

Submission  
No 945

## INQUIRY INTO BIRTH TRAUMA

**Organisation:** Down Syndrome NSW

**Date Received:** 20 September 2023

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Partially  
Confidential

# Congratulations, Not Sorry

Ensuring a bright, inclusive start for children with  
Down syndrome and their families in NSW

**Submission:**

**NSW Legislative Council Select Committee on Birth Trauma**

**August 2023**



**Down Syndrome**  
New South Wales

## About Down Syndrome NSW

The Down Syndrome Association of NSW was established in 1980 by parents of young people with Down syndrome. As the children of the founding members grew to adolescence and adulthood, so too our services extended to all life stages. We now provide information and support, advocacy, capacity building workshops, training in schools, community participation programs, pre-natal expert advice, new parent resources and support and specialist employment preparation and connection.

We are an enthusiastic team of professionals with expertise in our relevant fields of service provision, support and advocacy. Some of us have lived experience with a family member with Down syndrome, some bring a range of expertise and industry experience. We are here to support you – all working together to help our members with Down syndrome achieve their full potential.

In a world that is becoming increasingly homogenised, Down Syndrome NSW plays a key role in supporting, informing and advocating for people with Down syndrome, their families and carers. Our community shares unique experiences, synergies and a strong sense of connection. From our over 40 years in the advocacy space, it continues to be clear to us (if not increasingly clear in recent years) of the need for diagnosis/disability-specific expertise and advocacy.

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## Introduction

Down Syndrome NSW is pleased to provide input to the NSW Legislative Council Select Committee on Birth Trauma, a topic of great interest to our community. We are pleased to see this critical stage addressed.

We know that the early years in any child's life are critical, particularly for those requiring early interventions and additional supports which ultimately leads to outcomes and optimal impact when delivered in a timely, equitable and individualised manner.

We welcome the prioritisation of this critical yet often complex and fragmented part of the lifespan. By looking at prenatal and birth years with targeted intent, it is our hope that a number of lead indicators will emerge to inform how we can better inform, nurture and support expectant and new parents of children with Down syndrome.

Above all, it is hoped that by better understanding the deeply delicate prenatal and birth arena, honestly looking at the issues faced and establishing a robust framework for optimal outcomes, we will be addressing areas for change as articulated by people with disability, we will see an uplift in outcomes and impact for babies with Down syndrome, their families and carers who deserve to be warmly welcomed with a congratulations, not sorry. This welcome to life permeates throughout life and is remembered by parents for an eternity.

Specifically, the Terms of Reference state that a select committee be established to inquire into and report on birth trauma, and in particular:

- (a) the experience and prevalence of birth trauma (including, but not limited to, as a result of inappropriate, disrespectful or abusive treatment before, during and after birth, also referred to as "obstetric violence")
- (b) causes and factors contributing to birth trauma including: (i) evaluation of current practices in obstetric care (ii) use of instruments and devices for assisted birth e.g., forceps and ventouse (iii) the availability of, and systemic barriers to, trauma-informed care being provided during pregnancy, during birth and following birth

(c) the physical, emotional, psychological, and economic impacts of birth trauma, including both short and long term impacts on patients and their families and health workers

(d) exacerbating factors in delivering and accessing maternity care that impact on birth trauma generally, but also in particular: (i) people in regional, rural and remote New South Wales (ii) First Nations people (iii) people from culturally and linguistically diverse (CALD) backgrounds (iv) LGBTQIA+ people (v) young parents

(e) the role and importance of "informed choice" in maternity care

(f) barriers to the provision of "continuity of care" in maternity care

(g) the information available to patients regarding maternity care options prior to and during their care

(h) whether current legal and regulatory settings are sufficient to protect women from experiencing birth trauma

(i) any legislative, policy or other reforms likely to prevent birth trauma, and

(j) any other related matter.

Given our role as a peak advocacy organisation supporting people with Down syndrome and their families with over 40 years expertise in this space, we have consulted widely with our members across metro, regional and remote geographic locations, across a range of ages and diverse experiences to inform our response. We are also staffed by parents of children with Down syndrome who so graciously shared with us their experiences.

We advocate for a holistic approach to the full ecosystem of change and welcome the NSW Government leading the way to ensure a congratulations, not sorry.

## Congratulations, Not Sorry

Down Syndrome NSW commends the work of the Select Committee on Birth Trauma shining alight on this critical issue. This has been a priority area for Down Syndrome NSW since our inception in 1980.

### What We Know

Through research, speaking with families and our own lived experiences, we know:

- There is no single data set publicly available that captures how many babies with Down syndrome are born each year in NSW or Australia. Without this critical foundational data, service planning, supports and interventions are near impossible.
- We know that more than 90% of pregnancies with a diagnosis of Down syndrome choose to terminate.
- Whilst we absolutely respect the choice of families, we know from these same families that this is often based on:
  - very outdated information,
  - unrelenting pressure to terminate, and
  - discussions about limitations not possibilities.
- At what is probably the most vulnerable time in parents life - the words a medical professional speaks and the care they provide stay with them forever, whether negative or positive, this experience cannot be forgotten. We know we can do better.
- The current treatment of expectant and new parents and their babies with Down syndrome is in direct breach of the United Nations Convention on the Rights of Persons with Disabilities.

