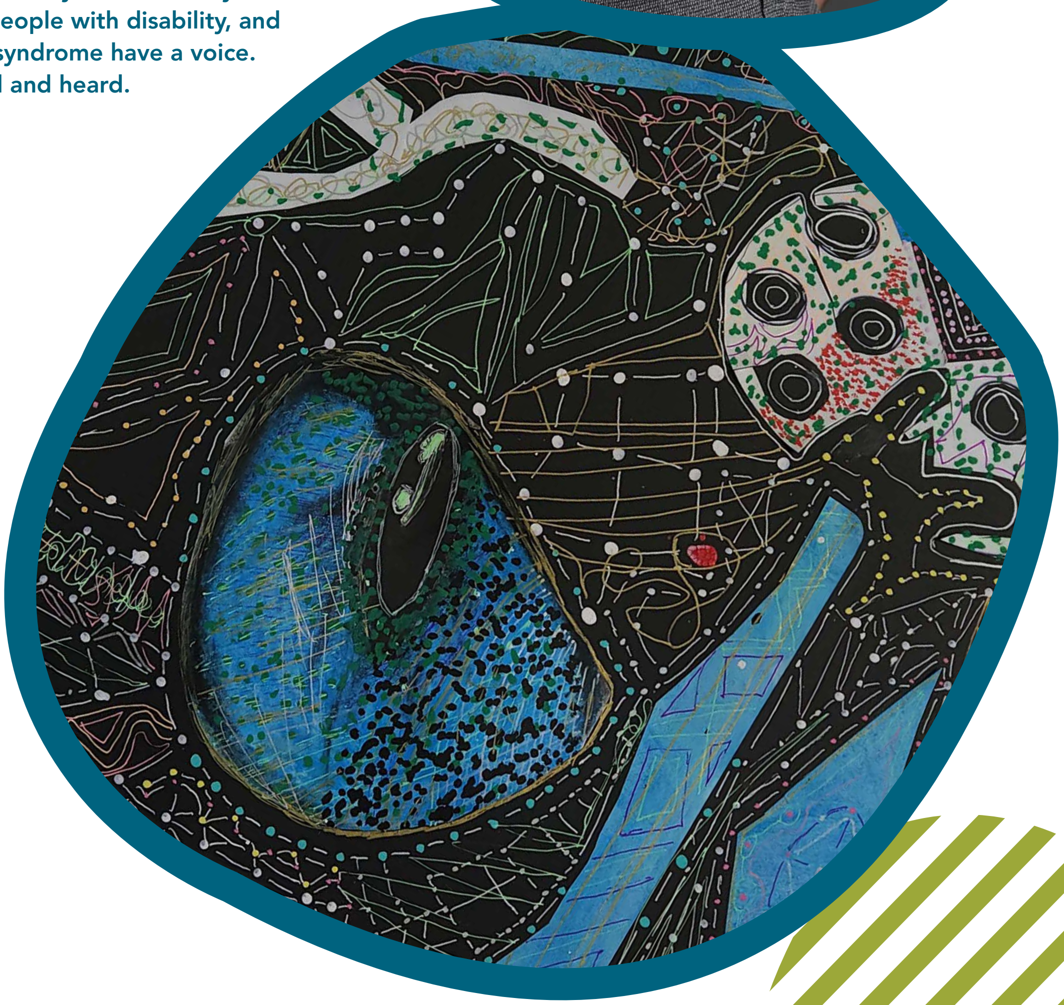
Daniel Payne
CEO

A message from our Advisory Network Chairperson

I would like to thank DSV for the opportunity to be the Chairperson of the Down Syndrome Advisory Network Victoria (DSANVic), it means a lot. DSANVic offers advice, feedback and support to make sure the voice of people with Down syndrome is heard and implemented at DSV.

I love working at DSV, it feels like my second family. DSV supports me to advocate for people with disability, and make sure people with Down syndrome have a voice. Together we will be supported and heard.

Matthew O'Neil
Chairperson Down Syndrome
Advisory Network Victoria



Down Syndrome Victoria Advisory Network

The Down Syndrome Advisory Network Victoria (DSANVic) is led by its Chairperson Matt O'Neil, working alongside Colby Hickey, Jenny Bowden, Katherine Mansour, Keziah Glenane, and Emily Porter.

Our DSANVic employees feel strongly about improving the livelihoods of people with Down syndrome by ensuring they are listened to, strengthening community understanding of Down syndrome, and advocacy. Through advice, feedback, and support, they ensure the voice of people with Down syndrome is heard and implemented at DSV.

DSANVic is thriving in its second year thanks to the NDIA Individual Capacity Building grant.

DSANVic meet monthly to raise issues they believe are important, and discuss their own experiences and opinions. In addition, DSV has co-opted employees of DSANVic as project consultants and co-facilitators for training, community engagement and events. This ensures the voice of people with Down syndrome is heard at all levels of the organisation, informing decisions, and implementing best practice.

