

Give the gift that
allows us to

Stand UP

for generations to come





“ I remember feeling really lonely in those early weeks. Turns out, having a child with Down Syndrome has been anything but lonely as I’ve been plugged in to the most wonderful community of people who have either been there before you or are experiencing alongside you the joys and puzzlements of raising a child with an extra chromosome. Anything you are wondering about, there is someone out there to offer advice, ideas, and friendship to help you and your child. You are not alone, even if it feels like it right now. I found Down Syndrome NSW was the best place to start our new journey.

Louise - Mother to Theodore

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Down Syndrome NSW became such a valuable resource for us. The parent support coordinator I spoke with was so helpful & experienced. She had a 7yr old daughter with Down syndrome. I learnt that the organisation was founded by parents. They linked us to information & workshops & invited us to meet with other parents & families. Social groups provided a wonderful network to share knowledge & make firm friendships. I hosted a regular coffee morning when Sarah was a toddler & the friendships we made between parents & children, remain. We have never felt alone. There is support on hand.

Mary - Mother to Sarah



CEO Message

Leaving a gift to a charity in your will is a powerful way to leave a lasting legacy and ensure your values and compassion continue to make a difference long after you're gone.

The impact of your bequest goes far beyond financial support. It represents a belief in the potential and worth of every person with Down syndrome. It signifies your commitment to breaking down barriers, fostering acceptance, and creating a society that embraces diversity.

By choosing to leave a gift in your will, you are helping to secure the future of Down Syndrome NSW and ensure that our vital programs and services continue to thrive. Your generosity will have a lasting impact, providing ongoing support to individuals with Down syndrome and their families for generations to come.

Leaving a gift in your will is a personal decision, and we understand that your loved ones come first. However, if you believe in our cause and the impact we can make together, we ask you to consider including Down Syndrome NSW in your estate planning. Even a small portion of your estate can make a significant difference.

I extend my heartfelt appreciation for your thoughtful consideration of leaving a gift in your will. Your commitment to making the world a better place is a testament to your compassion and generosity.

Together, we can create a legacy of hope and change that will endure for generations to come.

Emily Caska
Chief Executive Officer



Before this, I didn't even know Down Syndrome NSW existed but I will be forever grateful as the first thing they said to us upon entering our hospital room was, "Congratulations!" She then spoke about her experience as a mum of a child who has Down syndrome and totally normalised the whole situation for us.

Melissa - Mother of Alyssa



Our story

Once upon a time in New South Wales, Australia, there was a remarkable group of individuals who had children who were born with Down syndrome. Inspired by their children's journey and fueled by their desire to create a more inclusive society, the parents embarked on a mission to establish an organisation dedicated to supporting individuals with Down syndrome and their families. And so, the seeds of Down Syndrome NSW were sown.

As the word spread, more families joined these gatherings, forming a tight-knit community that offered support, understanding, and hope.

The parent group worked tirelessly to run programs and collaborated with healthcare professionals, educators, and community leaders to raise awareness about Down syndrome and advocate for improved services and opportunities.