***“It would have been such a great experience if we received a “congratulations” from the medical professionals instead of an “I’m sorry”. If I could change one thing in system that would be a big one.”***

parent of two-year-old son with Down Syndrome

***“People weren’t sure what to say to us. They mostly said they were sorry, which irritated. But we understood they meant well. Some said congratulations and it was marvellous to hear.”***

mother to

## Our Congratulations Initiative

In August last year, Down Syndrome NSW used generously donated funds to pilot our Congratulations Initiative, aimed at ensuring the very best start for all babies with Down syndrome and their families. In such a short space of time, our project has had a significant impact with demand outweighing our capacity to deliver to the full.

We also have big plans for future resources, capacity building and support as informed by both health professionals and parents. By taking a supportive, partnership approach with health professionals and families we are able to achieve optimal outcomes to ensure a congratulations, not sorry.

100% of staff working on our Congratulations Initiative are parents of children with Down Syndrome or people with Down Syndrome.

The following provides an overview of our project “why”, in service content to date, impact and feedback to May 2023 (our next impact reporting cycle is due at the end of this month, which will be more than double the following impact).



### Congratulations Initiative: Our Why

Our Congratulations Initiative aims to:

- Nurture, support, inform and connect families upon diagnosis through to 1 year old
- Upskill and partner with medical professionals including midwives, doctors, genetic counsellors, OBGYN, radiologists, pediatricians, social workers, therapists
- Develop a robust training and education program across resources, fact sheets, in services and online modules
- Gather and share family stories to support other families
- Deliver a congratulations, not sorry
- Ensure the very best start for all people with Down syndrome
- Gather statewide data on annual birth rates of Down syndrome, partnering with NSW Health



## Well Balanced Information

Testing Info  
and Consent  
+ Medical  
Diagnosis +  
All Options  
Available

+

Evidence  
Based, Up  
To Date  
Resources,  
Fact Sheets,  
Research

+

Real Stories  
of Lived  
Experience  
and  
Possibility

+

Connection  
to Down  
Syndrome  
NSW

+

Connection  
to Families  
of Loved  
Ones with  
Down  
Syndrome

Informed, Supported and Equipped Expectant and New Parents

It is our duty as trusted professionals to provide non-directive yet full information + support

## How We Nurture + Support Families

Prenatal Information Kit

New Parent Introduction Folder

New Baby Welcome Kit

Home + Hospital Visits, Calls, FaceTime (Prenatal + Postnatal)

Online Facebook Private Groups

Connection: New Babies Days, Local Connections, Events

Capacity Building: Workshops, Seminars, Fact Sheets, Conferences



## How We Partner with Health Professionals

Medical Professionals Information Pack

The Congratulations Initiative: Quarterly Magazine

Website: Resources, Research, Fact Sheets

Seminars and Workshops on Health Matters

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

In Services, Training, Online Training Modules



## Delivering a Diagnosis

### Prenatal (Positive vs Negative)

1. Results from the prenatal screening should be clearly explained as a chance assessment, not as a "positive" or "negative" result.
2. Prior to CVS or amnio, discuss all reasons for prenatal diagnosis.
3. Healthcare professional(s) most knowledgeable about Down syndrome should deliver the news - most likely OB and genetic professional together.
4. The news should be delivered in person. If not possible, a phone call but only at a pre-arranged time.
5. Answer: What is Down syndrome? What causes the condition?
6. Answer: What are realistic expectations for individuals with Down syndrome today?
7. Offer connection with parent support groups or chat with our prenatal specialists through DS NSW
8. Use non-directive language. Refrain from saying, "I'm sorry...unfortunately...bad news...etc"
9. Offer up-to-date materials or bibliography. Down Syndrome 02 9841 4444 or [admin@dsansw.org.au](mailto:admin@dsansw.org.au)
10. Make follow-up appointments, including specialists, as needed.



## Delivering a Diagnosis

### Postnatal (Positive vs Negative)

1. OBs and Pediatricians should coordinate their messaging. Ideally, they would meet together with parents to deliver the news.
2. Inform parents of suspicion for Down syndrome immediately, even if diagnosis is not yet confirmed.
3. Deliver the diagnosis in a private room
4. Parents should be informed together.
5. The infant with Down syndrome should be present and referred to by name.
6. Begin conversation with positive words, such as "Congratulations" on the birth of the child.
7. Provide accurate, up-to-date information.
8. Limit discussions to medical conditions that the infant has or might develop within one year of age.
9. Connect to local parent support groups and/or other families - DS NSW
10. Follow-up appointments should be arranged, as desired, and needed.



## Parent Directed Pathway

Parents are telling us that they would like to be provided with their options in a non-directive way. If they have made a decision, they would love support and respect with this decision.