This year, DSANVic employees have:

- presented at the World Down Syndrome Congress in Dubai
- been named as finalist for the 7NEWS Young Achiever of the Year Awards – Matt O'Neil
- written articles about Down syndrome advocacy, published on the DSV website
- participated in research projects regarding employment and health for institutions, such as La Trobe University and Melbourne University
- attended events as guest speakers for institutions, such as the NDIA and the Department of Social Services
- co-facilitated Club21 activities for the Building Leadership and Confidence project
- co-presented Capacity Building, Decision Making and Staying Healthy workshops
- MC'd and presented at DSV's Education Conference
- advocated for employment
- contributed to the Victorian State Disability Plan
- hosted three DSV podcasts: Episode 4: Wills and Estate Planning, Episode 5: Artist Robyn Doherty, and Episode 6: The Magic of Inclusion
- provided advice and feedback across projects such as: Building Knowledge, Pathways to Independence and Information for Life
- been involved in the planning and delivery of StepUP! and Family Fun Day
- presented and contributed to the AGM
- co-designed Get Active More Often and FitSkills.

We would like to acknowledge the contribution of our colleague Dominique Ressom who participated in the network until June 2022, and thank her for being a part of the network.

DSANVic looks forward to another year providing advocacy for people with Down syndrome in Victoria.

Family Support

At DSV, we believe families have the right to feel supported in their choices, no matter which paths they choose. We aim to provide balanced, researched information so that families can make informed decisions about how best to raise their children within the context of their family unit.

This year we've continued to focus on ensuring new and expectant families have access to DSV's information and support. We have supported 29 new families in the last 12 months, 40 per cent of which identified as coming from a culturally and linguistically diverse background. We did experience some challenges with accessing interpreters and resources in families' first language, exacerbated further by COVID-19 concerns and restrictions. However, in the interests of providing the best possible service for our families, we identified an opportunity to build and nourish our relationships and connections with the wider community, particularly through:

- hospitals
- community organisations
- allied health providers, and
- Maternal and Child Health Nurses.

We provided prenatal support to 13 families who made contact looking for information and assistance. Increasingly families are aware their baby will be born with Down syndrome and therefore we continue to seek innovative ways to support and welcome these new families. One way Family Support has provided this is via the Down Syndrome Australia (DSA) collaboration of the 321 Pregnancy Care page on Facebook.

We're also proud of our continued collaboration with The Perfect Gift Australia. Together with the volunteers at The Perfect Gift Australia, we have delivered 27 beautiful gift boxes filled with handmade blankets, cardigans, beanies and toys, amongst other items, to welcome the newest additions to our community and to congratulate their parents on their arrival. With special thanks to Cathy Gibb of the Hume Retirement Village for her hard work, leadership and dedication.

We also made contact with 15 families via the T21 Complex Care clinic at the Royal Children's Hospital. While many families were well known to DSV, for others it was their first contact with Family Support. We look forward to the continued development of the T21 Complex Care clinic and providing accessible, on-site support to families attending the clinic. This clinic is a first in Victoria and has been designed with input from paediatricians, families and people with Trisomy 21.

NEW BABIES 29

PEOPLE MADE CONTACT SEEKING PRENATAL SUPPORT 13

When Sandra was pregnant, she discovered there was a very high chance that Ella (then known as Baby Bud) would have Down syndrome.

There was never any doubt in their minds that 'Baby Bud' would be perfect just the way they were, but their immense love for their baby was accompanied by fear about what it would mean for their health, the life they'd be able to lead, and how they would participate and be included in the broader community.

Sandra reached out to DSV searching for information, but found so much more.

'Through DSV our world opened up and we were connected to not only information, but a community of support that made my pregnancy and Ella's first year of life much less lonely and scary. Sonia [DSV's Family Support Manager] visited us in our home during those early weeks and connected me with a pregnancy care support group, and a community of Victorian parents, and it made all the difference,' Sandra said.

'We will forever be grateful for Sonia and DSV's support. Our fear for Ella's future has been replaced with hope and a new confidence in our capacity as parents and advocates knowing that we have the support of DSV and an amazing community walking alongside us,' she said.

> 'The Complex T21 clinic at the Royal Children's makes it easier for families to receive expert care for their children. We are working closely with Down Syndrome Victoria to ensure that families receive the education and support they need.' **Dr Laura Marco, RCH.**

