

YOUR WEEKLY NEWS

DOWN SYNDROME
NEW SOUTH WALES



What's UP!

at
Down
Syndrome
NSW



YOUR WEEKLY NEWS | 8 February 2024

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CEO *Commentary*

Hello valued members and supporters,

Another busy week for us, and a wonderful one at that!

A few highlights from me:

- We warmly invite our valued members to join us at NSW Parliament House on Wednesday 20 March to celebrate World Down Syndrome Day with Minister for Disability Inclusion, the Hon Kate Washington. Details and link to register below for this special afternoon tea event, attended by many Members of Parliament.
- We are also looking to confirm an exclusive Training Day with the Sydney Swans on Thursday 21 March, to be confirmed so watch this space!
- Our World Down Syndrome Day and Lots of Socks campaign is off to a cracking start - so many of you have purchased our amazing socks, as have I! To buy socks, purchase raffle tickets, fundraise for us, see details below. Your support is vital for our important work across all life stages!
- This week, the Board and Executive held a brilliant strategic planning day to finalise our next Strategic Plan, to be launched by the Minister on 20 March. This was a great opportunity to reflect on our recent achievements, member feedback, member needs and shape our vision for the future firmly founded upon our members at the centre.
- You will have received an email from me this week seeking your powerful stories, which I am so excited to receive.
- Equally important is our Education Survey linked below, as this will inform our response to the Disability Royal Commission and the current NSW

- Our next New Babies Day is open for registrations and we love seeing you! Scroll down for full details, for Saturday 9 March in Hornsby. We hope to see members from the Central Coast and Newcastle join if possible, as well as other regional members and our beloved metro members too! Always a fabulous day to connect (and cuddle!).
- Dr Katie Frank's session on sensory processing this week was a real highlight! All the way from the USA, Dr Frank is a true world leader and so knowledgeable. It was an honour to have her present and we have the recording also for those who couldn't attend. Dr Frank is back later this year also - an expert not to be missed!
- Check out our workshops below - everyone's favourite Dr Brian Chicoine is back with a really incredible presentation not to be missed and we've got nutrition, puberty and other great topics coming your way! Share with your support workers, health staff, educators and family!

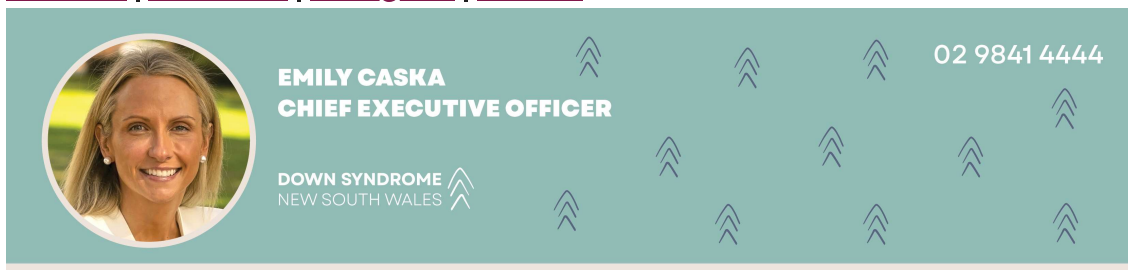
Until next week!

[Emily Caska](#)

[Chief Executive Officer](#)

Phone: 02 9841 4444

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[Your Powerful Stories](#)

We are proud to be presenting to government our key policy areas, and we need your stories. Each link below has a few short questions related to each area - you can fill in one or many.

These powerful stories will be used to illustrate our policy asks, they will be shared proudly with other families keen to learn your journey and lessons and will be on our website and social media.

[Your Story: Prenatal and New Baby](#)

[Your Story: Early Years](#)

[Your Story: Education](#)

[Your Story: Housing](#)

[Your Story: Employment](#)

[Your Story: Health and Wellbeing](#)

[Your Story: Relationships](#)

[Your Story: Community Life and Sports](#)

[Inclusive Education Survey: We Need Your Views](#)

Inclusive education is a hot topic at present, thanks particularly to the Final Report of the Disability Royal Commission. There are varying views and all are valid and have a place in the debate, all deserve to be heard.

So too, the NSW government have launched an Inquiry into Children and Young People with Disability in Education.

I want to hear from you to inform our position.

Down Syndrome NSW is proud to make a submission to both, and we need your views. We would also love to get the views of your teachers and educators on

Please see the two surveys below, due by 10 February.

Education Survey: For Parents and Families

Education Survey: For Teachers, Educators and Principals

[Get In Now: Get Organised with Our Exclusive Down Syndrome Calendars!](#)



Seize the Moment with Our 2024 Calendars

Time is ticking, but there's still time to make 2024 extraordinary! Our captivating 2024 Calendars are still available, and here's your chance to get involved, get organized, and infuse your year with inspiration.

Buy Your 2024 Calander Now and Support Down Syndrome NSW

[Upcoming Events](#)

Please see below exciting upcoming events and workshops. For UP! Club events, please refer to the programs provided later!

February 2024

DOWN SYNDROME
NEW SOUTH WALES



THE *Inclusion*
INSTITUTE

Workshop

Puberty for parents/carers
of adolescents with Down
syndrome with **FAMILY
PLANNING AUSTRALIA**

Date: Tuesday 20 February, 2024

Time: 10am – 11:30am (NSW/AEDT)

Format: Online via Zoom

Cost: Free



[Register Now](#)

March 2024

NEW SOUTH WALES 

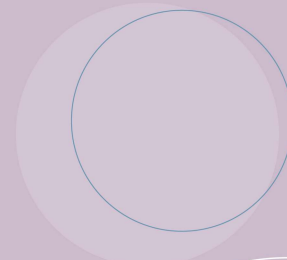
Up! Up! AND AWAY
TEENS

MONTHLY EVENT

For **children aged 13 - 17** who
have Down syndrome, their
siblings and parents/carers

SAVE THE DATE!