Parents would like their medical team to:

Record this decision.

Communicate it with the whole team.

Respectfully do not ask the parents repeatedly after their decision has been made.

Parents report to us frequently that once they made their decision, they were asked, re-asked and asked again if they were continuing and the options to terminate were repeatedly presented.



## Just Like Any Other Baby

It's refreshing for parents to know that babies who have Down syndrome have all the same needs and wants as any typically developing baby. They...

- Cry
- Need to be fed
- Need their nappy changed
- Need to be loved and cuddled
- Love to be spoken to /sung to /smiled at
- Achieve milestones at their own pace
- Will smile / laugh
- Will love their family
- Thrive in a family environment
- Thrive in inclusive education
- Thrive when all their health needs are met

Person First – Baby / Person / Child with Down Syndrome

Not: Downs Baby, Down Syndrome Person, Downsie, Down Syndrome Child, Disabled, Slow, Different (and more...)

The identity comes first – the person comes first – the disability comes after (strengths should be in there too)

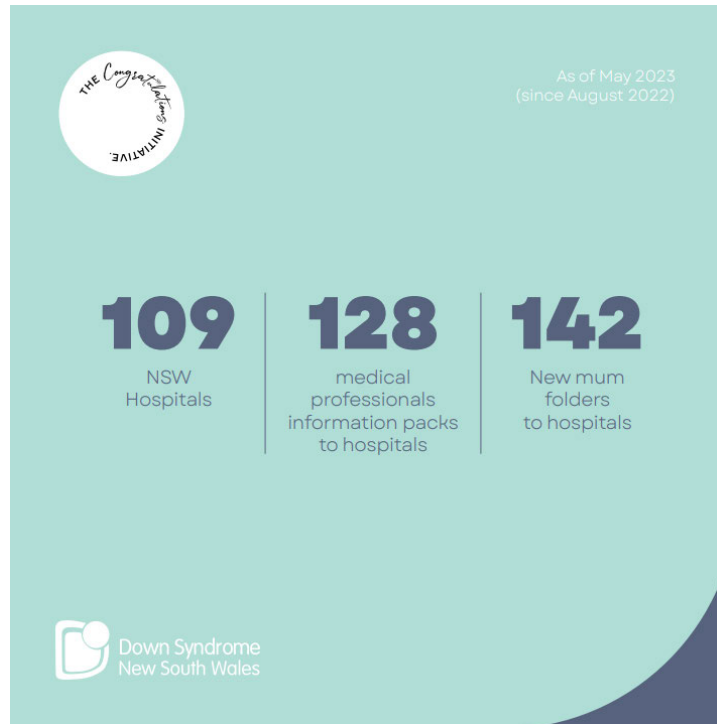
## Your Key Role

*A parent's experience during prenatal care and upon the birth of her baby (whether positive or negative) will stay with her forever and have lasting effects.*

Information Trumps Fear:

- Factual and well-balanced information about Down syndrome to enable women to make an informed choice (in the prenatal stage).
- Medical professionals are the first point of contact for a woman when she finds out her baby has Down syndrome.
- Set the tone for what can and should be a memorable and positive experience for all women and their babies.
- Positive and inclusive language is very important.
- Once a diagnosis has been made – a referral to Down Syndrome NSW for ongoing support, information and connection to other parents.
- Importance of connection with a pediatrician for ongoing medical check-ups
- Benefits of Early Intervention which include...speech therapy, occupational therapy and physiotherapy

## Our Impact








QUOTES

“Amazing, so many great resources and support. Every health professional, social worker, midwife, GP, radiologist, genetic counsellor needs this!”

“This is exactly what we need! The way diagnosis is communicated marks a very important part of how the parents take on the news. Education is key”

“I feel like this should be compulsory for all doctors to attend as they could learn so much more about how to communicate this subject in a more empathetic manner”

“This was 10/10!”


QUOTES

“This was easily one of the most fantastic, engaging in services I have ever attended. I truly learned so much. It was delivered informatively and an amazing opportunity to hear from mothers who had children diagnosed with Down Syndrome”

“We have just had a baby born here and we are so grateful to have your packs for us as well as a folder of up to date information to give to the family. It's great having you on the end of the phone”

“Loved it all – nothing to improve!”

“Great and powerful, helpful information about further paediatric assessments”





QUOTES

“This was excellent! Information given by the presenter was good, great to have someone directly affected by Down Syndrome is so great. Thank you for sharing with us, I am so pleased I was able to attend”

“The presenters experience and sharing the love they have for their children I enjoyed. I am so happy to have met your presenters, what beautiful strong women”

“Great presenters!”

“Your Medical Professionals Information Pack is perfect!”





## Birth Experiences: In Their Words

Read stories from our wonderful strong and gracious community on their birth experiences.