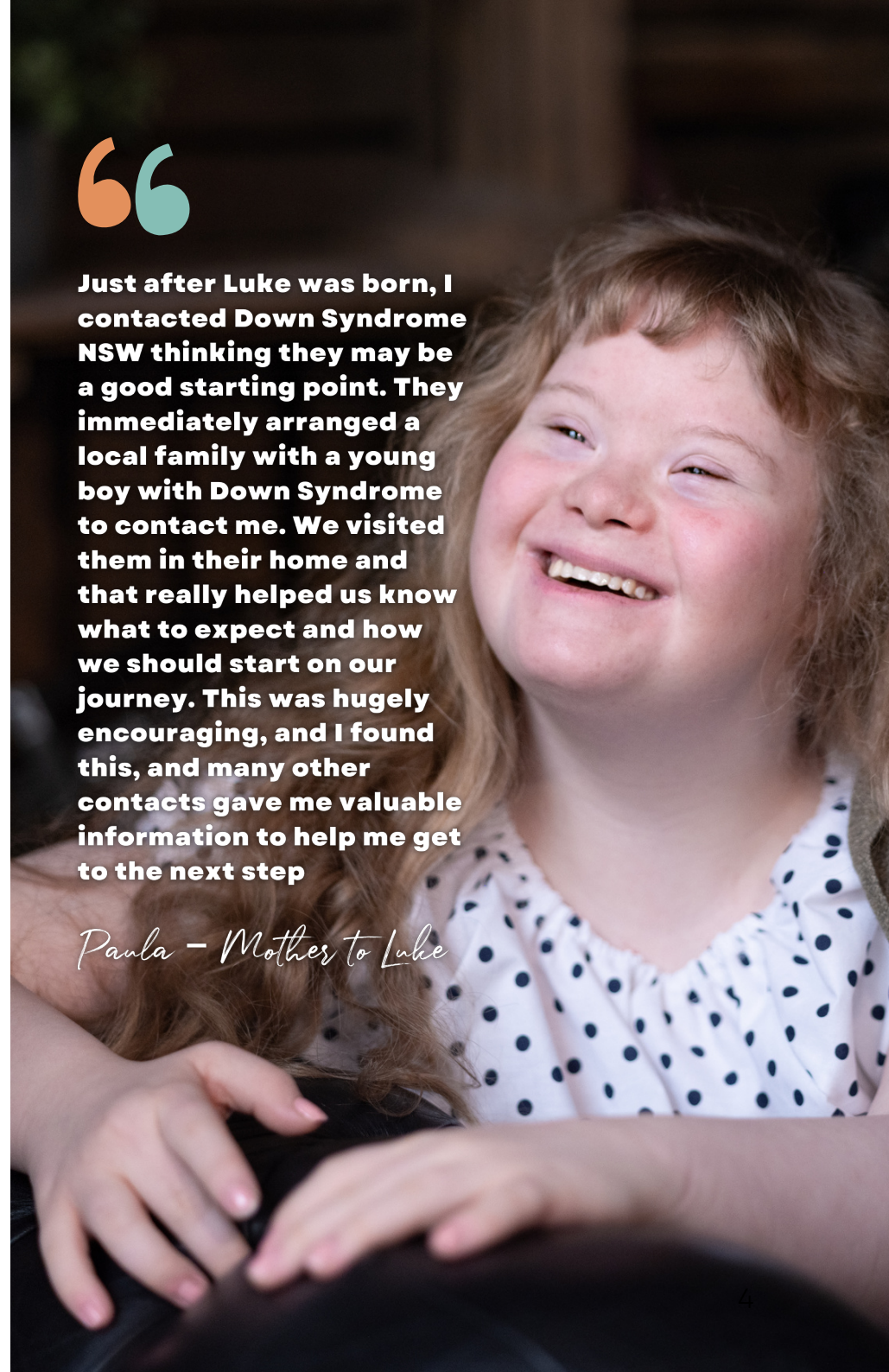
With the growing momentum, Down Syndrome NSW vision expanded beyond support groups and advocacy. They envisioned a dedicated organisation that could provide a wide range of services to individuals with Down syndrome, from newborn babies right through to support for the aging. With the help of passionate volunteers and the backing of the community, Down Syndrome NSW began to take shape.

Today, Down Syndrome NSW continues to evolve and adapt to the changing needs of the community. We have become a catalyst for change, breaking down barriers and championing the rights and abilities of individuals with Down syndrome. These parents and their story stand as a testament to the power of compassion, determination, and the enduring spirit of individuals, who make a profound impact on the world by turning their dreams into reality.