MyTime

‘This is the first time that I feel I am not alone.’
New MyTime participant

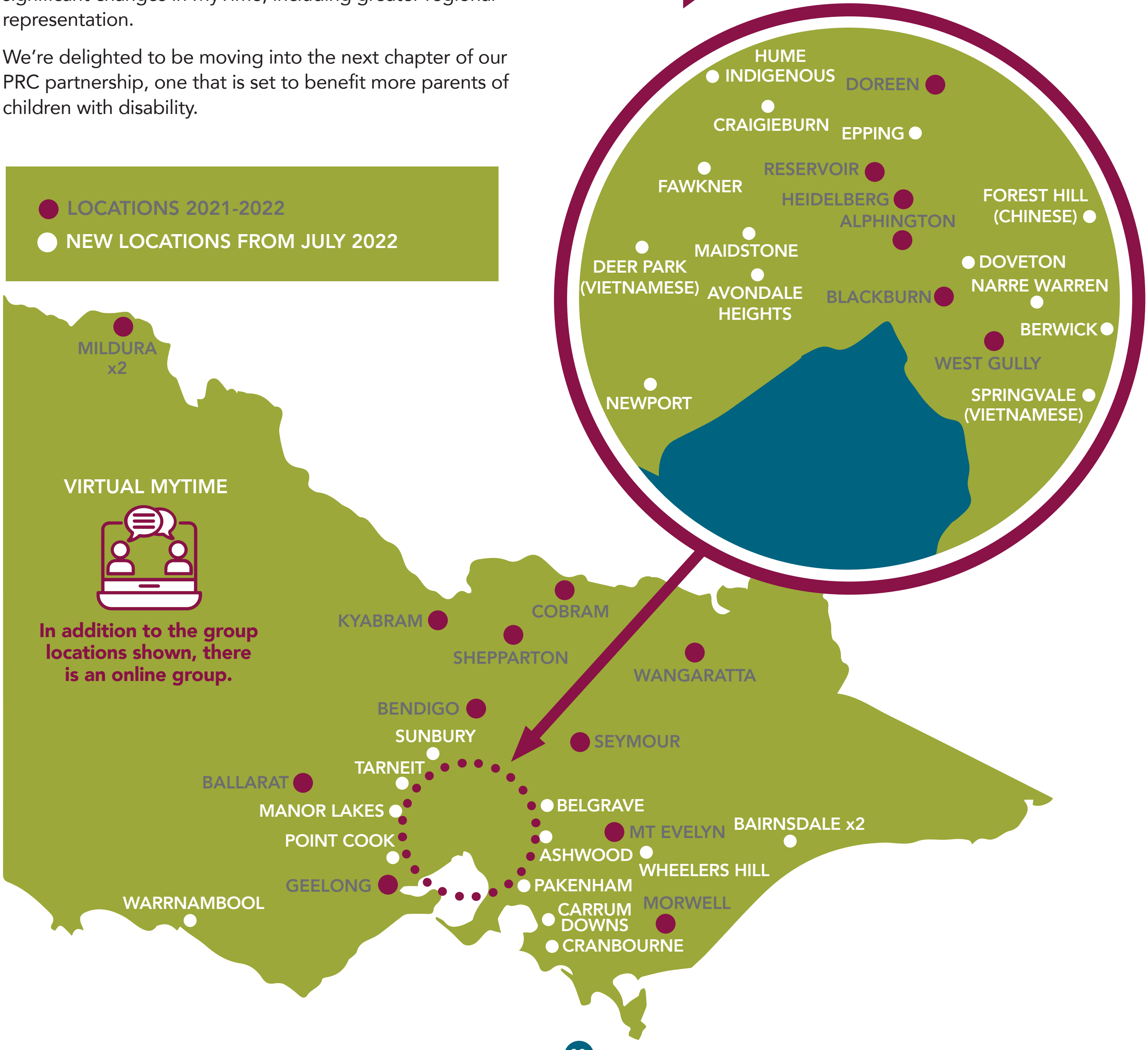
MyTime is a peer support program offering socialisation, information and support for carers of children with disabilities. On 12 April 2022, the Parenting Research Centre (PRC) awarded DSV the MyTime contract for Victoria, commencing from 1 July 2022. This exciting opportunity will see our program expand from 18 to more than 45 groups, allowing us to connect and offer support to more parents and caregivers across the state.

MyTime is a nationally operated program, providing peer support for parents and carers of a child with a disability, developmental delay or chronic medical condition. Prior to this announcement, we operated 18 MyTime groups around Victoria, connecting over 400 families.

DSV’s partnership with the PRC in delivery of MyTime began in 2007. Across the last 15 years, there have been significant changes in MyTime, including greater regional representation.

We’re delighted to be moving into the next chapter of our PRC partnership, one that is set to benefit more parents of children with disability.

‘MyTime completely changed my life.’ **MyTime participant**



In addition to the group locations shown, there is an online group.

Adult Support

Adult Support aims to support people with Down syndrome and their families through key life stages and transitions. For adults this can include ageing, health, housing, legal issues, employment, and more.

While COVID-19 had a significant impact on our services during this financial year, we are now well-versed in offering information sessions and opportunities to connect online. We have seen great success in being able to diversify our service offerings in this way. As an example, we now have an established monthly online peer connect 15+ years chat group, which maintains consistent members engaging, sharing, laughing and debriefing. These sessions have provided consistent support and engagement for many during turbulent times and will be an opportunity we will continue to provide.

We have responded to 183 enquiries from families and professionals seeking information and support pertinent to the adult years. Of these, the most common enquiries were health related (including mental health) accounting for 23 per cent, followed by housing enquiries at 13 per cent of the total contacts.

In June, Adult Support Manager Debby Fraumano and Employment Ambassador Keziah Glenane spent the day at the Australian Network on Disability Annual Conference. Kez is a fantastic networker, introducing Debby and herself to numerous other delegates at the event.