### Julie and Story



 **JULIE'S STORY**

"This story is about our now 17 year-old, fantastic, fabulous, [redacted]"

Like a lot of mums nowadays, I had some prenatal testing when I was pregnant with [redacted]. Nothing out of the ordinary was picked up and my pregnancy continued on as normal. Working in the medical field, I had lots of sneaky ultrasounds along the way and I found out we were expecting a little girl.

I went into labour early so we quickly got ourselves to the hospital expecting a C Section as she was in a difficult breech position. Our new little girl was in a hurry, delivered feet first at 1am before we even made it to surgery. After [redacted] was born, I was very unaware that there was an issue. She was perfect in all of our eyes, still is. The nurses suspected something though and our precious newborn underwent genetic testing.

[redacted] was seven days old when we were abruptly told that our daughter had Trisomy 21. After this very poorly delivered news, my husband and I took a moment to gather ourselves in the car park. Fortunately, I had already been put in contact with a social worker due to the traumatic nature of [redacted] birth. She helped us understand the situation better and gave us a red folder. She said, "When you are ready this will be of great help to you." The folder contained lots of information that we referred to for many years. Most importantly, it contained a phone number for Down Syndrome NSW. It also provided early intervention options, general information about Down syndrome and how to claim for Centrelink assistance, the NDIS wasn't launched at this stage.

It took us a few months to make contact with Down Syndrome NSW, I guess I needed time to get my head around the situation. Once I did reach out, I found care and support on the other end of the phone whenever I needed it.

“ [redacted] is a young adult now and of course 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.”

Earlier this year, I happily accepted a role with Down Syndrome NSW as a member of the support team. I'm able to offer my learning and understanding to parents who are exactly where I was 17 years ago. Although no longer a red folder, our New Baby Welcome packs that I now get to pass onto families, are filled with the same love and unwavering offer of support when it is most needed. " - Julie

## Melissa and Story



### MELISSA AND [REDACTED]

Melissa is the Down Syndrome NSW Up Up & Away Coordinator and Information & Support Officer. She is also mum to 4 beautiful girls including 16yo [REDACTED] who has Down syndrome. She shares her story to inspire and encourage others.

"I was once showing [REDACTED] a video of a group of mums singing a beautiful song with their children who have Down syndrome. All of a sudden, [REDACTED] had tears in her eyes and asked me to stop the video. I apologised to her, thinking the video had upset her and asked if they were happy or sad tears? She told me they were happy tears because she loves her name [REDACTED] and that she's glad she's my daughter. She added that she feels so special and loved by our family and expressed the beautiful memories she has of us singing just like the children in the video. We hugged and cried happy tears together.

I feel so blessed that [REDACTED] can articulate her deepest feelings and tell me that she knows she is loved.

I want to share my story to show how wonderful the journey of raising a child with Down syndrome can be and the importance of support from day one!

[REDACTED] was born on 16th May 2006. We discovered she had Down syndrome (Trisomy 21) shortly after. I didn't know anything about Down syndrome, but I did know I loved my baby very much and wanted to do all I could for her.

A lovely nurse came into our hospital room and gave me an information pack from Down Syndrome NSW and offered to arrange a visit from a parent-support team member at Down Syndrome NSW. This visit was the most amazing, supportive and informative welcome to the Down syndrome community my husband Michael and I could have asked for.

“

**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.**

Just seeing her talk so candidly, lovingly and kind to us gave us strength and tremendous hope for the years ahead.

She also talked about her daughter, who was twenty something at the time and her sense of humour. It was so reassuring. She also told us of all the information and supports Down Syndrome NSW offers, supports that I now get to provide in my role with all of my own lived experience to guide me!

In a world that can view the anomaly of having an extra copy of Chromosome 21 as not being worthy of life, holding my baby and having this hospital visit squashed society's understanding of normal. [REDACTED] is our normal and our kind of perfect, she's changed our lives for the better. 16 years into this journey I can honestly say it's been a beautiful one. Yes, parenting has its challenges (we have four beautiful children) and I don't always get it right as a mum... but they are all people first and I've learned that love can get you through any challenge."



## Chris and Story



### CHRIS'S STORY

I loved [redacted] from the moment I first saw her. When my wife had her twelve-week scan it was like [redacted] knew we were looking in and was waving her tiny arms and legs just for us. Having gone through the heartbreak of several failed pregnancies before this one, we breathed a huge sigh of relief when the doctor told us that our baby had a strong heartbeat and that she was "healthy and perfect". We knew next to nothing about [redacted] at that stage except that we loved her.

As part of the twelve-week check up, my wife also had a blood test. The results of that blood test showed a high chance of our little girl having Down syndrome and subsequent testing confirmed this diagnosis to be true.

Unsurprisingly, this news knocked me for six. I suppose it was natural to grieve the loss of the child I thought we were going to have but mostly my reaction came from a place of ignorance. Down syndrome was a complete unknown to me. I had never known anyone with Down syndrome, and I had no idea what life with Down syndrome was like. So my mind filled with outdated and incorrect stereotypes. 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.