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Just after Luke was born, I contacted Down Syndrome NSW thinking they may be a good starting point. They immediately arranged a local family with a young boy with Down Syndrome to contact me. We visited them in their home and that really helped us know what to expect and how we should start on our journey. This was hugely encouraging, and I found this, and many other contacts gave me valuable information to help me get to the next step

Paula – Mother to Luke



Our Impact

You can be a part of our story and make a difference for generations to come in one of these areas;

Prenatal and Diagnosis Support

We provide expert advice, backed up by lived experience in the prenatal stages. We work to ensure all parents have up to date, fair and equitable information and support.

Babies and Early Years

We celebrate new babies and the early years through hospital visits, parent support networks and individual guidance and support, as well as workshops and resources to support families for the very best start.

School Inclusion and Behaviour Support

We work closely with schools, parents and students to ensure the education setting is authentically inclusive and that behaviours are recognised as an outcome of other needs, in order to ensure that students with Down syndrome are afforded the same educational access and outcomes as all.

Children, Youth, Teens and Adults Community

Participation

We offer a wide range of engagement opportunities across the lifespan to enhance capacity, improve social skills, increase community participation.

Employment Connections

We provide expert support in job readiness and connecting people with Down syndrome with great employers, as well as training and support to employers to create diverse and truly inclusive workplaces.

Older Adults Support, Health and Ageing

We have a dedicated program for older adults with Down syndrome, aimed at capacity building, enriching activities and support in relation to health and ageing.

Advocacy, Policy and Research

- Pre-natal screening and diagnosis support
- Giving the very best start in early years
- Education inclusion and support
- Post school pathways, including employment
- Community engagement and participation
- Health and ageing
- Housing
- Future planning, including supporting siblings and ageing carers

Awareness and Inclusion

- World Down Syndrome Day
- Lots of Socks
- Step UP! for Down Syndrome
- World Down Syndrome Month
- Thumbs UP! for Down Syndrome and
- International Day of People with a Disability



We've had our up and downs as you do with any child, but throughout the journey I knew that Down syndrome NSW was there to encourage us and help make connections with other families in a similar situation. I'm so grateful for that little red folder, it opened up a whole new community of support and the chance to make some lifelong friendships.

Julie - Mother to Bridie

Leaving a lasting legacy

Henry's Story by Kieran

Back and forth, back and forth. I watch Henry's infectious cackle and smile move towards me and away as I push him a little bit higher. I cannot help but laugh with him. Soon his laughter makes the other parents around smile and laugh. It is his first time on a swing by himself at the park and he is loving life. I can't imagine life without him. Recalling the events of his prenatal diagnosis is always difficult. Time and the sharing of stories paves way for healing and making sense of difficult periods in our lives. I hope my experience will be able to help other families to navigate the uncertainty when receiving a diagnosis of down syndrome.

Three simple words had caused so much heartache and pain. "I'm so sorry". At that point my world froze. The doctor continued and rattled off on medical condition after condition. Each sentence compounded the unease in my mind as he bookended each statement, repeating those same three words. Each a punch in the gut and an assault on the mind. My wife, Jenny, and I left what we expected to be a routine 12 week scan in tears. We were deflated and broken. What were we to do? We were painted an image where our lives centred around constant medical appointments and chronic health problems. We were told our baby would be extremely sick.

A week went and a follow up test repeated the same result of the pregnancy being high risk. Again, the words "I'm so sorry" from the same doctor. Retrospectively, when I think about it, it wasn't the diagnosis that was upsetting. It was having someone speak about your growing child as if they were a burden. Diagnosis or none, the baby was always wanted.

We were able to get a balanced view and gain insight into the reality of lives lived with Down Syndrome when Jenny contacted Down Syndrome NSW. The voice over the phone gave us hope and clarity. Miriam shared stories of her parental experiences with her daughter and the array of young people she has worked with. She made it clear there would be some difficulty but it was possible to have the fulfilling family we craved. Our continued contact with DSNSW and our own research kept us informed of the world of down syndrome.