Saturday 2 March, 2024
(NSW/AEDT)



[Register here](#)

NEW SOUTH WALES 

THE *Inclusion*
INSTITUTE

Workshop

Reflections and Co-Occurring
Diagnosis and Data with
DR. BRIAN CHICOINE, MD

Date: Wednesday 6 March, 2024

Time: 9am – 10:30am (NSW/AEDT)

Format: Online via Zoom

Cost: Free



DR. BRIAN CHICOINE, MD

[Register Now](#)

INITIATIVE

NEW SOUTH WALES ^

New Babies day

This is a great opportunity for parents of babies 0-2 years to meet, network and learn about therapies at this early stage.

Date: 9th March 2024

Time: 11am - 2pm

Venue: Hornsby RSL - 4 High St
Or Online

Cost: FREE



[Register Now](#)

NEW SOUTH WALES 

THE *Inclusion*
INSTITUTE

Workshop

Is there a **'Right Diet'** for
people with Down syndrome?
With **NICKY CLARK,**
Nutritionist

Date: Tuesday 19 March, 2024

Time: 10am-11:30am (NSW/AEDT)

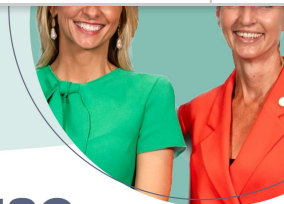
Format: Online via Zoom

Cost: Free



NICKY CLARK, Nutritionist

[Register Now](#)



NSW Parliament House

Afternoon Tea

NSW Minister for Disability Inclusion
The Hon Kate Washington, MP



**Jubilee Room, NSW Parliament House
6 Macquarie Street, Sydney**

Wednesday 20 March, 2024
2:30pm – 4:30pm

EXCLUSIVE MEMBER EVENT | RSVP ESSENTIAL

[Register Now](#)

NEW SOUTH WALES **THE** *Inclusion*
INSTITUTE*Workshop*

EARLY CHILDHOOD INTERVENTION and how to get the best out of your NDIS Package with EarlyEd (for families of babies, toddlers and preschoolers with Down syndrome) with **AMANDA CLIFFORD**, OT, Practice Lead, EarlyEd and **KERRY DOMINISH**, CEO of EarlyEd

Date: Tuesday 26 March, 2024

Time: 10am – 11:30am (NSW/AEDT)

Format: Online via Zoom

Cost: Free



[Register Now](#)

Do you have ideas for speakers or wish to speak? Great! Contact us at events@dsansw.org.au to share more.

[World Down Syndrome Day](#)
[Parliament House Event](#)

Parliament House Event

World Down Syndrome Day Parliament House Afternoon Tea



Parliament House - 6 Macquarie Street Sydney
Wednesday 20th March 2024
2:30pm - 4:30pm
Exclusive member event.



We would like to invite you to join us for an Afternoon Tea at NSW Parliament House to celebrate World Down Syndrome Day.

The Minister for Families and Communities, and Minister for Disability Inclusion the Hon Kate Washington is hosting an afternoon tea in the Jubilee Room of NSW Parliament House exclusively for Down Syndrome NSW members and their families.

This is a significant opportunity for our members to be included, to raise awareness and show Members of Parliament what a formidable community we are. We want you there to celebrate World Down Syndrome Day as well as showcase our strength.

In particular, we want to ensure people with Down syndrome of all ages are represented on the day. Parents, grandparents and siblings are welcome too as you all play an important role in the fabric of our community.

Part of a broader emerging partnership that we have been busy working on between Down Syndrome NSW and NSW Parliament House, it is our pleasure to invite our members to this amazing event.

The Hon Kate Washington is so very committed to increasing awareness, acceptance, authentic engagement and inclusion.

Who: Exclusive to DSNSW Members

When - Wednesday 20th March 2024

Time - 2:30pm - 4:30pm

Where - NSW Parliament House, 6 Macquarie Street Sydney

Cost - Free

To be fair to all we have a family limit of 4 tickets. If you require more than 4 tickets please email julie.louden@dsansw.org.au

If tickets are sold out there will be a waiting list.

This is a member only event.

Registration is essential. Each person attending must be registered.

Membership is Essential to attend this event.

Membership is FREE. Sign up here:

[Become a Member – Down Syndrome NSW](#)

We have lots of member only events throughout the year as well as discounts to our conferences, workshops and training and other great member benefits soon to be announced!

We look forward to seeing you there.

[Register Now](#)

[Join the Global Lots of Socks Movement Today](#)

DOWN SYNDROME
NEW SOUTH WALES

**WORLD DOWN
SYNDROME DAY**

21 March

lots OF socks

The graphic features a teal circular logo on the left with the text 'DOWN SYNDROME NEW SOUTH WALES' and 'WORLD DOWN SYNDROME DAY' above the date '21 March'. To the right, the phrase 'lots OF socks' is written in a yellow cursive font, with 'OF' in blue. Below the text, five colorful socks (green, orange, blue, red, and blue) are hanging from a blue clothesline with wooden clothespins.

and we're aiming high to make this year's Lots of Socks campaign the most memorable yet.

Ready to be a part of something extraordinary?