By doing a lot of reading and talking with other parents of children with Down syndrome we soon learned that advances in medicine, education and acceptance meant our little girl would live a very rich and rewarding life and she would enrich the lives of those around her – something we now know with absolute certainty. Getting the prenatal diagnosis was actually a blessing, as it gave us time to process the news and our emotions before [redacted] arrived. Our initial feelings of disappointment soon passed, and we were then just as excited as any expectant parents would be. After months of scans and appointments, the day of [redacted] birth was one of the happiest of my life. It was amazing to finally meet the little girl we had already learnt so much about. As she was born early and some of her levels were low, [redacted] spent her first few days in the Neonatal Intensive Care Unit.



Despite how ominous being in NICU may sound, the notes I was keeping on that first day end simply with 'Not overwhelmed, overjoyed'. As a dad, one of the biggest challenges I found in those early years was getting used to people doing a double take or even staring when they saw [redacted]. At times it feels like everyone notices there is something different about your child. However, once you move passed the urge to yell, you soon realise it's human nature for their eye to be drawn to that which they perceive as 'different'. And if people stare, hopefully they will see that what they perceived as different is actually not different at all. If people stare at [redacted] all they will see is a little girl doing the things that little girls do.



I would say to other parents expecting a child with Down syndrome that getting the diagnosis is the worst part. Once you have received that news, the worst part is over. You'll soon find out that most babies growing up with Down syndrome will lead ordinary lives. Just like you and me, all they need are the right supports and opportunities to reach their full potential. That is why reaching out to an organisation like Down Syndrome NSW is so important. That is where you can make valuable contacts and get reliable information.



For us, as vital as the prenatal and new birth support was, it was just the first step in a lifelong journey. As we move forward, it is reassuring to know that at every stage of [redacted] life Down Syndrome NSW will be there with the support and resources to ensure she lives a meaningful life as a valued and contributing member of her community.

Writing this now, I know my words cannot do justice to all [redacted] is and all she brings into our lives. She is still just as the doctor first described her at that twelve-week scan – healthy and perfect.



## Louise and Story



### Louise and Story

Dear new parent,

You've got this.

I know it seems really overwhelming right now and you are worried about what the future will bring. When my son, [redacted] was diagnosed with Down Syndrome, I felt the same way. I knew nothing about Down Syndrome really and had a lot of outdated ideas about what this meant.

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

[redacted] 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.**

[redacted] I felt really strongly about meeting other families with babies with Down Syndrome as I wanted my son to grow up with friends with Down Syndrome as well as with typical babies too. Thankfully, through playgroups I was able to make lots of friends for both myself and my son.



The thing that worried me the most in those early months was that my son was also diagnosed with having serious complications with his heart that would require surgery. He went in for his heart operation at 3 months of age and it was the scariest time of my life. I was so grateful to have made those friendships with other parents who offered me so much support during that time, with many parents having gone through similar experiences with their own children. Thankfully, the operation went really well and [redacted] has been doing very well since.

Above all, remember this is your baby. They are just a regular baby who needs to be loved and encouraged like anyone else. Some days will be harder than others, but you have a whole network of people who have your back. For me, seeing my son's cheeky face every morning fills me with so much gratitude that he is my son, I couldn't imagine wanting him to be any different. He is the best thing that has ever happened to me.

It might be a myth that people with Down Syndrome are 'always happy', but what they usually are is authentic. [redacted] has allowed me to embrace a more authentic life and in doing so has given me a richer and happier life than I thought possible. I hope your baby will do the same for you - congratulations!

Love from Louise and [redacted]



## Kieran and Story



### Story by Kieran

Back and forth, back and forth. I watch [redacted] 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. [redacted] 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 [redacted] 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 [redacted] 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, [redacted] 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.