Not long after, we found Dr Casikar who understood our situation and what we wanted. Her explanations and recommendations were non-judgemental and supportive of our decision. More importantly, she provided medical advice neutrally. We understood that we were 'taking the road less travelled'. My wife and I received balanced views on the health of babies and people with Down Syndrome. Her considerations to our situation in her practice ensured our baby Henry was getting the best support needed for him to succeed. I remember her saying "we are going to deliver your beautiful boy" after our first appointment. Those were words of reassurance which were much needed. They were a stark contrast to the initial ones received.

At 36 weeks, with a mix of excitement and panic of impending fatherhood, Henry entered the world. I remember feeling very proud but at the same time terrified as I didn't really know how to look after a baby. I had never been a parent before. He was born during the COVID19 lockdown which meant visits to the hospital and home from grandparents weren't allowed. My wife and I had to become experts overnight. The first time I held him I was very stiff and was scared to drop him. I recall him calmly breathing and sleeping on my chest. My fears were allayed. All my little guy wanted was support, warmth, and love. Something my wife and I had strived and fought to give him since his conception.

With Henry's diagnosis, we have had some challenges. At 2 months, Henry had open heart surgery to rectify 2 holes. Being the extraordinary individual that he is, he was back home in half the time we had been told to expect. Since the operation he has become stronger and developed a cheeky personality. Henry constantly defies expectations. He is a little man that does not let his diagnosis define who he is. From sitting, walking, learning to use sign language, to his dedication to practice his waving with every person we pass; he has tackled each milestone in his own way with his signature smile and dance moves.

I am extremely proud of Henry. When I think back, yes, he does not match the initial image of a family my wife and I thought we wanted, but Henry has opened a new world of learning and understanding for us. Henry has made our family extraordinary and more rewarding. He has taught me to be extra brave, to love fiercely, have patience and to embrace everyone's unique self. He is the boy that brings all the family together smiling. He is the boy that makes those stressful days at work seem insignificant. He is the boy that made me realise dancing could be fun. Henry is my perfect little man.

A close-up photograph of a young child with Down Syndrome, smiling broadly. The child's hand is held up, showing fingers painted with bright colors: yellow, red, blue, green, and orange. The background is a plain, light color.

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Thankfully we met with the hospital genetics counsellor who gave us an information pack from Down Syndrome NSW. This pack and the information it contained was a lifeline.

Chris – Father of Elsdon

Why leaving a gift in your will is so important to Down Syndrome NSW

We hope that when you create or update your Will, you will consider including a gift to Down Syndrome NSW

A significant proportion of our funds donated by individual members of the public come from bequests. We depend on this vital source of income to run our programs.

Knowing that we can depend on future income from bequests gives us financial security. We can plan ahead for our programs, knowing that we'll have the donations we need to make them succeed.

Ultimately, gifts in Wills help us ensure that we'll be around long into the future, supporting people with Down syndrome and their families

How to leave a gift to Down Syndrome NSW

To leave a gift to Down Syndrome NSW in your will, you can follow these steps:

1. Consult with a solicitor:

They will guide you through the legal process and ensure your intentions are properly documented.

2. Determine the Type of Gift:

Decide on the type of gift you would like to leave to Down Syndrome NSW. There are a few options you can consider:

- a. Estate Bequest: This involves leaving a percentage or a portion of your estate. Just 1%, 2% or 5% can make a huge difference
- b. Pecuniary Bequest: This involves leaving a specific monetary amount to Down Syndrome NSW
- c. Specific Bequest: This involves leaving a particular asset, such as property, shares, or personal belongings, to Down Syndrome NSW

3. Contact Down Syndrome NSW:

Get in touch with Down Syndrome NSW to express your intention of leaving a gift in your will. They can provide you with the necessary information and guidance to ensure your gift is directed to your preferred programs or initiatives within Down Syndrome NSW

4. Review and Update Regularly:

It's important to review and update your will periodically, especially if there are any changes in your circumstances or wishes. Keep your solicitor informed about any modifications you wish to make.