As a valued member, you play a crucial role as advocates for the impact we make on the Down syndrome community. We're looking for passionate individuals who want to contribute to a more inclusive world. If that sounds like you, there are plenty of ways you can join us and make a difference today:

Wear and Share: Start purchasing vibrant socks from our range. Wear them proudly on March 21st and share your colorful style on social media using #LotsofSocksNSW.

Create a Fundraising Page: Sign up to create your personal fundraising page. It's an easy and impactful way to rally your friends, family, and colleagues to contribute.

Donate: Every contribution brings us one step closer to our goal. Donate directly through our fundraising platform and know your gift is going directly towards supporting individuals with Down syndrome to live longer, happier and healthier lives

Purchase Raffle Tickets: Participate in our raffle and go into the draw to win fantastic prizes while supporting a meaningful cause.

Nominate Your Community: Make a significant impact by nominating your local school, hospital, or workplace to join the Lots of Socks movement. Encourage them to sign up as a team and make a colorful statement on March 21st.

Download this poster below for information on how you can support us!

JOIN THE GLOBAL LOTS OF SOCKS MOVEMENT ON MARCH 21ST!

Each year, on March 21st, people worldwide come together for Lots of Socks to commemorate World Down Syndrome Day. This special day invites us to engage in conversations that celebrate diversity and recognise the unique qualities that make each individual extraordinary.

The Lots of Socks Initiative draws inspiration from the vast array of socks available, symbolising the rich diversity within our community. By proudly donning vibrant and colourful socks, we not only embrace our differences but also contribute to the creation of a more inclusive society.

As a valued member, you play a crucial role as advocates for the impact we make on the Down syndrome community.

HERE ARE SOME WAYS YOU CAN PROUDLY REPRESENT DOWN SYNDROME NSW AND GET INVOLVED TODAY:

- ENGAGE YOUR SCHOOL OR CLUB**
Nominate your school/club/organisation to participate in the Lots of Socks initiative.
- TRY YOUR WORKPLACE INITIATIVE**
Encourage your workplace to join the initiative.
- FUNDRAISE FOR US**
Organise a fundraising event at your local business, club or school.
- BUY OUR LOTS OF SOCKS**
Purchase and wear our Lots of Socks, available in all sizes, colours and patterns.
- DONATE NOW**
Make a direct donation to our network.

Send your nominations and inquiries to partnerships@dsnsw.org.au.

Let's unite in celebrating diversity and making a positive impact on the Down syndrome community!

DOWN SYNDROME NSW SOUTH COAST
WORLD DOWN SYNDROME DAY

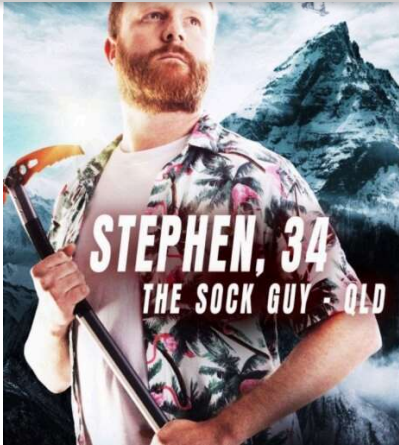
Download Lots of Socks Poster

[Meet our Lots of Socks Ambassador: Stephen Butler](#)

We're very excited to shine a spotlight on someone truly special – our Lots of Socks Ambassador, Stephen Butler!

Introducing Stephen

My name is Stephen, a proud ginger, father of two, stepfather of 1, entrepreneur, HR professional, and ultimate sock lover with the shortest stint ever on reality TV on The Summit screened on channel 9 in 2023!



Why you chose to support Lots of Socks:

I feel privileged to be able to get involved with such a worthy cause and raise awareness and kindness through my ambassadorship by putting smiles on faces with socks!

In my day job I campaign for diversity and inclusion as a HR professional, and pride myself on educating organisations in the value of equality for individuals who have Down Syndrome.

My parents built a children's indoor play centre in Tamworth called Kids Zone, where we had groups of kids of all ages with Down Syndrome come and play and build memories. I would facilitate small groups and parties, and dive headfirst into their excitement, celebrations and connection. It is a fond memory that will stay with me forever.

I hope to provide more education and awareness with my ambassadorship, whilst promoting some fun and exciting pairs of socks that are in my sock drawer.

Join Stephen Butler and you can make a difference today!

Order Your Lots of Socks Today

Lots of Socks Fundraiser



[Win Amazing Prizes in our Raffle](#)

Our raffle is now live and ready for you with amazing prizes to win!

First Prize: Family portrait photography gift voucher (RRP: \$600.00)

Second Prize: High Tea Experience for up to 8 Guests at Voco Kirkton Park (RRP: \$520.00)

Third Prize: Snuggle Hunny Gift Voucher (RRP: \$500.00)

Fourth Prize: Australian Rugby Union Signed T-Shirt (RRP: \$300.00)

Fifth Prize: Family Pass at Taronga Zoo (RRP: \$290.00)

Sixth Prize: Scented Candle, Lip Balm & Diffuser (RRP: \$100.00)

Thank you to our generous donors and supporters.

Our amazing raffle will be drawn on Monday 25 March, 2024.

All proceeds go directly to supporting people with Down syndrome and their families. Share the link with your family and friends to be in the running to win!

[Purchase Your Raffle Tickets Now!](#)



[The Inclusion Institute](#)

Inclusive education is not just a philosophy, but a fundamental right for every child. All children have the right to a high-quality education in an environment which celebrates their diversity and leads them to reach their full potential

With the Inclusion Institute, we look to introduce our comprehensive Primary and Secondary School Support Program, designed to benefit both mainstream and special schools.