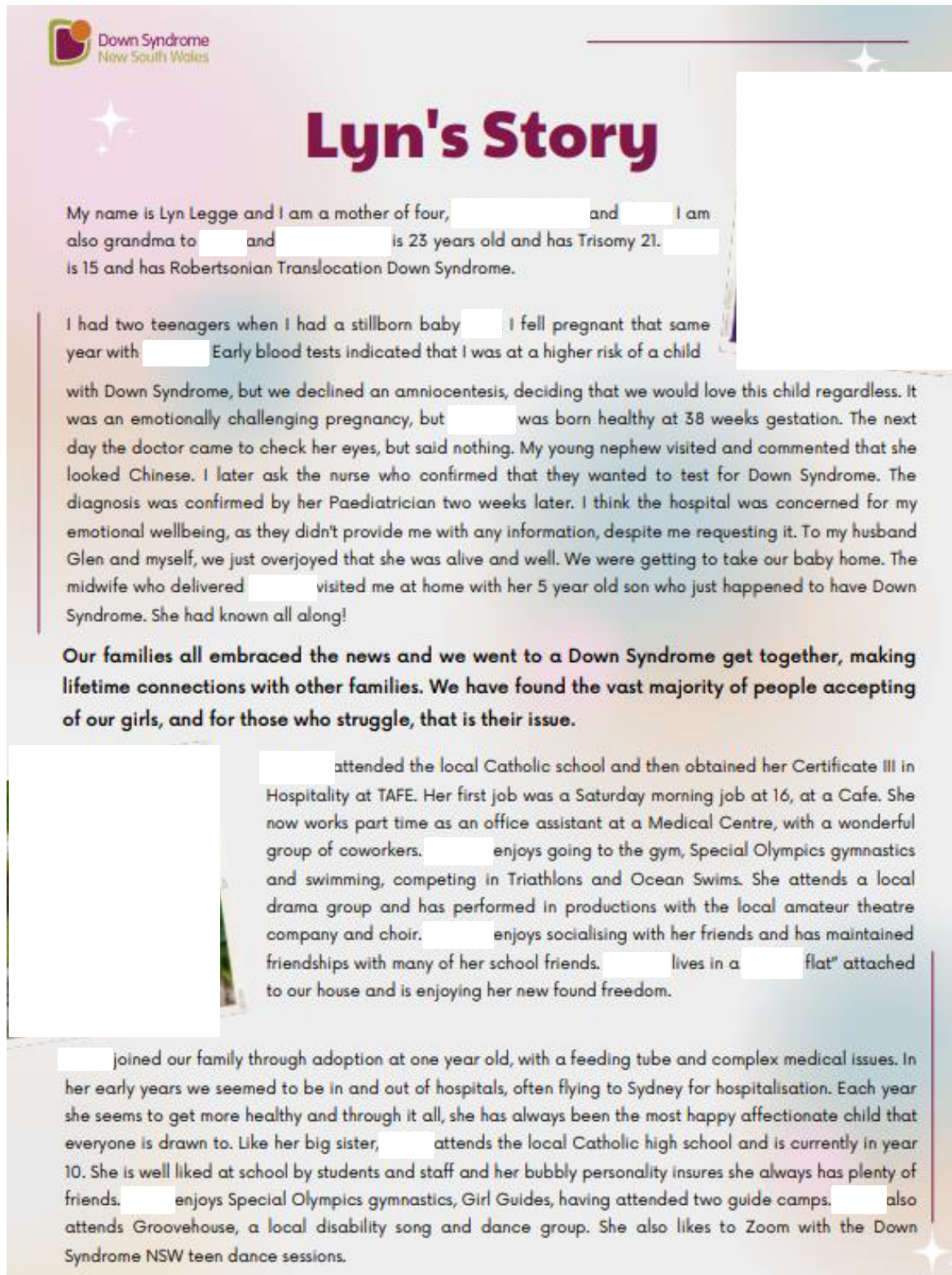
With [redacted] diagnosis, we have had some challenges. At 2 months, [redacted] had open heart surgery to rectify 2 holes. Being the extraordinary individual that he is, he was back home in half the time we had been told to expect. Since the operation he has become stronger and developed a cheeky personality. [redacted] 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 [redacted] When I think back, yes, he does not match the initial image of a family my wife and I thought we wanted, but [redacted] has opened a new world of learning and understanding for us. [redacted] 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.

[redacted] is my perfect little man.



## Lyn, and Story



**Down Syndrome  
New South Wales**

# Lyn's Story

My name is Lyn Legge and I am a mother of four, [redacted] and [redacted] I am also grandma to [redacted] and [redacted] is 23 years old and has Trisomy 21. [redacted] is 15 and has Robertsonian Translocation Down Syndrome.

I had two teenagers when I had a stillborn baby [redacted] I fell pregnant that same year with [redacted] Early blood tests indicated that I was at a higher risk of a child with Down Syndrome, but we declined an amniocentesis, deciding that we would love this child regardless. It was an emotionally challenging pregnancy, but [redacted] was born healthy at 38 weeks gestation. The next day the doctor came to check her eyes, but said nothing. My young nephew visited and commented that she looked Chinese. I later ask the nurse who confirmed that they wanted to test for Down Syndrome. The diagnosis was confirmed by her Paediatrician two weeks later. I think the hospital was concerned for my emotional wellbeing, as they didn't provide me with any information, despite me requesting it. To my husband Glen and myself, we just overjoyed that she was alive and well. We were getting to take our baby home. The midwife who delivered [redacted] visited me at home with her 5 year old son who just happened to have Down Syndrome. She had known all along!

**Our families all embraced the news and we went to a Down Syndrome get together, making lifetime connections with other families. We have found the vast majority of people accepting of our girls, and for those who struggle, that is their issue.**

[redacted] attended the local Catholic school and then obtained her Certificate III in Hospitality at TAFE. Her first job was a Saturday morning job at 16, at a Cafe. She now works part time as an office assistant at a Medical Centre, with a wonderful group of coworkers. [redacted] enjoys going to the gym, Special Olympics gymnastics and swimming, competing in Triathlons and Ocean Swims. She attends a local drama group and has performed in productions with the local amateur theatre company and choir. [redacted] enjoys socialising with her friends and has maintained friendships with many of her school friends. [redacted] lives in a [redacted] flat" attached to our house and is enjoying her new found freedom.