We look forward to continuing to provide assistance, information, resources and advice to families in the Down syndrome community.

‘These catch ups are always great. As a mum of a 15-year-old boy, it’s lovely to connect with others that have children older. It is very interesting and informative to hear about different things they have been doing with their child as this is where I am heading with my son.’ **Parent**

Regional Family Networks

DSV was pleased to appoint Linda Jungwirth as DSV’s Regional Family Network (RFN) Coordinator in March 2022. Linda is connecting with regional family networks to help identify how we can better respond to their needs. This may include referring to the DSV Family Support Manager or Adult Support Manager, or Education Support Service for individual assistance, providing information about upcoming training events, or providing information and resources. Our connection to regional families will continue to deepen as engagement with regional families increases and new opportunities are created.

With kind thanks to the Bank of Melbourne Foundation for the community grant which has enabled this appointment.

‘Thank you for your help as always your advice is very appreciated.’ **Professional**

Club21

Club21 is a peer support network providing the opportunity for people with Down syndrome to meet others with shared lived experiences, creating an intimate group fostering friendship development, social support and understanding.

During the first half of this financial year, Club21 met up online nearly every day of the week. It was a wonderful way to keep connected and maintain friendships during COVID-19 restrictions. As the year progressed, we were pleased to once again be able to offer in person opportunities. Club21 welcomed new members to the group and the Club21 facilitator team grew to three staff due to increased demand for the service.

CLUB21 IN PERSON

When Victoria's COVID-19 restrictions were lifted in December, Club21 members were able to meet in person again. A Christmas Craft session and the much-anticipated Christmas break up were held, where 23 participants enjoyed a lovely lunch at the College Lawn Hotel and did a Zumba 'flash mob' of their favourite song. Club21 Eastside met three times this year with 26 attendees. We're looking forward to welcoming the Club21 Teen group back in the 2022-23 financial year.

Club21 members have enjoyed an outdoor concert, played music in a park and been thrilled to watch their peers performing in other groups. A highlight in person activity: a lunch at the Espy in May. Club21 participant Eddie, who works at the Espy, helped plan the public transport route and showed Club21 around his workplace. Thanks Eddie.

> 'In Club21 there are really fun activities where people can go and do stuff. I love the activities and going out, especially the lunches. Sometimes we play games, sometimes we dance, sometimes we go for a picnic. Discos on a Saturday night are great. I like meeting new people and enjoying their company.' **Participant**

Club21

CLUB21 ONLINE

DSV completed a co-facilitation project from an Information, Linkages and Capacity Building (ILC) grant: 'Building Leadership and Confidence'. The project concluded with three online activities in July, co-hosted by three Club21 members. In August, Club21 member Kath presented the project to the ILC Branch and was awarded an 'Information, Linkages and Capacity Building Branch Certificate of Appreciation' for her contribution.

The most popular online activity continues to be the Saturday night disco, with a total of 49 discos this year! All the songs are requested by participants. Costumes and fanfare continue to be a highlight, with participants decorating rooms and hallways and even installing special disco lights.

Other popular online activities are the Zumba and exercise class. Each activity attracts on average 10+ members. A highlight of Zumba has been the introduction of participant-led routines, with Club21 member Seb choreographing a routine and teaching it to Club21 on a weekly basis.

Participants engage in a co-design process to develop the calendar of events. In 2021, this included some online-cooking classes, where each month a participant would share a new recipe. In 2022, a monthly Uno game was introduced, alongside some co-hosting activities, with participants teaching Zoom skills classes and helping the DJ with the Saturday disco.

CLUB21 SNAPSHOT

	ACTIVITIES	TOTAL PARTICIPANTS
ONLINE	449	4,892
IN PERSON	18	174
TOTALS	467	5,066

UNIQUE PARTICIPATION IN CLUB21 HAS INCREASED BY 20 PER CENT YOY.

Club21 Member Spotlight

Introducing Laura!

Laura has been in Club21 since the Club21 Eastside group began in 2018. Since then, she is a regular member of both Metro and Eastside groups, passionate about Club21 and has tried every single online activity. This year Laura attended more than 350 activities online and has joined us five times in person.

Thank you Laura!

About Me

Club21 is fun! I like to meet new people and make new friends. I have some close friends now in Club21.

Favourite Memory about Club21

Favourite memories from this year are playing bingo with Club21 online for my birthday and going to the Espy for lunch in May.

Favourite Activities

Online bingo, Zumba and the exercise class and I always have fun at the Saturday night disco. I had a great time at last year's Club21 online celebration of the MRC Race Day and I can't wait to return in person this year.

> 'Just a short note to say thank you for all your work, attention, patience and commitment to delivering the DSV online program … The Chat Sessions, Trivia, Bingo, Art and Craft Activities, Yoga and finally the Disco on Saturday nights make up a great program that are both enjoyable and educational. Thank you.' **Parent**

Training

DSV provided a total of 44 training events, including:

- information sessions
- peer support groups
- workshops
- professional development, and
- an education conference in 2021-2022.