The program's core objectives are to strengthen the capacity of schoolteachers, principals and SLSOs (School Learning Support Officers) and to foster strong connections among key stakeholders, including families, therapists, and behaviour support specialists, all with a focus on putting the student at the centre.



Down Syndrome NSW Fact Sheets

We have created insightful and informative Fact Sheets which you can view and download below.

Inclusive Education: The Legal Framework Fact Sheet

This fact sheet outlines the legal framework and principles surrounding inclusive education, emphasising the fundamental right of every child to access quality education regardless of disability, socio-economic status, or other factors. The passage highlights the importance of promoting diversity, ensuring equal access to education, and fostering inclusive environments in educational settings.

**INCLUSIVE EDUCATION:
THE LEGAL FRAMEWORK**

Inclusive Education in NSW

The position of the New South Wales Department of Education, regarding inclusive education is clear:

The NSW Education Standards Authority (NESA) is committed to ensuring curriculum is inclusive of all students, regardless of disability, ethnicity, cultural background, socioeconomic status, nationality, language, gender, sexual orientation or beliefs. NSW syllabuses are inclusive of the learning needs of all students.

Parents in New South Wales have legal avenues to support them in making a claim of discrimination. The first step is always **discussing and negotiating** with an educational facility. In most cases, this will lead to solutions where both parties have found a mutually agreeable solution.

⌵

Next, parents may seek advice from relevant **advocacy groups**, such as Down Syndrome New South Wales, who can provide guidance on navigating the process and offer assistance and support.

⌵

If discussions with the educational facility do not lead to a satisfactory resolution, parents might consider **lodging a complaint** with the Australian Human Rights Commission or the NSW Anti-Discrimination Board. These organisations handle complaints related to discrimination and can investigate individual cases.

⌵

In more serious cases, parents and carers may consider taking **legal action** through the court system. In this case, legal advice would be sought by solicitors specialising in disability discrimination.

⌵

It is crucial for parents and carers of individuals with special needs to be aware of their rights and protections under various governmental and legal bodies. It is equally important to **gather information and evidence**, when considering a claim of discrimination. This includes anecdotal evidence, such as communication with the school, as well as more formal evidence such as specialist assessments. It is always useful to be aware of **existing policies and procedures** in advocating for the rights of your child.

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**INCLUSIVE EDUCATION:
THE LEGAL FRAMEWORK**

Inclusive Education on a National Level

The *Disability Discrimination Act 1992* and the *Disability Standards for Education 2005* mandate the right of any child, with or without a disability, to attend their local government school. This reflects the global *Convention on the Rights of Persons with Disabilities 2006*.

The *Disability Discrimination Act 1992* mandates that a school (or any other educational facility) must not discriminate against any individual on the basis of disability, including:

- The decision-making process regarding admission to said facility;
- Discriminatory practices regarding terms and conditions of accepting an application, such as a parent paying higher fees to "cover" the cost of an educational assistant;
- By limiting a student's access to the full-range of educational activities on the ground of disability, such as external school excursions or sporting activities;
- By suspending or expelling a student on the grounds of disability;
- By failing to create and implement a curriculum which accommodates the unique learning needs of each individual;
- Subjecting a student to any other detrimental or discriminatory circumstances, because of disability.

"Unjustifiable Hardship"

A school (or other organisation) may claim that providing accommodations or adjustments for students with disabilities causes undue or excessive difficulty. Under the Disability Discrimination Act 1992, a facility is permitted to claim that these accommodations or adjustments will cause excessive hardship and may be entitled to deny enrolment or inclusion into other programs.

It is important to note that a claim of "unjustifiable hardship" must be rigorously investigated. The onus of proving this hardship falls upon the facility to demonstrate that:

- The nature and the extent of the adjustments or modifications are beyond the capabilities of certain limitations of the school;
- The financial and administrative resources of the organisation prohibit high degrees of adjustments or modifications;
- The impact on the school operations or services provided;
- Whether other alternatives or reasonable accommodations are available.

It is crucial to emphasize that the concept of unjustifiable hardship must not be used as an excuse to avoid making reasonable accommodations or to discriminate against individuals with a disability. Facilities must be proactive in seeking and implementing many different solutions in providing an inclusive education.

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[Click Here to View: The Legal Framework](#)

Inclusive Education: A Guide for Parents

This fact sheet explores the concept of inclusion in education, emphasising that every child in Australia has the right to an inclusive education environment. It discusses various aspects of inclusion, including respecting and celebrating diversity, fostering partnerships between families and schools, creating environments where all children can succeed, and promoting meaningful learning experiences. The passage challenges misconceptions about inclusion and highlights the importance of addressing individual needs and fostering a sense of belonging for all students.

DOWN SYNDROME
NEW SOUTH WALES

THE *Inclusive*
EDUCATION
INITIATIVE

WHAT IS INCLUSION?

PARENTS AND CARERS OF STUDENTS

WHAT IS INCLUSION?

Proven benefits of inclusion:

- Better literacy and numeracy skills
- Stronger friendships in both school and home environments
- Improved spoken language skills
- A greater level of independence into teenager years and adulthood
- Improved skills of communication, particularly in conversation and negotiation
- Greater world knowledge, including "real-world" skills

INTRODUCTION

All children in Australia have the right to an Inclusive education. There are many ideas and philosophies about inclusive education and what this looks like, and unfortunately there are some misconceptions too.

The New South Wales Department of Education and Training has focused heavily on inclusive education in recent years, stating that:

"All students, including students with disability, are welcomed by their school and supported to reach their full potential." (NSWDET, 2021).