[redacted] joined our family through adoption at one year old, with a feeding tube and complex medical issues. In her early years we seemed to be in and out of hospitals, often flying to Sydney for hospitalisation. Each year she seems to get more healthy and through it all, she has always been the most happy affectionate child that everyone is drawn to. Like her big sister, [redacted] attends the local Catholic high school and is currently in year 10. She is well liked at school by students and staff and her bubbly personality insures she always has plenty of friends. [redacted] enjoys Special Olympics gymnastics, Girl Guides, having attended two guide camps. [redacted] also attends Groovehouse, a local disability song and dance group. She also likes to Zoom with the Down Syndrome NSW teen dance sessions.



\_\_\_\_\_ also has a diagnosis of severe Apraxia of Speech, which is probably her biggest challenge. She uses Auslan sign and LAMP AAC device to assist her, when she can't be understood verbally. \_\_\_\_\_ is currently trialling a CPAP machine as she has sleep apnea. She is taking to this as the trouper she is. \_\_\_\_\_ maintains a connection with her birth family and I often reflect on how with better support for her parents from a non English speaking background may well have been able to raise her. I am quite passionate about families receiving the support they need to navigate the medical and educational needs of their child.

Anyone who thinks people with Down Syndrome are all the same need to come to our house. Our girls are completely different and one's strength is the other's weakness. We love them both for the joy they bring to our lives, each and every day. We celebrate their achievements, but their worth is not tied to those achievements.

I became involved with Down Syndrome NSW when \_\_\_\_\_ was born and we were fortunate enough to have a midwife who was a mum to a six year old with Down Syndrome. She put me in contact with Down Syndrome NSW. Each year I would organise a get together with other local families in Coffs Harbour, to celebrate Down Syndrome Awareness. \_\_\_\_\_ went to a local Catholic school with two other students with Down Syndrome. Down Syndrome NSW came to the school to train the staff in including our children.

The following year a few parents and \_\_\_\_\_ teacher travelled to Sydney to attend a three day conference, Our family also attended a family weekend, which was invaluable. I also attended a mother's weekend in the Hunter, prior to NDIS rolling out in our area. For a number of years I was the contact at the hospital for new families. I have handed the reigns over to younger families on a local level and they are doing a great job, running several very popular "Step up" events and starting a Facebook Group.

A couple of years ago I linked in by Zoom to the Health and Wellbeing Workshops, which was a wealth of information and integral in helping \_\_\_\_\_ achieve a 10 kilo weight loss. I am currently on the management committee, hoping to make a contribution to an organisation that has only been a phone call away, when I have needed support over the years.

## Recommendations

Down Syndrome NSW thanks the NSW Government for the opportunity to provide input to the Select Committee on Birth Trauma and is pleased to make the following recommendations:

### Recommendation One: Congratulations Initiative

That the NSW Government fund the Down Syndrome NSW Congratulations Initiative, to ensure the very best start for all babies with Down syndrome and their parents from conception. This project has three key streams: informing and nurturing families, upskilling and supporting health professionals and building robust data and capacity. A full project plan and budget is available,

This project includes the development of resources, fact sheets, videos from parents, medical professionals information packs and in service presentations, online learning modules, parent support line, parent information packs, sharing family stories, establishing local peer support networks particularly in regional and remote areas, online clearinghouse, evaluated research studies, surveys, experiential reports and so much more, all codesigned and cofacilitated by people with Down syndrome and parents of children with Down syndrome in a pro-information, non-directive manner.

### Recommendation Two: Recording and Respecting Choice

That NSW Health have a section on all health records for expectant parents has a section that states if a decision has been made by a family regarding termination if they have chosen to proceed, this decision is recorded and respected.

### Recommendation Three: A Seat At The Table

That an Advisory Committee be formed to carry forward the recommendations of this Select Committee on Birth Trauma, with Down Syndrome NSW afforded a seat at the table to positively contribute and support change.

### Recommendation Four: Data is Power

That NSW Health work with Down Syndrome NSW to develop an annual data set to track the number of diagnoses and the number of births of babies with Down syndrome. This may include reinstating, with consultation, the previous NSW Register of Congenital Conditions (last one we can



find is 2010), or the NSW Birth Defects Register (last we can find is 2004) with a note to change the titles for both.

## Recommendation Five: Rewarding Champions

That NSW Health work with Down Syndrome NSW to:

- Update the outdated [Prenatal Testing/Screening for Down Syndrome & Other Chromosomal Abnormalities \(nsw.gov.au\)](#)
- In the above, rather than having Down Syndrome NSW listed as a resource at the back, be more prescriptive in ensuring that all people with a diagnosis are given the details of Down Syndrome NSW by health professionals.
- See Hudsons Law passed in Mississippi in the US that mandates this referral by legislation: [Bill Text: MS SB2746 | 2021 | Regular Session | Introduced | LegiScan Hudson's Law; create to require dissemination of information relating to trisomy conditions by State Department of Health. \(United States\) \(global-regulation.com\)](#)
- Develop an awareness campaign of the role of Down Syndrome NSW as partners to health professionals, in line with the revised Policy Directive cited above.