For families with younger children, our regular sessions included:

- New Parent sessions
- Preparing for Kindergarten
- Sleep
- Positive Behaviour Support
- Toilet Training
- Transition to Primary School

A new offering in this age group was the peer support group for co-occurring diagnosis, which we ran in conjunction with Down Syndrome Queensland.

For families with an adult with Down syndrome, regular topics included:

- Housing Options
- Building and Supporting Independence

> 'This was the best info session I have attended. Extremely helpful and informative and brilliantly facilitated.' **Parent**

DSV introduced a number of new workshops for adults with Down syndrome, including Staying Healthy, Self Advocacy, and Decision Making. These topics will now be offered regularly as we look to expand topics for adults with Down syndrome.

We also offered Work Readiness training, designed to prepare young people for the world of work. We trialled this program as an online and face-to-face workshop as part of the Employment Connections project.

Professional development was provided to teachers, early educators and health professionals.

We're proud that many training sessions were co-designed and co-facilitated by employees of DSANVic.

Grateful thanks to the Department of Social Services and our philanthropic partners that enabled us to provide training free of charge throughout FY22.

8 TRAINING EVENTS

People with Down syndrome

TRAINING DELIVERED AS PART OF PROJECT:
Pathways to Independence and Employment Connections projects

70 PARTICIPANTS

25 TRAINING EVENTS

Parents/Carers

TRAINING DELIVERED AS PART OF PROJECT:
National Information for Life project and Better Start

416 PARTICIPANTS

6 TRAINING EVENTS

DSV Community

TRAINING DELIVERED AS PART OF PROJECT:
'Lockdown Relievers' provided by DSV during COVID-19 lockdown

68 PARTICIPANTS

5 TRAINING EVENTS

Professionals

TRAINING DELIVERED AS PART OF PROJECT:
Education Support Service and Building Knowledge health project

126 PARTICIPANTS

TOTAL

44 TRAINING EVENTS

680 PARTICIPANTS

Major projects

In the last Financial Year DSV achieved many positive outcomes for our community in the refinement and revitalisation of our existing services and in the provision of new supports, programs and projects in our response to our community's needs and interests as well as the ongoing challenges of the COVID-19 pandemic.

The **Information for Life** project provides individual capacity building by providing accurate, contemporary, objective information to families and professionals. This is provided via individual consultatation, workshops, podcasts, resources, our website, social media, and our monthly newsletter, DNews. The aim is to increase the independence and social and community participation of people with Down syndrome and their families, to live an ordinary life.

The **Providing a Voice** project saw the establishment of the DSANVic in 2020. Over the past year, the work of DSANVic employees went to another level, as they built their skills and confidence. Their contribution to all of DSV's work, by co-design, co-facilitation of DSV training sessions, and providing their unique and authentic voice, has greatly enhanced and improved DSV's offerings. A highlight was the nomination of DSANVic Chair, Matt O'Neil, for the 7NEWS Young Achiever award.

In the first phase of our **Building Knowledge** health project, we partnered with the Royal Children's Hospital to create the RCH T21 clinic. The clinic is held once a month and targets children with Down syndrome with complex needs. DSV's Family Support Manager, Sonia Bonadio, staffs the clinic alongside medical personnel, to assist families with non-medical queries. In the second phase of this project, we will partner with Albury Wodonga Health (AWH) to employ a person with Down syndrome as Health and Education Ambassador to work at AWH, providing training to medical staff about working with people with Down syndrome. A highlight of this project has been co-facilitation of training to health professionals by a DSANVic member.

In year two of our **Pathways to Independence** project, DSV ran workshops for adults with Down syndrome and for parents. The workshops included topics such as Housing Options, Staying Healthy, Decision Making, and Self Advocacy. They aimed to empower adults with Down syndrome and their families to develop independence and make choices about their lives. These sessions have been co-hosted by a DSANVic member and been well attended. Pathways to Independence sessions will be run in two regional locations in 2022-23.

Beyond our project expansion the involvement of our community through our appointed Advisory Network and the co-design process has kept us committed to our Vision and focused on our Mission towards social and economic inclusion. Across the past year, DSV's systemic approach to change has facilitated access and engagement of a more diverse workforce skillset; the building of inclusive leadership capabilities fostering a culture of belonging; and the increasing embedment of equity and inclusion across every function at the organisation.

Under the national **Employment Connections** project, we trialled a work readiness program and employment connection service to facilitate and increase employment opportunities for people with Down syndrome. Over the coming 12 months we look forward to exploring partnerships and developing a model that continues to improve employment outcomes for people with Down syndrome.

FITSKILLS, TRANSLATING RESEARCH INTO ACTION

The importance of physical activity for our community is well documented, and many will be familiar with La Trobe University's FitSkills research project, an evidence-based physical activity program, where people with a disability exercise over a 12-week period with a peer mentor in their local gym.

We are excited to partner with Disability Sport & Recreation and La Trobe University after successfully obtaining a grant to expand this research into a program offering. More about this in 2023.