But what does inclusion **really** look like?

>>> INCLUSION IS: RESPECTING AND CELEBRATING DIVERSITY

An inclusive school is not just a school which accepts diversity, but celebrates it. This includes race, gender, sexuality, social and economic background, religion, and ability. A truly inclusive school is a place where the differences between individuals in the community are seen to make that community stronger through diversity.

Society as a whole is a diverse place, made up of many different people with unique strengths and abilities. If schools are a place where students learn how to interact and thrive in the world, our classrooms need to reflect this diversity.

>>> INCLUSION IS: A PARTNERSHIP

Collaboration is the key to a successful inclusive education. Relationships built on trust and respect between the child, the family and the school will ensure that children not only learn, but thrive.



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WHAT IS INCLUSION?

ABOUT DOWN SYNDROME NSW

Once upon a time in NSW, 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.

About our Inclusive Education Initiative

We look to introduce our comprehensive Primary and Secondary School Support Program, designed to benefit both mainstream and special schools. The program's core objectives are to strengthen the capacity of schoolteachers, principals, and SLSOs (School Learning Support Officers) and to foster strong connections among key stakeholders, including families, therapists, and behavior support specialists, all with a focus on putting the student at the center.



Alison Maunder
Education Specialist
Down Syndrome NSW



Emily Caske
CEO
Down Syndrome NSW

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[View Here: Inclusive Education Guide for Parents](#)

A Short History of Down Syndrome

This Fact Sheet offers a quick lesson on the biology, early identification, the representation and depiction of Down Syndrome in Renaissance art and also featuring compelling photographs showcasing individuals with Down Syndrome in the past throughout history.

Down syndrome is not a disease, it is a genetic condition. People with Down syndrome are not sufferers, they are people first with diverse talents, strengths, desires and contributions. Join us as we explore the history of Down syndrome, touching on a little biology along the way.

It is important to note that in the representation of the history of Down syndrome, many now outdated and inappropriate names have been associated with Down syndrome in the past. This fact sheet serves merely as a historical overview and in no way condones the use of this language or approach in the present day. We wish to reflect the history to show how far we have rightly come.

A Quick Lesson In Biology

An exciting development of the 20th century was the discover of DNA - or deoxyribonucleic acid - composed of nucleic acids linked with sugars capable of forming long chains and reproducing itself.

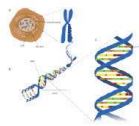
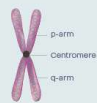
Appearing in human cells as a double stranded helix or spiral, DNA comprises ladder like formations connected by struts of chemical called purines and pyrimidines - namely, adenine and thymidine (purines) and cytosine and guanine (pyrimidines) - the sequencing of which is critical to cell activity and the production of protein. Any disruption in this can lead to issues pertaining to cell structure or cell function, or both. Most DNA within a human cell is concentrated in the cell nucleus, within which chromosomes form a key part.



Humans typically have 23 pairs of chromosomes - 22 of which are identical pairs though varying in size to other pairs, while the 23rd pair of chromosomes determines the sex of an individual, often referred to as X and Y chromosomes.



Each chromosome is made up of two strands of DNA - known as a chromatid - joined together by chiasmata at a specific site known as the centromere. Despite its name indicating otherwise, this often is not in the centre, resulting in each chromatid having a long arm (referred to as q) and a short arm (referred to as p).



Down syndrome is a result of extra chromosomal material found on chromosome 21, between segments 21q22.1 and 22.3, meaning it is between the first and third parts of the 22nd segment on the long arm of chromosome 21. The whole of the human genome carries over 30,000 genes. The section affected by Down's syndrome accounts for around 50 to 100 genes, a strikingly small amount in comparison to the whole. Of the 50 to 100 genes affected, only a few have been identified to date. The structure and function of cells becomes very specialised as the foetus grows - some cells make up the brain, others the muscles, some the skin and so on. This process is known as differentiation, which is governed by the genetic codes within the cells which activates only beginning to understand. This forms the basis of the commonalities we see across people with Down syndrome, derived from this cell differentiation.

The Identification of Down Syndrome

In 1866, Langdon Down first described the characteristics of the most common cause of learning and intellectual disability. He set the condition apart from mental disability by coining the first term used to describe those with Down syndrome: "mongoloid". In Down's opinion, the children with the genetic condition shared similar characteristics to the people of the Mongolian race. The term "Down syndrome" was suggested later by a group of geneticists who wrote to the British medical journal, The Lancet, with four alternatives to "mongoloid." Down syndrome was later endorsed by the World Health Organization and officially accepted as standard terminology in 1965.

Theories on the causation of Down's syndrome and its impairment mechanisms have varied greatly. Though to 1978, it was asserted that Down syndrome was caused by the foetus adopting radical characteristics during the developmental stages. This theory persisted right up to 1978, as evidenced in "The Psychology of Mongolism". Also during this period, it was also thought that Down syndrome was caused by stress during pregnancy.



Some aspects of the condition were described earlier by French psychiatrist Jean-Étienne Dominique Esquirol in 1838 and by French physician Édouard Séguin in 1844. The genetic cause of Down syndrome was discovered in 1959. In this year, French paediatrician and geneticist Jérôme Lejeune demonstrated that Down's syndrome was in fact due to additional genetic material carried on chromosome 21, identifying it as Trisomy 21. Since this time, the characteristics of Down's syndrome correlate to a relatively small part of the long arm of chromosome 21.

It remains unknown what may predispose cells to carry additional material during the splitting process, how this in turn affects development and function. There is, however, a current state of knowledge that provides some insights in what is an ever growing field of research. To learn more of this, see our fact sheet series.