5. Inform Your Loved Ones:

Communicate your decision to leave a gift to Down Syndrome NSW with your loved ones. This will help ensure your wishes are understood.

Recommended wording for your will

This page contains specific wording recommended for leaving a gift in your Will to Down Syndrome NSW. In all cases, the most important thing is your own peace of mind, so we encourage you to discuss your Will with your legal advisor.

To include Down Syndrome NSW in your Will you could include the following:

If you wish to donate a percentage of your estate after providing for loved ones

“I give to Down Syndrome NSW (ABN 39 023 586 389), for its general purposes, free of all duties, _____ % of my residuary estate for which an authorised receipt from Down Syndrome NSW (ABN 39 023 586 389) will be a sufficient discharge for the executor(s) or trustee.”

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After a great conference last year, run by Down Syndrome NSW on Independent Living Options, we are now exploring the options for Sam to move out of home and live independently in the community. This is a big step and we find ourselves with mixed emotions of excitement for him to take this next important step towards independence but we are also slightly terrified!

Chris – Father to Sam



Elizabeth is mostly a happy young lady who brings joy to us and many people she comes in contact with. Thanks to the Zoom Up Club programs introduced during Covid lockdowns, she has been able to develop connections with others with Down Syndrome despite us living 7 hours drive from Sydney.

Jo - Mother of Elizabeth

If you wish to donate what's left over of your estate after providing for loved ones

"I give to Down Syndrome NSW (ABN 39 023 586 389), for its general purposes, free of all duties, the whole of the residue of my estate for which an authorised receipt from Down Syndrome NSW (ABN 39 023 586 389) will be a sufficient discharge for the executor(s) or trustee."

If you wish to donate a specific sum

"I give to Down Syndrome NSW (ABN 39 023 586 389), for its general purposes, free of all duties, the sum of \$_____ for which an authorised receipt from Down Syndrome NSW (ABN 39 023 586 389) will be a sufficient discharge for the executor(s) or trustee."

If you wish to donate a specific item

"I give to Down Syndrome NSW (ABN 39 023 586 389), for its general purposes, free of all duties, my _____ for which an authorised receipt from Down Syndrome NSW (ABN 39 023 586 389) will be a sufficient discharge for the executor(s) or trustee."

Down Syndrome Advocacy Angels

By leaving a gift to our work in your Will, you will join an honoured group of supporters within the Down Syndrome Family: Advocacy Angels.

Together, the Advocacy Angels are shaping a world where members have somewhere trusted and safe to turn for help, comfort and support, no matter what. You will share in our achievements, connect with inspirational people and be part of our story.

We celebrate our Advocacy Angels today, and every day, for the hope that they inspire in our collective 'tomorrow'.

We are so grateful for their commitment, and we hope one day to welcome you.

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We have been to many, many Down Syndrome NSW picnics, walks, dinners, lunches and meetings over these 35 years and DSNSW are still supporting Sophie through innovative social activities plus there are age-related information sessions for me. We are so fortunate to be a part of this community.

Robyn – Mother of Sophie





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Sam has had an amazing experience with Down Syndrome NSW UpClub starting with a Camp and then during Covid connecting on line. He has made lots of wonderful and valued friendships and at his first camp met his much loved and amazing girlfriend! Their relationship has brought a lot of joy to him and both our families! They have both loved more camps and activities with UpClub. Sam affectionately counts the dates and at last count this was at 75 and still going strong!

Chris - Father to Sam

Our Promise to you

- We will handle whatever gift you leave us efficiently, so that it can do the greatest good in the areas where it is needed most.
- We will ensure your gift goes to the exact program, initiative area you specified in your will
- You have every right to change your mind about a gift in your Will at any time.
- Any information you share with us will be kept strictly confidential and will be used respectfully and appropriately.



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