## Recommendation Six: Investing in Capability

That Down Syndrome NSW is engaged to provide training, resources and support to all medical students and health professionals across NSW, including co-facilitation by people with Down syndrome and parents to share their stories and ensure a congratulations, not sorry.

## Recommendation Seven: Specialised Support

That investment is made in specialised services and supports within trusted organisations such as Down Syndrome NSW to provide birth trauma counselling and support.

## Annexure Three: About Down Syndrome



Down syndrome 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 sometimes known as trisomy 21.



There is no national data collection on the number of people with Down syndrome in Australia.

According to Western Australia data, there are **13,000 - 15,000** individuals with Down syndrome in Australia as of 2019



Applying these numbers to the Australian population, **every 10,000 people there are 5.14 people with Down syndrome**. This is similar to other countries like the UK.



Down syndrome is the most commonly occurring chromosomal condition.



Approximately **1 in every 1100** babies born in Australia will have Down syndrome.



Each year there are approximately **290 new babies** who have Down Syndrome.



The incidence of births of children with Down syndrome **increases** with the age of the mother.



The chance of a woman conceiving a child with Down syndrome varies from



**1 in 1400 for a woman 20 years of age to  
1 in 30 at age 45 years.**

Younger women have babies more frequently, so the majority of babies born with Down syndrome are born to women **under 35 years of age.**



People with Down syndrome are living **longer and healthier lives** than they have in the past.



Life expectancy of people with Down syndrome has dramatically **increased** over the past 50 years



With the average life expectancy of a person with Down syndrome in Australia **being 60 years of age**



Down syndrome is a genetic condition, sometimes referred to as Trisomy 21. It is the most common genetic disability. There are approximately 13,000 people in Australia with Down syndrome. The birth rate in Australia for Down syndrome is one in every 1,100 births. Evidence tells us that 9 out of 10 pregnancies in Australia are terminated if Down syndrome is detected.

Most people have 23 pairs of chromosomes, making 46 in total. People with Down syndrome have 47 chromosomes in their cells, having an extra of chromosome 21.

People with Down syndrome have:

- Areas of strengths and other areas where they need support;
- Some level of intellectual disability;
- Some characteristic physical features;
- Increased risk of some health conditions;
- Some developmental delays and learning difficulties.

Down syndrome is a genetic condition, it is not an illness or a disease. It is nobody's fault. There is no cure and it does not go away.

In the 1950's (not that long ago), the life expectancy for people with Down syndrome was as low as 15 years of age. In recent times, progress in medical and social sciences has improved the quality of life enjoyed by people with Down syndrome. In Australia today, the life expectancy of people with Down syndrome averages 60 years of age.

Whilst this is a milestone to be celebrated, it also presents us with the first generation of people with Down syndrome who will, in the main, outlive their parents. This creates an even greater need for representative associations like Down Syndrome NSW to provide critical services, supports and advocacy at all stages across the lifespan.

With the right supports, people with Down syndrome are able to live full and active lives in their communities. From education, to employment, to community participation, to relationships and housing options, people with Down syndrome enjoy the same needs and aspirations just like everyone else. However, achieving these goals can be harder for people with Down syndrome, with some level of support needed to help them achieve the kind of life that most people take for granted.

Down Syndrome NSW proudly works with passion to support all people with Down syndrome to live inclusive, valued and active lives.

## Annexure Two: Our Important Work

Down Syndrome NSW provides services and supports currently to all people with Down syndrome in NSW, their families and carers across the full lifespan including:

- Information and support;
- Library and resources;
- Workshops and training;
- Parent support networks and regional hubs;
- Prenatal and early years resources and support;
- Inclusive education support, teacher training and behaviour management;
- Transition to school, school years and teens support and advice;
- Post school years transitions including travel training,
- Community engagement and participation for children, teens and adults;
- Accessibility support to participate in events and access infrastructure.
- Health, sexuality and ageing advice, advocacy and support;
- Guardianship and wills resources;
- Self advocacy, capacity building and mentoring;
- Individual advocacy support, advice and resources;
- Systemic advocacy, policy submissions and research.
- Policy, lobbying and proactive government relations;
- Community capacity building, awareness, inclusion and social capital.

We work to promote and represent the views of people with Down syndrome, their families and carers in all that we do. We are governed by a Board comprised of parents and family members, as well as a Down Syndrome Input Council comprised of people with Down syndrome. We hold monthly “Have Your Say” sessions with our adult cohort also to ascertain their views at frequent intervals and undertake robust consultation in a variety of forms to ensure all members have their views heard and represented.

We are enthused to work together with the Commonwealth, state and territory governments to support an inclusive, vibrant and diverse Australia where every person with disability is heard and valued.



## **Contact**

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**Down Syndrome**  
New South Wales

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