In 1910, the expected age of survival for children with Down syndrome was nine years. After the discovery of antibiotics, the average age of survival had increased to roughly 19 or 20 years. In 1980, the life expectancy was 25 years old. With recent advancements in clinical treatment such as heart surgery, about 80% of adults with Down syndrome are living to the age of 60 and at times even longer.

[Click Here to View: A Short History of Down Syndrome](#)

About Down Syndrome

This fact Sheet is an easy-to-read resource which presents information and data around Down Syndrome in Australia. From prevalence to demographics, this resources provides a quick overview of Down Syndrome.

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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 5.64 people with Down syndrome**. This is similar to other countries like the UK.



Down syndrome is the most commonly occurring chromosomal condition.

Approximately **11 in every 1100** babies born in Australia will have Down syndrome.



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



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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**



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Causes and Incidence of Down Syndrome

CAUSES AND INCIDENCE OF DOWN SYNDROME

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Down syndrome is not a disease, it is a genetic condition. In fact, it is the most common genetic chromosomal condition. In this fact sheet, we answer some questions in relation to the causes of Down syndrome, as well as an approximate table of incidence as it links to age of the mother.

Causes of Down Syndrome

Regardless of the type of Down syndrome a person may have, all people with Down syndrome have an extra, critical portion of chromosome 21 present in some or all of their cells. This additional genetic material alters the course of development and causes the characteristics associated with Down Syndrome.

The cause of the extra full or partial chromosome is still unknown. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome resulting from nondisjunction or mosaicism. However, due to higher birth rates in younger women, 88% of children with Down syndrome are born to women under 35 years of age. There is no definitive scientific research that indicates that environmental factors or parents' activities cause Down syndrome.



The additional partial or full copy of the 21st chromosome which causes Down syndrome can originate from either the father or the mother. Approximately **8% of the cases** are traceable to the father.

There are 3 types of Down syndrome:

- Trisomy 21
- Translocation
- Mosaicism

All 3 types of Down syndrome are genetic conditions (that is, they relate to the genes of an individual). Only 1% of all cases of Down syndrome have a hereditary component being passed from parent to child through the genes. This only occurs in translocation. Heredity is not a factor in trisomy 21 (or nondisjunction) and mosaicism. However, in one third of cases of Down syndrome resulting from translocation there is a hereditary component. This accounts for about 1% of all cases of Down syndrome.

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CAUSES AND INCIDENCE OF DOWN SYNDROME

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Incidence of Down Syndrome

Down syndrome occurs in people of all races and economic levels. However, older women have an increased chance of having a child with Down syndrome.

A 35 year old woman has about a one in 350 chance of conceiving a child with Down syndrome. This chance increases gradually to 1 in 100 by age 40. At age 45 the incidence becomes approximately 1 in 30, at 49 it is approximately 1 in 10. The age of the mother does not seem to be linked to the risk of translocation. For more on the three types of Down syndrome, including translocation, see our fact sheet on this topic.

Maternal Age	Incidence of Down syndrome	Maternal Age	Incidence of Down syndrome	Maternal Age	Incidence of Down syndrome
20	1 in 2,000	30	1 in 900	40	1 in 100
21	1 in 1,700	31	1 in 800	41	1 in 85
22	1 in 1,500	32	1 in 720	42	1 in 70
23	1 in 1,400	33	1 in 650	43	1 in 60
24	1 in 1,300	34	1 in 600	44	1 in 50
25	1 in 1,200	35	1 in 550	45	1 in 45
26	1 in 1,100	36	1 in 500	46	1 in 40
27	1 in 1,050	37	1 in 450	47	1 in 35
28	1 in 1,000	38	1 in 400	48	1 in 30
29	1 in 950	39	1 in 350	49	1 in 25

However, despite this table of incidence and the fact that families are having children later than previously, younger women continue to have more babies than older women, so, on an overall measure, more children with Down syndrome are born to younger mothers.

Down Syndrome NSW is the peak organisation in NSW, proudly representing people with Down syndrome, their families and carers. We offer advocacy, resources and support across the lifespan. We work with passion to ensure that all people with Down syndrome achieve their full potential in all life stages. We champion the rights of people with Down syndrome to be valued and to have their rightful place in the community.

Written By: **Emily Caska** CEO Down Syndrome NSW



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[NDIS Fact Sheets](#)

[About the NDIS](#)

An easy to read Fact Sheet explaining the National Disability Insurance Scheme.

ABOUT THE NDIS

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The NDIS is an Australia - wide scheme

It supports people aged **0 to 65 years** with permanent and significant disability.

In NSW, about **140,000 people** with disability are expected to join the NDIS - including 40,000 children and young people.

A PERSON WILL BE ELIGIBLE FOR THE NDIS:

- If they have a **lifelong disability** that significantly affects their ability to participate in the community.
- People can check their **eligibility on the NDIS website** using an eligibility checklist.

THROUGH THE NDIS, PEOPLE WITH DISABILITY WILL BE ABLE TO:

- ✓ Have more choice and control over their disability supports and how those supports are provided.
- ✓ Access 'reasonable and necessary' supports to achieve their personal goals.
- ✓ Live an ordinary life that is, to build their skills and capabilities so they can engage in education, employment and community activities.

The NDIS is managed by the **National Disability Insurance Agency, or NDIA**. The NDIA is responsible for determining eligibility for the scheme and for developing personalised support plans for participants.

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ABOUT THE NDIS

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What Services and Support does the NDIS fund?