CLUB21 REGIONAL EXPANSION

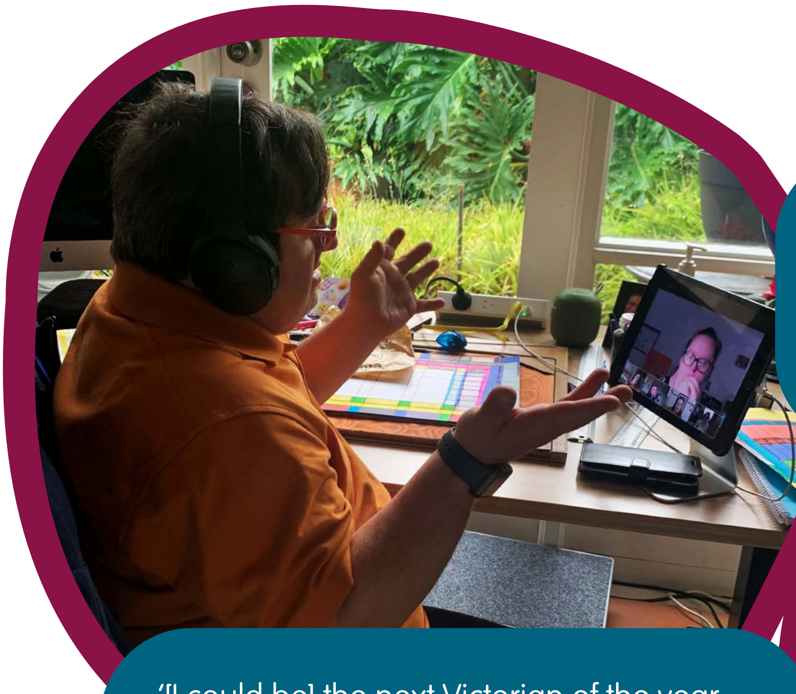
DSV is excited to announce the expansion of Club21 to four Victorian regional locations in the next two years: Ballarat, Geelong, Shepparton and Warrnambool. This will include the trial of Club21 events that encourage friends, partners and families to participate, further providing opportunity for increased social, civic and economic participation in local Victorian communities.

GET ACTIVE MORE OFTEN: AN INITIATIVE WITH SPORT INCLUSION AUSTRALIA (SIA)

SIA and DSV have partnered for the *Get Active More Often* project, aiming to increase the involvement of people with Down syndrome with a variety of sports, and to encourage engagement in sports to an elite level. The program will promote a different sport, activity and sporting pathway every second month.

With grateful thanks to the Department of Social Services, the Department of Jobs, Precincts and Regions for their financial contribution to these projects.

> 'The feedback was super positive from all of the [participants] and it was so refreshing to hear from people with lived and worked experience.'
> **Professional**



'[Doing the workshops] gave me a lot of skills, motivation and confidence. Confidence in my ability to do it. I'm a quick learner.' **Kez Glenane**

'[I could be] the next Victorian of the year, my work at DSV has helped me realise I can do these things. I feel like the workshops have helped me become a better leader and role model.' **Matt O'Neil**

Project Spotlight: Pathways to Independence

Pathways to Independence is a national project rolled out by the Down Syndrome Federation and supported by the Department of Social Services. The aim is to deliver workshops to family members and adults with Down syndrome to build independence. All workshops were delivered with co-hosts of family members and people with Down syndrome.

This year, we delivered 15 workshops in Victoria.

Eight workshops were delivered to a total of 247 family members on the topics of:

- Housing Options
- Building & Supporting Independence
- Community Connections.

Thank you to our family co-hosts for these sessions: Jo Middleton, Diane Dean and Julie Fisher.

For people with Down syndrome, seven workshops were delivered to a total of 63 adults on the topics of:

- Staying Healthy
- Self Advocacy
- Community Participation
- Decision-making.

All evaluations strongly indicated that what participants found most useful in workshops was hearing and discussing the lived experiences of our co-hosts. One-hundred per cent of participants reported having a greater understanding of the topic, while 93 to 100 per cent of participants felt more confident and would do something different as a result of the workshops.

These workshops are not only of benefit to the DSV audience, but also provide people with Down syndrome the important opportunity to learn new skills and participate in facilitation. Matt O'Neil and Keziah Glenane excelled in their co-host roles, noting improvements in skills, confidence and delivery.

In particular Matt and Kez reported:

- increased confidence in public speaking
- increased confidence and skills in online workshop presentation
- increased skills and confidence in sharing their stories of lived experience
- increased confidence co-facilitating workshops.

Thank you Matt and Kez for all the work you have contributed to this project.

Education Support Service

This financial year the Education Support Service (ESS) resumed onsite school visits and is delivering both online and in person professional development. The service has been enhanced by the additional offering of online options.

Data reflects a busy year for ESS with the team fielding 904 education enquiries, supporting 72 schools and 84 students, and delivering 26 professional development sessions.

DSV increased coverage of Education Support in regional Victoria with the recruitment of Megan Bramble in the Gippsland area in late 2021 to increase support within this region.