The NDIS funds supports for eligible people based on their individual needs. The types of supports the NDIS may fund include:

- Daily personal activities.
- Transport to participate in community.
- Social, economic, academic life activities.
- Employment help to get or keep a job in the supported labour market.
- Therapeutic supports - allied health and behaviour support.
- Help with household tasks.
- Aids and equipment - assessment, set up and training.
- Mobility equipment home or vehicle modifications.

The Early Childhood Early Intervention (ECEI) Approach

Support for children aged to **0 to 6 years** with a disability or development delay

Focuses on integrating supports to meet the child's needs across various settings including:

- preschools
- playgroups and
- the early years of school

Timely, comprehensive and well-integrated early intervention supports will foster inclusion and participation in the child's environment and offers the best chance of achieving their potential. The NDIS has engaged experienced service providers, known as Early Childhood Partners, to deliver the ECEI approach. **Children do not need a diagnosis to access ECEI supports and families can self refer.** Some children who access ECEI supports may go on to receive an individual NDIS plan.

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[Click Here to View: About the NDIS](#)

[NDIS Eligibility Fact Sheet](#)

Our **NDIS Eligibility Check List** is an essential tool to help you determine your eligibility for NDIS Support.

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If you are aged between 7 and 65, a local area coordinator can help you to understand the NDIS, apply and connect with other government and community supports. If you have a child aged under 7, an early childhood partner can provide supports to children before they apply, and let families know if the NDIS is right for their child.

Age Requirements

QUESTION 1: ARE YOU AGED BETWEEN 7 AND 65?

YES Go to the next question.

NO I have a child under 7. Find out more about [help for children under 7](#).

NO I'm over 65. You must be under 65 to access the NDIS. [You may be able to access other supports](#). Find out about NDIS and [aged care](#).

Residence Requirements

QUESTION 2: ARE YOU AN AUSTRALIAN CITIZEN, PERMANENT RESIDENT, OR PROTECTED SPECIAL CATEGORY VISA HOLDER?

YES Go to the next question.

NO You may be able to access other supports. The NDIS is only available to:

- [Australian Citizens](#)
- [Permanent Visa Holders](#)
- [Protected Special Category Visa Holders](#)

QUESTION 3: DO YOU LIVE IN AUSTRALIA?

YES Go to the next question.

NO You may be able to access other supports. The NDIS is only available to people [who live in Australia](#).

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Disability Requirements

QUESTION 4: DO YOU HAVE A DISABILITY CAUSED BY A PERMANENT IMPAIRMENT?

YES Go to the next question.

NO The NDIS is only available to people who have a [disability caused by a permanent impairment](#). The impairment may be intellectual, cognitive, neurological, sensory, physical, or psychosocial.

QUESTION 5: DO YOU USUALLY NEED DISABILITY-SPECIFIC SUPPORTS TO COMPLETE DAILY LIFE ACTIVITIES?

YES [If you usually need disability-specific supports to complete daily life activities you may be eligible. Find out how to apply.](#)

NO Go to the next question.

Early Intervention Requirements

QUESTION 6: DO YOU HAVE A DISABILITY CAUSED BY A PERMANENT IMPAIRMENT?

YES You may be eligible if you need some [supports now to reduce your future need for support](#). [Find out how to apply.](#)

NO Go to the next question.

QUESTION 7: DO YOU NEED SOME SUPPORT NOW FOR YOUR FAMILY TO BUILD THEIR SKILLS TO HELP YOU?

YES You may be eligible if you need some [supports now to reduce your future need for support](#). [Find out how to apply.](#)

NO The NDIS may not be the best way to support you, but a local area coordinator can help you connect with other government and community supports.

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[Click Here to View: NDIS Eligibility Check List](#)

[Congratulations Initiative: Online Catch Up!](#)

Come and join our free fortnightly Online Catch UP! for families who have a baby aged 0-2 years who has Down syndrome.

This is a safe space for parents/carers/grandparents to get to know our Congratulations Initiative team and connect with other families.

Everyone has a chance to contribute to the conversation and we love seeing all the beautiful babies on the screen and celebrating their wins and milestones.

Occasionally we'll have a special guest join a session to present on relevant topics.

Facilitated by Melissa Cotterill (Down Syndrome NSW staff member and mother to Alyssa) this is a platform to share information and experiences and ask questions over a cuppa.

Best part is it's online so you can join from all over NSW!

The next session will be on at 10am Thursday 22 February 2024 followed by another session on 7 March 2024. Here's the link to register.

Catch up!

For: Parents, Carers, Grandparents of bubs with Down Syndrome 0-2 years, as well as pre-natal parents.



Start Date: Thursday 25th January, 2024
THIS EVENT WILL OCCUR EVERY FORTNIGHT
Venue: Online
Time: 10am - 10.30am (NSW AEDT)



REGISTRATION/COST:
Free for DSNSW members

[Register Here](#)

UP! Club

March Program Out Now

March Program is here! Woohoo! Nice an early so you can check out all our awesome activities and book in for the fun with friends!

Check it out below, we've got great things lined up plus our Travel Clubs are back!

Don't forget about February though, we've got so many fun activities online and in person, with something for everyone! Jump on the links below and get booking! We love seeing you!

Programs: February to March

Check out our amazing events, lunches, adventures, live music, online catch ups as well as our Travel Club weekends which have been super popular!