AUTHENTIC INCLUSION IN SCHOOLS EDUCATION CONFERENCE

A successful conference was delivered on 2 March 2022 at the Westpac Building, 150 Collins Street, to an enthusiastic audience who were delighted to meet face-to-face. The speakers were very well received with teachers reporting that the content was both valuable and informative, providing practical strategies for their classrooms.

With thanks to Kath Mansour of DSANVic who MC'd the event, alongside speakers including Dr Kate de Bruin, Jacinta Conway, Belinda Webb, Megan Bramble, Carolyn Warren, and Stefania Lipoma.

'I thoroughly enjoyed the conference. Thank you for such an inspirational and informative opportunity.'

EDUCATION WEBINARS

TEACHERS

To support teachers at the beginning of the school year, the ESS delivered an online webinar Setting up the Year for Success. Attendees reported greater confidence in their professional development skills along with their knowledge of Down syndrome and experience in order to be an effective teacher.

'I think it was a great presentation and very clear to understand - thank you!'

'Very useful, practical ideas to try with the student we work with.'

'Your advice is invaluable to us all and we really appreciate your kindness and your time.'

PARENTS

Two new training sessions were added to the ESS calendar this year. Kate Rogers, the mother of a student with Down syndrome, presented Getting Ready for Kinder. The session was informative, insightful and practical.

Heidi Gregory, founder of Dyslexia Victoria Support, shared with parents her knowledge of how to get organised and prepare for their child's school meetings and create a student support folder.

'As a parent just beginning the school journey it was good to have an idea of what needs to be kept and organised effectively so that everything is at hand when needed.'

Down Syndrome Victoria has been nothing short of an amazing support. They have been a fantastic advocate for children with Down syndrome and have willingly and openly shared their wealth of knowledge in a non-judgemental, compassionate and reassuring way, both in person and virtually. From the beginning of our journey, the expertise and offers of support have been invaluable and have ensured that we were on the right track and had the tools to best support our little learner to not only adjust to school life but to also grow educationally and socially, in an inclusive environment.

Hope Fitzgerald - Foundation Teacher, Orrvale Primary School

'Fantastic opportunity to do an online info session for us as we are in such a rural area of Vic. Fabulous info presented, easy to follow and understand. Easy to enrol and access. So grateful for the opportunity to take part. Thank you DSV.'

Thank you to the Department of Education for their continued partnership, including the financial contribution of 35 funded ESS places.

YOUR LOCAL EDUCATION CONSULTANT:

Ro O'Dwyer - Melbourne
Paula Kilgallon - Melbourne
Dianne Hickey - Barwon
Amy Fitzgerald - Western District
Carolyn Warren - Goulburn, Loddon Mallee, Ovens and Murray
Megan Bramble – Gippsland

Events

StepUP! #21YourWay 2021

Every October we StepUP! to celebrate Down Syndrome Awareness Month by celebrating, recognising and promoting the diversity and achievements of people with Down syndrome.

In 2021 we invited our community to participate virtually with StepUP! #21YourWay from anywhere in Victoria. We received support from within Victoria and nationwide, with countless fun and unique challenges being completed! We thank our community for their response which saw 18 teams, 72 individual fundraisers and 848 donations in Victoria alone. More than $134,000 was raised for the Down Syndrome Federation, including almost $60,000 in Victoria.

A huge thank you to everyone who participated and donated. We loved following your challenges and seeing all your great contributions online!

World Down Syndrome Day – Family Fun Day 2022

On Sunday 20 March 2022, almost 500 people joined us to celebrate World Down Syndrome Day at Werribee Zoo for our annual Family Fun Day. The event was a huge success and many families had the chance to meet and connect in person with those they had formed friendships with online. We enjoyed some fantastic entertainment and the sun was shining as families gathered for a picnic lunch before exploring the zoo.

A big thank you to everyone who attended and supported the day. Special thanks goes to: Werribee Open Range Zoo, BAM Allstars, Club21 Music Club and Merrill D'Souza, the Advisory Network, the Funky Monkey Family Band, Zumba, Fairyfields and all of our wonderful volunteers and stall holders. Thank you for making our event such a memorable celebration of World Down Syndrome Day.

A SPECIAL THANKS TO OUR TOP FUNDRAISERS:

1. Fabulous Francesca	$11,343
2. DS Tribe - Victoria	$10,065
3. Sophie's Stars	$6,049
4. Advisory Network	$5,134
5. Team Blake	$2,505

Communications

We're continuing to evolve the way we reach and interact with our community.

Our integrated and multi-platform communications approach plays an integral role in informing, connecting and engaging the community. We utilise a number of social media platforms, with Facebook, Instagram and email marketing our main means of social communication and connection.

Here's how our social media channels grew this year.

Our e-newsletter DNews is delivered monthly to approximately 2,800 people with a 33 per cent average open rate. This is eight per cent higher than the average open rates for not-for-profits according to Mailchimp. In addition, 40 per cent of our subscribers are rated 'highly engaged', often opening and clicking within our emails.

We recorded three episodes of the Down Syndrome Victoria podcast this year, including interviews with featured artists and authors from our community. We look forward to developing more episodes over the coming 12 months.

Follow us on social media by following the links on our website: www.downsyndrome.org.au/vic

FACEBOOK

DSV open page:
4.5% increase in followers
266% increase in organic reach

Family Support Private Group:
5% increase in members
641 posts
4,623 comments
12,229 reactions

Adult Support Private Group:
9% increase in members
205 posts
293 comments
834 reactions

INSTAGRAM

10.5% increase in followers
336% increase in organic reach

TWITTER

2% increase in followers

LINKEDIN

74% increase in followers

> 'Being part of the podcast was one of the highlights of my year. Thanks for making it happen!' **Trent McGregor, Wills and Estates Lawyer, Episode 4.**

> 'I enjoy being a host on DSV'S podcast. The first podcast I did was wills and estate planning that was a success and it went well. The second podcast we interviewed Robyn on her fashion design, I thought that was very interesting. The latest podcast was the most inspirational for me. It really reaches a different perspective. I learned that Julie is an author of a book about her son. The interview was so inspiring.'
> **Kath Mansour, DSV Advisory Network employee**

Volunteers

From Club21, Family Fun Day and StepUP!, to students volunteering in the office, we depend greatly on the support and commitment of our wonderful volunteers. A total of 21 volunteers contributed to DSV this year.

We welcomed back our Club21 volunteers in person at the 2021 Christmas lunch and are continuing to re-engage with volunteers in 2022.

We were fortunate to receive a Volunteer grant from the Department of Social Services Community Grants Hub funding several volunteers to complete First Aid Training Day with VIC First Aid.

We had another successful day at Werribee Zoo for Family Fun Day; seven volunteers helped us set up and pack down, were a welcoming face at the front gate, provided support to members, brought fun to the games and took the official photographs.

Thank you also to the skilled volunteers at the University of Melbourne, Master of Genomics and Health Students who helped with the Building Health Knowledge Project.

Each year we are incredibly grateful to the DSV board members who all donate many hours of expertise.

Thank you

Financial Snapshot

Five years at a glance

Down Syndrome Victoria is a responsible custodian of the funds provided by our generous partners and supporters. Every donation we receive is important and carefully distributed across our organisation to deliver services and support with and for people with Down syndrome, their families and the community.

	INCOME	EXPENSES
2018	$1,490,855	$1,058,751
2019	$1,211,180	$1,221,562
2020	$1,405,758	$1,395,764
2021	$1,622,320	$1,541,336
2022	$1,580,604	$1,668,368

A copy of our complete Financial Statements are available on our website or on request.

Donors, Sponsors and Supporters

In gratitude to our members and supporters

Since 1978, DSV has a long and proud history of partnering with our community, members and other organisations including, government agencies, traditional trusts and foundations, as well as corporate foundations and donors to support the delivery of genuine impact for Victorians with Down syndrome and their families. All our supporters are members of a very generous and exceptional community. Our heartfelt gratitude and sincere appreciation to all of you. Thanks also goes out to our donors who requested to remain anonymous.

Individuals

5,000+
Roslyn Allen
Carmine Santomartino
Bernard Sweeney

3,000+
Tina Orr

1,000+
Joel Deane
Aaron Dawson
Patricia Feast
Bill Hearn
Weihao Zhang

500+
Rebecca Dal Pra
Khaled Halabi
Leon Howlett
Bianca Italiano
Colleen McDonald
Ben O'Rourke
Peter Sloan
Andrew Slutzkin
Lachlan Vella
Kerrie Vlietstra

In Memoriam

Michael J. Nicoll
Rhys Vella

Organisational Donors

5,000+
YourLand Management Pty Ltd

Black Widow Design

1,000+
Al-Taqwa College

Building Impressions

Dulce Gelateria
The Leadership Sphere

500+
AFL Umpires Association

Kalinda Primary School

Lions Pride Holden Car Club Inc.

Northern Auto Paint Supplies (NAPS)

Rosie's Love and Care

Rotary Club of Koo Wee Rup Lang Lang Inc

St Ambrose Primary School

Trusts and Foundations

Bank of Melbourne Foundation

Collier Charitable Fund

The Flora and Frank Leith Charitable Trust

The Marian & E.H. Flack Trust

Nelson Alexander Charitable Foundation

The William Angliss (Victoria) Charitable Fund

Westpac Foundation

MRC Foundation

Tender

Parenting Research Centre – MyTime Tender

The Melbourne University, Melbourne Disability Institute – Community Based Research Program

Government Funding

Local
City of Monash

State
Department of Education and Training

Department of Families, Fairness and Housing

Department of Jobs, Precincts and Regions

Department of Health and Human Services – Office for Disability

Federal
Department of Social Services

National Disability Insurance Agency

With thanks to DSV's Life Members:

Roslyn Allen
Fae Egan
Peter Egan
Tony McDonald
Josie & Geoff McGivern
Ken Milligan
Papaleo Family
Prof Carl Parsons
Pat Willis (deceased)

Down Syndrome Victoria
Supporting Victorian families since 1978

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