Day	Program	Event	Time	Speaker
Friday 2nd	UPI Club	Live Music & Chat	3:30pm - 5:00pm	
Saturday 3rd	UPI Club	Get Growing! Gardening Botanical Gardens	1:30pm - 4:00pm	
	UPI Club	Saturday Night Fever	6:00pm - 9:00pm	
Tuesday 6th	Inclusion Institute	Strategies to Support Individuals with Down Syndrome	10:00am - 11:30am	Dr Katie Frank
Wednesday 7th	UPI Club	Fit n Fun	3:30pm - 5:00pm	
	UPI Club	Information Session	6:00pm - 6:30pm	
Thursday 8th	Congratulations Initiative	Online Catch UPI	10:00am - 10:30am	
Friday 9th	UPI Club	Live Music & Chat	3:30pm - 5:00pm	
Saturday 10th	UPI Club	Culture Club Blanc de Blanc Encepe & Perle	1:00pm - 7:30pm	
	UPI Club	Saturday Night Fever	6:00pm - 9:00pm	
Wednesday 14th	UPI Club	Fit n Fun	3:30pm - 5:00pm	
Friday 16th	UPI Club	Live Music & Chat	3:30pm - 5:00pm	
Saturday 17th	UPI Club	Saturday Night Fever	6:00pm - 9:00pm	
Tuesday 20th	Inclusion Institute	Puberty & Healthy Relationships for Parents/Carers	10:00am - 11:30am	Ashleigh Tikolevu and Dhvani Patel
Wednesday 21st	UPI Club	Fit n Fun	3:30pm - 5:00pm	

UPI Club Inclusion Institute Congratulations Initiative

FEBRUARY 2024



Day	Program	Event	Time	Speaker
Thursday 22nd	Congratulations Initiative	Online Catch UPI	10:00am - 10:30am	
Friday 23rd	UPI Club	Live Music & Chat	3:30pm - 5:00pm	
Saturday 24th	UPI Club	Saturday Night Fever	6:00pm - 9:00pm	
Sunday 25th	UPI Club	Culture Club Mini Golf & Pub Lunch	11:00am - 4:00pm	
Wednesday 28th	UPI Club	Fit n Fun	3:30pm - 5:00pm	

UPI Club Inclusion Institute Congratulations Initiative

[View Here: February Calendar](#)

Day	Program	Event	Time	Speaker
Friday 1st	UPI Club	Live Music & Chat	3:30pm - 5:00pm	
Wednesday 6th	Inclusion Institute	Reflections and Co-Occurring Diagnosis and Data	9:00am - 10:30am	Dr. Brian Chicoine
	UPI Club	Fit n Fun	3:30pm - 5:00pm	
Thursday 7th	Congratulations Initiative	Online Catch UPI	10:00am - 10:30am	
Friday 8th	UPI Club	Live Music & Chat	3:30pm - 5:00pm	
Saturday 9th	UPI Club	Culture Club Lawn Bowls & Lunch Mungahibee	10:00am - 3:30pm	
	UPI Club	Saturday Night Fever	6:00pm - 9:00pm	
Wednesday 13th	UPI Club	Fit n Fun	3:30pm - 5:00pm	
Friday 15th	UPI Club	Live Music & Chat	3:30pm - 5:00pm	
Saturday 16th	UPI Club	Saturday Night Fever	6:00pm - 9:00pm	
Sunday 17th	UPI Club	Culture Club Lunch & Live Music Risby	10:00am - 3:30pm	
Tuesday 19th	Inclusion Institute	'Right Diet' for People with Down Syndrome	10:00am - 11:30am	Nicky Clark

UPI Club Inclusion Institute Congratulations Initiative

MARCH 2024



Day	Program	Event	Time	Speaker
Wednesday 20th	UPI Club	Fit n Fun	3:30pm - 5:00pm	
		World Down Syndrome Day Event NSW Parliament House	2:30pm - 4:30pm	
		World Down Syndrome Day Event NSW Government House	6:00pm - 7:30pm	
Thursday 21st		WORLD DOWN SYNDROME DAY		
	Congratulations Initiative	Online Catch UPI	10:00am - 10:30am	
Friday 22nd	UPI Club	Live Music & Chat	3:30pm - 5:00pm	
	UPI Club	Travel Club - Blue Mountains NSW	2:30pm	
Saturday 23rd	UPI Club	Travel Club - Blue Mountains NSW	2:30pm	
Sunday 24th	UPI Club	Travel Club - Blue Mountains NSW	2:30pm	
Tuesday 26th	Inclusion Institute	Early Childhood: How to Get the Best From NDIS Package	10:00am - 11:30am	Amanda Clifford and Kerry Dominish
Wednesday 27th	UPI Club	Fit n Fun	3:30pm - 5:00pm	
Friday 29th	UPI Club	Live Music & Chat	3:30pm - 5:00pm	
Saturday 30th	UPI Club	Saturday Night Fever	6:00pm - 9:00pm	

UPI Club Inclusion Institute Congratulations Initiative

[View Here: March Calendar](#)

Contact UP! Club

If you have questions or need help with the new registration platform for UP!

[Get Involved](#)

Get involved with us and be a vital part of the Down Syndrome NSW community! Join our journey of advocacy, support, and celebration by following us on social media. Connect with fellow members, stay updated on events, and share your inspiring stories. Follow us on **Facebook**, **Instagram**, **LinkedIn Family Support Group** and **Humanitix** to engage in meaningful conversations and contribute to the positive impact we're making together.

[Join Facebook](#)

[Join Instagram](#)

[Family Support Group](#)

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Please consider contributing today to Down Syndrome NSW. Your support is essential for us to sustain our programs, initiatives, and advocacy efforts. Your donation makes a significant impact on our ability to carry out our work.

We Need Your help: Support Our Vital Work Today

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